# The Effectiveness of a Psychoeducation Intervention Delivered Via WhatsApp for Mothers of Children with Autism Spectrum Disorder (ASD) in the Kingdom of Saudi Arabia

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# Summary of Thesis

Parents of children with autism spectrum disorder (ASD) experience numerous challenges caring for their children. Research shows that those parents, and specifically mothers, suffer from high levels of stress and poorer well-being compared to parents of children with other disabilities. Developing and evaluating interventions to help enhance their well-being and their interaction with their children is recommended (NICE, 2013). Parenting interventions have been shown to be efficacious for parents of children with ASD , yet practical barriers may have an impact on their widespread uptake (McConachie & Diggle, 2007). Self-help parenting interventions with minimal therapists' support, which have the potential to overcome barriers to adherence, have been used with parents of children with other neurodevelopmental disorders. However, there is limited evidence evaluating these interventions and their effectiveness for parents of children with ASD. Moreover, most parenting interventions for parents of children with ASD focus on developing the parents' abilities to enhance specific skills in their children, while only few include psychoeducation components addressing knowledge about ASD and parental well-being. The main aims of this thesis were to understand the impact of having a child with ASD on parental functioning both internationally and for Saudi Arabian mothers and to then develop and evaluate both quantitatively and qualitatively the effectiveness of a brief psychoeducation intervention for mothers of children with ASD in the Kingdom of Saudi Arabia (KSA).

Chapter One provides an introduction to ASD including its current definition, diagnosis, co-morbidities, risk factors, and treatment options. In addition, it discusses the theoretical models related to parenting children with ASD, and autism within the context of KSA including gaps in current research there. Chapter Two (study one), presents a systematic review investigating the impact of having children with ASD on parental life. Autism was found to impact areas including response to ASD, parental well-being, relationships, positive perception, financial problems, and future worries. Differences in findings between mothers and fathers were identified. Chapter Three (study two) explores the unmet needs of Saudi mothers of children with ASD in KSA through a pilot qualitative study that used semi-structured interviews. Mothers expressed a range of issues and needs including feelings of lack of sufficient information about ASD, the need for parental training, shortage of quality ASD services, lack of fathers' assistance, and stigma associated with having children with ASD. Moreover, mothers insisted that barriers such as lack of transportation add to their burden. Chapter Four (study three) presents a meta-analysis evaluating the effectiveness of parenting interventions on parental functioning of parents of children with ASD. Analyses revealed that parenting interventions are effective in enhancing parental well-being (stress, depression, and anxiety), parenting practices, and in increasing parents’ sense of competence SOC. Chapter Six (study four) delivers the findings from a small-scale randomised controlled trial (RCT) investigating the effectiveness of a self-help psychoeducation intervention with minimal therapists’ support, delivered via WhatsApp for mothers of children with ASD in KSA. The intervention was successful in reducing maternal reports of stress, depression, ASD symptoms, and child behaviour problems. Change of clinical significance was minimal and limited to maternal depression. Chapter Seven (study five) describes a qualitative study that evaluates the acceptability and views of mothers who participated in the trial in Chapter Six. Mothers had positive views of the intervention and many of them were actively engaged in the intervention and discussed new parenting skills and behaviours that they had acquired. Finally, Chapter Eight provides a general and overall discussion of the thesis findings, including a summary of the findings of all the studies within the thesis. In addition, methodological strengths and considerations, clinical implications, and direction for future research are discussed. Collectively, the studies within this thesis provided evidence for the effectiveness of self-help psychoeducation parenting intervention with minimal therapist support and delivered via a virtual medium for mothers of children with ASD in KSA indicating that such interventions may have a place in future routine care.

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## Publications and Presentations

### Publications

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## List of Abbreviations

| | |
|---|---|
| ASD | Autism spectrum disorder |
| DSM | Diagnostic and Statistical Manual for Mental Disorders |
| KSA | Kingdom of Saudi Arabia |
| TDC | Typically developing children |
| HF | High functioning |
| Yr | Years |
| mos. | Months |
| F | Female |
| M | Male |
| QUAL | Qualitative |
| QOL | Quality of life |
| RCT | Randomised controlled trial |
| NRS | Non-randomised studies |
| RevMan | Review Manager Software |
| SD(s) | Standard deviation(s) |
| M | Means |
| ANOVA | Analysis of variance |
| ANCOVA | Analysis of covariance |
| IG | Intervention group |
| CAU | Care as usual |
| KAU | King Abdulaziz University |
| SMD | Standardized mean difference |
| SES | Socioeconomic status |

# Chapter One: Introduction to Autism Spectrum Disorder ASD

## Overview

This Chapter introduces the concept of autism spectrum disorder (ASD[1]), characteristics of people with ASD, prevalence, risk factors, diagnosis, co-morbidities, and treatment options. Moreover, this Chapter will explain some theories pertaining to parenting children with ASD and discuss background information about ASD in the context of the Kingdom of Saudi Arabia (KSA).

## Definition and Characteristics

According to the *American Psychiatric Association* (APA), autism spectrum disorder refers to a group of neurodevelopmental disorders characterised by repetitive and restricted patterns of behaviour and difficulties with social and communication interaction (APA, 2013). The first account of the disorder was published by Dr. Leo Kanner in 1943 who described a group of 11 children who had "autistic disturbances of affective contact" (Kanner, 1943). Hans Asperger, an Austrian paediatrician, described at the same time as Kanner a similar group of children with a milder form of autism, Asperger syndrome, which was named after him (Asperger, 1944). Infantile autism (IA) is a term introduced in the third edition of the Diagnostic and Statistical Manual (DSM III) under the heading of pervasive developmental disorders (PDD), along with atypical autism (when the child does not display all of the IA behavioural criteria) and childhood onset PDD (children who display IA behaviours later than the 30-months age cut-off for IA diagnosis but no later than 12 years of age) (APA, 1980). The revision to DSM III introduced the term autistic disorder while atypical autism and childhood onset PDD were combined under the term PDD-NOS (APA, 1987). The fourth version of the DSM redefined autistic disorder, and added Asperger disorder, childhood disintegrative disorder (late onset regression) and Rett disorder (APA, 1994). Rett disorder is a genetic neurological disorder that mostly affects females and its clinical manifestation includes small hand and feet with a rapid acceleration of head growth around the age of five months (A. S. Davis & D'Amato, 2010).

With the emergence of DSM-5, the five distinct pervasive developmental disorders of the DSM-IV (i.e., autistic disorder, Asperger disorder, childhood disintegrative disorder, pervasive developmental disorder, not otherwise specified PDD-NOS) have been merged together under an overarching category of ASD.

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[1] The terms ASD and autism will be used interchangeably in this thesis to refer to ASD.

The word "spectrum" suggests that people with ASD have challenges that run from mild to severe, with different levels of abilities and disabilities. The learning and cognitive abilities of people with ASD can range from gifted to severely challenged (APA, 2013).

One of the most significant changes of the DSM-5 criteria is replacing the term 'Pervasive Developmental Disorders' with 'Autism Spectrum Disorder' and removing Rett syndrome (Wing, Gould, & Gillberg, 2011). Another major change is that the criteria (symptoms) can now be met at the time of the diagnosis or in the past, which is a departure from the previous diagnosis criteria according to which the symptoms should have currently manifested. The DSM-5 also has a note that if an individual has a well-documented DSM-IV diagnosis of autistic disorder, Asperger disorder, or PDD-NOS, he or / she should continue to receive a diagnosis of ASD under DSM-5 (Kim et al., 2014). Moreover, DSM-5 changed from the axial system of DSM-IV and now contains specifiers (e.g., with or without intellectual impairment, language impairment) (APA, 2013). The system of specifiers for ASD includes a functional severity level across a three-level scale (requiring support, requiring substantial support, and requiring very substantial support). The specifiers also provide information related to the presence of accompanying intellectual disability and/or language impairment and associations with other known medical or genetic conditions; environmental factors; neurodevelopmental, or behavioural disorders; and catatonia (APA, 2013). Finally, DSM-5 merges the domains of social and communication impairments into one 'social communication' domain so that children who meet the criteria for social communication but not the repetitive restricted pattern of behaviour criteria are assigned as having a Social Communication Disorder and not ASD.

Based on DSM-5 (APA, 2013), anyone having ASD should meet the following two diagnostic criteria. First, persistent difficulties with social communication and social interaction including deficits in the use and understanding of nonverbal behaviour (e.g., appropriate use of eye contact and facial expressions) and relationship difficulties (e.g., difficultly understanding appropriate social behaviour; difficulty making and maintaining friendships). The second diagnostic criteria is restricted, repetitive patterns of behaviour, interests, or activities including stereotyped movement or speech (e.g., hand flapping, repeating the speech of others), the need for routine (e.g., emotional distress in relation to the modification of sleeping time), and abnormal focus on particular interests (e.g., preoccupations with specific objects) (APA, 2013). The majority of children with ASD are described as overly responsive or unresponsive to sensory stimuli (e.g., adverse reactions to lights, sounds or textures) (Kim et al., 2014).

Children with ASD develop at different rates in different areas. They may have delays in developing language and social skills, while their ability to walk and move may be about the same as other children of their age. They might be very good for example at putting puzzles together or solving computer problems, but they might have trouble with social activities like talking or making friends (Simpson & de Boer-Ott, 2005). Each person with ASD has different communication skills. Some people can speak well, others can not speak at all or only very little. Approximately 40% of children with ASD do not talk at all, while 25%–30% of children with ASD use some words at 12 to 18 months of age but then lose them (C. P. Johnson, 2008). Some children display ASD symptoms from infancy while others develop normally until a certain age ( usually around 18 months) and then they begin to lose language and communication skills (Kern, Geier, & Geier, 2014; Wiggins, Rice, & Baio, 2009). People with ASD who do speak might use language in unusual ways as they might not be able to put words into sentences or only say one word at a time. Others repeat the same words or phrases over and over a condition that is called echolalia (Bogdashina, 2006). Moreover, people with ASD might have a hard time using and understanding gestures, body language, or tone of voice. For example, they might not understand what it means to wave goodbye.

Several psychological theories attempt to explain the nature of specific symptoms in ASD as abnormalities in brain structure or function that have an effect on behaviour through abnormal development of psychological functions. The most common ones are *Theory of Mind (*ToM*)*, The *Executive Function Theory (EF)*, and the *Central Coherence Theory*. Theory of Mind refers to the understanding that other people have their own thoughts, perceptions, and intentions separate from one’s own and it stems from the concept that a typically developed individual has the ability to interpret and infer the intentions, feelings and thoughts of those around them (Premack & Woodruff, 1978). It allows an individual to make predictions of how others will act, which is a critical component in the development of social skills. A number of studies on ToM following acquired brain damage (e.g., stroke) suggest an association between orbito- and medial-frontal cortex and the loss of abilities to understand social clues which might relate ASD behavioural symptoms to certain brain areas (Rowe, Bullock, Polkey, & Morris, 2001; Stuss, Gallup, & Alexander, 2001). Beaumont & Newcombe (2006) found that people with ASD displayed deficits in ToM compared to typically developing (TD) individuals, following a task that required mental state detection of displayed cases. The term *executive function* is a term covering a range of high-level abilities such as planning, future action, modifying behaviour according to feedback and shifting between different behaviours (Diamond, 2013). The theory of EF postulates deficits in those abilities thought to depend on the frontal lobes that allow for flexible behaviour (Ozonoff & McEvoy, 1994). In people with ASD, executive dysfunction is thought to underpin both repetitive restricted behaviours and atypical social interaction and social communication (Ozonoff & McEvoy, 1994). However, the relationship between executive dysfunction and ASD symptoms and disorder is not specific to ASD and extend to other neurodevelopmental disorders (Halperin, 2016; McGrath et al., 2016).*The Central coherence theory* is defined as the ability to focus on both details and wholes, or a bigger picture in relation to details so as to derive and interpret overall meaning from a large body of detail (Shah & Frith, 1983). This is explained by the tendency to put information together to extract meaning from different contexts, to remember, for example, the main theme of a story rather than its details or exact words (Happé, 1997). Weak *central coherence* has been found to be apparent in visuo-spatial and linguistic tasks in children with ASD compared to typically developing (TD) ones (Booth & Happé, 2010; Keehn et al., 2009). Difficulties in global processing displayed in a sentence completion task asking children to select the appropriate word for the context manifest in children with ASD as a frequent inability to choose the appropriate word for the context compared to TD children with the same IQ (Booth & Happé, 2010). Moreover, children with ASD perform faster than TD children in locating a small shape within a larger figure consisting of different smaller shapes (Keehn et al., 2009). The results of these studies suggest that weak central coherence does in part account for deficits in some cognitive domains in children with ASD. However, not all children with ASD display difficulties in both linguistic and visuospatial domains as some might experience difficulties in only one task and not another (Loth, Gómez, & Happé, 2008; Vanegas & Davidson, 2015)

**Prevalence and Co-morbidity**

According to the *Centers for Disease Control and Prevention*, one in 42 males compared to one in every 189 female children is diagnosed with ASD (i.e.1:4 male-female ratio) (Christensen et al., 2012). The prevalence of ASD was estimated at five cases per 10.000 individuals prior to 1980 (APA, 2000), However, the number has risen in the last decade with a prevalence of approximately 60 to 70 cases per 10.000 (Fombonne, 2009). The DSM-5 states that around 1% of the global population is affected with ASD (APA, 2013).The increase in the prevalence could be due to increased awareness among professionals and the public or due to more cases being included within the broad diagnostic criteria specified by the DSM-5 (Greenberg, Seltzer, Hong, & Orsmond, 2006; Michael D Kogan et al., 2009). Usually, ASD is diagnosed before the age of three and lasts throughout a person's life, although symptoms may improve over time and studies have shown that some parents of children with ASD notice a problem before their child's first birthday, while nearly 80%–90% saw problems by the age 24 months (Christensen et al., 2012). It occurs in all racial, ethnic, and socioeconomic groups Blumberg et al. (2013), with almost half the children diagnosed with ASD having average to above average intellectual ability (Christensen et al., 2012).

ASD is a disorder with a high degree of co-morbidity with more than 70% of individuals with ASD exhibiting one or more co-existing medical, developmental, or psychiatric conditions in their lifetime (Hofvander et al., 2009; Mattila et al., 2010; Simonoff et al., 2008b). Some of the most common co-morbid conditions occurring in ASD are intellectual disability, Attention-Deficit Hyperactivity Disorder (ADHD), anxiety disorders, sleep disturbances and gastrointestinal problems (e.g., constipation or diarrhoea) (Leyfer et al., 2006; Simonoff et al., 2008a). The prevalence of ADHD in those with ASD has ranged from 14% to 78% (Gargaro, Rinehart, Bradshaw, Tonge, & Sheppard, 2011; Mannion & Leader, 2013). Moreover, children with autism were found to have significantly more feeding problems and ate a significantly narrower range of foods than children without autism (Schreck, Mulick, & Smith, 2004). Rzepecka, McKenzie, McClure, and Murphy (2011) found that 77.2% of children with ASD had sleep problems and Mannion and Leader (2013) found that 80.9% of children and adolescents with ASD presented with sleep problems. Toileting problems are also manifested in many individuals with ASD (Kroeger & Sorensen-Burnworth, 2009).

### Aetiology and Risk Factors

Research into the aetiology of ASD suggests that a combination of genetic and environmental factors may account for differences in the development of symptoms. Studies using magnetic resonance imaging (MRI) have now reported increased brain volume in children and adults with ASD, and there is some preliminary evidence for a disproportion in the grey matter to white matter ratio (Courchesne et al., 2001; McAlonan et al., 2005). However, there is not enough evidence to date to draw definite conclusion regarding the relationship between brain size and its direct effect on ASD, and similar brain structural abnormalities have been identified for other neurodevelopmental disorders (Nagel et al., 2011).

Studies of twins have suggested that autism is affected by genetic factors. Identical twins were found to have higher concordance rate (the risk of developing autism for co-twin of a twin with autism) than non-identical twins (Hallmayer et al., 2011; Ronald et al., 2006; Rosenberg et al., 2009) . Ritvo, Freeman, Mason-Brothers, Mo, and Ritvo (1985) found that the concordance rate for autism was 95.7% (22 of 23 pairs) for identical twins and 23.5% (4 of 17 pairs) for non-identical twins; Rosenberg et al. (2009) reported respective values of 88% (95 of 67 pairs) and 31% (64 of 210 pairs); and Steffenburg et al. (1989) also reported respective values of 91% (10 of 11 pairs) and 0% (0 of 10 pairs). Moreover, previous sibling studies have also suggested that parents who have a child with ASD have a higher chance of having another child who is also affected. In Sumi, Taniai, Miyachi, & Tanemura (2006), the recurrence incidence of siblings with ASD among families of children with ASD was found to be 10%, in contrast with 2.1% ASD incidence in the general population from the same geographical region. Ozonoff et al., (2011) found sibling recurrence rate of 18.7% (95% CI: 13.34-25.5) among infants with an older sibling with ASD (132 infants developed ASD out of 664 infants with older siblings with ASD).

Some factors occurring pre-birth might also contribute to developing ASD later in life, for example, children born to older parents are at a higher risk for having ASD (Christensen et al., 2012). Increased age of parents at birth has been identified as one of the factors associated with autism (Gardener, Spiegelman, & Buka, 2009). The most recent meta-analysis of almost 26,000 autism cases and 8.7 million controls supported the finding of the advanced maternal age as a risk factor for autism; this effect remained significant while controlling for the paternal age (Sandin et al., 2012). However, advanced paternal age has also been previously reported as a risk factor (Reichenberg et al., 2006), leading to the conclusions that the maternal and paternal advanced age act as independent risk factors for increased incidence of autism.

Children conceived through *Assisted Reproductive Technology* (ART) are about two times more likely to be diagnosed with ASD compared to children conceived without ART. Evidence suggests that in case of babies conceived with ART, the increased risk for ASD is, in part, due to the higher likelihood of adverse pregnancy and delivery outcomes. In other words, ART may lead to factors that are known to put children at risk for ASD, such as being born too early or being born with low birth weight. More research is needed to explore the relationship between ART and ASD (Fountain et al., 2015; Kissin et al., 2015).

Neonatal factors (e.g., parents’ age or conceiving through ART) are possible risk factors for ASD as well as for other neurological disorders (e.g., ADHD, intellectual disability, epilepsy, and cerebral palsy). Therefore, it is not possible to suggest that ASD is caused mainly by these factors (Atladottir, Schendel, Parner, & Henriksen, 2015).

It has been suggested that environmental toxins are a leading factor in the development of ASD in children who are heavily exposed to such influences. Varieties of toxic chemicals have been identified as harmful to foetus neurodevelopment (during the first trimester of pregnancy) and may contribute to the emergence of developmental disabilities. These may include heavy metals (e.g., lead and methyl mercury) and alcohol and chemical pesticides (Landrigan, 2010). However, a systematic review by Rossignol, Genuis, and Frye (2014a) examining the relationship between environmental toxicants and ASD revealed that the evidence behind the connection between environmental toxicants and ASD is not conclusive, as further studies are needed to investigate whether people with ASD are more susceptible to the effect of toxins than people with typical development.

In addition, an anecdotal cause often mentioned in the ASD discussion is the relationship between vaccines and ASD. The first suggestion that vaccination of infants against the measles, mumps and rubella (MMR) led to increased autism prevalence was made in 1998 (Wakefield et al.). It resulted in public panic and diminished parents’ confidence in the MMR vaccine, which ultimately protects children from life threatening diseases. Upon the release of the 1998 paper, research bodies across the globe performed epidemiological studies in several countries and found no support for the claim that the MMR can cause ASD (Barile, Kuperminc, Weintraub, Mink, & Thompson, 2012). In a recent meta analysis, vaccines were not found to be associated with autism (Taylor, Swerdfeger, & Eslick, 2014).

### Diagnosis

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, PDD-NOS, and Asperger syndrome. These conditions are now collectively called ASD (Christensen et al., 2012). For an individual to receive a diagnosis of ASD, the symptoms must be evident in early development, across a variety of contexts, and must cause a significant disturbance in multiple areas of functioning (APA, 2013).

Concerns about vision and hearing were more often reported in the first year, and problems in social and communication skills were evident from six months of age (Bolton, Golding, Emond, & Steer, 2012; Christensen et al., 2012; Kozlowski, Matson, Horovitz, Worley, & Neal, 2011). Autism can sometimes be detected at 18 months or younger (Kleinman et al., 2008; Lord et al., 2006).

As no medical or biological test to date exists to diagnose ASD, the diagnosis is based mainly on a behavioural assessment. The DSM-5 and the International Classification of Disease, Tenth Edition (ICD-10) are the two most commonly used diagnostic criteria (Matson, Hess, Kozlowski, & Neal, 2011; Tissot, 1999). Each of them provides a comprehensive list of criteria including symptoms for diagnosis and age of onset, which has provided a structured framework for clinicians to be able to assess and diagnose autism. Both tools have almost similar criteria, which are mostly based on the triad of impairment in autism. Thus, the similarities between the two classifications have led to an almost worldwide consistency in diagnosis (Matson et al., 2011; Tissot, 1999). Based on the diagnostic criteria, several assessments and screening tools to diagnose autism were developed, for instance, the Autism Diagnostic Interview-Revised (ADI-R) (Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000). Such tools serve to not only help diagnose the child, but also assess him/her so that educational intervention can be designed. As the main studies in this thesis were conducted in KSA, the DSM criteria for ASD will be the focus of discussion throughout this thesis as DSM is the most recognised and frequently used in diagnosing children with ASD there.

There are many tools to assess ASD in young children, but due to the diversity of ASD presentations, no single tool should be used as the single basis for diagnosis. Diagnostic tools usually rely on two main sources of information—parents' or caregivers' descriptions of their child's development and a professional's observation of the child's behaviour.

Following are selected examples of the most common diagnostic tools of ASD:

- Autism Diagnosis Interview – Revised (ADI-R): Is a semi-standardised interview of established characteristics of ASD as specified in the ICD-10 and DSM IV, which include the core domains of abnormalities in reciprocal social interaction, deficits in communication, and restricted, repetitive, and stereotyped patterns of behaviour. It has good reliability and validity (Lord et al., 1994). Individuals are objectively scored in each of these areas by an expert and the interview is carried out with a parents or caregivers. This tool can also be problematic particularly in adults as assessors rely on the parents' accurate recall and report of past events. The ADI-R is appropriate for children and adults with mental ages of about 18 months and above (Tissot, 1999).

- Autism Diagnostic Observation Schedule (ADOS): Is a semi-structured, standardised assessment of social interaction, communication, and imaginative use of materials for individuals suspected of having ASD. The observational schedule consists of four 30-minute modules, each designed to be administered to different individuals according to their level of expressive language (Lord et al., 2000). The schedule follows a standardised interview and observational assessment consisting of a number of activities carried out with the individual. The ADOS assesses current symptoms while the ADI-R assesses symptoms retrospectively and thus ADOS and ADI-R are typically used together as the gold-standard diagnosis of ASD (Lord et al., 2000).

- Childhood Autism Rating Scale (CARS): Is a brief assessment suitable for use with any child over the age of two. The CARS includes items drawn from five prominent systems for diagnosing autism; each item covers a particular characteristic, ability, or behaviour ( Schopler, Robert. Reichler, Robert. DeVellis, & Daly, 1980).

- Gilliam Autism Rating Scale – Second Edition (GARS-2) : Is a tool to assists teachers, parents, and clinicians in identifying and diagnosing autism in individuals ages three through 22. It also helps estimate the severity of the child's disorder (Gilliam, 2006).

The ADI-R and ADOS have plenty of evidence that support their accuracy in diagnosing ASD, and when used together can produce a high accuracy rate (Falkmer, Anderson, Falkmer, & Horlin, 2013). The 'gold standard' classification and diagnosis of autism is still considered to be multi-disciplinary team (MDT) in which clinical assessment including the use of the ADOS and ADI-R, as well as other assessments (e.g., paediatrician, special educators, and autism organisations) are taken into considerations (Falkmer et al., 2013).

**Treatment**

There are no medications that can cure ASD or treat the core symptoms. However, there are medications that can help some people with ASD function better. For example, medication can help manage high energy levels, inability to focus or depression. Strikingly, little evidence exists to support the benefit of most treatments as Risperidone and Aripiprazole have proved beneficial for challenging and repetitive behaviours, but their accompanying adverse effects limit their use to patients with severe impairment (McPheeters et al., 2011)

Moreover, there is not enough scientific evidence to support the efficacy of using multivitamins including vitamin B6, Omega 3 supplements, and secretin in reducing the symptoms of ASD (Levy & Hyman, 2008). As a result, various kinds of intervention approaches for autism have been developed and these have built upon different psychological theoretical perspectives. The following are examples of some well recognised and widely used interventions within the ASD domain.

- The Discrete Trial Teaching or Applied Behavioural Analysis (ABA) approach is based on operant conditioning principles that are based on task analysis and performance (Lovaas, 1987). Applying behavioural principles to educational interventions that target the core deficits of autism, have been widely used and implemented within the autism domain (T. Smith, 2001). This approach focuses on observing, identifying, defining and measuring behaviours to obtain a sound understanding of such behaviours and how the individuals' learning is influenced. Indeed, applying such principles might take several forms based on intervention goals, whether to manage the child's difficult behaviour or to teach a child specific skills (T. Smith, 2001). Positive reinforcement is used to encourage or prevent a specific behaviour and ignoring the targeted behaviour is believed to be an essential technique to increase or decrease the occurrence of the behaviour in question (Lovaas, 1987).

- Pivotal Response Training (PRT) (Robert L Koegel & Kern Koegel, 2006) is an incidental teaching methodology that has at its core the teaching methods and reciprocal imitation training approaches that focus on enhancing the child's motivational ability. This represents a more naturalistic intervention that relies on naturally occurring teaching opportunities and consequences (Schreibman, 2000). The overall aim of PRT is the improvement of autonomy, self-learning, and generalisation.

- The Picture Exchange Communication System (PECS) is an augmentative communication approach based on a pictorial system which can be used as a form of communication especially for nonverbal children (Bondy & Frost, 2001).
- *Floor Time* (Greenspan, Wieder, & Simons, 1998), and *The Denver Model* (Rogers & Dawson, 2010) are two approaches that focus on enhanced social and communicative abilities and a discovery process through the use of the natural environment and developing relationships (Eikeseth, Smith, Jahr, & Eldevik, 2007; Landa, 2007; Vismara, Colombi, & Rogers, 2009). They focus on promoting social interaction between a child with ASD and an adult. In *Floor Time*, adults are instructed to follow the child's lead and build on what the child does to encourage further interaction. By following the child’s interests and motivations, parents help their child learn how to attend to others, engage in a dialogue and take initiative in social interaction with others.
- The *Treatment and Education of Autistic and related Communication-handicapped Children* (TEACCH) is a clinical service and professional training programme, based at the University of North Carolina. TEACCH is based on the principle of understanding an individual’s needs, interests and strengths, rather than emphasising his or/ her deficits in order to develop intervention strategies (Schopler, Reichler, DeVellis, & Daly, 1980). This approach focuses on learning within an organised structured environment and designing activities in ways that are understandable to the individual (Sheehy, 2001).

Evidence suggests that some intervention approaches such as TEACCH or ABA could be effective with children with ASD (Eikeseth et al., 2007; Rogers & Vismara, 2008). However, there is a lack of sufficient longitudinal studies that can provide evidence for the long-term effects of any of these approaches. In addition, there is no research evidence that favours one approach over another (Reichow, Volkmar, & Cicchetti, 2008), and it is widely agreed that there is no specific approach that could fit all children with ASD nor one method that could fit an individual’s different developmental levels throughout their life (Dymond, Gilson, & Myran, 2007; Reed, Osborne, & Corness, 2007).

Training parents of children with ASD might lead to an increase in their stress levels due to the increased demand on them (Wallen & Stagnitti, 2006). Limited findings have been reported on parental training courses currently provided (Pillay, Alderson-Day, Wright, Williams, & Urwin, 2011). Some of these parental programmes, such as *Early Bird* and *the Son-Rise* programmes have been designed specifically for parents of children with ASD.

*The Early Bird Programme* designed by the National Autistic Society (NAS) is a short-term early intervention package for parents of pre-school children with ASD. It is a three-month programme that aims to build parental confidence by providing the parent with the following: an explanation of the underlying deficit of ASD, ways of establishing communication with the child and examining triggers of the child's behaviour problems.

The *Son-Rise* programme by Kaufman and Kaufman (1976) was developed by Barry and Samahria Kufman after the couple were advised to institutionalise their child, Raun, who was diagnosed as severely autistic. They designed a home-based programme to help Raun and other parents of children with ASD, the Kufmans established the Option Institute and the Autism Treatment Centre of America. Their approach is intended to promote spontaneous, child-initiated social interactions following the child's lead. The Son-Rise programme is normally delivered by parents and volunteers within the family environment.

The *Stepping Stones Triple P and Triple P Programmes (*SSTP*)* are parenting interventions designed to improve the quality of parenting advice available to parents of children who have a developmental disability (Sanders, Mazzucchelli, & Studman, 2004). It includes intensive individually delivered face-to-face interventions, group interventions, cost and time effective brief interventions, large group seminars and media based interventions and is based on a number of contemporary theoretical perspectives in psychology including learning theory and applied behaviour analysis (Sanders, 1999) .

## Important Theoretical Perspectives Related to Parenting Children with ASD

A growing area of focus in the literature is the impact of raising a child with ASD on the family system. Exploring parents' experiences raising children with ASD is essential for developing programmes to support parents. Given the pervasive nature of ASD, research has investigated the wider impact of raising a child with ASD on members of the family unit. This literature suggests that ASD can have a detrimental effect on family life and, in particular parental well-being, marital relationship, and family functioning (Cridland, Jones, Magee, & Caputi, 2014; Hayes & Watson, 2013). The following section discusses three of the most dominant psychological theories of parenting in the literature and how these theories have been applied to parenting children with ASD. The theories are the *Double ABCX Model* by (McCubbin & Patterson, 1983), The *Transactional Model of Stress and Coping* (Richard S Lazarus & Folkman, 1984), and Social Learning Theory (Bandura, 1973).

The Double ABCX Model developed by McCubbin and Patterson (1983) explains the process of adaptation through the identification of key risk and protective factors (resources and appraisals) that may influence family functioning. Risk factors are considered as variables that increase the likelihood of adverse or negative outcomes in families (Kazdin, Kraemer, Kessler, Kupfer, & Offord, 1997), such as poorer well-being and maladaptation. Alternatively, protective factors act to reduce the impact of risk factors (stressors) on family outcomes, acting as potential buffers to improve well-being and support successful adaptation (Kazdin et al., 1997). In the Double ABCX Model, event (A) is defined as expected or unexpected life events that cause changes in the family system (e.g., diagnosis of a child with a disability). In addition to the initial stressor, the model accounts for a pileup of demands (aA factor) (e.g., prior strains within the family unit) that may add to the initial stress experienced by families (Manning, Wainwright, & Bennett, 2011; McCubbin & Patterson, 1983). Two variables proposed to moderate the impact of stressors on family outcomes are family resources and appraisals. While resources (B) include existing skills and resources that the family draws upon to cope with stressors (e.g., the support of family members, community), appraisals (C) consider the family’s interpretation and meaning they attribute to the situation (e.g., seeing the stressor as a challenge that can be overcome (Manning et al., 2011; McCubbin & Patterson, 1983). The model also accommodates for expanded resources (bB factor) obtained over time, as families learn to cope with the stressor, and subsequent changes in definitions and meaning (cC factor) of the overall crisis event. In addition to the three variables described, coping (BC factor) is an important factor that connects family resources and appraisals (Manning et al., 2011). Coping is viewed as the ability of family members to seek out and apply resources to manage a stressful event and restore balance within the family unit (e.g., seeking support from the community or one’s spiritual beliefs (McCubbin & Patterson, 1983; Pakenham, Samios, & Sofronoff, 2005). Family adaptation (xX) represents the outcome of interactions between the four components of the model. Represented by positive and/or negative outcomes, it symbolises a family's attempt at reaching a new level of stabilisation following a crisis event to the family system and when coping strategies  do not result in the restoration of family stability , maladaptation occurs (McCubbin & Patterson, 1983). The utility of the Double ABCX Model to explain adaptation in families raising children with ASD has been demonstrated in a number of studies in diverse populations (e.g., (Kaniel & Siman-Tov, 2011; Manning et al., 2011; Pozo, Sarria, & Brioso, 2013). It helps to explain the association between a child's ASD symptoms and the stress experienced by family members (Ekas & Whitman, 2010; Hastings & Johnson, 2001). Stressors (A) are related to ASD symptomatology and child behaviour problems (Brobst, Clopton, & Hendrick, 2009; Firth & Dryer, 2013). While child characteristics are identified as major stressors in the Double ABCX Model, additional stressors such as the pile-up of family demands (a) also impact families. Pile-up of demands refers to factors that may be indirectly related to difficulties experienced as part of raising a child with ASD (e.g., the loss of a family member) (McCubbin & Patterson, 1983). Such factors have been found to play an important role in family adaptation (M. M. Bristol, 1987). Family resources are one factor (bB) suggested by the Double ABCX Model that influence the interaction between stressors and family adaptation while raising children with ASD including marital and social support. Social support may act as a buffer against the negative impact of stressors (Benson & Karlof, 2009; Kapp & Brown, 2011). Moreover, adaptation is affected by the manner in which families perceive and interpret the stressful event (cC) (e.g., in a negative or positive way). Forms of appraisals in families of children with ASD include self-control(Bristol, 1987); challenge and threat (Kaniel & Siman-Tov, 2011); and reframing (Manning et al., 2011). Family cohesion and its sense of commitment, ability to see stressors as a challenge, and a sense of control help in appraising the situation in a positive way (Reed et al., 2007; Seligman & Darling, 2009). In the Double ABCX Model, coping (BC) is the factor that connects resources, appraisals, and behavioural strategies to restore a balance in family functioning, and there is evidence to suggest that applying coping strategies to a stressful event is associated with reports of greater parental well-being in families of children with ASD (Benson, 2010; Cappe, Wolff, Bobet, & Adrien, 2011). Family Adaptation (xX) explains both positive and negative outcomes occurring in families raising children with ASD predicted by different factors (Hastings 2002).

Richard S Lazarus and Folkman (1984) also provided a model of stress and coping in which they suggested that stress is dependent on the appraisal that arises from the interaction of the person and the environment and that a stressor is defined by the subjective judgment of the situation that is appraised as harmful. This suggests a conscious strategy in responding to stressful events that could be divided into primary and secondary appraisals (Richard S Lazarus & Folkman, 1984). A primary appraisal is a cognitive event in which a potentially stressful situation is evaluated in terms of its significance for the well-being of the individual as being stressful, irrelevant, or positive (Folkman & Lazarus, 1980). A secondary appraisal involves the evaluation of coping recourses and options in determining what might and can be done in response to that event.

The nature and degree of emotions experienced is dependent on the meaning of the event to the individual. In their study of American Latino mothers of children with autism, Chavira, Lopez, Blacher, and Shapiro (2000) found that mothers who attributed a high versus low degree of responsibility to their children when they exhibited problem behaviours were significantly more likely to report experiencing negative emotions such as anger and to report that they respond in aggressive ways. Moreover, studies that have examined self-blame in mothers of children with developmental disorders such as autism, have found that the experiences of grief, worry, anger, and sadness, that occur when given a diagnosis can often be combined with questioning if they somehow contributed to their child’s developmental delay (Siegel, 1997; Sullivan, 1997). The above suggests a fairly important role for parental understanding of ASD and how parental appraisal of child behaviour and the parents’ ability to relate that to the child’s autism or stage of development has significant implications for how that parent copes with on-going care demands.

The *Social Learning Theory* developed by Bandura (1973) stipulates that learning is a cognitive process that takes place in a social context. The learner does not passively receive information from the surrounding environment; rather, it is the behaviour, cognitive process, and the environment that all influence each other. Learning occurs by observing the behaviour and its consequences, then extracting information from the observable situation, and finally making the decision to display the observed behaviour. Therefore, learning occurs even if the observed behaviour was not reproduced. Learning involves observation, extraction of information, and making decisions about the performance of the behaviour (observational learning or modelling) (Bandura, 1977). Bandura (1977) outlined that children are presented with many models in their environment, such as friends and caregivers who can be considered to be influential models.

The Social Learning Theory has been applied in previous studies to children with ASD (Buggey, 2005; Wert & Neisworth, 2003). Attention and motivation are essential to observational learning and most children with ASD display deficits in these skills due to the nature of ASD. In a meta-analysis by Bellini and Akullian (2007) of video modelling interventions involving individuals with ASD watching a video demonstration and then imitating the behaviour of the model, video modelling has been proved to be significant in increasing social communication skills and reducing behaviour problems. The results of a systematic review by Ayres and Langone (2005) of the literature of using video modelling with children with ASD has supported the notion that skills children learned via video modelling were applied across different settings and that the positive gains made during the video modelling intervention are maintained for months following the end of the interventions. This is particularly important for children with ASD who have considerable difficulties transferring skills from one setting to another. Therefore, based on the Social Learning Theory, parents can act as models for their children with ASD’s behaviour. Some examples of well-known interventions for children with ASD based on the Social Learning Theory is the *Pivotal Response Training* (PRT) which is based on Social Learning Theory and operant conditioning techniques. Also *social stories* training and practice helps in accurate understanding of social situations and enables a child with ASD to respond appropriately to different social cues (McConnell, 2002).

### Autism in the Context of the Kingdom of Saudi Arabia

As the focus of this research lies within the Saudi context, it is imperative to discuss ASD and related services within that particular context. The KSA, which is located in the Arabian Peninsula in the Middle East, has an estimated population of 27.5 million (22.0 million of which are Saudis) who live in approximately 2,150,000 Km2 (The Saudi Central Department of Statistics and Information, 2013). It is a monarchy with a Council of Ministers and Consultative Council (Al-Mosa, 1999). The national language is Arabic and the dominant religion is Islam (Al Zahran, 2007). The country consists of thirteen provinces and Saudi’s main cities are Riyadh (the capital), Jeddah (the port and Saudi’s second biggest city), Makkah and Madinah (the two holy Islamic cities).

The earliest recorded history of special education in KSA was in 1958 when Mr Al-Ghanem, a foreigner working in the country, who introduced the Braille system to other blind men in KSA (Al-Mosa, 1999). In response to the demand for establishing educational services for people with disabilities in KSA, the Ministry of Education has established in 1962 the Department of Special Learning to target children experiencing difficulties due to visual or hearing impairments and intellectual disabilities (Al-Turaiki, 2000).

Educational and intervention services for people with ASD in KSA are still in the infancy stage. The establishment of autism centres in Saudi Arabia began with the individual efforts of a mother of a child with ASD who established a small class for children with ASD in Jeddah in 1993 (Al-Turaiki, 2000). This class was the first of its kind to offer educational and intervention services for people with ASD in KSA. This class grew to become one of the pioneering private centres for children with ASD in Jeddah. After that the government started to facilitate and establish government sponsored programmes for children with ASD in 1998; the first of which were educational programmes attached with special educational institutes in Saudi's main cities of Riyadh, Jeddah, and Dammam (The Saudi Autistic Society, 2003). One year after that, another private centre was established in Riyadh, in 1999. An important step towards establishing services for people with ASD was the launch of the *National Project for Children with Autism* by the Council of Ministers in 2003 which aimed to establish governmental centres for the diagnosis and education of children with ASD in KSA. Another aim was to encourage the establishment of training courses and programmes that would help to prepare qualified teachers in the field of ASD (The Saudi Autistic Society, 2003). As a result of that, in 2004, the first governmental autism centre was established in Jeddah to provide services for school aged girls with ASD. Then, the first government centre for the diagnosis of ASD was opened in Riyadh in 2007. Saudi Arabia is trying to find ways to cope with the growing number of autistic children as both early intervention programmes and parental training courses are limited due to the shortages of professionals and facilities (Al Jarallah, Al Waznah, Al Ansari, & Al Hazmi, 2005). Therefore, to meet the increased demand for ASD services, most ASD organisations were provided by charitable (not-for-profit) organisations run by the voluntary sector and supervised by the Ministry of Labour and Social Development (Al-Turaiki, 2000). Al-haider (2006) has discussed some issues based on parents' complaints regarding the shortages of services that are being provided for people with autism and their families , the same issues were also raised by (Alsunbal, Alkhatib, Metwally, & Nuraldin 2004).

Early intervention services are provided in ASD organisations in KSA for children with ASD which includes a multi-disciplinary service, where multiple approaches are provided for children based on their own developmental needs. This might include psychological services, diagnosis and assessment, family counselling and training, occupational therapy, speech therapy and behavioural modification. Autism organisations only accept children with a formal diagnosis of ASD from psychiatrists or a neurodevelopmental paediatrician but they also perform a comprehensive evaluation of the children before accepting them. This evaluation includes a confirmation of their clinical diagnosis based on DSM-5 criteria, performed using the CARS /and/ or the ADOS and the ADI-R, along with an assessment of the child's educational needs. Autism organisations are single-sex as Saudi culture is primarily centred around Islamic religious beliefs, which prevents the mixing of genders (Al-Salloom, 1995). It should be noted that ASD services in KSA are only day care with no full-time services and they accommodate only mild to moderate cases of ASD so that more severe cases usually have to travel to surrounding countries (e.g., Jordan) for more services (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009b).

There was found to be a lack of studies that aim to develop or evaluate KSA educational services and their effectiveness on both the child and the family. As a result, the Council of Ministers issued an order for a study to be undertaken by the Ministry of Health to investigate ASD in KSA including its prevalence rate (The Saudi Autistic Society, 2003). The study results were published in 2005, and the results showed that the overall prevalence rate of ASD in KSA is 0.6 with the highest prevalence in the western province of the country (in the cities of Makkah and Jeddah) (Al Jarallah et al., 2005). The limited number of studies that have been conducted on ASD in KSA have focused mainly on evaluating the effect of different types of interventions on children's outcomes, including for example the effect of dietary intervention (Al Luhaibi, 2009); art therapy (Al Najjar, 2014); and verbal communication (Sulyman, 2014). Only three studies to date, to the best of the author's knowledge, have evaluated parental interventions for parents of children with ASD in KSA. Qutub (2012) has evaluated the efficacy of electronic counselling in training mothers of young children with ASD, who live in remote areas to build and implement educational plans for their children with minimal online therapist support. The study was a randomised controlled trial that included only 12 mothers in each arm and only the children's outcomes were measured to evaluate the proposed intervention (Qutub, 2012). Another study by Al Qadi (2010) has evaluated in a non-randomised controlled trial the effectiveness of a counselling intervention for reducing stress in parents of children with ASD. The study included only 15 parents (eight in the intervention arm and seven in the control) who were recruited from one class in one ASD organisation and the study used only one measure of stress that was designed by the author of the study (Al Qadi, 2010). The third study by Jaber (2007) has evaluated in a randomised controlled trial the effectiveness of a proposed counselling programme for reducing stress in mothers of children with ASD in KSA. The programme focused mainly on enhancing maternal well-being and strategies to help mothers deal with pressure, while nothing about ASD was included. The study included 30 mothers (15 in each arm) and used only one measure of stress that was created by another researcher (Jaber, 2007).

It is clear from the discussion above that there is an increased need for services for parents of children with ASD in KSA and more scientifically rigorous studies to design and evaluate parental intervention.

### Thesis Aims

This thesis had many aims. First, to understand the impact of having children with ASD on parental life both internationally and in the context of KSA. Second, to explore the unmet needs and requirements of mothers of children with ASD in KSA. Third, to evaluate the effectiveness of the available parenting interventions on parental functioning, for parents of children with ASD. Fourth, to develop and evaluate quantitatively and qualitatively the effectiveness of a brief psychoeducation intervention for mothers of children with ASD in KSA.

To attain thesis aims, this thesis employed a series of qualitative and quantitative studies separately and the main trail used what is referred to as an *embedded mixed-method* approach developed by (Creswell & Clark, 2011). According to Creswell and Clark (2011), in an embedded study, "one data set plays a supportive secondary role in a study based primarily on the other data type" (p.296). The purpose of using the embedded design with the main trail in this thesis was to collect different types of data (quantitative and qualitative) to answer different questions which allows for a further qualitative exploration of the participants' acceptability and views on the trial. Qualitative studies can provide information that help to capture further information about treatment outcomes, which is not otherwise possible using quantitative measures (Campbell et al., 2000). To achieve the first aim of the thesis, a systematic literature review of international literature was undertaken to investigate the impact of having children with ASD on parental life (Chapter 2). Next, to accomplish the second aim, a qualitative pilot study exploring the unmet needs of mothers of children with ASD in KSA was undertaken as the literature yielded only limited findings about mothers of children with ASD in KSA (Chapter 3). To achieve the third aim, a meta-analysis was conducted to quantitatively evaluate and measure the effect of parenting intervention on parental functioning and practices for parents of children with ASD (Chapter 4). Finally, to attain the fourth aim of this thesis, a pragmatic RCT was run to investigate the effectiveness of a self-help psychoeducation intervention with minimal therapist support delivered via WhatsApp for mothers of children with ASD in KSA (Chapter 6). A qualitative study that employed semi-structure interviews with mothers who took part in the intervention was conducted to qualitatively evaluate mothers' views of the intervention (Chapter 7).

# Chapter Two: The Impact of Childhood Autism Spectrum Disorder on Parental Life: A Systematic Review

## Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that leads to "persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behaviour, interest, or activities" (APA, 2013, p. 53). The American Psychiatric Association in the DSM-5 states that the worldwide population prevalence of ASD is about 1%. The subcategories of ASD in the DSM-IV were combined into one ASD broad-spectrum category in DSM-5 (APA, 2013). The new category now encompasses Autistic disorder, Asperger syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (APA, 2013).

ASD impacts the whole family, as children with ASD can place excessive demands on parents and high stress on the family unit (McConkey, MacLeod, & Cassidy, 2011). The core difficulties associated with ASD lead to challenges for parents, and prior research findings have highlighted challenges associated with parental well-being and adjustments. This is in keeping with the Double ABCX Model of stress and coping, which helps to explain adjustment in parents of children with disabilities (M. Bristol, 1987). This model suggested that the outcome of adaptation depends on several factors, including stressors, social support, perception of the situation, and coping strategies.

Previous reviews on ASD have focused on diverse topics from evaluating parental or child interventions (Case-Smith, Weaver, & Fristad, 2014; Warren et al., 2011) to medical interventions and environmental toxicants (McPheeters et al., 2011; Rossignol, Genuis, & Frye, 2014b).

To our knowledge, no systematic review exists that explores the impact of ASD on parental life, as most of the available reviews have focused on evaluating educational or medical interventions. One broader narrative review exploring the impact of autism on parents and families that develops a model of intervention evaluation does exist, but this was not conducted systematically (Karst & Van Hecke, 2012). Therefore, the main aim of this review was to systematically examine the available literature related to the effects of ASD on parental life, including the well-being of parents of children with ASD and their unmet needs and challenges.

## Method

### Search Strategy

A systematic literature search was conducted to identify studies that examined the impact of ASD on parental life. Articles published in peer-reviewed journals from the inception of the DSM-IV in 1994, to January 15, 2014, were investigated. Web of Knowledge, Psych Info., Pub Med, and the Cochrane library (for reviews) were searched for relevant studies. Key journals were searched by hand, including the Journal of Autism and developmental disorders, Autism, and the journal of Autism research. Reference lists of identified papers were also searched for additional information. Searches were conducted using a combination of the following MeSH terms and words: *autism, autistic disorder, childhood autism, autism spectrum disorder, parent, family, impact, mother, father, challenge, parenting, ASD*, *Asperge*r and *effect.*

The systematic search generated 6,792 citations for screening which involved three stages: (a) inclusion based on title only, (b) inclusion based on abstract, and (c) inclusion based on full text (Figure 1). Each stage was completed by a minimum of two independent reviewers and the reasons for excluding certain studies were documented (Appendix 1). Due to the diverse nature of the included studies in this review in terms of methods, measures, outcomes, and the heterogeneity of the study designs, meta-analysis was not conducted and the narrative synthesis approach was used to summarise the findings.

### Inclusion and Exclusion Criteria

Studies were included if they explored the impact of childhood ASD on parental life and functioning. Studies were excluded for the following reasons: i) they were not published in English ii) not in a peer-reviewed journal iii) the sample age was not in the range 18 months to 12 years ( infancy to primary school age) iv) the study was conducted with participants who did not have a formal diagnosis of autism v) children with autism were chosen on the basis of their social and communication difficulties only in line with DSM-5 criteria for ASD vi) studies that focused only on children with ASD with unusual or unique co-morbidity (e.g., children with ASD who were blind) viii) studies that focused only on the impact of autism on siblings, grandparents, caregivers, and teachers ix) studies that explored medical interventions for parents of children with ASD, and x) review papers. To avoid selection bias, screening and selection procedures were independently conducted by two reviewers, AH and DD, with an agreement rate of 88% that was resolved by discussion until consensus was reached. Fifty three papers were included in the final review.

The quality of the included papers were assessed using the Mixed Methods Appraisal Tool (MMAT) designed for appraising the quality of studies in systematic reviews with mixed methods studies (Appendix 2) (Pluye et al., 2011). The results from the tool lead to an overall methodological score calculated as a percentage and the criteria for determining the quality score varies by design. The majority of the included studies (26 studies in 25 articles) scored 75%, and (23 studies) scored 100%, while only four studies scored 50% and one study scored 25% (more details and reasons for scoring each article is presented in Appendix 3) . Overall, the MMAT study quality tool indicated that the majority of the included studies were of high study quality.

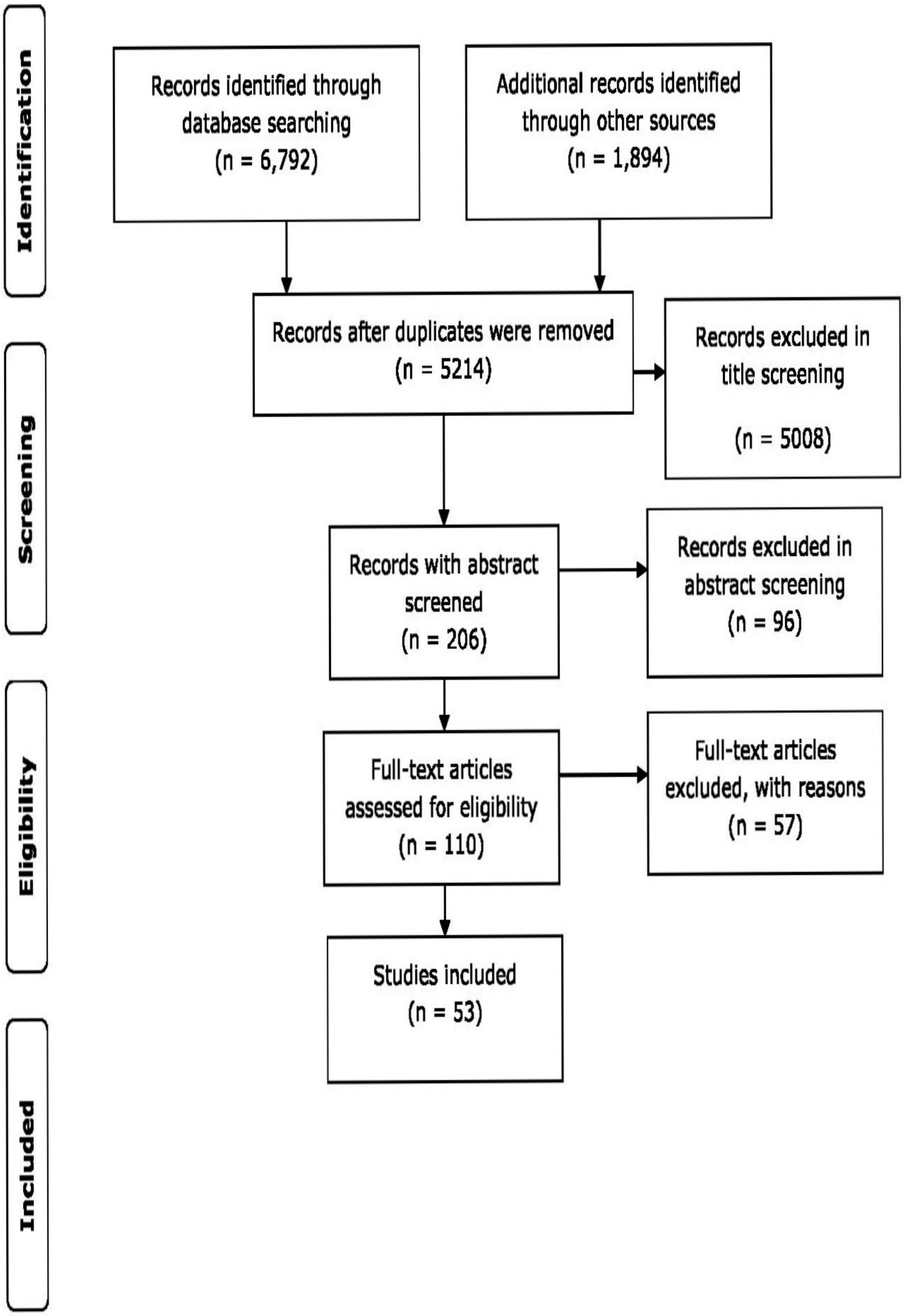

**Figure 1. Adapted PRISMA diagram (Moher et al., 2009)**

# Findings

## Studies’ Characteristics

The identified studies consisted of 40 quantitative studies, nine qualitative studies, and four mixed methods studies (Table 1) with the majority of included studies being cross-sectional in design. The studies were from different countries around the world with the majority based in the US or in European countries. The studies’ characteristics along with their main findings are shown in Table 1.

**Table 1. Characteristics of Included Studies**

| Study ID* | Study design | Country | Sample size | Gender (F) female (M) male | Child mean age (Yr) year (mos.) mon-ths | Study aim | Summary of main conclusions |
|---|---|---|---|---|---|---|---|
| Allik 2006 | 2 groups cross sectional | Sweden | 61 parents of ASD children +<br>59 parents of TDC | 61<br>95 | 10 .8 yr | To evaluate aspects of health-related quality of life in parents of children with HF ASD | Mothers of HF ASD/ Asperger children experienced poorer physical health than mothers of TDC |
| Al-Mansour 2013 | Retrospective cohort | Saudi Arabia | 50 cases ;50 controls | 34<br>16 | 5.24 yr | To evaluate the presence of depression and anxiety in parents | High levels of parental depression and anxiety |
| Altiere 2009 a | Cross sectional | USA | 52 parents | 26<br>26 | 7.5 yr | To analyse coping behaviours for parents | Family cohesion associated with use of positive coping strategies |

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|---|---|---|---|---|---|---|---|
| Altiere 2009 b | Qualitative<br>(QUAL) | USA | 52 parents | 26<br>26 | 7.54 yr | Exploring parents struggles and success parenting their children | Parents who experienced social isolation, emotional and financial problems also have positive views of child |
| Aylaz 2012 | QUAL | Turkey | 12 parents | 6<br>6 | 10 yr | Investigate the difficulties experienced by parents on their relationship | Families had difficulties coping with the social and economic burden which negatively affected their relationship |
| Baeza Velasco 2013 | Longitudinal | France | 119 parents | 119<br>119 | 4.9 yr | Examine the occurrence and timing of separation of parents | ASD was not found to be a cause of separation |
| Baker-Ericzen 2005 | Quasi-experimental | USA | 37 mothers and 27 fathers of ASD children and 23 mothers and 16 fathers of TDC | 60<br>43 | 28.35 mos. | Investigate the association of having a child with ASD on parental stress | Parents of children with ASD more stressed than parents of TDC |
| Belgin 2010 | QUAL | Turkey | 43 mothers | 43 F | 9 yr | Explore the impact of having ASD child on Turkish mothers | Mothers burdened by financial problems |

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|---|---|---|---|---|---|---|---|
| Benson 2009 | Longitudinal | USA | 90 parents | 84<br>6 | 7.6 yr | Investigate the relation between ASD symptoms, depression, anger, and stress | Stress mediates ASD symptoms and depression, anger mediates ASD symptoms and stress |
| Bishop 2007 | cross sectional | USA | 110 mothers | 110 F | 9.28 yr | Identify predictors of perceived negative impact on mothers | Perceived negative impact associated with less social support, less adaptive behaviour, and more ASD symptoms |
| Bundy 2009 | Mixed methods | USA | 24 parents | 83% F | Average 9.5 yr | Explore the experiences of stress in parents of HF ASD | Parents of HF ASD have higher levels of stress |
| Carter 2009 | Longitudinal | USA | 43 mothers | 143 F | 28.3 mos. | Examine developmental patterns in maternal depressive symptoms | Elevated levels of depression stabilise over time |
| Cidav 2012 | 3 groups cross sectional | USA | 261 children with ASD and 2921 children with limitation and 64349 children with no limitation | Not available | 10.45 yr | Examine parental labour force, participation,<br>hours of work, and annual earnings | Families earned less money than families of TDC or families of children with other disabilities |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Dardas 2013 | 2 groups cross sectional | Jordan | 114 mothers and 70 fathers | 114<br>70 | 6.3 yr | Examine psychological correlates of QOL of parents | Parenting stress highly associated with QOL |
| Davis 2008 | 2 groups Cross sectional | USA | 108 parents | 54<br>54 | 26.9 mos. | Examine differences in mothers and fathers experiences with stress | Mothers and fathers responded differently to ASD characteristics |
| Dillenburger 2010 | Mixed methods | Ireland | 95 parents and<br>67 professionals | 88% F<br>9% fathers and<br>3% guardians | 8 yr | Examine the impact of ASD child on parental views of their life and its differences from professionals' views | Parents of ASD children more susceptible to psychological problems than general population |
| Divan 2012 | QUAL | India | 10 families of ASD children+ 10 stakeholders from child care sectors+ 74 special educators | 9<br>3 | 10.4 yr | Describe the experiences and unmet needs of families in India | Families faced many social and personal challenges as a result of ASD |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Dunn 2001 | Cross sectional | USA | 85 parents | 39<br>19 | 7.47 yr | Examine the relation between stressors, social support, coping styles, and negative outcomes | Coping styles and social support moderated stress and negative outcomes |
| Ekas 2009 | Cross sectional | USA | 119 mothers | 119 F | 9.45 yr | Examine whether and how religious resources related to maternal functioning | Religious beliefs associated with lower negative and higher positive outcomes |
| Ekas 2011 | Daily diary method | USA | 46 mothers | 46 F | 10.17 yr | Investigate the relation between stress and negative affect | Stress associated with negative affect |
| Epstein 2008 | 2 groups cross sectional | Scotland | 39 parents | 38<br>24 | 9.42 yr | Study parenting stress and its relation with associated difficulties with ASD | Parents of children with ASD reported elevated level of stress |
| Estes 2013 | 3 groups cross sectional | USA | 46 ASD parents and 25 DD parents and 25 TDC parents | 96 F | 23.33 mos. | Examine parent stress in mothers | Higher maternal stress compared to TDC sample |

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|---|---|---|---|---|---|---|---|
| Faso 2013 | Cross sectional | | 71 parents | 53<br>18 | 4-12 yr | Examine how vicarious<br>futurity related to hope, and how each predicted well-being | Vicarious futurity predicts less stress and trait hope predicts less depression |
| Gray 2003 | QUAL | Australia | 53 parents | 32<br>21 | Median age 12 yr | Explore the role of gender in coping in families of HF ASD | Mothers and fathers of HF children cope differently |
| Gau 2012 | 2 groups cross sectional | Taiwan | 151 parents of ASD + 113 parents of TDC | 63<br>102 | 7.83 yr | Investigate the psychopathology, marital relationship, and family<br>function in parents | Parents reported more mental health and marital problems than parents of TDC |
| Hall 2011 | 2 groups cross sectional | USA | 73 parents | 51<br>24 | 8 yr | Examine adaptive behaviours, family support, parenting stress, and parent coping | Parents of children with ASD reported elevated levels of stress |
| Hastings 2003 | 2 groups cross sectional | UK | 18 couples | 18<br>18 | 11.8 yr | Investigate interrelationships between mothers' and fathers' | Maternal stress associated with child behaviour problems and paternal mental health |

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|---|---|---|---|---|---|---|---|
| | | | | | | psychological<br>well-being | |
| Hastings 2005 | Cross sectional 2 groups | UK | 89 parents<br>of 48 ASD children | 48<br>41 | Mean 37 mos. Range 28-45 | Address relationships between child, partner, and parent variables | Maternal depression higher than paternal but mothers have more positive perceptions |
| Hoffman 2008 | Cross sectional | USA | 72 mothers | 72 | 8.3 yr | Examine children's sleep difficulties, ASD severity, and mothers' sleep problems in relation to stress | Child sleep problems related to ASD symptoms are predictive to maternal stress |
| Hoffman 2009 | 2 groups cross sectional | USA | 104 mothers of ASD and 342 mothers of TDC | 446 F | 8.61 yr | Examine the relation between maternal stress and closeness | High maternal stress did not impact closeness to child |
| Huang 2013 | Cross sectional | Taiwan | 52 caregivers | 86.5% F | 6.33 yr | Examine the effect of ASD symptoms on parental stress | Curvilinear relationship between stress and ASD |
| Kaniel 2011 | 2 groups cross sectional | Israel | 176 parents | 88<br>88 | 10.3 yr | Examine differences in coping between mothers and fathers | Both parents of ASD children viewed ASD as a threat to their marriage |

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|---|---|---|---|---|---|---|---|
| Kapp 2011 | Mixed methods | South Africa | 19 mothers | 19 F | Median age 7 yr | Explore adjustment and adaptation in families | Mothers are resilient employing many coping mechanisms |
| Kuhaneck 2010 | QUAL | USA | 11 mothers | 11 F | 8.3 yr | Examine effective coping strategies for mothers | Mothers of ASD children used many successful coping strategies |
| Lee 2009 a | 2 groups cross sectional | USA | 89 parents of ASD children and 46 parents of TDC | 65<br>27 | 9.5 yr | Examine QOL in parent of HF ASD compared to parents of TDC | Parents of children with HF ASD experience low quality of life |
| Lee 2009 b | 2 groups cross sectional | USA | 48 of parents of HF ASD and 26 of parents of TDC | 38<br>36 | 10.43 yr | Investigate coping differences in relation to psychological adjustment in parents of HF ASD compared to TDC | High levels of stress, depression, marital problems and coping difficulties in parents of HF ASD |
| Lickenbrock 2011 | Daily diary method | USA | 49 mothers | 49 F | 10.18 yr | Examine the associations between mothers' perceptions of children, martial adjustment, and well-being | Positive maternal perceptions predicted maternal well-being and marital adjustment |

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| Lin 2008 | QUAL | Taiwan | 17 parents | 13<br>4 | 4.5 yr | Understand coping mechanisms of Taiwanese parents | Parents used changing their views, and support seeking as coping methods |
| Meltzer 2008 | Longitudinal | USA | 32 parents of ASD and 25 parents of TDC | 35<br>22 | 6.3 yr | Examine sleep patterns in parents of ASD children and parents of TDC | Parents reported poorer sleep quality than parents of TDC |
| McCabe 2010 | QUAL | China | 70 mothers | 70 F | 3-12 yr | Examine experiences with and meaning of employment in the lives of mothers | Mothers had to sacrifice their employment to take care of their child |
| Meirsschaut 2010 | Mixed methods | Belgium | 17mothers of ASD and TD children | 17 F | 68.94 mos. | Examine parenting experiences of mothers in a family with ASD child and TDC | Mothers experience high stress and depression and low parenting self-efficacy |
| Meltzer 2011 | 2 groups cross sectional | USA | families of 34 ASD and 34 TDC children | 17<br>11 | 6.6 yr | Examine child and parent sleep as factors associated with depressive symptoms | Parental sleep quality predicted depression |

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|---|---|---|---|---|---|---|---|
| Mori 2009 | 2 group cross sectional | Japan | 193 families (30 Asperger’s families + 163 ASD families) | 193<br>181 | Asperger’s<br>8.40 yr<br>ASD<br>7.20 yr | Examine levels of stress in parents of ASD children in comparison to parents of Asperger | Stress higher in parents of children with Asperger compared to parents of ASD children |
| Osborne 2009 (study1) | Longitudinal | UK | 65 children and their parents | 6<br>59 | 3.4 yr | Evaluate the relation between ASD symptoms, behaviours and parenting stress | ASD in younger children associated with parenting stress |
| Osborne 2009 (study2) | Longitudinal | UK | 72 parents | 2<br>70 | 8.8 yr | Examine the interaction between parenting stress and child’s behaviour problems | High stress at T1 predicts behaviour problems at T2 |
| Pakenham 2005 | Cross sectional | Australia | 47 mothers | 47 F | 10 -12 yr | Examine maternal adjustment in mothers of Asperger children | High levels of maternal depression and anxiety impacting adjustment |

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| Phetrasuwan 2009 | Cross sectional | USA | 108 mothers | 108 F | 6 yr | Examine the relation between stress and maternal psychological status | Low education and income predicted high parenting stress |
| Rivard 2014 | 2 groups cross sectional | Canada | 118 families | 118<br>118 | 2-5 yr average age 4 yr | Compare and analyse each parent's stress and identify factors that might predict their stress | Fathers reported higher levels of stress than mothers |
| Safe 2012 | QUAL | Australia | 7 mothers | 7 F | 8.6 yr | Explore the daily life experiences of mothers | Mothers experienced a paradox of emotions and social isolation |
| Siman-Tov 2011 | 2 groups cross sectional | Israel | 176 parents | 88<br>88 | 10.3 yr | Validate a multivariate model that predicts parental adjustment to coping | Parental stress associated with social support, ASD & locus of control |
| Sivberg 2002 | 2 groups cross sectional | Sweden | 66 parents of ASD children + 66 parents of TDC | 74<br>58 | 7.5 yr | Investigating relations between coping behaviour and the family system in Parents of ASD children in comparison to parents of TDC | Parents report higher level of strain in family compared to parents of TDC |

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|---|---|---|---|---|---|---|---|
| Wang 2012 | Cross sectional | China | 290 families | 42<br>248 | 5.44 yr | Determine the health expenses incurred by families of children with ASD | Families in China spent most of their yearly income on health expenses |
| Wang 2013 | Cross sectional | China | 150 mothers | 150 F | 5.15 yr | Examine maternal parenting stress and its associated variables | Maternal stress associated with depression, anxiety and child behaviour problems |
| Wisessathorn 2013 | Cross sectional | Thailand | 303 parents | 71.3% mothers +9.2 fathers+ 14.5 grandparents+5.0 others | 7.83 yr | Investigate the impact of ASD symptoms severity and optimism on QOL | ASD severity negatively correlated with QOL but optimism positively correlated with QOL |

*The study ID is the first author and the year of publication

Six different themes were identified from the literature search: i) response to children with ASD, ii) parental well-being, iii) relationships, iv) financial problems, v) positive perceptions, and vi) future worries (Table 2)

**Table 2. Themes and subthemes in included studies**

| **Study ID** | Well Being | | | | Relationship | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Anxiety | Depression | Stress + Coping | QOL | Marital | Divorce | Social Isolation | Stigma | Financial Problems | Positive Perception | Response | Future Worries |
| Al-Mansour 2103 | X | X | | | | | | | | | | |
| Alik 2006 | | | | X | | | | | | | | |
| Altiere 2009a | | | X | | | | X | | | | X | |
| Altiere 2009b | | | X | | | | X | | X | X | X | |
| Aylaz 2012 | | | | | X | | | | X | | X | X |
| Baeza Velasco 2013 | | | | | | X | | | | | | |
| Baker-Ericzen 2005 | | | X | | | | | | | | | |
| Benson 2009 | | X | X | | | | | | | | X | |
| Belgin 2010 | | | | | | | | X | X | | X | |
| Bishop 2007 | | | X | | | | X | | | | | |
| Bundy 2009 | | | X | | | | | | | | X | |
| Carter 2009 | X | X | | | | | | | | | | |

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|---|---|---|---|---|---|---|---|---|---|---|
| Cidav 2012 | | | | | | | | X | | |
| Dardas 2013 | | | X | | | | | X | | |
| Davis 2008 | | X | X | X | | | | | | |
| Dellinburger 2010 | | | X | | | X | | X | | |
| Divan 2012 | | | | | X | X | X | | | X |
| Dunn 2001 | | X | X | | X | X | | | | |
| Ekas 2009 | | X | | | | | | | | |
| Ekas 2011 | | | X | | | | | | X | |
| Epstien 2008 | | | X | | | | | | | |
| Estes 2013 | | | X | | | | | | | |
| Faso 2013 | | X | X | | | | | | X | |
| Gau 2012 | | | X | | X | | | X | | |
| Gray 2003 | | X | | | | | | X | | |
| Hall 2011 | | | X | | | | | | | |
| Hastings 2003 | X | | X | | | | | | | |
| Hastings 2005 | | X | X | | | | | | X | |
| Hoffman 2008 | | | X | | | | | | | |
| Hoffmann 2009 | | | X | | | | | | | X |
| Haung 2013 | | | X | | | | | | | |
| Kaniel 2011 | | | X | | X | | | | | X |

| | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|
| Kape 2011 | | | | | X | | | | X | X | |
| Kuhaneck 2010 | | | X | | | | | | X | | |
| Lee 2009a | | | X | X | | | | | | | |
| Lee 2009b | X | X | X | | X | | | | | | |
| Lickenbrook 2011 | | | X | | X | | | | | | |
| Lin 2008 | | | X | | | | | X | | X | X |
| Maltezer 2008 | | | X | | | | | | | | |
| McCabe 2010 | | | | | | | | X | | | |
| Meirrchaut 2010 | | X | X | | | | | X | | X | |
| Meltzer 2011 | | X | | | | | | | | | |
| Mori 2009 | | | X | | | | | | | | |
| Osborne 2009 | | | X | | | | | | | | |
| Pakenham 2005 | X | X | | | | X | | | | | |
| Phetrasuwan 2009 | | X | X | | | | | | | | |
| Rivard 2014 | | | X | | | | | | | | |
| Safe 2012 | | | | | X | X | X | | | X | |
| Siman-Tov 2011 | | | X | | X | | | | | | |
| Sivberg 2002 | | | | | | | | | | X | |
| Wang 2013 | X | X | X | | | | | | | | |
| Wang 2012 | | | | | | | | X | | | |
| Wisessathorn 2013 | | | | X | | | | | | | |

## Response to Children with ASD

Fourteen papers explored themes related to parental responses to children with ASD, including anger, denial, and emotional responses; they consisted of five quantitative studies, six qualitative studies, and three mixed methods studies (Table1). The quantitative research findings demonstrated that parents of children with ASD who perceived their children's ASD as a challenge rather than a problem demonstrated better coping skills (Huang et al., 2013). Sivberg (2002) found that parents of children with ASD were more likely to use avoidant coping strategies such as distancing and escape behaviour, while parents of typically developing children (TDC) were more likely to use problem solving and social support behaviours. Longitudinal studies demonstrated that viewing the stress of having a child with ASD as a threat led to poorer mental health and marital relationships in mothers but only poorer marital relationships in fathers (Kaniel & Siman-Tov, 2011). Benson and Karlof (2009) showed that parental anger was a significant predictor of both stress and parental depression and anger mediated the relationship between ASD symptom severity and parental stress as well as the relationship between parental stress and parental depression. However, Hoffman, Sweeney, Hodge, Lopez-Wagner, and Looney (2009) in their cross-sectional study showed that mothers of children with ASD maintained close emotional relationships with their children despite high levels of stress.

Qualitative studies demonstrated that parents of children with ASD respond with denial, anger and despair (Altiere & von Kluge, 2009b; Meirsschaut, Roeyers, & Warreyn, 2010) grief, and hopelessness, and they feel that having a child with ASD is a burden (Bilgin & Kucuk, 2010b). Parents of high-functioning (HF) autistic children worried about their parenting abilities and the lack of available resources (Bundy & Kunce, 2009) and blamed themselves and each other for their children's disabilities (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012).

## Parental Well-Being

Forty-three papers explored themes relating to parental well-being, including stress, depression, anxiety, coping, and quality of life (QOL); they consisted of 37 quantitative studies and six qualitative studies.

**Stress and coping**. Parents of children with ASD were found to experience higher stress levels than parents of typically developing children (TDC) (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005) .Up to one third of parents score above the clinical cut-off for stress in N. O. Davis and Carter (2008), while Hoffman et al. (2008) reported that the mean scores for stress in their maternal sample equated to the 90th percentile of normative scores,  Maternal stress was specifically associated in Hoffman's sample with children's sleep problems and ASD severity , and only with sleep problems in (Meltzer, 2008). However, Huang et al. (2013) reported a curvilinear relationship between ASD symptoms and stress, with caregivers of children with mild to moderate ASD reporting the highest stress levels.  Rivard, Terroux, Parent-Boursier, and Mercier (2014) reported positive associations between parental stress and child age, IQ, delay in provision of services, and adaptive behaviour.  In contrast, Estes et al. (2013) found that children's behaviour problems but not adaptive behaviour predicted stress in mothers of children with ASD although their sample was younger than that of Rivard et al. (2014).  Osborne and Reed (2009) demonstrated strong associations between ASD symptoms and parenting stress. Longitudinally, in two different studies, parenting stress at time 1 was a strong predictor of child behaviour problems at T2 rather than vice versa, highlighting the influence of parental stress on later child behaviour (Osborne & Reed, 2009).

Siman-Tov and Kaniel (2011) found that stress in parents of children with ASD was negatively associated with internal locus of control, meaning parents who felt they had more control were less stressed. Dardas and Ahmad (2013c) also reported a negative association between stress and quality of life.

Moderator analysis demonstrated that the relationship between ASD severity and parenting stress was moderated by age, with parents of younger children reporting higher stress (Osborne & Reed, 2009). Acceptance and escape avoidance coping moderated the impact of stress on QOL (Dardas & Ahmad, 2013c), and Phetrasuwan and Miles (2009) found that lower education and lower income were associated with higher maternal stress in parents of children with ASD. Meditational analysis demonstrated that ASD symptoms and parental stress is partially mediated by government support (Ji Wang et al., 2013), while parents with higher social support experienced less stress and therefore reported less severe ASD symptoms (Siman-Tov & Kaniel, 2011).

In qualitative findings, Altiere and von Kluge (2009b) showed that parents were stressed and depressed caring for their children with ASD. Parents of children with ASD used different coping techniques such as, sharing child responsibility with others, and educating themselves about autism to cope with the stress (Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010; Lin, Tsai, & Chang, 2008).

**Depression and anxiety**. Parents of children with ASD reported higher levels of depression than those of TDC (Lee, 2009 b; Meltzer, 2011). Parents of HF autistic children displayed very high levels of depression compared to parents of TDC (35% vs. 7.7%) (Lee, 2009 b). Comparable results were reported by Pakenham et al. (2005) in their Australian study. Carter, Martinez-Pedraza, and Gray (2009) showed that high depression scores in parents of children with ASD remained stable over a two-year period, while Lickenbrock, Ekas, and Whitman (2011) showed that negative maternal perception of children with ASD was associated with negative maternal affect 30 days later, which suggests that negative perception may drive the development of depression in these families.

Almansour, Alateeq, Alzahrani, Algeffari, and Alhomaidan (2013) in their cross-sectional study found that depression and anxiety scores were significantly higher in parents of children with ASD than parents of TDC. Lower levels of depression have also been found to associated with a higher internal locus of control (M. E. Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001), deeper religious beliefs, optimism, and self-esteem in mothers of children with ASD (Ekas, Whitman, & Shivers, 2009) as well as greater levels of hope (Faso, Neal-Beevers, & Carlson, 2013). Stress and depression have been shown to impact parents' perceptions of their parenting skills, as well as other siblings in the family (Meirsschaut et al., 2010) and to erode coping (Lee, 2009 b). Both maternal and paternal depression have been shown to be predicted by partners' depression levels (Hastings et al., 2005). Benson and Karlof (2009) demonstrated that informal social support was negatively associated with a depressed mood in parents over a two-year period.

Moderator analysis revealed that income and parent age moderated the relationship between Asperger symptoms and maternal depression; mothers with lower maternal age and lower maternal income experienced higher levels of depression (Pakenham et al., 2005). 'Marital adjustment' moderated the relationship between negative maternal perception and negative affect; negative perceptions in mothers with low 'marital adjustment' were found to be positively related to their negative affects (Lickenbrock et al., 2011). Marital relationship was also found to partially mediate the relationship between maternal positive perception and maternal well-being (Lickenbrock et al., 2011). Mediator analysis demonstrated that parental stress mediated the relationship between ASD symptom severity and depressed mood in parents of children with ASD (Benson & Karlof, 2009).

In a qualitative study by D. E. Gray (2003), mothers of children with HF ASD and/or Asperger syndrome reported feeling depressed about their children's disabilities.

**Quality of life.** Having a child with HF ASD affected parental QOL compared to parents of TDC (Allik, Larsson, & Smedje, 2006; Lee et al., 2009 a). Parental QOL was associated with the child's behaviour problems (Allik et al., 2006) and the severity of child's autism (Wisessathorn, Chanuantong, & Fisher, 2013). It was also positively correlated with the family's income (Dardas & Ahmad, 2013c) and optimism (Wisessathorn et al., 2013).

A moderator analysis revealed that stress, income, and the number of children in the family  moderated the effect of ASD on parental QOL; a higher income and the number of children were found to be associated with a better QOL, while higher stress was associated with a lower QOL (Lee et al., 2009 a).

A mediator analysis demonstrated that optimism acted as a partial mediator between ASD symptom severity and parental QOL; optimism in parents was found to buffer the effect of ASD symptoms on QOL (Wisessathorn et al., 2013).

### Future Worries

Two qualitative papers explored themes related to worries about the future of children with ASD. Parents were worried about the futures of their children, specifically after their parents' deaths (Aylaz, Yilmaz, & Polat, 2012). As a coping mechanism they were training siblings to take care of their children with ASD (Lin et al., 2008).

### Relationships

Seventeen papers explored relationship-related themes in parents of children with ASD, including marital problems, divorce, social isolation, and stigma; this included 10 quantitative studies, five qualitative studies and two mixed methods studies.

Parents were found to be socially isolated as a result of the stigma attached to their children's disabilities (Bilgin & Kucuk, 2010b) and restrictions in planning for their leisure activities (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Social support for parents of children with ASD was found to be positively associated with parental adjustment (Pakenham et al., 2005) and fewer marital spousal problems (M. E. Dunn et al., 2001), and it was negatively associated with the perceived negative impacts of ASD, which were also influenced by ethnicity and ASD severity (Bishop, Richler, Cain, & Lord, 2007). African American mothers, for example, were found to experience fewer negative impacts of having children with ASD than Caucasian mothers (Bishop et al., 2007). In contrast, social support did not help Chinese parents to reduce their stress (Jia Wang et al., 2012), and parents of children with ASD viewed social support groups as unhelpful (Hall & Graff, 2010).

Parents of HF children with ASD experienced lower marital adjustment than parents of TDC (Lee, 2009 b). Marital adjustment was associated with positive perception in mothers of children with ASD (Lickenbrock et al., 2011). Quality of marriage was negatively associated with the severity of ASD symptoms (Siman-Tov & Kaniel, 2011).

Baeza-Velasco, Michelon, Rattaz, Pernon, and Baghdadli (2013) found that raising a child with ASD did not cause couples to separate, as was believed; 74.8% of couples in the study remained together over a 10-year period. This was the only study identified in this review to study separation in couples raising children with ASD.

A moderator analysis revealed a complex picture in which decreased social support led to greater isolation during times of higher stress (M. E. Dunn et al., 2001). Coping styles practiced by parents moderated the relationship between stressors and isolation, and the use of avoidance and escape as coping methods led to more isolation in stressful times (M. E. Dunn et al., 2001). The quality of marriage was found to partially mediate the negative relationship between sense of coherence and stress in parents of children with ASD; a high sense of coherence in parents led to more confidence in parenting their children, which eventually led to less stress in those parents (Siman-Tov & Kaniel, 2011).

Parents of children with ASD were socially isolated because of the stigma associated with autism and they experienced marital conflict (Aylaz et al., 2012; Divan et al., 2012). Therefore, Huang et al. (2013) highlighted the importance of social support and good relationships between spouses in the adjustment process.

### Financial Problems

Twelve papers explored themes related to financial problems having children with ASD, including four quantitative studies, six qualitative studies, and two mixed methods studies.

Parents reported many financial problems resulting from low income (Bilgin & Kucuk, 2010b), career disruption (Altiere & von Kluge, 2009b; Lin et al., 2008; Meirsschaut et al., 2010), and the need to pay for expensive treatment and education for their children (Aylaz et al., 2012). Parents reported that their employment had been affected as a result of their children’s disabilities (Dillenburger et al., 2010; Gau et al., 2012); they were also less able to hold down full-time jobs and had to work for fewer hours due to the care demands of their children (Dillenburger et al., 2010).

Autism had a major economic effect on families of children with ASD (Cidav, Marcus, & Mandell, 2012; Jia Wang et al., 2012). ASD was found to cause more financial problems for families of children with ASD compared to a normal Chinese sample, as most of their yearly income was spent on services that are not covered by medical insurance in China (Jia Wang et al., 2012). Mothers were willing to sacrifice their employment to take care of their children due to the lack of special education services in China (McCabe, 2010). Only 56% of children with ASD had both parents who were employed, which is 15% less than parents of TDC, and mothers of TDC worked seven hours per week more than mothers of children with ASD (Cidav et al., 2012). The total income of American families of children with ASD was $17,763 less on average than that of families of TDC children (Cidav et al., 2012).

### Positive Perception

Six papers explored themes related to positive perception of children with ASD, including three quantitative studies, two qualitative studies, and one mixed methods study.

Huang et al. (2013) emphasised the importance of positive perception in families coping with ASD (Kuhaneck et al., 2010). Parents experienced positive growth as a result of their children’s disabilities, and they learned new ways to cope with problems and view the world (Altiere & von Kluge, 2009b).

## Differences in Findings between Mothers and Fathers

Mothers were found to experience higher levels of depression (N. O. Davis & Carter, 2008; Hastings et al., 2005) and anxiety (Hastings, 2003), but more positive perceptions (Hastings et al., 2005) than fathers, a finding also supported by previous narrative reviews (Karst & Van Hecke, 2012). Mothers were more reliant than fathers on informal social support from relatives and friends (Altiere & von Kluge, 2009a; Lee, 2009 b) and experienced poorer QOL (Allik et al., 2006). The cross-sectional findings of Rivard et al., (2014) showed that Canadian fathers reported higher stress than Canadian mothers of children with ASD, due to the fact that fathers worked full time and they were less able to be involved in their children’s care.

Parents also respond differently to stressors, with mothers more likely to respond to adaptive behaviours and fathers more likely to respond to problem behaviours in toddlers (N. O. Davis & Carter, 2008), while maternal but not paternal stress has been associated with child problem behaviours in school-aged children (Hastings, 2003; Hastings et al., 2005). Maternal stress has been associated with greater child impairment (T. Epstein, Saltzman-Benaiah, O'Hare, Goll, & Tuck, 2008), while paternal but not maternal stress has been associated with ASD symptom severity (Rivard et al., 2014). Maternal depression was predicted by sleep quantity, while paternal depression was predicted by sleep quality (Meltzer, 2011). A moderator analysis revealed that the child's age acted as a moderator only for mothers, with older children causing higher levels of stress (Rivard et al., 2014).

Qualitative results showed that fathers reported fewer impacts of their children's ASD symptoms than mothers, who reported that their careers had been affected because of their children's difficulties (D. E. Gray, 2003).

## Discussion

This review has used a systematic approach to search and identify the literature on the impact of childhood ASD on parental life. Fifty-three papers that explored the impact were identified, and the different impacts were highlighted in the review and grouped into six overarching themes: parental well-being, response, relationship, financial problems, future worries, and positive perception. The majority of the included studies focused on the well-being of parents of children with ASD, including their stress, depression, and QOL. The differences in findings between mothers and fathers were also identified.

The findings of this review were consistent with those of other reviews that looked at parental life of children with ASD. For instance, a review by Hayes and Watson (2013) that evaluated stress in parents revealed that parents of children with ASD suffered from higher levels of stress than parents of TDC. They also highlighted that mothers were mostly the participants in the included studies, with a lack of father's involvement, a conclusion that is similar to the findings in this review (AlHorany, Younis, Bataineh, & Hassan, 2013; Hayes & Watson, 2013). In a review that explored factors affecting depression in parents of children with ASD, AlHorany et al. (2013) demonstrated that mothers were more depressed than fathers, a finding that was also seen in this review, however, they concluded that there was not enough evidence in the literature about factors affecting depression, which contradicted the findings of this review that parental depression was predicted by ASD severity(Benson & Karlof, 2009), parental anger (Benson & Karlof, 2009), and partner's depression (Hastings et al., 2005).

The relationship between parental stress and ASD symptom severity is complex; while Hoffman et al. (2008) reported the expected linear relationship between ASD severity and parental stress, Hastings et al. (2005) reported no relationship between ASD severity and parental stress. Huang et al. (2013) demonstrated a non-linear relationship between ASD severity and parental stress, and other studies that did not show a relationship between ASD symptom severity and stress may have failed to establish any relationship by attempting to fit a linear model to a non-linear relationship (Phetrasuwan & Miles, 2009), while other studies only demonstrated a linear relationship for fathers but not mothers (Rivard et al., 2014). When children have very low levels of ASD symptoms, parents have fewer challenges to overcome, when children have very high levels of ASD symptoms, parental expectations for normative development are very low, and service provision may be very high, leading to few challenges. However, when ASD symptoms are moderate, parental expectations for normative development are high and service provision may be lower, leading to high levels of stress in the parents. Service providers need to target greater resources to support parents of children with moderate levels of ASD symptoms. Greater exploration of the relationship between ASD severity and parental stress is warranted to fully understand its relationship.

Only few studies have examined QOL, mostly among parents of HF children with ASD (Allik et al., 2006; Lee et al., 2009 a). This means that less is known about QOL in parents of children with more severe ASD symptoms. More studies are needed to compare QOL differences between parents of children with ASD at different levels of functioning or symptom severity, which would help to better understand QOL in parents. In line with the findings of this review, L. O. Smith and Elder (2010) in their systematic review also discovered that parents of children with ASD suffered from financial problems, lower QOL, and future worries.

Anxiety was understudied as a construct in parents of children with ASD. This is in direct contrast with depression, for which studies have not only compared rates of depression between parents of children with and without ASD but have also looked at what predicts depressive scores, as well as how depression mediates and moderates the relationship between ASD severity and other aspects of family life (Benson & Karlof, 2009; Pakenham et al., 2005). More research is required to better understand the role anxiety plays within families of children with ASD, as these parents are more anxious than parents of TDC.

Parents reported greater marital difficulties in cross-sectional studies (Gau et al., 2012; Lee, 2009 b) , a finding also supported by a previous narrative review (Karst & Van Hecke, 2012). However, in the only longitudinal study identified in this review on separation in parents of children with ASD (Baeza-Velasco et al., 2013), ASD severity did not predict separation. While this finding might appear counter intuitive the presence of a child with ASD may help to bring the parents together as they focus on helping their child, although this is at odds with the high levels of stress in these families (Kaniel & Siman-Tov, 2011). More studies are needed to explore the relationship between having a child with ASD and marital conflict and separation.

Fewer fathers than mothers participated in the studies included in this review. While we have attempted to appraise differences between parents, the views, roles and actions of fathers are considerably less well understood. While in most cases mothers are the primary caregivers and should remain the focus of research, greater effort needs to be made to ensure that research findings generated from mostly maternal samples translate to fathers of children with ASD.

Most studies included in the review recruited their sample via support groups or online groups, influencing the samples included in the analysis. For example, support groups are not available in all locations and are more likely to exist in urban than rural areas. More importantly, even if a support group is available, not all parents of children with ASD may wish to join, leading to an overrepresentation of parents who want to seek support in this systematic review and a potentially overrepresentation of the impact of ASD on the family.

Despite the many negative impacts of ASD on parental life, studies have also identified positive perceptions associated with having a child with ASD. The examination of positive perceptions remains understudied, and to date it has mostly been explored qualitatively. Greater examination of positive perceptions within families of children with ASD is warranted, especially a more sophisticated exploration of the possible mediating and moderating role of positive perception on parental life, building on Wisessathorn et al. (2013), who showed that optimism mediated the relationship between ASD severity and parental QOL.

Most of the studies identified in the literature that explained the themes of future worries and financial problems were qualitative in nature (Aylaz et al., 2012; Bilgin & Kucuk, 2010b; Dillenburger et al., 2010). More quantitative studies are needed to investigate the relationship between future worries, financial problems, and other constructs to ensure that the impact of ASD on family finances is objectively demonstrated rather than just a parental perception.

Few studies have explored the role of age on parental functioning. Almansour et al. (2013) found no effect of child’s age on parents’ anxiety and depression, while Rivard et al. (2014) found that parents of older children with ASD had higher levels of stress, which was assumed to be linked to poorer service provision for older children. Greater emphasis needs to be placed on exploring the influence of developmental age on parental functioning in families of children with ASD.

The influence of the socioeconomic status (SES) of parents of children with ASD on family life is not well understood and warrants greater exploration in the literature. The role of SES will need to be explored within different cultures and social care systems, which may offer greater or lesser support depending on parental SES.

The role of culture was also underexplored within the literature, as only a few studies looked at the role of culture (Bilgin & Kucuk, 2010b; Dardas & Ahmad, 2013c; Jia Wang et al., 2012), and as our society is becoming more multicultural, it will be of increasing importance to understand whether culture influences the impact of ASD on family life. In Bilgin and Kucuk (2010b), for example, Turkish mothers of children with ASD indicated that they felt that their problems would be resolved if shared with others who had similar problems.

The vast majority of the measures within the studies in this review were parental self-rated questionnaires, and the reliance on self-reported data leads to the possibility that associations are inflated by the use of self-reporting only. Future studies need to work harder to ensure greater independence of data, especially in mediation and moderation analyses (Pluye, 2013).

The majority of the studies within this review were cross-sectional, and more studies employing longitudinal methods are needed to examine how having children with ASD influences parental life over time and to explore the putative role of the development of children with ASD on their parents.

### Strengths

This review has explored an understudied area in the literature on childhood ASD. The main strengths of the methodology used in this review were the use of independent reviewers to check for the eligibility of the included studies and the inclusion of studies published in peer-reviewed journals only. Database searches were augmented by searching key autism journals manually. The review took an international viewpoint, with studies included from US, UK, China, Turkey, India, KSA, and South Africa. Many of the findings discovered in the literature are relevant across different countries. Knowledge about the impact of ASD on parental life will help in identifying the unmet needs of those families and therefore informing parenting interventions. The findings of this review are relevant to DSM-5 criteria.

### Limitations

A limitation in this review is that it only included studies published in English. The findings of this review might not extend to parents of children with ASD before receiving a formal diagnosis of ASD or for those whose children are still undergoing assessment.

## Recommendations for Practice

- Early interventions for parents of children with ASD should target children’s behaviour problems.
- Targeting stress in parenting interventions could be achievable through enhancing positive thinking in parents and encouraging them to use productive coping mechanisms like acceptance.
- By enhancing parental well-being, interventions may facilitate a balance in parental life.
- It would be useful for interventions to provide parents with means of allocating financial resources in their countries.
- Cultural values should be taken into consideration when designing and delivering interventions, as differences in values in the target participants might affect the target outcomes.

## Conclusions

Autism was found to affect the well-being of parents of children ASD; with stress and depression found to be the most recurrent well-being constructs in the literature. Autism was also found to cause marital conflict but not separation. It affected the economic life of parents, especially maternal employment. The importance of social support to parental adjustment was highlighted. Differences in findings between mothers and fathers were identified highlighting maternal stress to be more elevated than paternal stress in most of the studies.

# Chapter Three: An Exploration of the Unmet Needs of Mothers of Children with Autism Spectrum Disorder (ASD) in the Kingdom of Saudi Arabia (KSA)

## Introduction

Autism spectrum disorder (ASD) is a term used for a group of neurodevelopmental disorders (APA, 2013). These disorders are characterised by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviours. With the May 2013 publication of the DSM-5 diagnostic manual, all autism disorder categories were merged into one umbrella diagnosis of ASD. Autism statistics from the U.S. *Center for Disease Control and Prevention* (CDC) identify around 1 in 68 American children as having ASD (Centres for Disease Control and Prevention, 2014). According to the latest statistics from the King Abdulaziz City for Science and Technology, the prevalence rate of ASD among children in the Kingdom of Saudi Arabia (KSA) is one in every 180 (Salman, 2011). The low prevalence rate of ASD in KSA compared to the U.S could be attributed to the lack of up to date statistics about the prevalence of ASD and the difficulties associated with accessing diagnosis services in KSA which are only accessible to some of the population, specifically to those who live in big cities.

Parenting is widely acknowledged as a challenging role and can be associated with stress (Webster-Stratton, 1990) . Research has revealed that raising a child with ASD is a unique challenge for parents due to the nature of the disorder (McCubbin & Patterson, 1983). There is a lack of clarity about the most effective treatment options for ASD (Howlin, 1998). Uncertainty about the causes of ASD also adds to the challenges facing parents of children with autism (Dale, Jahoda, & Knott, 2006). Each person with ASD is unique and has different demands. Each of the behaviours associated with ASD may range from mild to severe. There is no biological or medical test for ASD; a diagnosis is only made through a thorough evaluation by a team of professionals.

Families with autistic children face many challenges because of the care demands and behavioural problems associated with the disorder. Having a child with autism in the family may have adverse affects on various domains of family life including marital relationship, sibling relationships and family routines (Greeff & Walt, 2010).

In their study about ASD in developing countries, Samadi and McConkey (2011) argue that research about parenting children with ASD "has been limited largely to families in Western countries" and that "research is needed to identify the particular needs of families in non-western countries" (p. 1). There is a gap in the literature on studies exploring the needs of mothers of children with ASD in KSA. Therefore, the goal of this study was to identify the unmet needs of mothers of children recently diagnosed with ASD in KSA. A multitude of information is available in the literature with regards to parenting experiences of mothers of children with ASD, mostly based on American and European samples. However, little is known about these experiences for mothers of children newly diagnosed with ASD in KSA. This study would thus not be similar to theses from other parts of the world due to the unique characteristics of each community. In Iran, for example, limited number of materials are published in Persian language for parents of children with ASD (Samadi & McConkey, 2011). Therefore, parents in Iran receive information about ASD through other parents due to their "inability, or limited ability, in English Language: which makes international sources of information inaccessible for them" (Samadi & McConkey, 2011, p. 5).

The traditional role of Saudi mothers involves taking complete care of their children, while the fathers take care of providing financial support for their families. Therefore, fathers have an inactive role in the care of their children with ASD. This may enhance the care burden for mothers. As no current evidence is available to inform research about the unmet needs and issues of Saudi mothers parenting their children with ASD, it was important to explore these needs within the cultural context of KSA.

### Objectives

The main objective of this study was to identify what mothers of children with ASD in KSA want and need to be able to support their children.

The second objective of this study was to examine the perspectives of mothers of children with ASD in KSA regarding the optimal support and services they expect to be provided following the diagnosis of their children.

## Methods

### Study Design

Patton (2002) argued that when "little is known about the nature of the phenomenon, qualitative inquiry is a reasonable beginning point for research" (p. 193). By using a qualitative methodology, the current study obtained extensive and detailed information that is directly relevant to the participating mothers and hopefully, therefore, to other mothers of children with ASD in KSA. A qualitative design was identified as the most appropriate way to meet the research aim of exploring the unmet needs of mothers of children with ASD in KSA. This study utilised semi-structured telephone interviews with eight mothers of children with ASD in KSA. The interview schedule (Appendix 4) was designed using open-ended questions to give the participants the opportunity to explain their needs and difficulties dealing with their children following the diagnosis. The interview schedule covered four main areas including: participants' experiences of having a child diagnosed with ASD; their unmet needs as mothers of children with ASD in KSA; their child's behaviours and how they cope with it; and their concerns and hope for the future of their children. Interviews were conducted in Arabic, the mother tongue language of people in KSA. The researcher is bilingual in both Arabic and English. She also holds a Bachelor degree in English Language. Two interview scripts were back translated into English for quality assurance so that the reliability of the coding could be verified by the supervisor DD.

### Data Collection

With the approval of the Faculty of Medicine Ethics committee at the University of Nottingham (Appendix 5) and the approval of the Ethics committee at the Joint Supervision Programme in King Abdulaziz University in KSA (Appendix 5) for the study to be conducted under their supervision, study information sheets and consent forms (Appendix 6) were distributed by the collaborating ASD organisation to all mothers of children recently diagnosed with ASD (in the past year) and whose children were still in the waiting list to be accepted into day care services. Those mothers who consented to participate in the study were asked to sign the consent forms, and they returned it in the pre-paid envelopes provided by the researcher, however, five mothers handed the sealed envelopes to the organisation's secretary in person, who delivered it to the researcher. This was because a physical delivery was more convenient for them as their children took speech therapy sessions in the outer clinic of the organisation and they therefore visited the organisation regularly. Once consent forms were collected, the researcher arranged a convenient time with each mother to be interviewed about their experiences of parenting their children with ASD and their unmet needs and concerns following their children's diagnosis. The researcher also informed the mothers that the telephone interviews would be digitally recorded. Seven interviews were digitally recorded with the agreement of the respondents. However, one of the participants requested that her interview not be recorded, and therefore extensive notes were taken during that interview. It is very common in studies conducted in Arab countries and within female communities in particular that participants do not accept the use of technology including recorders during interviews (Opdenakker, 2006a). Each interview lasted approximately 30 minutes. The researcher transcribed all the transcripts into Arabic and sent copies to participants to ensure the accuracy of transcription. All except two mothers responded that the researcher had accurately interpreted what they had said, and the ones who did not respond sent text messages saying they had no time to check the transcripts as they were studying for college degrees.

### Participants

A purposeful sampling method was employed by the researcher to select the participants on the basis of "what cases they can learn the most from" (Patton, 2002). As the main aim of this study was to explore mothers' unmet needs, it was thought that interviewing mothers whose children had just been diagnosed with ASD would help elicit the required information to help understand and explore their challenges and needs.

The number of participants in case of qualitative research is not as important as the quality of the information they provide to the research. "The validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information richness of the cases selected and the observational/analytical researcher than the sample size" (Patton, 2002). Moreover, the term *data saturation* refers to the criteria widely used in qualitative research for assessing the suitability of the sample size to address the study's aims. According to Strauss and Corbin (1998), data saturation refers to the point when no new or relevant data seems to emerge regarding a theme. Data saturation was achieved in this study after six interviews, after which no new themes or subthemes emerged. Participants were recruited through a local voluntary support organisation that provides a variety of support services for families of children with ASD as well as educational services for the children. This organisation distributed information packs on behalf of the researcher to all mothers of children newly diagnosed with ASD whose children had not yet joined the organisation and were on its waiting list.

Interviews were conducted with eight mothers who agreed to participate in the study. The demographic characteristics of the interviewed mothers are presented in Table 3. All mothers in this sample were married and their educational levels vary from less than high school to bachelor degree with the majority of them being high school graduates. The mothers' mean age was (M=28.5) years, with their child's mean age being (M= 42.75) months. Only two mothers in this sample were employed (25%).

**Table 3. Demographic Characteristics of Participants**

| Participant's ID | Age (years) | Child's age (months) | Number of children | Educational level | Working status | Interview length (minutes) |
|---|---|---|---|---|---|---|
| P1 | 28 | 36 | 2 | High school | No | 25.53 |
| P2 | 33 | 48 | 2 | Bachelor | Yes | 29.50 |
| P3 | 23 | 40 | 3 | High school | No | 22.07 |
| P4 | 29 | 36 | 3 | High school | No | 39.27 |
| P5 | 35 | 48 | 2 | High school | Yes | 20.28 |
| P6 | 29 | 48 | 4 | Less than high school | No | 47.57 |
| P7 | 26 | 36 | 2 | High school | No | 23.41 |
| P8 | 25 | 50 | 2 | High school | No | 33.38 |

## Data Analysis

The method used to analyse the data collected in this study’s interviews was *thematic analysis*. Thematic analysis “seeks to unearth the themes salient in a text at different levels” (Attride-Stirling, 2001, p. 387). It “involves the search for and identification of common threads that extends throughout an entire interview or set of interviews” (P. A. Field & Morse, 1985, p. 114). The analysis followed the six stages to thematic analysis proposed by Braun & Clarke (2006) which are as follows:

1. Familiarisation with the data by transcribing interviews verbatim and thoroughly reading the transcripts.
2. Generating initial codes by looking for ideas about what is significant about the data and then organizing the data to form codes.
3. Searching for themes by sorting the codes into meaningful groups to form potential subthemes.
4. Reviewing and refining potential themes, and grouping related subthemes and labels with an overarching theme.
5. Defining and labelling themes in a code book with a theme description, an example of a quote to illustrate the theme and another one that does not illustrate theme.
6. Finalising the analysis and writing it up using detailed extracts to demonstrate the themes and subthemes.

The researcher used an inductive analysis approach to code relevant data and to identify emergent themes and subthemes. The interviews were transcribed verbatim and then transcripts were re-read several times after which the preliminary codes were assigned to the data. During this process, anything interesting or significant about what the participant had said, or appeared not to have said, was noted as part of the initial coding process. The codes, which were assigned to segments of data with similar ideas, were refined in order to better depict the data. These codes eventually become categories that helped in the identification of the various themes and subthemes, which was then used to report the results of the qualitative study (Pope, Ziebland, & Mays, 2000). Moreover, once themes and subthemes were established, a codebook was developed to describe each one (Appendix 7). For each theme in this study, five elements are described in the created codebook, as outlined by Boyatzis (1998) including: a meaningful theme label, a definition of the theme, a description of how to identify the theme, a description of an exclusion to the theme, and positive and negative examples of the theme.

During transcription, all the participants, and anyone they referred to in their interviews, were assigned pseudonyms that would be used in the reporting of the study results. Participants were given an identification number based on the order in which they were interviewed so that, for example, the participant interviewed first, received the ID P1. Long extracts from the data were used under the description of each theme and subtheme in the findings section. The interview length varied between approximately 20 minutes and 47 minutes, with a mean interview length of approximately 30.12 minutes. To enhance the credibility of the data, the consistency of the themes' identification between the researcher and DD were explored. Two interview scripts were back translated into English and given to DD to identify themes and subthemes using the codebook and a discussion with the researcher. The extent of agreement between the researcher and the supervisor DD was calculated using a percentage agreement index formula (agreements divided by agreements plus disagreements and multiplied by 100). An agreement was defined as when both raters assigned the same codes, themes, subthemes to the same quote. The percentage agreement between the two coders was established at 87.5%, indicating that the themes were consistent and reliable to a recommended standard. Boyatzis (1998) has recommended that percentage agreement between two coders above 70% demonstrates acceptable reliability. This process resulted in minor adjustments to the descriptions of the themes in the codebook and merging some subthemes to best reflect mothers' opinions about their needs. Once the codebook was modified to include the suggested amendments, all previously coded transcripts were reviewed to ensure they were consistent with the changes.

### Trustworthiness

Trustworthiness in qualitative research refers to the quality and rigor in conducting research and reporting data through ensuring credibility, dependability, and transferability (Miles & Huberman, 1994). Credibility (equal to validity in quantitative research) is defined as "how we ensure rigor in the research process and how we communicate to others that we have done so" (Gasson, 2004, p. 95). Credibility can be achieved by prolonged engagement with data; the use of peer examination; identifying negative case; researcher reflexivity; member check; multiple analysts; and triangulation (Miles & Huberman, 1994; Morrow, 2005; Patton, 2002). Credibility was ensured in this study through different procedures. First, the researcher spent intensive periods of time engaging with the data before conducting data analysis, which led to a clear understanding of the participants' opinions and answers. Second, negative cases (that are not considered to belong to a specific theme or subtheme) were identified when creating the codebook which allows the readers to get a hint of the differences between what belongs to the theme and what does not. Third, transcripts of the interviews were sent to the participants for validation to ensure that the researcher did not misinterpret what was said, a criteria termed by Lincoln and Guba (2002) as *member check.* Six participants checked their interview transcripts and most of them replied to the researcher saying "go ahead", "great job" or "no more comments". The remaining two participants apologized for not having the time to read the transcripts. Moreover, one participant indicated that she wanted her profession to be removed from the transcript as it would make her identifiable. Therefore, the researcher removed it upon her request and it was not mentioned in any quotes taken from that participant. Fourth, a reflexive statement about the role of the researcher in the study has been described in detail (at the end of this section). Fifth, *analyst triangulation* as a method of ensuring credibility was employed in this study. The term refers to a situation in which multiple analysts review the findings of the research (Patton, 2002). In this study analyst triangulation was used as two English versions of the interview transcripts were read in details by the supervisor DD to check for the accuracy of the assigned codes, themes, and subthemes, and the inter-rater percentage was calculated and reported in the previous section. Finally, the credibility of the findings in this study was checked through *peer examination,* in which a volunteer medical student, who was bilingual in Arabic and English, voluntarily read two transcripts in Arabic to check for the consistency of the identification of themes and subthemes between him and the researcher. He was able to identify all the main themes in both transcripts; however, he could not clearly identify some subthemes in one of the transcripts. This was due to his limited knowledge in ASD aetiology which was clarified to him by the researcher. The percentage agreement between the researcher and the medical student was established at 81.25%, indicating that the themes were consistent and reliable to a recommended standard.

Dependability refers to the extent that a given study can be replicated to attain similar results (equal to reliability in quantitative research) (Patton, 2002). *Low-inference descriptors,* is a term introduced by Seale 1999 which describes ways to achieve reliability in qualitative research. Silverman (2001) identified three ways to achieve low-inference descriptors in qualitative research. The first one is by tape recording all interviews. The second is by being careful and accurate while transcribing the data, and finally by using long quotes from the data when presenting the findings of the study. The researcher of this study digitally-recorded seven interviews. She then carefully transcribed them and when reporting the findings, included extracts from the participants' replies to verify the themes and subthemes. This was because direct quotations should be included in the findings to allow the reader to view the situation from the perspective of the people interviewed in the study (an example of a coded transcript is presented in Appendix 8).

### Reflexive Statement

Reflective practice refers to the researcher’s role in knowledge production during the research process (Braun & Clarke, 2006). AH is a female postgraduate student who has completed her undergraduate education in KSA followed by a postgraduate (Master) in Canada. She is married and a mother of two children. Prior to starting her PhD, she was working as an academic lecturer at a university in KSA for two years and part of her job involved supervising graduate students during their training at autism organisations. The researcher introduced herself to the participants at the beginning of the interview. She took extensive notes describing her feelings towards several things during the interviews including her impressions of the mothers (e.g., “She is giving detailed descriptions of her personal life”), and other points of interest (e.g., “I felt bad that she had to send her son with ASD to Jordan”). Moreover, one participant was known to AH as that participant was a former student. The researcher tried to be objective and not let any of her feelings affect her interpretation of the data. It should be noted that being a mother and living in the same country (KSA) could have impacted the participants to talk freely about their needs and challenges raising their children with ASD. Finally, an important factor that could have impacted the researcher during the interview is her training as a qualitative researcher in Canada and her familiarity with interview skills in which she used active listening and paid attention to the participant’s tone of voice to gain more insight about the data.

### Findings

Six broad themes emerged from the interviews, along with subthemes under most themes, which reflected the unmet needs of mothers of children with ASD in KSA (Table 4).

**Table 4. Themes and subthemes**

| Themes | Subthemes |
|---|---|
| Mothers' identification of their lack of information about their children with ASD | • Insufficient information about ASD<br>• Inconsistent diagnosis for children with ASD |
| Mother's perceptions about their mental and physical well-being | • Understanding their well-being and the need for help<br>• Wanting their own time |
| Mothers' recognition of their constant challenges raising children with ASD | • Lack of support and assistance<br>• The stigma associated with having a child with ASD |
| Suggestions to increase public awareness about ASD | |
| Mothers' identification of their training needs | • Managing behaviour problems<br>• Removing barriers to engagement |
| Mothers' perceptions of their children's educational needs | • Need for ASD organisations with quality services<br>• The inclusion of children with ASD in general classroom education |

### Mothers’ Identification of their Lack of Information about Children with ASD

This theme captured mothers’ expressing their lack of information about ASD and its causes, diagnostic process, and treatment options. Two subthemes emerged under this main theme including insufficient information about ASD and an inconsistent diagnosis of ASD.

**Insufficient information about ASD.** Mothers felt that they lacked sufficient information about ASD and its aetiology and that they needed to understand the disorder. P2 described that “a mother needs someone to explain to her what is ASD, how does ASD affect her child and her relationship with him, she needs to know what she can do to be able to communicate with him, it is never enough to tell the mother that her child is autistic, nobody ever told me what ASD is all about”. All the mothers in this study indicated that they did not understand the meaning of ASD and that they were not aware of the possible causes and treatment options. Some of them thought that it was a curable disease and not a permanent developmental disability. Five of the participants indicated that their children did not suffer from ASD but rather according to P3 “a touch of autism” or as P8 noted, “my son does not have ASD, he is only on the spectrum”. P1 described her son as having “a beginning of autism and not autism”.

Mothers described relying on searching the Internet and learning from other mothers’ experiences to find out about treatment options for children with ASD, physicians who diagnosed their children, and how to deal with their children. P1, who was looking for treatment options for her son after his diagnosis, noted that “when I was searching the net, I was not able to find scientific information as most of the stuff there were regular things, I mean unclear and non-scientific information about ASD”. P5 indicated that “I always search the web, the web is full of useful things for mothers and how to deal with her child”. P8 indicated that she was searching the web to “look for qualified physicians in the country who would be able to give me a better diagnosis for my son”.

Some mothers mentioned that they felt that seeking information about ASD from other mothers who have children with ASD did give them a better understanding of their children’s conditions and how to deal with difficulties related to its symptoms. P3 noted

> I did not have enough time to attend training and I did not want to put my child in special care because his case is mild and it was only a few behaviours that I needed to modify at the time, therefore, I decided to learn from other mothers' previous experiences and I followed all their advice blindly. (P3)

Mothers also expressed their feelings of fear about their children's future and the lack of services for adults with ASD in the country. They indicated that they wanted more information about growing up with ASD. P3 mentioned that

> My biggest fear is, will my child be able to join regular school or should he remain in special education?, I need someone to tell me about my child and what ASD will look like a few years from now, I do not want him to attend special schools because the more time he spends with special cases the more wrong behaviours he will learn from them and I do not want him to learn bad things. (P3)

**Inconsistent diagnosis for children with ASD.** The participants in this study highlighted their feelings of confusion during the process of their children's diagnosis. They expressed that the journey to receive an official diagnosis for their child's condition was misleading as they received multiple diagnosis of their children's conditions. P2 said that

> I received three different diagnoses for my child. One doctor told me that he has mild autism, another doctor told me that he has moderate autism, and a third doctor told me that he only has mental retardation and therefore I decided to take him to X hospital and I told them that we have three different diagnoses for the child and they evaluated him and we are waiting for their report. (P2)

The majority of mothers described that their children received double diagnoses of ASD along with mental retardation, speech disorders, and learning disabilities. This, according to them, has put more pressure on them as they did not know how to deal with their children and which type of services to seek. They also described how not receiving an accurate diagnosis for their children has led them to seek many services trying to find answers for their concerns. P6 mentioned that the clinic where she took her son has guided her to begin speech therapy for him, but she also took her son for an "EEG [electroencephalogram] in the XXX centre in Jeddah" because her husband's friend whose "son had hyperactivity" took his son there.

### Mother’s Perceptions about their Mental and Physical Well-being

This theme captured the participant’s thoughts about their unmet mental and physical needs, which according to them need to be addressed by government and professionals in the field. Two subthemes emerged under this main theme, understanding their well-being and the need for help, and wanting their own time.

**Understanding their well-being and the need for help.** Participants in this study acknowledged their poor psychological well-being after the diagnosis of their children. They felt that the diagnosis of their children had cause the majority of them to be depressed, stressed, and anxious most of the time. They highlighted their needs for psychiatrists’ appointments to help them go through the pain after the diagnosing of their children as some of them went through denial and got depressed. P2 said

> When the mother receives the news that her child has ASD, she needs psychological and emotional support, which means she needs a Psychiatrist or a social worker to help her calm down and tell her not to have fear and that having that child is not the end of this world. (P2)

Mothers also expressed their need for counselling services. They explained how they needed somebody to listen to them and give them advice. P4 discussed that “It’s very good to find someone who asks about you. We have many problems here and many problems related to the children being harassed, but no one knows and no one cares. It’s good to ask and care about us”. P 8 said “I wish I had found somebody to listen to me and guide me through this difficult process”.

**Wanting their own time.** All the participants felt that they wanted their own time when they can relax and not worry about taking care of their children with ASD. They indicated that the lack of full time care for their children including the lack of government organisations that provide such services for parents of children with ASD has prevented them from having what they call “me time”(P2). P4, who sent her son with severe ASD to Jordan, expressed

> I took a decision and told my husband that I would not continue with him as a wife except if we took the boy to an environment where he could learn. The boy can find people who could take care of him the whole day long, day and night; he also needs to see people. He needs a complete schedule, he needs learning. I mean he needs somebody to take care of him over the whole year. During vacations and weekends, oh my God, the situation was so bad. (P4)

Another reason mothers mentioned the need for full time care is that they work or study full time, which makes it harder for them to provide care for their children. P7 noted "my situation is really difficult as I am a full time student and I only come back home in the evening, I need time to relax". Mothers discussed that although some private organisations are starting to provide full day care for children with ASD, however, they insisted that "they are costly and prefer money over the quality of their services" (P2). P5 mentioned that she needs "time to socialize and go to parties", which was not possible according to her as nobody will be there to take care of her child.

### Mothers' Identification of their Training Needs

This theme explained mothers' opinions about the need for training that they felt was necessary for them as mothers of children with ASD. Two subthemes emerged from this theme, including managing behaviour problems and removing barriers to engagment.

**Managing behaviour problems.** All the mothers in this study expressed their need for training to help them manage their children's behaviour problems. Some mentioned that behavioural training is important for them to be able to deal with their children's behaviours such as spitting and hitting. P1 mentioned "there was a time when my son used to hit me very badly that sometime I want to cry, now he is better but I noticed that he is starting to hit his younger sister and I need a solution". Another mother mentioned that her child only displayed behaviour problems outside home. P2 expressed "when we go to the mall and as soon as my son sees the lifts, he let go of my hands and runs, he is also very nervous, so I could never go out with him by myself, I wish I can find a solution". Some mothers believed that their children learned behaviour problems from other children in day care settings as P8 noted

> My son was copying what other ASD kids were doing in the class, which prompted me to take him out of the autism organisation and send him to a regular nursery. But then he is not benefiting, as they do not know how to deal with autistic children, I wish that there were courses and lectures to tell us what to do with our kids when they behave in certain ways. (P8)

**Removing barriers to engagement.** Mothers described that they felt many issues had prevented them from participating in training. The high cost of workshops is one issue expressed by mothers that prevent them from attending the necessary training. P2 mentioned "courses are overpriced for parents and not affordable by many". Another issue is transportation difficulties as women do not drive in KSA and mothers had to find a male who would take them to attend the training. P4 noted that transportation is one of the major obstacles preventing her from attending training because "my husbands' work is so far and it took him two hours to go to his work and other two hours to come back. This means 18 hours outside the home". Therefore, most of the participants preferred to undergo training using the android application called WhatsApp. P6 explained

> When I was in secondary school, the computers were still not there. I don't use PC and I don't know how to use them. I only know and use WhatsApp. If there are links, lectures, group discussion or anything that I can have using WhatsApp then that will be really helpful not just for me but for all other mothers who are suffering as well. I am pretty sure there are many. Even if I missed a session in WhatsApp then I can read it once I have time and that is the benefit of it everything gets stored there. The good thing about it is that I do not have to worry about leaving the kids they might be sleeping in the next room and I am attending the session or watching a link. (P6)

Mothers expressed the need to hear about parent's training workshops or lectures that are not usually advertised in the media. P2 mentioned "we need to know about these workshops, we only hear about them coincidently as there are not enough adds for such things. May be sending WhatsApp messages to mothers or information about free online courses would be a good idea to explore".

## Mothers' Perceptions of their Children's Educational Needs

All the mothers in this study have acknowledged the importance of education and training for their children with ASD. This theme reflected the mothers' opinions about the educational needs of their children. Two subthemes emerged; the need of ASD organisations with quality services and the inclusion of children with ASD in the general education classroom.

**The need of ASD organisations with quality services.** Mothers felt that it is extremely essential for their children to be placed in ASD organisations that provide quality services. According to them, the long waiting lists, shortage of qualified staff, and expensive services at these organisations have prevented their children from receiving the interventions necessary for their development and skills' acquisition. The majority of mothers expressed their complaints about the long waiting lists for children to get accepted at ASD organisations. They mentioned that only few organisations exist to serve children with ASD while the number of cases is increasing every year. P1 said that

> we wanted our son to join the autism organisation but they told us to come after Hajj [one month] but when we went back after Hajj they told us that they are overbooked and you can leave your name and number and if there is a space we will call you and since then we were waiting and I do not know where to go or which organisation. (P1)

Mothers also mentioned how essential speech therapy was to help with their children's symptoms and how their language improved after just a few sessions. They insisted on the importance of increasing the number of speech therapy sessions for their children and especially government subsidised sessions within government organisations, as these tend to be less expensive. P3 mentioned "I am paying from my own pocket for at-home speech therapy sessions as my child has still not been accepted into any autism organisation and he improved a lot after these sessions". Few mothers mentioned Jordan as a country which provided good services for ASD children and they wished they could take their children to organisations their as P6, who is a mother of three children with ASD explained

> I told my husband that I'm ready to go to Jordan because they have a centre for similar cases. I was ready to go and live there till they grow up then we could come back to the kingdom. I tried talking to my husband many times but he refused. (P6)

Mothers felt that there is a shortage of qualified ASD staff in the country and that day care settings rarely have qualified professionals who know how to deal with children with ASD. P6 stated that

> My eldest son went to school but the teacher didn't continue with him. She told us that she teaches the whole class and can't show him everything separately and waste time with him. So the best place for him to learn is XXX autism Centre. In that school, I noticed he didn't know that he shouldn't pee in front of others. He did that once and they told me. So I think the best place for him is a specialised centre like XXX Centre. (P6)

Some mothers mentioned that people can donate money in some private organisations to pay for services for children with ASD whose parents would not be able to pay for themselves. This according to mothers is beneficial, however, they would prefer if more government ASD organisations exist so they do not have to look for assistance elsewhere.P2 mentioned that

> Generous people pay for kids whose parents are needy, however, sometimes ASD organisations report a list of needy kids to charitable organisations in the country who can sponsor some spots for needy them, but the thing is that some people will prefer to leave their children at home as they do not want to ask people for money. (P2)

**The inclusion of children with ASD in the general classroom education.** Mothers felt that it is a necessity to include their children with ASD in the regular classroom as some of the children have mild ASD symptoms and would be able to perform well in the regular class with the assistance of the teachers. P2 mentioned that

> They rejected my son in the regular school because he has autism. All day care setting these days should have teachers who are trained to deal with special cases, probably not all the teachers in the school but at least one teacher of special cases per school, early childhood education is important and it is unfair to put a child whose behaviour is good with children with problem behaviours because he will learn from them. (P2)

P1 mentioned that "I want my child to learn and join the regular classroom; I knew he is not normal but he is smart and can understand things so why would they not give him the chance".

### Mothers' Recognition of their Constant Challenges Raising their Children with ASD

This theme highlighted mothers' concession of their constant demands and challenges raising their children with ASD. Two subthemes emerged from this theme, lack of support and assistance, and the stigma associated with having a child with ASD.

**Lack of support and assistance.** All the mothers in this study repeatedly cited the lack of assistance as one of their biggest concerns. They reported that they are the parent responsible for daily childcare of their children with ASD, while fathers work outside the homes to earn income. They insisted that even when fathers were at home, they rarely looked after their children. P4 described her life

> It is like I was living alone in a separate world that has only me and my son. Even my husband, I was living away from him. He usually leaves me at home and goes to visit his relatives and friends and only comes back home to sleep. I'm lonely with my son. No one with is with us. (P4)

Mothers also mentioned their need for a maid to look after their children so that they can find time to do other things. Some mothers insisted on the importance of having a maid who is specifically trained to take care of children with ASD. P1 noted that

> I wanted a nurse or a maid who understands my son and has a strong background with these matters [ASD symptoms] because I have another daughter who needs my attention and needs me to stay with her. Nobody else knows how to take care of him, even his father does not know about him, I wish I could have a maid or a nurse. (P1)

P1 mentioned that as a result of the lack of assistance, she was not able "to get a job" because she would not be able to leave her son.

Some mothers indicated that they relied on their faith in God to help and guide them through their difficult experiences. P3 noted that

> We are contented with God's will and so as my husband, in the beginning I refused to accept it but then when I heard that some ASD people are holding PhD degrees then I looked at my son and I believed that Allah[God] will cure him and take this disease away from him. I also believe that I am only surviving because God is enlightening my way with energy. (P3)

The use of electronic devices like tablets and laptops was mentioned by some mothers as a method they used to occupy their children's time. P4 explained that

> My daughter had a bad luck that time when I was pregnant and she was crying. Her father's relatives were in Jeddah and we had to spend most of the time with them, so we didn't go out frequently. Most of her time was spent on her i Pad and about 4-5 hours watching TV. The whole time was spent on these devices. (P4)

Only few mothers mentioned that they felt that their families and in laws were not supportive after their children's diagnosis. They did not offer to take care of the children and even when the mothers asked for help, they were turned down. P 7 indicated that "not all families are caring and cooperative in such a situation". In other cases, families blamed the mother if she decided to have other children. P6 described her situation as follows

> I had multiple pregnancies and they were asking me why you are pregnant. I got annoyed. Throughout my pregnancy days, I had trouble with my own health in addition to caring for my other kids. Even congratulations, I didn't

> even receive congratulations, except for my eldest son. The others were born later and they kept asking me why I did so. That was so annoying and depressing. (P6)

**The stigma associated with having a child with ASD.** Mothers expressed that they felt stigmatised as a result of their children's disability. According to some mothers, it was very hard going outside the home with their children because people in public places are annoyed by their children's behaviour. Therefore, mothers reported being isolated as a result of having a child with ASD. P6 discussed how the criticism they received from people regarding their child's behaviour had prevented them from attending social event. She noted that

> Even my husband got tired of people talking about our kids. When we go to his brother's house, he tells me to keep the kids with him and I go sit with the other ladies. I prefer to take them to play with other children to communicate with them. He prefers not to do so, so as to prevent people from saying bad words as a result of the children hyperactivity or in case they destroy things. He feels ashamed of his kids even in front of his family. (P6)

Moreover, some mothers indicated that they did hide their children's disability from family and friends because according to P3 "I did not accept having a child with ASD from the beginning and I was really annoyed so I decided that nobody will know except me and my husband and when people ask me why my child is not normal I tell them that he has a touch of autism and not full autism".

### Suggestions to Increase Public Awareness about ASD

This theme focused on mothers' suggestions regarding the importance of increasing society's awareness about ASD. Some mothers highlighted the importance of public lectures about ASD as well as the provision of easy to read materials and manuals to educate the public about ASD and how to deal with children with ASD. P3 explained that "the mother is shocked by the news of having ASD child and there is nobody to advise her, especially as not all people know about ASD, therefore, I wish there was more information available for mothers such as guides and manuals". Moreover, one mother noted that it is essential to teach children in regular classrooms about ASD and its symptoms so that the public becomes more aware about autism and the people affected by it. P6 explained that

> Autism should be taught in schools' curriculums and there should be subjects on these cases so that the whole community, schools, hospitals and people, knows about it. The same way people study English and computer in schools, they should study these cases so that when they grow up and see these cases in malls or streets, they don't call them crazy. Mothers and fathers feel ashamed and don't go out more often; consequently children get isolated because of low social communication. P6

## Discussion

This study explored the unmet needs of mothers of children with ASD in KSA. The findings of this study revealed many of these mothers' needs which were reflected in the six main themes and 10 subthemes (Table 4). The main themes were mothers' identification of their lack of information about their children with ASD, their perceptions about their mental and physical well-being, mothers' their recognition of their constant challenges while raising children with ASD, suggestions to increase public awareness about ASD, the mothers' identification of their training needs, and mothers' perceptions of their children's educational needs.

Mothers' identification of their lack of information about ASD aetiology, causes, symptoms, and treatment options is one of the major concerns for all the mothers in this study. The same finding was found by (Kapp & Brown, 2011; Kuhaneck et al., 2010; O'Brien, 2007) who acknowledged the need for clear information about the nature of ASD for parents of children with ASD for. The diagnosis process of children with ASD was reported by mothers to be lengthy and complicated, with no clear diagnostic process to follow in hospitals and clinics. Most parents in KSA seek diagnosis for their children with ASD from psychiatrists, but each clinic uses different measures and diagnostic tools and there is no clear guidelines for clinics to follow during the diagnosis process, therefore, parents usually get different diagnosis for their children with ASD when they seek a second opinion, such as mental retardation, pervasive developmental disorder, and mild or severe autism. This finding is consistent with the findings of other studies in which parents reported the diagnostic process to be complicated and confusing for parents of children with ASD (Hutton & Caron, 2005; Osborne & Reed, 2008).

There is a wealth of information available online for parents of children with ASD. However, most of the available information is in Arabic, not scientifically based, and consists mainly of websites or articles written by the general public. The findings of this study revealed that mothers in KSA rely on information on the Internet to help understand their children and deal with their problem behaviours. Thus, it is an important for autism related service providers and academics in the field to publish useful information based on evidenced research (Elder & D'Alessandro, 2009). This study also revealed that mothers are looking for treatment and cures for their children as a result of their lack of sufficient information about ASD. They did not realise that ASD is an incurable neurodevelopment disability. M. J. Weiss, Fiske, and Ferraioli (2008) observed that "this understandable desire for a 'cure' leaves many vulnerable and susceptible to the appeal of treatments that are based solely on hearsay, anecdotal evidence, and biased report" (p.33). The same finding was replicated by Lin et al. (2008) who found that parents of children with ASD are always looking for cure for their children. The findings of this study revealed that many mothers in KSA get information and support from other mothers of children with ASD. This idea is also relevant in the Turkish culture where parents share their experiences with others as a mean of exchanging information and a coping mechanism (Bilgin & Kucuk, 2010b).

Contrary to the findings of this study, Alqahtani (2012) found that parents of children with ASD in KSA often choose informal intervention and treatments such as diet intervention containing gluten-casein-free, however, this study revealed that parents do not usually rely on informal treatment as it is expensive and not reliable and they instead prefer to seek behavioural and educational interventions.

Another major concern for mothers in the findings of this study was their perceptions about their own mental and physical well-being, which includes their need for psychiatric intervention, counselling, and full time child care to help them relax and have their own time. Many mothers insisted on their needs for psychiatric treatment after the diagnosis of their children. According to A. Gupta and Singhal (2005), parents experience periods of depression and self-blame, which makes it necessary for them to get psychiatric intervention. Mothers in KSA do not usually get referrals for psychiatric or counselling therapy after the diagnosis of their children. Only those mothers who can afford to pay for private clinics would be able to access such service. This study also highlighted the mothers' needs for training in dealing with their children's' behaviour problems as one of the major complaints was their uncertainty about how to deal with their children's behaviours in different situations. This is consistent with the findings of the review by McConachie and Diggle (2007), in which parent trainings for parents of children with ASD were found to enhance parents' communication skills with their children and also their knowledge about their children's behaviour.

The mothers' perceptions about their children's educational needs, is a major concern discussed by the participants in this study. This is in contrast to what Alqahtani (2012) found that parents of children with ASD in KSA were not concerned about the educational and behavioural interventions for their children. Speech therapy is the most valued form of therapy for Saudi mothers (Alqahtani, 2012). According to the mothers in this study, this is because they noticed improvements in their children's language through therapy, and the lack of language development is one of the first signs a mother usually notices in her toddler who eventually gets an ASD diagnosis. Some autism organisations in KSA provide speech therapy sessions for children with ASD on an outer clinic basis so that even children who are in the waiting list can start speech therapy sessions soon after their diagnosis. This study highlighted the unavailability of qualified professionals who works in ASD organisations. In accordance with this study, Alqahtani (2012) found that parents of children with ASD in KSA did suffer from trying to find full time organisations for their children as well as shortage of well-trained people who works in these organisations.

Mothers' recognition of their lack of assistance and support is another major finding of this study. Mothers of children with ASD in KSA suffer from the heavy load of care giving for their children, as they are considered to be the main care provider for the home and the children as well, while the fathers are responsible for providing the family's income. This is consistent with Bilgin and Kucuk (2010b) according to which "maternal roles include more responsibility of a child with disability than paternal roles" (p2). Altiere and von Kluge (2009b) highlighted the lack of support from surrounding family to parents of children with ASD. This study also found that mothers of children with ASD felt that they were not receiving support from their family and some of the families blamed the mothers for having more children. Mothers in this study reported their need for respite and a time for themselves due to the constant burden of care giving. They insisted that it is difficult to find a reliable person to look after their children and many mothers wished they could have a maid or nurse trained to help them in the care of their children. House maids are very common in Saudi culture (Alqahtani, 2012), however, these days, it has become expensive to have a house maid due to new policies established by the Ministry of Labour and a consequent increase in salaries. Therefore, it is not affordable for each family to have a maid.

The need to increase public awareness is one of the major concerns identified in this study. Mothers of children with ASD are stigmatised due to their children's disability. They are also isolated from their social system due to their fear of being criticised for having children with ASD and the lack of public awareness about the nature of autism. This finding is consistent with D. Gray (2006) who explained that "Because of social stigma, there is a lot of discrimination not only of the autistic child but also of the family as a whole" (p3). This study also suggests that more materials should be designed and made available to the public in KSA about the nature of ASD and how to deal with children with ASD.

Many mothers in this study reported that they would prefer to take their children to Jordan if they could. This is because Jordan has more advanced services and organisations for children and adults with ASD than KSA. They have many university programs that train professionals to work in the field of ASD. In addition, the royal family members in Jordan pay personal attention to the implementation of disability regulations in the country (Stone, 1999).

## Limitations of this Study

First, it is important to acknowledge that the interviews were conducted with only a small sample of Saudi mothers of children with ASD, all from one voluntary organisation in the country. Therefore, the findings may be unique and only representative of this region. However, the sample number is usually small in qualitative studies as the main aim is to gain more in depth insights from the target population about the studied topic. A second major limitation was that only mothers were interviewed; the other parent in the family was not interviewed about their perspective, which may have differed greatly. However, in the context of KSA it might not be possible to interview fathers due to ethical and religious restrictions. Moreover, as mothers are the primary caregivers for their children in KSA, it was more logical and informative to interview them about their unmet needs raising their children with ASD.

## Conclusion

Mothers of children with ASD in KSA face multiple challenges and difficulties caring for their children due to the demands of the child with ASD and the cultural issues related to their surroundings and social life. This study contributed to the literature on parenting children with ASD in the Saudi culture as well as to Saudi literature about the unmet needs of mothers of children recently diagnosed with ASD. The findings of this study will help professionals address the main issues facing mothers. Academics might use the findings of this study to help in the design of a parenting intervention that can take into consideration the mothers' needs.

### Contribution and Recommendation for Future Research

Through increasing awareness and understanding about the unmet needs of mothers of children with ASD in KSA, this study could possibly lead to the development of culturally sensitive interventions and services for parents in KSA.

However, more research is needed on the issues affecting mothers of children ASD, to gain a greater understanding of these themes and how they affect the quality of life not only of Saudi mothers but also of fathers raising children with autism. It is hoped that this study will add to the body of literature in this area to assist social workers in advocacy and support planning for mothers raising children with ASD in KSA. Another recommendation is the need to develop more materials for grandparents and other family members to help them understand the nature of ASD because if they knew more about the disorder then they could become an invaluable source of support for the mothers.

# Chapter Four: Are Parenting Interventions Effective in Improving Parental Functioning in Parents of Children with ASD? A Meta-analysis

## Introduction

According to international guidelines, training should be provided for children with ASD to help them meet their social, educational, and emotional demands (NICE, 2013). There are many available interventions for children with ASD that cover the entire range of behavioural and developmental difficulties associated with the disorder (L. K. Koegel, Koegel, Hurley, & Frea, 1992; Lovaas, 1987). The efficacy of these interventions in enhancing the skills of children with ASD and improving their deficiencies has been demonstrated in previous meta-analyses (Kokina & Kern, 2010; Virues-Ortega, Julio, & Pastor-Barriuso, 2013). A meta-analysis by Flippin, Reszka, and Watson (2010) which explored the effectiveness of the Picture Exchange Communication System (PECS) demonstrated the positive impact of PECS intervention on the communication skills of children with ASD. Another meta-analysis by Howlin, Magiati, and Charman (2009) explored the effectiveness of behavioural interventions and their positive impact in reducing behavioural problems in children with ASD.

However international guidelines also recommend the provision of training and support for parents of children with ASD to specifically enhance parental functioning, well-being and to provide skills to help the parents manage their children with ASD (NICE, 2013). These parent-mediated interventions focusing on enhancing the children’s skills are widely available, and their efficacy has been well documented in the literature with many studies showing their effectiveness (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Minjarez, Williams, Mercier, & Hardan, 2011). A systematic review by McConachie and Diggle (2007) of studies evaluating the effectiveness of parent implemented interventions for children with ASD and their parents found a significant effect of such interventions on maternal depression. However, the review included studies in which the main aim of the interventions was to train parents as therapists to deliver skills’ based interventions (e.g., ABA techniques or TEACCH) to their children with ASD.

Fewer interventions are available to parents that include elements focusing on enhancing their well-being and parental functioning, as the majority of interventions focus primarily on the children’s gain and not parental outcomes (McIntyre, 2008; Pillay et al., 2011). It would not be possible with the limited number of trials evaluating the effectiveness of parenting interventions, to decide which ones are more effective and recommended for parents to enhance their parental functioning (Karst & Van Hecke, 2012). A meta-analysis  by Singer, Ethridge, and Aldana (2007) of parenting interventions that combined both psychoeducational components and behaviour problems management techniques found these interventions to be effective in enhancing parental well-being in parents of children with developmental disabilities. However, this meta-analysis included parents of children with a wider range of disabilities including children with ASD, intellectual disabilities, and other genetic-based disorders. Therefore, it was not possible to conclude that these gains were specific to parents of children with ASD.

To date, there has been no meta-analysis, to the researchers' knowledge, that has evaluated the effectiveness of parenting interventions on parental functioning specifically in case of parents of children with ASD. Therefore, the main aim of this meta-analysis was to quantitatively evaluate the effectiveness of parenting interventions on parental functioning. This may help to explain which interventions should be recommended for parents of children with ASD to enhance their parental functioning.

## Methods

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)  by Moher, Liberati, Tetzlaff, Altman, and The Prisma Group (2009) guided the planning, conduction, and report of this meta-analysis.

### Study Eligibility

The study eligibility criteria have been reported in accordance with the PICOS principles for reporting systematic reviews and meta-analyses (Petticrew & Roberts, 2008); Population, Intervention, Comparison, Outcomes and Study designs.

**Population.** The population of interest was parents of children aged between 18 months and 12 years of age (infancy to primary school age), with a confirmed diagnosis of ASD. Studies including parents of children with ASD with unusual or unique co-morbidities (e.g., children with ASD who were blind) were not included.

**Intervention.** Interventions of interest were any parental intervention that gave parents strategies to enhance their parental functioning, whether these strategies targeted elements in the parents themselves (e.g., stress reduction techniques) or in the parents’ relationship with their children (e.g., behavioural management techniques). Studies that explored the effect of medical or pharmaceutical interventions on parents of children with ASD were not included.

**Comparison group.** Comparison groups of interest in the controlled studies were those in which parents did not receive anything except the usual care and services that other parents in the intervention groups were offered.

**Outcomes.** All outcomes related to parental functioning were considered of interest. These included parental well-being (e.g., stress and depression), parental sense of competence (e.g., efficacy and satisfaction), and parenting practices (e.g., adaptability and laxness). Parenting practices were found in previous studies to be related to parental well-being and child behaviour problems (Emerson, 2001; Greenberg et al., 2006). Studies of parental interventions that only reported child outcomes were not included.

**Study designs.** Studies of interest were classified into two categories: controlled studies and pre to post studies. Studies were considered to be controlled if they were either randomised controlled or a controlled non-randomised trials. A randomised controlled trial (RCT) is where participants were randomly allocated to either an active treatment group or a controlled non-treatment group, while in a controlled trial, there is no random allocation of participants to the intervention group. A study was classified as pre to post if it contained only a treatment group assessed before and after treatment or if it compared multiple treatment groups without a control group for any of the treatments.

Only studies published in peer-reviewed journals and in English were included. Studies were not included if children with ASD were chosen mainly on the basis of their social and communication difficulties only (in line with DSM-5 criteria for ASD where social and communication disorder is under a separate category).

### Search Methods

The following databases were searched: Pub Med, Psyc INFO, and Web of Knowledge from 1994 (publication of DSM IV where autism was lastly defined before the emergence of DSM 5 in 2013) until 1st August 2015. Search terms included: "Autism" OR “ASD” OR “Autism Spectrum Disorder” OR “Autistic disorder” AND “training” OR “intervention*” OR “programme*” AND “parent*” OR “maternal” AND “function*” OR “well-being” OR “stress” OR “depression” OR “anxiety” OR “sense of competence” OR “efficacy” OR “confidence” OR “satisfaction” OR “adaptability” OR “cohesion”. Reference lists of relevant review articles and included studies were manually searched. Two reviewers, the thesis researcher and the supervisor, independently reviewed the titles and abstracts and studies that did not meet the inclusion criteria were excluded (reasons for excluded studies are presented in

Appendix 9). When the abstract suggested potential eligibility, the full article was retrieved. Inclusion was based on a mutual agreement between the researcher and her supervisor and reasons for exclusion were recorded. Inter-rater agreement was obtained by dividing the total number of agreements by the total number of agreements plus disagreements and multiplying by 100.

### Data Extraction and Study Quality

The researcher and her supervisor independently extracted the data, and variations in data extraction were resolved through discussion (The outcomes are presented in Appendix 10). Inter-rater agreement on the coding of the variables of interest was 90.9 % and disagreements between the coders were resolved by referring back to the original study. Wherever there was insufficient detail reported, the authors of the article were contacted by the researcher via email for clarification.

The methodological quality of the studies was assessed based on the Mixed Methods Appraisal Tool (MMAT), which is a reliable and valid tool designed for appraising the quality of studies in reviews including mixed methods studies (Pace et al., 2012; Pluye et al., 2011). The MMAT has criteria for appraising RCTs, non-randomised studies (NRS), observational studies, and qualitative studies and, therefore, was believed to be the best tool to appraise the quality of the included RCTs and NRS in this meta-analysis.

Risk of bias in the included RCTs was assessed using the criteria specified by the Cochrane Collaboration for assessing risk of bias in RCTs (Higgins et al., 2011). The tool assesses study bias across five methodological domains: sequence generation, allocation concealment, blinding, incomplete outcome data and selective reporting. The risk of bias is categorised into three levels: low, high and unclear risk of bias (Higgins et al., 2011). On the other hand, risk of bias in the included NRS was assessed using the criteria specified by the Cochrane Collaboration tool (ACROBAT) for assessing risk of bias in NRS (Sterne, Higgins, & Reeves, 2011). Alterations were made to the risk of bias tool settings in the

Review Manager (‘RevMan’) software to accommodate the NRS based on the ACROBAT criteria. The types of bias explored included selection bias, performance bias, bias in measurement of outcomes, attrition bias, reporting bias, confounding bias, and other biases (Cochrane Collaboration, 2012).

**Process for Meta-Analysis**

Meta-analyses were planned to explore the effects of interventions upon stress, depression, anxiety, parents’ sense of competence, and parenting practices outcomes. Outcomes were analysed in two sub-groups: 1) pre-post intervention in all the included studies; 2) intervention vs. inactive control in controlled studies only. For controlled studies, a sensitivity analysis was conducted which removed the non-randomised studies. This allowed the researcher to assess the impact of randomisation on the efficacy of parenting interventions. If a controlled trial contained more than one active intervention arm then the data from the arm in which parents were more actively involved in an intervention was inputted into analysis (Sofronoff & Farbotko, 2002a; Tellegen & Sanders, 2014). Studies which insufficiently reported their outcome data were not included in the meta-analysis. Analyses were run for an outcome as long it had been measured by an appropriate measuring scale, in at least three included studies (See Appendix 10 for outcomes in included studies).

Post and pre intervention means and standard deviations (SDs) data from relevant outcome measures were extracted for pre to post studies, and post and pre intervention means and SDs for both intervention and control arms in controlled studies, were all inputted into the RevMan software (Cochrane Collaboration, 2012). Effect sizes for pre-post design studies were calculated by subtracting the post-test mean from the pre-test mean and dividing by the standard deviation of the pre-test mean, for controlled studies it was calculated as mean pre to post intervention group change minus the mean pre to post treatment control group change divided by the pooled pre-test standard deviation (Hedges & Vevea, 1996). In studies where outcome measures yielded two or three different scores (a score for each subscale), an average score for all the subscales of a measure was inputted into RevMan (Bendixen et al., 2011; Chiang, 2014; Keen, Couzens, Muspratt, & Rodger, 2010; Tellegen & Sanders, 2014; Whittingham, Sofronoff, Sheffield, & Sanders, 2009). Moreover, in studies where separate scores were provided for mothers and fathers for a measure, an average score of both was inputted into the analysis ( et al., 2011a; Keen et al., 2010).

The Standardised Mean Difference (SMD) was expressed as Hedges' *g* and SMDs were calculated with an adjustment for sample size differences (Hedges & Vevea, 1996). Inferences of Hedges' *g* can be made using Cohen's d conventions as small (*d* ≥0.2), medium (*d* ≥0.5), large (*d* ≥ 0.8), and very large (d≥1.3) (Cohen, 1988). Included studies were anticipated to be heterogeneous due to the different types of parenting intervention, and therefore to account for expected heterogeneity, Random Effects Models (RAM) as recommended by A. P. Field and Gillett (2010) with 95% confidence intervals (CI) were applied throughout the analysis. The $I^2$ statistic was calculated to explore heterogeneity and is expressed as a percentage indicating its degree; 25% indicates low heterogeneity, 50% suggests moderate and 75% is a threshold marker for high heterogeneity (Higgins, Thompson, Deeks, & Altman, 2003). The *Q* statistic was also calculated and provided the statistical significance of heterogeneity. RevMan was used to calculate effect sizes in pre-post studies and to enable the calculation of confidence intervals (CIs), and calculations were checked using an online Hedges'*g* calculaton.

Due to the small number of studies included in this analysis, it was not possible to investigate the effects of publication bias using funnel plots. It has been suggested that analyses need to include substantially more than 10 studies to begin interpreting publication bias and that interpretation based on a small number of studies is ambiguous and misleading (Ioannidis, 2008; Sterne et al., 2011).

## Results

The initial search yielded a total of 338 studies (Figure 1). Eleven studies were included in this review after filtering according to the inclusion criteria. The studies included eight controlled studies (six RCTs and two controlled non-randomised studies) and three pre to post studies, published between 2002 (Drew et al., 2002a) and 2015 (Ginn, Clionsky, Eyberg, Warner-Metzger, & Abner, 2015b). Studies were conducted in four different countries; five in Australia (Keen et al., 2010; Sofronoff & Farbotko, 2002a; Tellegen & Sanders, 2014; Tonge et al., 2006; Whittingham et al., 2009); three in the USA (Bendixen et al., 2011; Chiang, 2014; Ginn et al., 2015b); two in the UK (Drew et al., 2002a; Grahame et al., 2015a); and one in Iran (Samadi, McConkey, & Kelly, 2013). The characteristics of the included studies are presented in (Appendix 11).

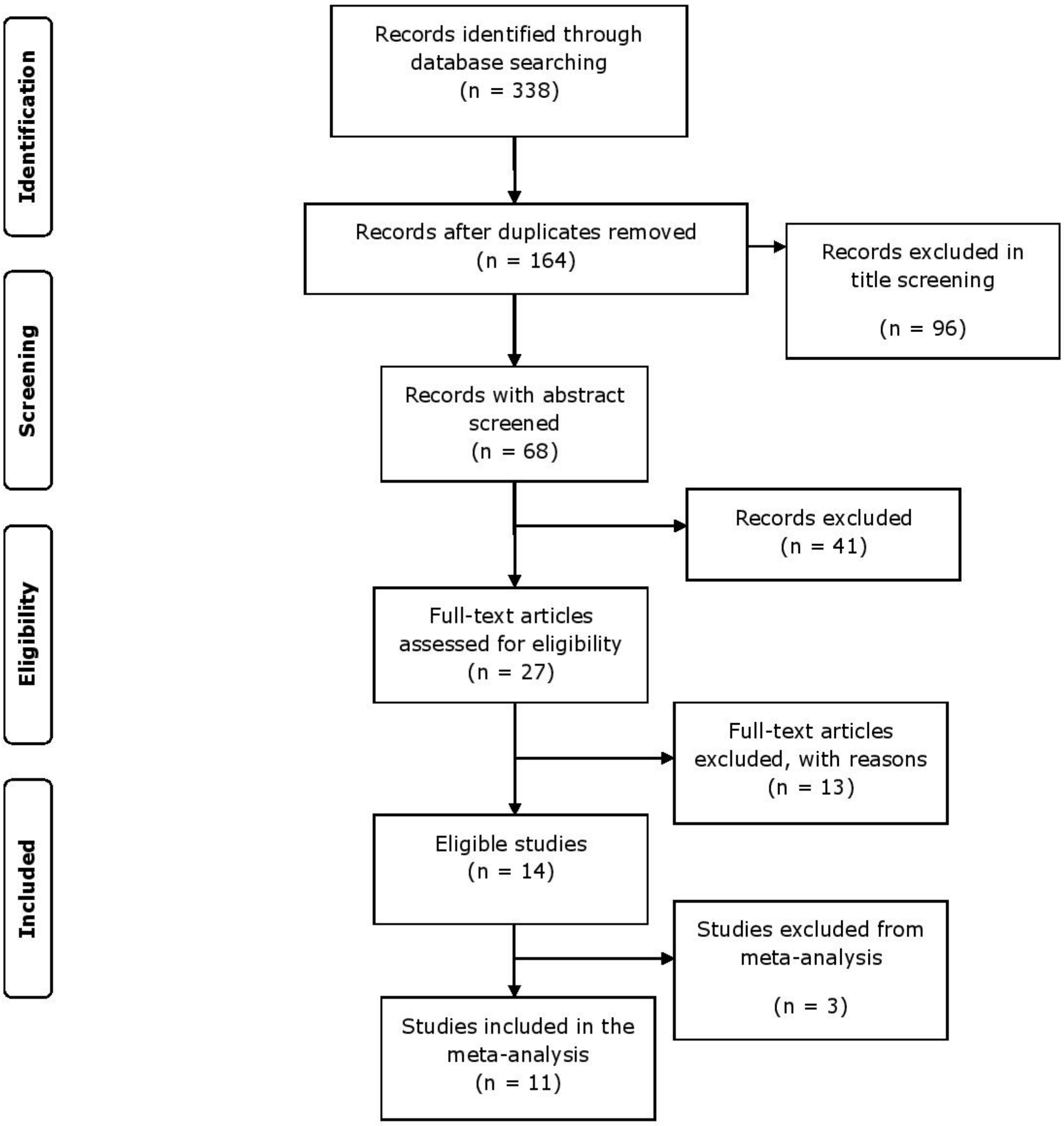

**Figure 2. Flowchart of studies for meta-analysis**

## Participants

Sample sizes ranged between 11 (Chiang, 2014) and 105 (Tonge et al., 2006), with a total of 576 participants. The mean age of participants' children with ASD ranged from mean=22.5 months (SD=13.4) (Drew et al., 2002a) to mean=8.3 years (Sofronoff & Farbotko, 2002a). Most studies included both parents even though the majority of participants were mothers, except (Ginn et al., 2015b) which included only mothers.

## Intervention

Some interventions included psychoeducation (Bendixen et al., 2011; Chiang, 2014; Samadi et al., 2013; Sofronoff & Farbotko, 2002a; Tonge et al., 2006); others helped parents by enhancing their understanding of ASD and communications skills with their children (Drew et al., 2002a; Ginn, Clionsky, Eyberg, Warner-Metzger, & Abner, 2015a; Grahame et al., 2015b; Keen et al., 2010); and some provided behavioural strategies and training of *The Stepping Stones Triple P (*SSTP) (Tellegen & Sanders, 2014; Whittingham et al., 2009). Only few interventions were held at the participants' homes (Bendixen et al., 2011; Drew et al., 2002a; Keen et al., 2010), while the majority were held at universities or in community settings. The length of interventions ranged from six (Sofronoff & Farbotko, 2002a) to 12 weeks (Drew et al., 2002a) with the duration of interventions lasting from 15 (Tellegen & Sanders, 2014) to 120 minutes (Chiang, 2014; Grahame et al., 2015a; Keen et al., 2010). A more detailed description of the interventions is provided in Table 5.

**Table 5. Description and Duration of Interventions in Included Studies**

| Study | Duration | Description of intervention |
|---|---|---|
| Bendixen 2012 | 12 weeks | A home based intervention for fathers designed to increase social communication and interaction between parents and children. Fathers were trained by a therapist and were given certain strategies to apply with their children. They were asked to train the mothers as well and both parents were asked to apply the strategies during the study. |
| Chiang 2014 | 10 weeks- 120 minutes long group sessions per week | A parental educational programme consisting of lectures delivered by a special educator with a doctorate degree at a community centre. It included topics about teaching skills for ASD children, behaviour management, ASD aetiology and available resources. The design of the intervention was inspired by parental needs and recommendations. |
| Drew 2002 | Three hours every six weeks for12 months | Parents were visited by therapists at their homes and were taught the principals of joint attention and tips on how to enhance it in children with ASD. They were also given several exercises to help in the application of these principles and received feedback from the therapist while implementing these exercises. |
| Ginn 2015 | Eight 60-75 minutes long sessions across 10 weeks | Child-Directed Interaction CDI Therapy by McNeil, Eyberg, Hembree Eisenstadt, Newcomb, and Funderburk (1991) which focuses on strengthening the emotional |

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| | | bond between parents and their children. Sessions were held by a clinical psychologist following the intervention manual. Each session was followed by an individualised behavioural coaching session tailored according to each family's needs. |
| Grahame 2015 | Two hours per week for eight weeks | A group-based intervention held by ASD professionals with parents to help them understand and manage repetitive behaviour. Individual support was provided twice for each family during the intervention helping them to deal effectively with specific patterns of repetitive behaviours in their children. |
| Keen 2010 | Two-day group workshops followed by an hour twice a week for 10 home-visits over 5-6 weeks | During the workshops, parents were given lectures about aetiology of ASD, behaviour management, and different approaches to enhance their children's communication skills. Parents were given group activities to enhance their communication with each other and introduce their concerns and interests.<br>The home visits were conducted by doctoral students to help parents identify the goals they want to achieve for their children and to help them in implementing the strategies explained in the workshop to achieve these goals. |
| Samadi 2012 | Seven sessions (60-90 minutes each) | A group-based intervention held by a psychologist with a doctoral degree at a special education school. It included educational sessions about ASD aetiology, diagnosis, interventions, and available services. Printed and audio/video materials were provided for parents to use at home |

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| | | after each session. |
| Sofronoff 2002 | Hour-long weekly sessions for six weeks | The one-day session and the first of the six sessions were held at the University of Queensland and an intervention manual was distributed for parents. It was a psychoeducational intervention aiming to increase self-efficacy of parents of children with HF ASD. It also covered management strategies for behaviour problems. |
| Tellegen 2014 | Four sessions lasting 15-105 minutes each | Primary Care Stepping Stones Triple P (PCSSTP) is an intervention designed to target specific child problems (e.g., aggression). It was delivered by practitioners with degrees in psychology along with individualised sessions with each family to help them manage behavioural problems. |
| Tonge 2006 | Ten sessions of 90 minutes over 20 weeks | A parental educational and skills based training held for groups of parents by a psychologist or special educator. The intervention is a manual based including topics about ASD aetiology, behaviour management, communication skills, and stress management tips for parents. Workbooks were distributed and home work was given for each session. |
| Whittingham 2009 | Nine weekly sessions | Stepping Stone Triple P is a behavioural intervention designed for families of children with disabilities. Five sessions in the intervention of this study are delivered in group format by a clinical psychologist during which parents are taught behavioural strategies. Four sessions are |

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| | individual ones with each family and their child helping them to apply the strategies learned and receive feedback from the therapists. |

### Outcome Measures

This meta-analysis explored the effectiveness of interventions across five different outcomes including stress, depression, anxiety, sense of competence, and parenting practices for pre-post studies and stress, depression, anxiety, and sense of competence for controlled studies. Sense of competence included studies that measured parental confidence, efficacy, and satisfaction while parenting practices included studies measuring adaptability, cohesion, and parenting styles. Stress was measured using *Parenting Stress Index-Short Form (*PSI-SF) by Abidin (1995) in (Bendixen et al., 2011; Drew et al., 2002a; Ginn et al., 2015b; Samadi et al., 2013); PSI by Abidin (1995) in (Chiang, 2014; Keen et al., 2010); the *Parenting Stress Thermometer* by N. B. Epstein, Baldwin, and Bishop (1983) in (Tonge et al., 2006); and the Depression, Anxiety, and Stress Scale-21 (DASS-21) by Lovibond and Lovibond (1995) in (Tellegen & Sanders, 2014). Depression and anxiety were measured using the General Health Questionnaire (GHQ) by Goldberg and Williams (1988b) in (Samadi et al., 2013; Tonge et al., 2006); and by using DASS-21 in (Tellegen & Sanders, 2014). Sense of competence was measured using (Johnston & Mash, 1989) *Parenting Sense of Competence Scale* in (Keen et al., 2010; Whittingham et al., 2009); *Parent Self-Efficacy Questionnaire* by (Sofronoff & Farbotko, 2002b) in (Grahame et al., 2015a); the *Parenting Tasks Checklist* by Sanders and Woolley (2005) in (Tellegen & Sanders, 2014); the *Confidence degree questions for families (CDQ*) by Okuno et al. (2011) in (Chiang, 2014); and the using *Parental self-efficacy in the management of Asperger Syndrome* questionnaire created by the authors of the article for the purpose of the study (Sofronoff & Farbotko, 2002a). Parenting practices were measured using *The Parenting Scale* by Arnold, O'Leary, Wolff, and Acker (1993) in (Tellegen & Sanders, 2014; Whittingham et al., 2009); and the *Family Adaptability and Cohesion Evaluation Scales II (FACES II)* by Olson (1986) in (Bendixen et al., 2011). In Tellegen and Sanders (2014) where stress was measured using two scales in the same study, DASS-21 score was included in this analysis as the measure has good psychometric properties and is widely used in the literature to measure stress.

### Effect of Intervention

Intervention effects will be presented per outcome.

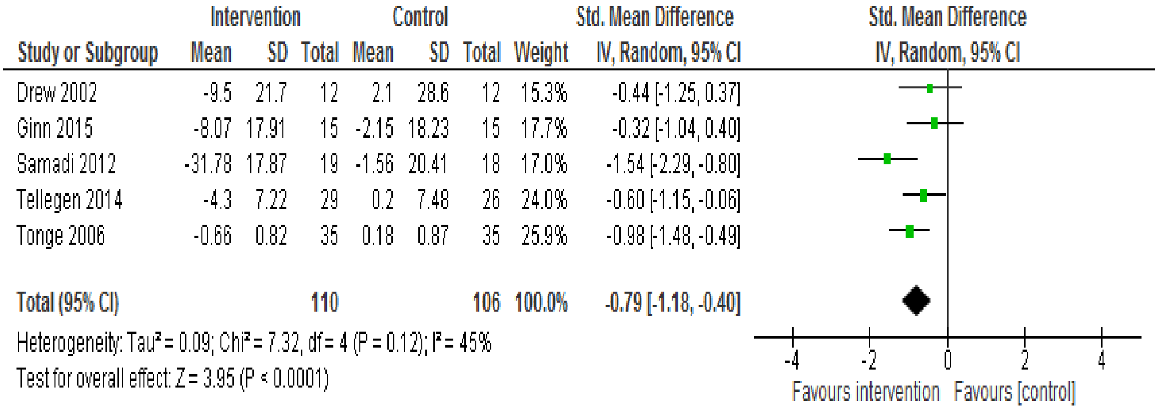
**Stress**. Eight studies (five controlled and three pre-post studies) were analysed based on a pre-post effect of intervention including 203 participants.

The analysis revealed a medium and significant effect of parenting interventions on parents' reports of stress (SMD= -0.60, 95% CI=[ -0.92- -0.28], z = 3.67, *p*< 0.001) (Figure 3). However, a significant amount of heterogeneity amongst the studies was also found ($X^2$ [7] = 16.42, *p*= 0.02, $I^2$ = 57%). Five controlled studies were analysed based on a controlled effect of intervention including 216 participants. The analysis revealed a medium and significant effect of parenting interventions on parent report of stress (SMD= -0.79, 95% CI=[ -1.18- -0.40], z = 3.95, *p*< 0.001) (Figure 4). No significant amount of heterogeneity was found amongst the studies ($X^2$ [4] = 7.32, *p*= 0.12, $I^2$ = 45%). A sensitivity analysis that excluded controlled but non-randomised studies revealed a reduced yet still medium and significant effect of parenting interventions on parent report of stress SMD= -0.67, 95% CI=[ -0.97- -0.37], z = 4.34, *p*< 0.001). Removal of studies involving non-randomised interventions reduced heterogeneity ($X^2$ [3] = 2.79, *p*= 0.43, $I^2$ = 0%) (Figure 5).

| | Post | | | Pre | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| **Study or Subgroup** | **Mean** | **SD** | **Total** | **Mean** | **SD** | **Total** | **Weight** | **IV, Random, 95% CI** |
| Bendixen 2011 | 86.8 | 17.2094 | 38 | 93.45 | 21.9102 | 38 | 15.6% | -0.33 [-0.79, 0.12] |
| Chiang 2014 | 144.935 | 21.703 | 18 | 148.78 | 22.7764 | 18 | 11.6% | -0.17 [-0.82, 0.49] |
| Drew 2002 | 104.3 | 20 | 10 | 113.8 | 21.7 | 10 | 8.2% | -0.44 [-1.33, 0.45] |
| Ginn 2015 | 91 | 14.66 | 15 | 99.07 | 17.91 | 15 | 10.4% | -0.48 [-1.21, 0.25] |
| Keen 2010 | 137.3605 | 20.6521 | 33 | 143.5581 | 18.9379 | 33 | 14.9% | -0.31 [-0.79, 0.18] |
| Samadi 2012 | 86.05 | 12.65 | 19 | 117.31 | 17.87 | 19 | 9.5% | -1.98 [-2.77, -1.19] |
| Tellegen 2014 | 8.55 | 5.78 | 35 | 12.85 | 7.22 | 35 | 15.0% | -0.65 [-1.13, -0.17] |
| Tonge 2006 | 1.86 | 0.94 | 35 | 2.51 | 0.82 | 35 | 14.9% | -0.73 [-1.21, -0.24] |
| **Total (95% CI)** | | | **203** | | | **203** | **100.0%** | **-0.60 [-0.92, -0.28]** |

Heterogeneity: $Tau^2 = 0.12; Chi^2 = 16.42, df = 7 (P = 0.02); I^2 = 57\%$
Test for overall effect: Z = 3.67 (P = 0.0002)

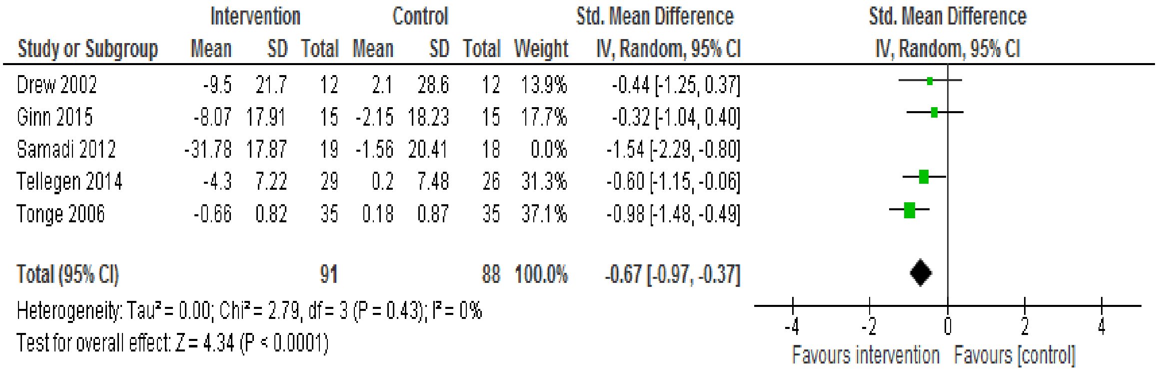
**Figure 3. Estimate of the size of pre-post intervention change in stress**



| | Intervention | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| **Study or Subgroup** | **Mean** | **SD** | **Total** | **Mean** | **SD** | **Total** | **Weight** | **IV, Random, 95% CI** |
| Drew 2002 | -9.5 | 21.7 | 12 | 2.1 | 28.6 | 12 | 15.3% | -0.44 [-1.25, 0.37] |
| Ginn 2015 | -8.07 | 17.91 | 15 | -2.15 | 18.23 | 15 | 17.7% | -0.32 [-1.04, 0.40] |
| Samadi 2012 | -31.78 | 17.87 | 19 | -1.56 | 20.41 | 18 | 17.0% | -1.54 [-2.29, -0.80] |
| Tellegen 2014 | -4.3 | 7.22 | 29 | 0.2 | 7.48 | 26 | 24.0% | -0.60 [-1.15, -0.06] |
| Tonge 2006 | -0.66 | 0.82 | 35 | 0.18 | 0.87 | 35 | 25.9% | -0.98 [-1.48, -0.49] |
| **Total (95% CI)** | | | **110** | | | **106** | **100.0%** | **-0.79 [-1.18, -0.40]** |

Heterogeneity: $Tau^2 = 0.09; Chi^2 = 7.32, df = 4 (P = 0.12); I^2 = 45\%$
Test for overall effect: Z = 3.95 (P < 0.0001)

**Figure 4. Forest plot showing estimate of the size of controlled intervention change in stress**



| | Intervention | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Drew 2002 | -9.5 | 21.7 | 12 | 2.1 | 28.6 | 12 | 13.9% | -0.44 [-1.25, 0.37] |
| Ginn 2015 | -8.07 | 17.91 | 15 | -2.15 | 18.23 | 15 | 17.7% | -0.32 [-1.04, 0.40] |
| Samadi 2012 | -31.78 | 17.87 | 19 | -1.56 | 20.41 | 18 | 0.0% | -1.54 [-2.29, -0.80] |
| Tellegen 2014 | -4.3 | 7.22 | 29 | 0.2 | 7.48 | 26 | 31.3% | -0.60 [-1.15, -0.06] |
| Tonge 2006 | -0.66 | 0.82 | 35 | 0.18 | 0.87 | 35 | 37.1% | -0.98 [-1.48, -0.49] |
| **Total (95% CI)** | | | **91** | | | **88** | **100.0%** | **-0.67 [-0.97, -0.37]** |

Heterogeneity: Tau² = 0.00; Chi² = 2.79, df = 3 (P = 0.43); I² = 0%
Test for overall effect: Z = 4.34 (P < 0.0001)

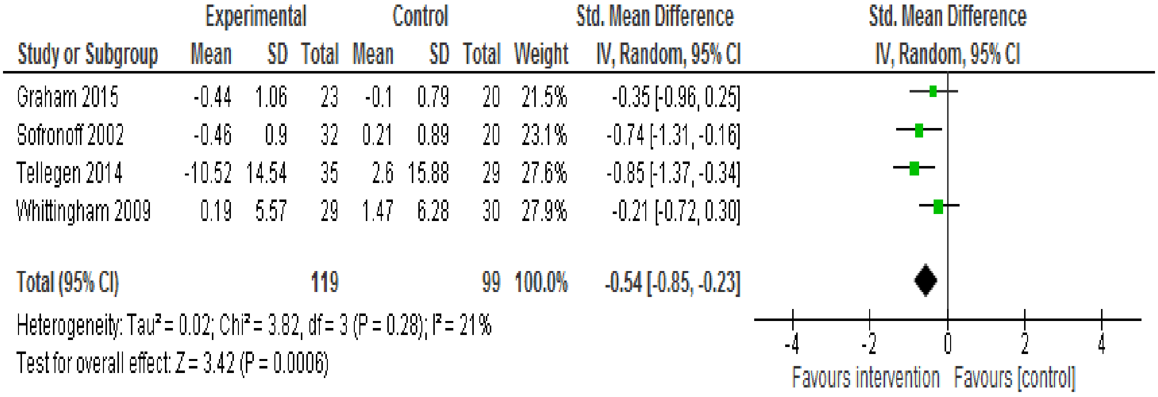
**Figure 5. Forest plot showing estimate of the size of change in stress in randomised interventions only**

**Sense of competence.** Six studies (four controlled and two pre-post studies) were analysed based on a pre-post effect of intervention including 162 participants. The analysis revealed a large and significant effect of parenting interventions on parent sense of competence (SMD= 0.83, 95% CI =[0.50 – 1.16], z = 4.88, *p*< 0.001) (Figure 6). No significant amount of heterogeneity was found amongst the studies ($X^2$ [7] = 10.04, *p*= 0.07, $I^2$ = 50%). Four controlled studies were analysed based on a controlled effect of intervention on sense of competence including 218 participants. The analysis revealed a medium and significant effect of parenting interventions on sense of competence (SMD= -0.54, 95% CI=[ -0.85 - -0.23], z = 3.42, *p*< 0.001) (Figure 7). No significant amount of heterogeneity was found amongst the studies ($X^2$ [3] = 3.82, *p*= 0.28, $I^2$ = 21%). A sensitivity analysis that excluded controlled but non-randomised studies revealed a reduction in the effect size from medium to small yet still significant (SMD= -0.48, 95% CI =[-0.88 -0.08], z = 2.36, *p*=0.02) (Figure 8). Removal of studies involving non-randomised interventions slightly reduced heterogeneity but not to a significant level ($X^2$ [2] = 3.25, *p*= 0.20, $I^2$ = 38%).

| | Post | | | Pre | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Chiang 2014 | 71.89 | 9.01 | 9 | 66.56 | 9.22 | 9 | 9.1% | 0.56 [-0.39, 1.50] |
| Graham 2015 | 3.38 | 0.97 | 23 | 2.94 | 1.06 | 23 | 16.6% | 0.43 [-0.16, 1.01] |
| Keen 2010 | 33.0419 | 4.8466 | 34 | 29.3935 | 4.7059 | 34 | 19.5% | 0.76 [0.26, 1.25] |
| Sofronoff 2002 | 3.25 | 0.7 | 32 | 2.79 | 0.9 | 32 | 19.2% | 0.56 [0.06, 1.06] |
| Tellegen 2014 | 88.83 | 6.7716 | 35 | 76.94 | 15.2878 | 35 | 19.3% | 0.99 [0.50, 1.49] |
| Whittingham 2009 | 39.41 | 5.933 | 29 | 29.29 | 6.5897 | 29 | 16.3% | 1.59 [1.00, 2.19] |
| **Total (95% CI)** | | | **162** | | | **162** | **100.0%** | **0.83 [0.50, 1.16]** |

Heterogeneity: Tau² = 0.08; Chi² = 10.04, df = 5 (P = 0.07); I² = 50%
Test for overall effect: Z = 4.88 (P < 0.00001)

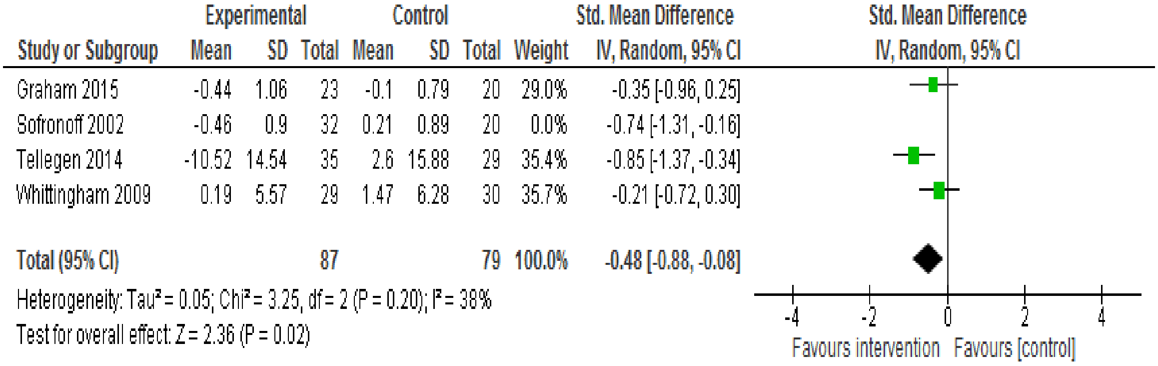
**Figure 6. Estimate of the size of pre-post intervention change in sense of competence**



| | Experimental | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Graham 2015 | -0.44 | 1.06 | 23 | -0.1 | 0.79 | 20 | 21.5% | -0.35 [-0.96, 0.25] |
| Sofronoff 2002 | -0.46 | 0.9 | 32 | 0.21 | 0.89 | 20 | 23.1% | -0.74 [-1.31, -0.16] |
| Tellegen 2014 | -10.52 | 14.54 | 35 | 2.6 | 15.88 | 29 | 27.6% | -0.85 [-1.37, -0.34] |
| Whittingham 2009 | 0.19 | 5.57 | 29 | 1.47 | 6.28 | 30 | 27.9% | -0.21 [-0.72, 0.30] |
| Total (95% CI) | | | 119 | | | 99 | 100.0% | -0.54 [-0.85, -0.23] |

Heterogeneity: Tau² = 0.02; Chi² = 3.82, df = 3 (P = 0.28); I² = 21%
Test for overall effect: Z = 3.42 (P = 0.0006)

**Figure 7. Forest plot showing estimate of the size of controlled intervention change in sense of competence**

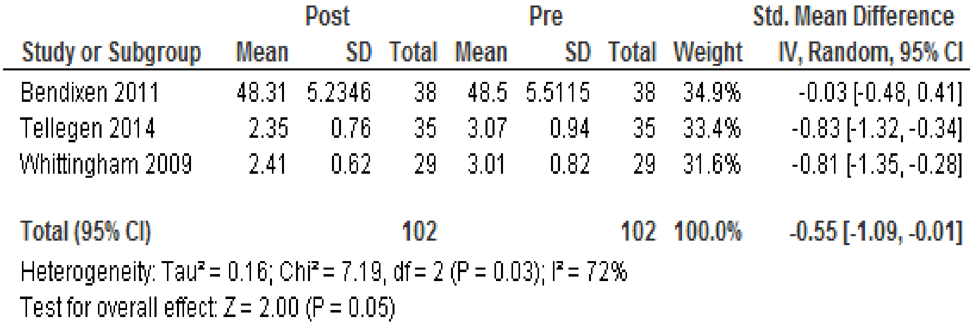


| | Experimental | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Graham 2015 | -0.44 | 1.06 | 23 | -0.1 | 0.79 | 20 | 29.0% | -0.35 [-0.96, 0.25] |
| Sofronoff 2002 | -0.46 | 0.9 | 32 | 0.21 | 0.89 | 20 | 0.0% | -0.74 [-1.31, -0.16] |
| Tellegen 2014 | -10.52 | 14.54 | 35 | 2.6 | 15.88 | 29 | 35.4% | -0.85 [-1.37, -0.34] |
| Whittingham 2009 | 0.19 | 5.57 | 29 | 1.47 | 6.28 | 30 | 35.7% | -0.21 [-0.72, 0.30] |
| Total (95% CI) | | | 87 | | | 79 | 100.0% | -0.48 [-0.88, -0.08] |

Heterogeneity: Tau² = 0.05; Chi² = 3.25, df = 2 (P = 0.20); I² = 38%
Test for overall effect: Z = 2.36 (P = 0.02)

**Figure 8. Forest plot showing estimate of the size of change in sense of competence in randomised interventions only**

**Parenting practices.** Three studies (two controlled and one pre-post study) were analysed based on a pre-post effect of intervention including 102 participants. The analysis revealed a medium and significant effect of parenting interventions on parenting practices (SMD= -0.55, 95% CI = [-1.09 – -0.01], z = 2.00, *p*=0.05) (Figure 9). However, a significant amount of heterogeneity was found amongst the studies (X$^2$ [2] = 7.19, *p*= 0.03, I$^2$ = 72%). No analysis was performed for parenting practices on controlled studies as only two studies were available.

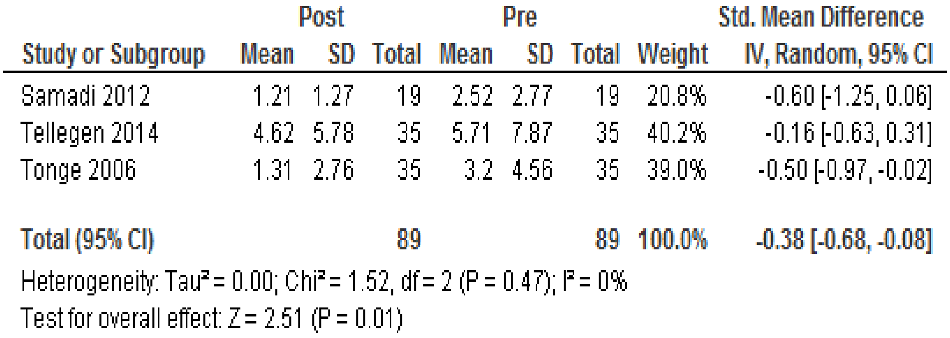


| | Post | | | Pre | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Bendixen 2011 | 48.31 | 5.2346 | 38 | 48.5 | 5.5115 | 38 | 34.9% | -0.03 [-0.48, 0.41] |
| Tellegen 2014 | 2.35 | 0.76 | 35 | 3.07 | 0.94 | 35 | 33.4% | -0.83 [-1.32, -0.34] |
| Whittingham 2009 | 2.41 | 0.62 | 29 | 3.01 | 0.82 | 29 | 31.6% | -0.81 [-1.35, -0.28] |
| **Total (95% CI)** | | | **102** | | | **102** | **100.0%** | **-0.55 [-1.09, -0.01]** |

Heterogeneity: Tau$^2$ = 0.16; Chi$^2$ = 7.19, df = 2 (P = 0.03); I$^2$ = 72%
Test for overall effect: Z = 2.00 (P = 0.05)

**Figure 9. Estimate of the size of pre-post intervention change in parenting practices**

**Depression.** Three studies (controlled) were analysed based on a pre-post effect of intervention including 89 participants. The analysis revealed a small but significant effect of parenting interventions on depression (SMD= -0.38, 95% CI =[ -0.68 – -0.08], z = 2.51, *p*=0.01) (Figure 10). No significant amount of heterogeneity was found amongst the studies (X$^2$ [2] = 1.52, *p*= 0.47, I$^2$ = 0%). Three controlled studies were analysed based on a controlled effect of intervention on sense of competence including 162 participants. The analysis revealed a small yet significant effect of parenting interventions on depression (SMD= -0.34, 95% CI=[ -0.65 - -0.03], z = 2.16, *p*=0.03) (Figure 11). No significant amount of heterogeneity was found amongst the studies (X$^2$ [2] = 1.85, *p*= 0.40, I$^2$ = 0%). A sensitivity analysis that excluded a controlled but non-randomised study revealed a reduction in the effect size that is still small but not significant (SMD= -0.23, 95% CI = [-0.58 - 0.12], z = 1.29, *p*=0.20) (Figure 12). Heterogeneity remained non-significant (X$^2$ [1] = 0.08, *p*= 0.20, I$^2$ = 0%).

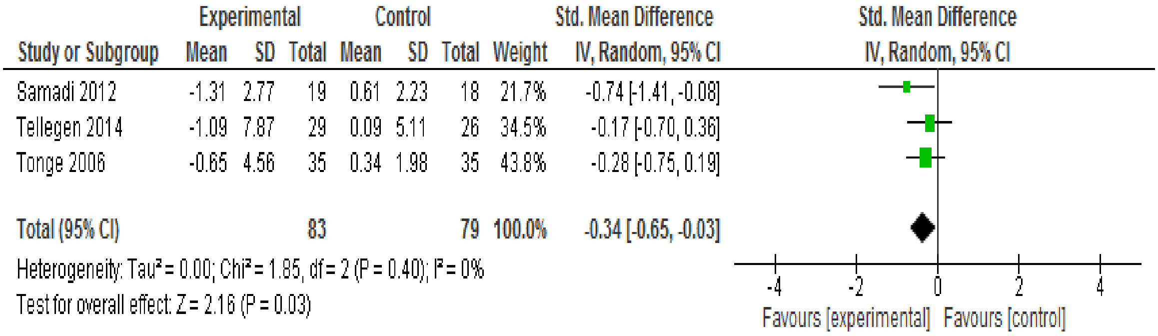


| | Post | | | Pre | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Samadi 2012 | 1.21 | 1.27 | 19 | 2.52 | 2.77 | 19 | 20.8% | -0.60 [-1.25, 0.06] |
| Tellegen 2014 | 4.62 | 5.78 | 35 | 5.71 | 7.87 | 35 | 40.2% | -0.16 [-0.63, 0.31] |
| Tonge 2006 | 1.31 | 2.76 | 35 | 3.2 | 4.56 | 35 | 39.0% | -0.50 [-0.97, -0.02] |
| **Total (95% CI)** | | | **89** | | | **89** | **100.0%** | **-0.38 [-0.68, -0.08]** |

Heterogeneity: Tau² = 0.00; Chi² = 1.52, df = 2 (P = 0.47); I² = 0%

Test for overall effect: Z = 2.51 (P = 0.01)

**Figure 10. Estimate of the size of pre-post intervention change in depression**

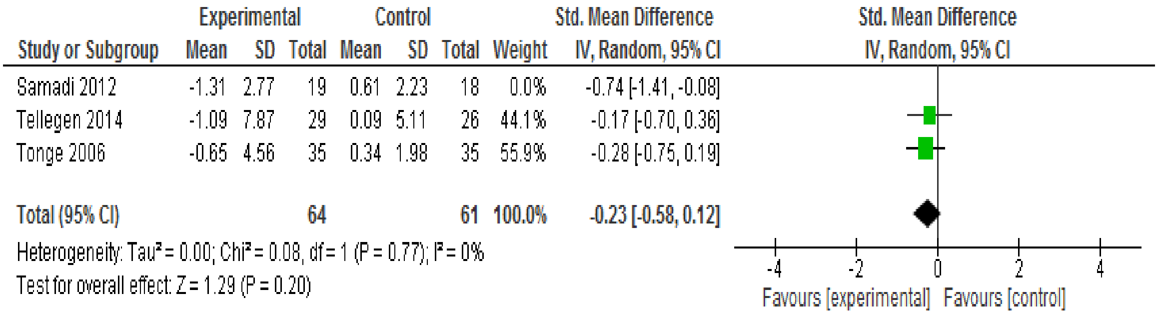


| | Experimental | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Samadi 2012 | -1.31 | 2.77 | 19 | 0.61 | 2.23 | 18 | 21.7% | -0.74 [-1.41, -0.08] |
| Tellegen 2014 | -1.09 | 7.87 | 29 | 0.09 | 5.11 | 26 | 34.5% | -0.17 [-0.70, 0.36] |
| Tonge 2006 | -0.65 | 4.56 | 35 | 0.34 | 1.98 | 35 | 43.8% | -0.28 [-0.75, 0.19] |
| **Total (95% CI)** | | | **83** | | | **79** | **100.0%** | **-0.34 [-0.65, -0.03]** |

Heterogeneity: Tau² = 0.00; Chi² = 1.85, df = 2 (P = 0.40); I² = 0%

Test for overall effect: Z = 2.16 (P = 0.03)

**Figure 11. Forest plot showing estimate of the size of controlled intervention change in depression**



| | Experimental | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| Study or Subgroup | Mean | SD | Total | Mean | SD | Total | Weight | IV, Random, 95% CI |
| Samadi 2012 | -1.31 | 2.77 | 19 | 0.61 | 2.23 | 18 | 0.0% | -0.74 [-1.41, -0.08] |
| Tellegen 2014 | -1.09 | 7.87 | 29 | 0.09 | 5.11 | 26 | 44.1% | -0.17 [-0.70, 0.36] |
| Tonge 2006 | -0.65 | 4.56 | 35 | 0.34 | 1.98 | 35 | 55.9% | -0.28 [-0.75, 0.19] |
| **Total (95% CI)** | | | **64** | | | **61** | **100.0%** | **-0.23 [-0.58, 0.12]** |

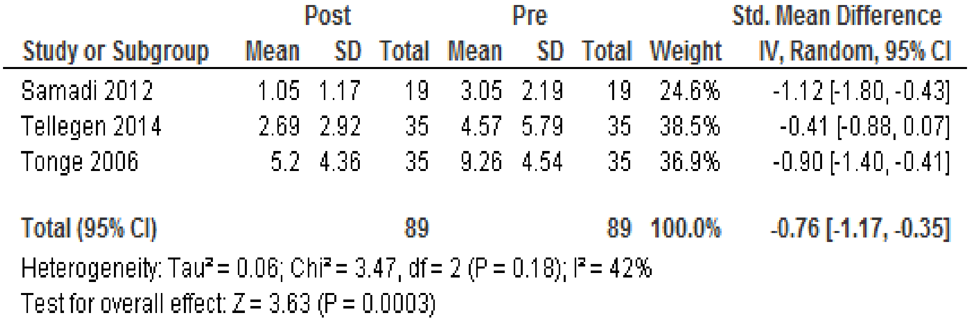
Heterogeneity: Tau² = 0.00; Chi² = 0.08, df = 1 (P = 0.77); I² = 0%

Test for overall effect: Z = 1.29 (P = 0.20)

**Figure 12. Forest plot showing estimate of the size of change in depression in randomised interventions only**

**Anxiety.** Three studies (controlled) were analysed based on a pre-post effect of intervention including 89 participants. The analysis revealed a medium but significant effect of parenting interventions on anxiety (SMD= -0.76, 95% CI = [-1.17 – -0.35], z = 3.63, *p*< 0.001) (Figure 13). No significant amount of heterogeneity amongst studies was found ($X^2$ [2] = 3.47, *p*= 0.18, $I^2$ = 42%).

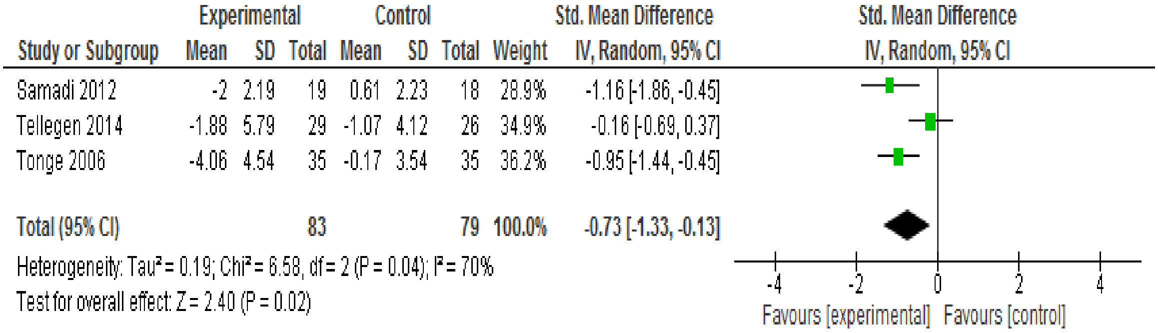
Three controlled studies were analysed based on a controlled effect of intervention on anxiety including 162 participants. The analysis revealed a medium yet significant effect of parenting interventions on anxiety (SMD= -0.73, 95% CI = [-1.33 - -0.13], z = 2.40, *p*=0.02) (Figure 14). However, a significant amount of heterogeneity was found amongst the studies ($X^2$ [2] = 6.58, *p*= 0.04, $I^2$ = 70%). A sensitivity analysis that excluded a controlled but non-randomised study revealed a reduction in effect size that is still medium but not significant (SMD= -0.56, 95% CI = [-1.33 - 0.21], z = 1.41, *p*=0.16) (Figure 15). Heterogeneity remained non-significant ($X^2$ [1] = 4.52, *p*= 0.03, $I^2$ = 78%).



| | Post | | | Pre | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| **Study or Subgroup** | **Mean** | **SD** | **Total** | **Mean** | **SD** | **Total** | **Weight** | **IV, Random, 95% CI** |
| Samadi 2012 | 1.05 | 1.17 | 19 | 3.05 | 2.19 | 19 | 24.6% | -1.12 [-1.80, -0.43] |
| Tellegen 2014 | 2.69 | 2.92 | 35 | 4.57 | 5.79 | 35 | 38.5% | -0.41 [-0.88, 0.07] |
| Tonge 2006 | 5.2 | 4.36 | 35 | 9.26 | 4.54 | 35 | 36.9% | -0.90 [-1.40, -0.41] |
| **Total (95% CI)** | | | **89** | | | **89** | **100.0%** | **-0.76 [-1.17, -0.35]** |

Heterogeneity: Tau² = 0.06; Chi² = 3.47, df = 2 (P = 0.18); I² = 42%
Test for overall effect: Z = 3.63 (P = 0.0003)

**Figure 13. Estimate of the size of pre-post intervention change in anxiety**



| | Experimental | | | Control | | | | Std. Mean Difference |
|---|---|---|---|---|---|---|---|---|
| **Study or Subgroup** | **Mean** | **SD** | **Total** | **Mean** | **SD** | **Total** | **Weight** | **IV, Random, 95% CI** |
| Samadi 2012 | -2 | 2.19 | 19 | 0.61 | 2.23 | 18 | 28.9% | -1.16 [-1.86, -0.45] |
| Tellegen 2014 | -1.88 | 5.79 | 29 | -1.07 | 4.12 | 26 | 34.9% | -0.16 [-0.69, 0.37] |
| Tonge 2006 | -4.06 | 4.54 | 35 | -0.17 | 3.54 | 35 | 36.2% | -0.95 [-1.44, -0.45] |
| **Total (95% CI)** | | | **83** | | | **79** | **100.0%** | **-0.73 [-1.33, -0.13]** |

Heterogeneity: Tau² = 0.19; Chi² = 6.58, df = 2 (P = 0.04); I² = 70%
Test for overall effect: Z = 2.40 (P = 0.02)

**Figure 14. Forest plot showing estimate of the size of controlled intervention change in anxiety**

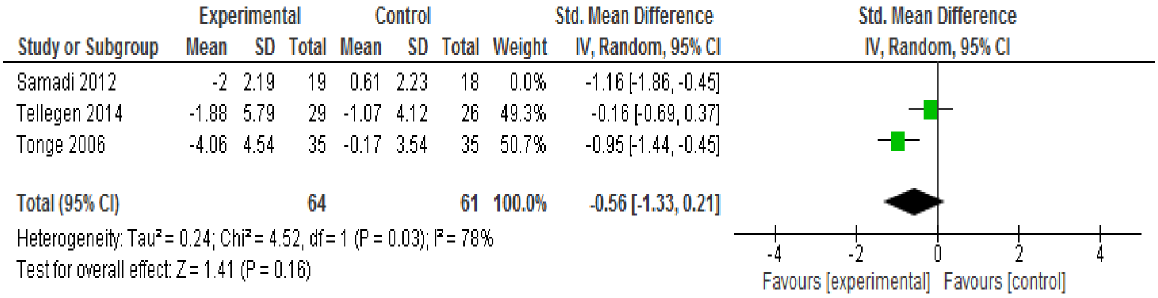
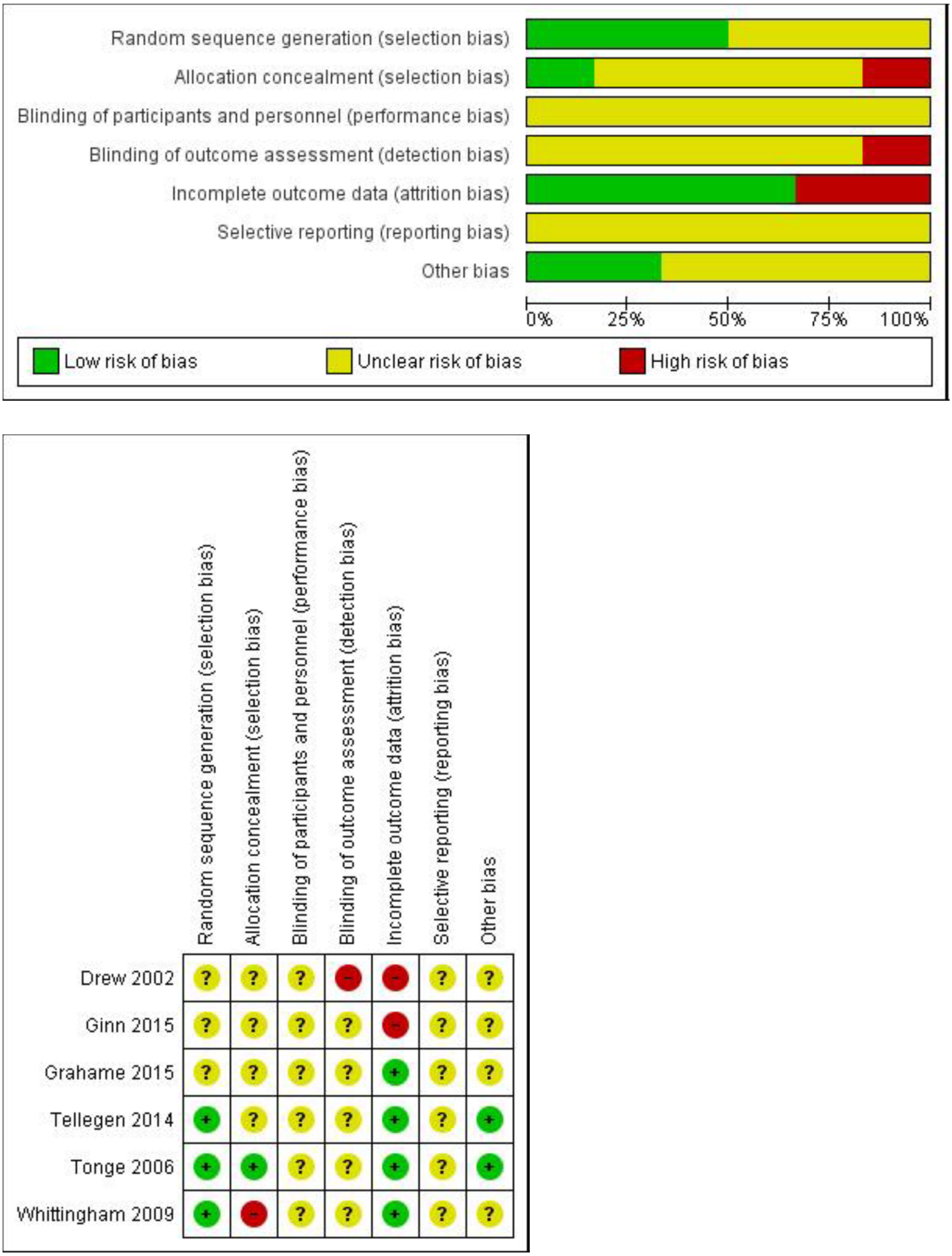


**Figure 15. Forest plot showing estimate of the size of change in anxiety in randomised interventions only**

### Methodological Quality and Risk of bias

The quality of the included studies using the Mixed Methods Appraisal Tool (MMAT) revealed that 36.36% of the studies (4 studies) scored 100% (Samadi et al., 2013; Tellegen & Sanders, 2014; Tonge et al., 2006; Whittingham et al., 2009), 36.36% of the studies (4 studies) scored 75% (Bendixen et al., 2011; Chiang, 2014; Drew et al., 2002a; Karst & Van Hecke, 2012), 18.18 % of studies (2 studies) scored 50% (Ginn et al., 2015b; Grahame et al., 2015a), and 10% of the studies (1 study) scored 25% (Sofronoff & Farbotko, 2002a). Overall the MMAT study quality tool indicated that the majority of the included studies were of high study quality. See Appendix 12 for more details on scoring.

The overall risk of bias for the included studies in this meta-analysis was felt to be unclear .The majority of RCTs displayed unclear risk of bias (Figure 16), mostly due to the studies not reporting sufficient information to assess bias. The highest risk of bias in RCTs was due to incomplete outcome data and reporting of attrition. Similar to RCTs, risk of bias for the majority of NRS were unclear with the highest risk of bias being due to selection of participants and lack of blinding (Figure 17).



| | Random sequence generation (selection bias) | Allocation concealment (selection bias) | Blinding of participants and personnel (performance bias) | Blinding of outcome assessment (detection bias) | Incomplete outcome data (attrition bias) | Selective reporting (reporting bias) | Other bias |
|---|---|---|---|---|---|---|---|
| Drew 2002 | ? | ? | ? | – | – | ? | ? |
| Ginn 2015 | ? | ? | ? | ? | – | ? | ? |
| Grahame 2015 | ? | ? | ? | ? | + | ? | ? |
| Tellegen 2014 | + | ? | ? | ? | + | ? | + |
| Tonge 2006 | + | + | ? | ? | + | ? | + |
| Whittingham 2009 | + | – | ? | ? | + | ? | ? |

**Figure 16. Risk of bias for RCTs**

| | Selection bias | Blinding of participants and personnel (performance bias) | Bias in measurement of outcomes | Incomplete outcome data (attrition bias) | Confounding bias | Selective reporting (reporting bias) | Other bias |
|---|---|---|---|---|---|---|---|
| Bendixen 2011 | ? | − | − | + | ? | ? | + |
| Chiang 2014 | ? | − | − | + | ? | ? | + |
| Keen 2010 | − | ? | + | + | + | ? | ? |
| Samadi 2012 | − | − | + | + | + | ? | ? |
| Sofronoff 2002 | − | ? | ? | + | ? | ? | ? |

**Figure 17. Risk of bias for NRS**

## Discussion

Given the potential of parenting interventions to enhance parental functioning, this meta-analysis aimed to establish the efficacy of parenting interventions for parents of children with ASD. Analyses revealed medium but significant effects of interventions on parents' stress pre-post intervention. This effect remained medium and significant when controlled studies were analysed and also following sensitivity analyses removing non-randomised trials. Moreover, the analyses showed a large and significant effect of interventions on parental sense of competence pre-post intervention. The effect decreased to medium and significant for sense of competence when controlled studies were analysed and remained medium and significant after sensitivity analyses removing non-randomised trials. Analyses of depression displayed a small but significant effect of interventions on parents' depression pre-post interventions. The effect remained small and significant for depression when controlled studies were analysed but small and non-significant following sensitivity analyses removing a non-randomised trial. Moreover, analyses of anxiety displayed a medium but significant effect of interventions on parents' anxiety pre-post interventions. The effect remained medium and significant for anxiety when controlled studies were analysed but medium and non-significant following sensitivity analyses removing a non-randomised trial. Analyses of parenting practices revealed a medium and significant effect pre-post interventions. Heterogeneity was only found to be significant in stress and parenting practices pre-post interventions, and in anxiety analysed in controlled studies even after the removal of a non-randomised study from the analysis. The included studies displayed an overall high quality using the MMAT tool but unclear risk of bias using the Cochrane collaboration risk of bias tools for RCTs and NRS.

The findings of this meta-analysis are in line with and extend the findings of a meta-analysis by Jane Barlow, Coren, and Stewart-Brown (2002) which found a significant effect of parenting interventions on parental stress, depression, and anxiety in parents of TDC. The findings in this analysis that stress was significantly reduced post interventions in parents of children with ASD contradicts the results of Oono, E. J. Honey, and H. McConachie (2013) who did not report a significant reduction in parental stress following their intervention for parents of children with ASD. However, this could be due to the fact that Oono et al. (2013) intervention was child–focused and not parent-focused intervention and the involvement of parents was mainly to enhance children's acquisition of skills. In addition, Oono et al. (2013) analysis of parental stress included only two studies in which study selection bias may have influenced the results. The finding that parents' sense of competence was  significantly enhanced post intervention in our study concurs with W. Dunn, Cox, Foster, Mische-Lawson, and Tanquary (2012) who found that parents' sense of competence was increased post intervention in parents of children with ASD. However in contrast, Estes et al. (2014) did not find an effect of their parenting intervention on parental sense of competence in parents of children with ASD. The challenges of trying to enhance child language competence and the slow rate of improvement may help to explain why small intervention improvements in child language skills in Estes et al. (2014) were not accompanied by enhancements in parental sense of competence. McConachie and Diggle (2007) found in their systematic review that the quality of parental interactions was significantly increased post interventions in parents of children with ASD; a finding that is in line with the results of Robert L. Koegel, Bimbela, and Schreibman (1996) as well as this study which found significant positive effects of interventions on parental practices in parents of children with ASD. The small but significant effect of interventions on depression found in this analysis concurs with Singer et al meta-analysis which also found small but significant effects of intervention on parental depression. This finding was also found to agree with results of McConachie and Diggle (2007) review and Bristol, Gallagher, and Holt (1993) which found significant effect of interventions on parental depression in parents of children with ASD. This study displayed a significant effect of interventions on anxiety, which was also found in Julie Barlow, Powell, and Gilchrist (2006) who found a significant positive effect of parenting intervention on parents' anxiety in parents of children with disabilities including ASD. The lack of a significant effect on depression and anxiety after the removal of the non-randomised study could be possibly attributed to study characteristics as only two RCTS were included in that analysis, or it may be related to study design. However, the current analysis is not able to extrapolate further. The small decrease in effect sizes in sense of competence, depression and anxiety between pre-post and controlled analyses could be due to the fact that pre-post effect sizes may be inflated by events that controlled studies are able to eliminate.

The moderate to high heterogeneity found in stress, parenting practices, and anxiety could be due to the variability in types of interventions or differences in baseline characteristics. However, it was neither possible nor feasible in this meta-analysis to conduct separate analyses for similar interventions due to the small number of studies. An extensive evaluation of study quality suggests that while the overall quality of the included studies is high, an examination of risk of bias yielded an overall unclear risk of bias for the majority of studies which suggests a lack of confidence in the overall quality of the included studies. While the MMAT tool explored the methodological quality of studies and the Cochrane collaboration's risk of bias tool measured different aspects of bias and quality (e.g., performance bias), the lack of concordance between the two tools of assessment is a cause of concern. Therefore, it is important for future studies to determine if methodological quality of studies is more important than reporting where there are disagreements between the two.

### Limitations

The findings should be considered in light of some considerations. First, all outcomes are based on responses from the most proximal informants (parents) where it was not possible to control for the efforts involved in participation in the intervention and its impact on parental perceptions. However, in measuring the effect of interventions on parental outcomes (e.g., well-being), parental report on their conditions might give a better picture of the measures' outcomes. Only four studies (Grahame et al., 2015a; Sofronoff & Farbotko, 2002a; Tellegen & Sanders, 2014; Tonge et al., 2006) included follow-up assessment of outcomes and therefore due to insufficient data, only post-intervention outcomes were analysed and it is unclear to what extent treatment effects were maintained. There were only few studies to investigate in this analysis which highlights the lack of literature in the area. In addition, it was not possible to examine different modes of delivery (e.g., group vs. individual training). It was also not possible to explore implementation fidelity of the interventions, as insufficient information about fidelity was provided in case of most studies. The efficacy of the interventions independent of any cost (health economics) was not considered in this study. This meta-analysis included studies that measured stress in parents using global stress measures (Tellegen & Sanders, 2014; Tonge et al., 2006) instead of specific parenting stress measures (e.g., PSI-SF), however, these measures are widely used to measure stress in parents of children with ASD and other neurodevelopmental disorders. It was not possible in this study to explore moderators of outcomes' due to the insufficient number of studies which made it difficult to comment on the impact of parents', children's, and therapists' factors on the magnitude of the outcomes. Finally, the inclusion of NRS increased the risk of bias in this meta-analysis, but the knowledge gained provides a valuable insight into existing interventions and parental outcomes, which warrants their inclusion. It was argued that evidence from observational studies as well as from RCTs would complement each other specifically in well conducted observational studies, which is extremely important in a developing research field with a large number of uncontrolled studies and relatively few RCTs (Barton, 2000; Ehring et al., 2014).

**Recommendations for Future Research**

Future studies will need to consider the following important issues in order to enhance research in this area

- As very few studies have explored the long-term outcomes of interventions, beyond short term effects. Maintenance follow-up data are required to explore whether changes in parental outcomes are sustained beyond the intervention period.

- As very few studies have explored treatment fidelity, very little is known about the impact of therapists' factors on treatment outcome. The fidelity of intervention delivery should be monitored and reported in future studies so that therapist factors can be explored in greater detail.

- The impact of mode of delivery on treatment outcomes is very unclear. Historically group interventions for neurodevelopmental disorders have been assumed to be better and cheaper to deliver (NICE, 2008). However a recent study on ADHD has demonstrated that individual home based treatment, is more cost-effective for young children with ADHD than group based treatment (Sonuga-Barke et al., Submitted). It will therefore be important in the future to explore differences in outcomes based on different modes of intervention delivery.

- It is not possible at present to understand for whom parenting interventions for ASD work best. In the future, it will be important to conduct studies with larger sample sizes to be able to explore potential moderators of outcome.

- This meta-analysis has been conducted without any reference to the costs of delivery of various interventions. Future research will need to consider not only the efficacy of interventions but also cost-effectiveness to better guide the realistic provision of services for parents of children with ASD

# Chapter Five: Justifying the Need for a Psychoeducation Intervention to Address Parental Stress and Child Outcomes

## Overview

The main objective of this chapter is to justify the need for a psychoeducation intervention that aims to address parental stress and child outcomes in parents of children with ASD. It begins by discussing the role of parental stress and child characteristics within the context of ASD, including the utility of the double ABCX model by McCubbin and Patterson (1983) in explaining adjustment in parents of children with ASD. This chapter will then explain each of the components to be addressed in the proposed intervention (Chapter 6). It will also evaluate critically and embed the intervention components and outcomes in the wider empirical literature, and the earlier studies in this thesis (systematic review, qualitative pilot study, and meta-analysis).

## The Role of Parental Stress, Symptoms Severity, and Child Behaviour Problems in the Context of ASD

Studies suggest mothers of children with ASD are at an increased risk for stress compared to mothers of children with other disorders or mothers of typically developing children (TDC) (Baker-Ericzen et al., 2005; Herring et al., 2006). The relationship between parental stress and child characteristics in children with ASD (ASD symptoms and behaviour problems) is complex. Evidence from several longitudinal studies suggests the relationship between parental stress and child behaviours is bidirectional supporting both the influence of parenting stress on later child behaviour (Osborne & Reed, 2009); as well as the influence of childhood behaviour on later maternal stress (Baker et al., 2003; Lecavalier, Leone, & Wiltz, 2006). Another longitudinal study of maternal stress in mothers of children with ASD found that mothers reported high levels of stress and child behaviour problems at both T1 and T2 over a period of 4.5 years, which they attributed to mothers continuing to perceive their situations as stressful or to the children's behaviour problems persisting over time (Pozo & Sarria, 2014 b). Despite the small sample size (n=21) in that study, its longitudinal design provided researchers with an understanding of the complexity of the adaptation process in parents of children with ASD over time.

The double ABCX model by McCubbin and Patterson (1983) provides an overarching framework that could include many variables related to parental well-being and adjustment, and it could explain interactions among these variables to predict parental adjustment. The double ABCX model suggests that the adaptation outcome (xX factor) depends on interrelations among several factors: stressors (aA factor), resources (bB factor), the definition of the situation (cC factor), and coping strategies (BC factor). Several researchers have applied the double ABCX model to examine the relationship between stress and adaptation in families of children with ASD. These studies have supported using the double ABCX model in explaining adjustment in the families of children with ASD to stressors associated with having a child with ASD (Bristol, 1987; Manning, Wainwright, & Bennett, 2011; Pakenham et al., 2005; Pozo, Sarria, & Brioso, 2014 a). In a longitudinal study, Bristol (1987) used parent-report measures to examine and explain the utility of the different components within the double ABCX model in understanding family adjustment in parents of children with ASD. The study found that family adaptation was predicted by social support, coping strategies, and parents' perceptions of their child's diagnosis predicted. Moreover, Manning et al. (2011) investigated well-being and psychological distress in racially-diverse families with children with ASD and found a significant variance in family functioning, and parental distress was accounted for by this model. They found that despite parents' reports of high stress levels, their reports on family functioning were within the normal range. This supports one of the main assumptions of the double ABCX model, which is that a stressor does not always lead to a crisis if the family is able to utilise available resources. However, it should be noted that the study examined cross-sectional data as opposed to longitudinal data from the same sample over time, therefore, it is not possible to draw conclusions about changes in family adjustment over time. Pakenham et al. (2005), in a sample of mothers of school-aged children with high functioning (HF) ASD, demonstrated that a number of double ABCX model variables has explained maternal adjustment. Based on maternal reports, they found maternal adjustment to be related to greater social support, less stress and fewer child behaviour problems.

Pozo et al. (2014 a) proposed a theoretical model of family adaptation and psychological well-being in families of children with ASD based on the double ABCX model. Their model included ASD symptoms severity, child behaviour problems, social support, sense of coherence (SoC), and coping strategies as components (Figure 18). They studied the interrelationships among these components in (n=118) parents of children with ASD to identify direct and indirect effects. In Pozo's et al. (2014 a) proposed a model of adaptation, the (aA) variables represent the severity of ASD and behaviour problems; the (bB) variable represents Social support and the (cC) variable represents SoC. The model focused on two coping types, including positive and problem-focused coping, and active avoidance coping (BC) variables. Adaptation (xX factor) was evaluated based on quality of life (QOL) and psychological well-being variables. The model suggested social support (bB), SoC (cC), and coping (BC) factors play mediating roles between ASD symptoms and child behaviour problems (aA), and QOL and psychological well-being (xX) (Pozo et al., 2014 a). Child behaviours was found to be indirectly related to QOL and psychological well-being through SoC; parents with high levels of SoC were satisfied with their QOL and had a positive psychological well-being (Pozo et al., 2014 a). This was due to the positive relation between SoC and QOL and psychological well-being. The study also found that child behaviour problems and ASD symptoms had a negative relationship with SoC; parents who reported severe ASD symptoms or more child behaviour problems were more likely to report a lower SoC (Pozo et al., 2014 a). In addition, social support was found to have a positive relation with QOL; parents who reported having adequate social support were more likely to report having good QOL. The severity of ASD symptoms had a negative impact on maternal satisfaction with QOL; mothers but not fathers of children with severe ASD symptoms were less satisfied with QOL. Moreover, the use of positive and problem-focused coping strategies was found to predict psychological well-being in mothers (Pozo et al., 2014 a).

The patterns of interactions explained above between the different components of the proposed model by Pozo et al. (2014 a) were also evident in different studies in the literature. These studies helped in explaining variables related to family adjustment and outcomes when caring for children with ASD. Characteristics of children with ASD play an important role in parental adaptation. A longitudinal study by Lecavalier et al. (2006) investigated whether child behaviour problems predict parental maladjustment over time. Lecavalier et al. (2006) measured child behaviour problems and parental stress in (n=81) families with children with ASD at two time points over a year. They found that child behaviour problems at T1 predicted increased parental stress at T 2 after controlling for stress at T1. A strength of that study was the large and heterogeneous sample, however, they relied on self-report measures in which the rating of items depend on a subjective interpretation. In another study by ( Allik et al., 2006; Lee et al., 2009 a), having a child with HF ASD was found to impact parental QOL compared to parents of TDC. Maternal QOL was found to be associated with children's behaviour problems in a cross-sectional study comparing QOL among (n=61) parents of children with ASD with QOL among (n=59) parents of TDC (Allik et al., 2006). However, due to the small sample size in that study, it is quite possible that small differences in QOL between parents of HF ASD children and parents of TDC were not detected (Allik et al., 2006). Moreover, ASD severity was found to be negatively associated with parental QOL in a cross-sectional study of (n=303) parents of children with ASD (Wisessathorn et al., 2013). A limitation of that study was that it would not be possible to predict the impact of ASD severity on parental QOL overtime due to the study being cross sectional. A non-randomised controlled trial of (n=27) mothers of children with ASD, where the mothers in the intervention group were assigned to a support group programme, found that mothers who attended the support group programme experienced better subjective well-being, which had a significant effect on their QOL (Shu & Lung, 2005). Attending the support group and being part of the group could have reduced maternal social isolation, which eventually led to improvements in adaptation (social support variable in the model proposed by (Pozo et al., 2014 a). However, findings from Shu and Lung (2005) should be interpreted with caution due to the small sample size and associated risk of bias resulting from the non-random allocation of participants to trial groups.

According to Pozo et al. (2014 a), SoC is considered a personality characteristic or coping style that may be affected by a crisis, but it can return to its previous values (Antonovsky, 1987). In a two group cross-sectional study, Olsson and Hwang (2002) compared (n=216) parents of children with developmental disabilities, including ASD, to (n=213) parents of TDC, parents of children with developmental disabilities who had a low SoC were found to be more depressed than parents of TDC with a low SoC. As this was a cross-sectional study, it could not be concluded that low a SoC leads to depression. Another cross-sectional study by McStay, Trembath, and Dissanayake (2014) that explored predictors of stress and QOL in parents of children with ASD among (n=196) parents found lower levels of parental SoC to be associated with higher levels of stress, and higher SoC levels to be associated with greater QOL. Findings from that study should be interpreted with caution, as parents in their sample belongs to high socio-economic status groups, which could limit the generalisability of the findings to other groups of parents of children with ASD (McStay et al., 2014). In addition, due to the cross-sectional nature of the study design, causality could not be asserted.

Moreover, Pozo's et al. (2014 a) model also suggested the utility of using coping strategies (BC factor) to address parental well-being in parents of children with ASD. Glidden, Billings, and Jobe (2006) in their cross-sectional study of (n=97) parents of children with developmental disabilities, found that mothers tend to use problem-focused coping strategies more than fathers, which was associated with lower levels of maternal depression. However, due to the study being cross-sectional, it would be difficult to predict whether the use of coping strategies among parents in the present will influence parental well-being outcomes in the future (Glidden et al., 2006). Findings from Hastings et al. (2005 b) also supported Pozo's et al. (2014 a) proposed model. They found that the use of problem-focused coping strategies by parents of children with ASD was associated with lower levels of parental depression (Hastings et al., 2005 b). Their result should be interpreted with caution, as the study was cross-sectional and therefore would be unable to predict the nature of the relation between using coping strategies and parental well-being over time.

The specific interaction patterns explained above between the different components of the double ABCX model and the model proposed by Pozo et al. (2014 a) contribute to the understanding of psychological adaptation in parents of children with ASD. Findings therefore could be considered in interventions with families of children with ASD.

The majority of the findings reported in the studies in the above section related to family adaptation in families of children with ASD were from cross-sectional studies. This is due to the lack of longitudinal studies examining parental variables within the literature of parenting children with ASD which was also highlighted in the first systematic review in this thesis (Chapter 2). Longitudinal studies provide stronger evidence of the association between outcomes, while cross-sectional studies display the associations found at one time, which prevents the analysis of changes in variables over time. Therefore, more studies employing longitudinal methods are needed within the literature of parenting children with ASD to examine how having children with ASD influences parental life over time.

Lazarus and Folkman (1984) also provided a model of stress and coping which suggested stress is dependent on the cognitive appraisal of the situation. Therefore, a stressor according to this model is defined by the subjective judgment of the situation that is appraised as threatening. This suggests a conscious strategy in responding to stressful events (Lazarus & Folkman, 1984). Findings from the study by Plant and Sanders (2007) support the role of parental appraisal on parental stress levels. They measured parental appraisals related to caregiving tasks among (n=105) mothers with pre-school aged children with developmental disabilities (including children with ASD). Maternal cognitive appraisal of their child's level of disability and behaviour problems was found to directly influence their stress level ; mothers who had children with more severe symptoms and behaviour problems were more likely to perceive care-giving demands in a more negative way, which negatively impacted their stress level (Plant & Sanders, 2007). Whilst these results support the transactional model of stress by (Lazarus & Folkman, 1984), it is noteworthy that Plant and Sanders (2007) used a sample that was unrepresentative due to their high socioeconomic status. It is therefore unclear whether maternal appraisals affect adjustment in the same way for mothers from lower socioeconomic backgrounds. The above suggests important role of parental understanding of ASD, including how parental appraisal of child behaviour has significant implications for how that parent copes with on-going care demands.

Research on parental adaptation in families with a child with ASD has generally focused on negative outcomes such as stress, anxiety and depression.

However, in the last decade, there has been a tendency to study positive experiences and variables associated with raising children with ASD. The findings from the systematic review (Chapter 2) indicated the scarcity of studies that explored positive outcomes within the literature of parenting children with ASD (Altiere & von Kluge, 2009 b; Faso et al. 2013). In a cross-sectional study by Faso et al. (2013) that examined the relations between vicarious futurity, hope, and parental well-being in (n=71) parents of children with ASD, greater vicarious futurity was found to be associated with lower parenting stress while greater hope was associated with lower levels of parental depression. It is worth noting that no data were collected in that study about the services received by children with ASD or their parents which could have influenced the extent of their positive perceptions Faso et al. (2013). In a qualitative study by Altiere and von Kluge (2009 b), after interviewing (n=52) parents of children with ASD to explore their challenges while raising their children, parents were found to experience positive growth as a result of their children's disabilities, and they learned new ways to cope with challenges (Altiere & von Kluge, 2009 b). Results from that qualitative study should be interpreted with caution due to the sample being predominantly European-American and it is unknown whether parents from different racial groups would have viewed their children with ASD differently. It was decided to include a measure of a positive outcome (happiness) in the trial (Chapter 6) to measure a positive outcome in mothers of children with ASD and explore whether participating in a psychoeducation intervention could lead to a change in that outcome.

**Outcomes.** The above findings from the literature support the assertion of the double ABCX model in that multiple variables may be needed to describe outcomes in parenting children with ASD. Based on the proposed model of family adaptation in families of children with ASD studied by Pozo et al. (2014 a) discussed above, and the findings from other studies in the literature that provided evidence to support that model, parental well-being outcomes (xX factor) are considered essential variables in the adaptation process in parents of children with ASD. This is also in line with the findings of the systematic review in this thesis (Chapter 2) that showed parental well-being outcomes (stress and depression) were the most prominent constructs affecting parents, as highlighted in the literature of parenting children with ASD. Moreover, the above discussion also showed evidence that ASD symptoms severity and child behaviour problems (A factor) are important variables that affect parents during their adaptation in parenting their children with ASD. This was also in line with the findings from the systematic review in this thesis (Chapter 2) that showed the severity of ASD symptoms and child behaviour problems are among the variables with the greatest effect on parental well-being. In addition, evidence from the pilot qualitative study (Chapter 3) found that mothers of children with ASD were facing many challenges dealing with behaviour problems in their children with ASD. The proposed model by Pozo 2014 above also supported the necessity of positive appraisal of ones situation for parents of children with ASD (cC factor) to enable them to adapt to stressful life demands, making it an important construct within the context of parenting children with ASD. This was also found in the pilot qualitative study (Chapter 3), where mothers indicated their lack of understanding of autism which made it hard for them to apprehend their situations.

## Components of the Intervention

This section provides a description of each component to be addressed in the proposed intervention (Chapter 6). The relevance and importance of these intervention components will be discussed within the wider empirical literature as well as findings from the first three studies in this thesis (systematic review, pilot qualitative study, and meta-analysis).

**Stress.** Kissel and Nelson (2016) conducted a cross-sectional study to evaluate the differences in parental stress between (n=48) parents of children with ASD and (n=16) parents of TDC. They found parental stress to be higher in parents of children with ASD compared to parents of TDC (Kissel & Nelson, 2016). Findings from studies within the first systematic review in this thesis (Chapter 2) also revealed that parents of children with ASD show high stress compared to parents of TDC (Hastings et al., 2005 a; Hoffman et al., 2009). Hoffman's et al. (2009) study investigated parental stress in a cross-sectional study comparing (n=104) parents of children with ASD to (n=342) parents of TDC. Both studies of Hoffman et al. (2009); and Kissel and Nelson (2016) mentioned that they relied on self-reported measures of parental stress, however, this could not be considered a weakness in the context of studies measuring stress as other physiological measures of stress (e.g., saliva or cortisol level) have not been proven reliable measures of stress and can fluctuate throughout the day time. A longitudinal study by Zaidman-Zait et al. (2014) investigating the relationship between parental stress and child behaviour problems in (n=184) mothers of children with ASD over a four year period found that parenting stress at T1 was a strong predictor of child behavior problems at T2 highlighting the influence of parental stress on later child behavior. Even though child behavior problems were measured relying on parental self-report data, the longitudinal design of that study provided strong evidence of the transactional effect of parental stress on child behavior problems overtime (Zaidman-Zait et al., 2014). There is growing evidence that stress is responsive to psychoeducation in parents of children with ASD. A randomised controlled trial examining the effectiveness of a 20-weeks parenting intervention that included psychoeducation for parents of children with ASD has randomly allocated parents to either an intervention group (n=35) or a control group (n=35) (Tonge et al., 2006). The study found that the intervention was significantly effective in reducing parental stress, but the majority of the included parents were mothers with only a few fathers participating, making it difficult to generalise the findings to fathers of children with ASD (Tonge et al., 2006). Based on the findings from the meta-analysis (Chapter 4), parental psychoeducation interventions that focused on educating parents about ASD and provided strategies for them to enhance their well-being, were successfully significant in reducing parental stress levels. Therefore, psychoeducation interventions are beneficial for parents of children with ASD suffering from high levels of stress making stress a credible treatment target.

**Depression.** In a cross-sectional study examining the differences in psychological adjustment in parents of children with ASD (n=48) compared to parents of TDC (n=26), parents of ASD children displayed very high depression levels compared to parents of TDC (35% vs 7.7%) (Lee, 2009 b). However, results should be interpreted with caution due to the small sample size in (Lee, 2009 b). A similar finding was obtained in a longitudinal study by Carter et al., 2009, where mothers of children with ASD (n=143) were found to suffer from high depression levels and their elevated depression levels remained stable over two years. This suggests that mothers did not seem to adapt, necessitating the need for interventions targeting parental well-being in mothers of children with ASD (Carter et al., 2009). Moreover, there is a growing evidence that depression is responsive to psychoeducation in parents of children with ASD. A controlled trial examining the effectiveness of a seven-session (60-90 minutes each) intervention that included psychoeducationa for parents of children with ASD has allocated parents to either an intervention group (n=19) or a control group (n=18) ( Samadi et al. 2013). The study found that the intervention was significantly effective in reducing parental depression. However, Samadi's et al. (2013) results should be interpreted with caution, as participants were given the choice of which group to join, which could have resulted in parents who were motivated to join the intervention group and led to bias in the results. Based on the findings from the meta-analysis (Chapter 4), parental psychoeducation interventions that focused on educating parents about ASD and provided strategies for them to enhance their well-being, were successful in reducing parental depression. Therefore, psychoeducation interventions are beneficial for parents of children with ASD suffering from high levels of depression making depression a credible treatment target.

**Child behaviour problems.** In a longitudinal study over a period of 14 months by Chandler et al. (2016), children with ASD were found to display high levels of child behaviour problems. The study included parents of children with ASD (n=277) and (n=228) teachers and found that high levels of child behaviour problems remained stable over time (Chandler et al., 2016). A strength of that study is that it collected data from both parents and teachers, making the results of child behaviours more reliable than other studies that collected data from parent reports only. However, the authors indicated they did not confirm the diagnosis of ASD in children, even though that might not be necessary considering all children in their sample have received a formal diagnosis of ASD from paediatricians or psychologists (Chandler et al., 2016). Moreover, the relationship between high levels of child behaviour problems and stress were found to be stable over a year in mothers of children with ASD (n=81), suggesting child behaviour problems and stress exacerbated each other over time (Lecavalier et al., 2006). A strength of that longitudinal study is that data were collected from multiple informants (parents and teachers), with high correlations between the findings from the different informants, and this resulted in reliable findings. There is growing evidence that child behaviour problems are responsive to psychoeducation in parents of children with ASD. In a randomised controlled trial by Whittingham et al., 2009) examining the effectiveness of a nine-week parenting intervention that include psychoeducation for parents of children with ASD (n=59), child behaviour problems were found to be significantly reduced for the intervention group at T2 and treatment effects were maintained after six months. An identified risk of bias in that trial was due to participants not being blind to treatment allocation, however, that would be expected in studies where the participants are actively involved in the intervention. Findings from the pilot qualitative study (Chapter 3) indicated that all mothers referred to their child’s behaviour problems and their inability to deal with them. They highlighted their needs for training and reliable resources to provide them with more information about their children’s behaviours. It is evident that child behaviour problems is a construct that affects parents of children with ASD and is responsive to psychoeducation, making it a credible treatment target. On the other hand, behavioural interventions designed to target child behaviour problems with no psychoeducation training for parents have not been found effective in enhancing parental well-being and family adjustment. Remington et al. (2007), for example, in a controlled study (intervention n=23, control n=21) examining the effectiveness of an intensive child behavioural intervention for parents of children with ASD found the intervention was ineffective in enhancing parental well-being. This would be expected as an intervention that required parents to use behavioural strategies intensively for 25.6 hours per week for two years with their children might be demanding and stressful, considering those parents challenging responsibilities raising their ASD children. However, a lack of significance in Remington's et al. (2007) study could be attributed to the small sample sizes. It should be noted that the majority of studies within the literature of parenting children with ASD (including the studies in the systematic review and meta-analysis in Chapters 2 and 4) were limited to a small sample size. Therefore, efforts will be made to recruit participants from multiple sites for the trial in this thesis, with the aim of having large sample size (Chapter 6).

**Information about ASD and its Aetiology.** A cross-sectional study by Jones, Hastings, Totsika, Keane, and Rhule (2014) examined the mediating role of mindfulness and acceptance between child behaviour problems and parental well-being in (n=71 mothers and n=39 fathers) of children with ASD. Psychological acceptance was found to act as a mediator for maternal stress, depression, and anxiety, and for paternal depression (Jones et al., 2014). The cross-sectional design of the study does not allow for inference of causality between the variables of interest, however, the results of Jones's et al. (2014) study contributed to the evidence that psychological acceptance might be a crucial parental construct to target in interventions for parents of children with ASD. A longitudinal study by Lickenbrock et al. (2011) with (n=49) mothers of children with ASD that examined the relations among mothers’ perceptions, marital adjustment, and maternal well-being over a month found marital adjustment to mediate the relation between positive maternal perception and maternal well-being. A positive maternal perception of children with ASD was associated with better marital adjustment and better maternal well-being Lickenbrock et al. (2011). However, due to the short time interval between T1 and T2, it was unclear how relations found between variables in this study would change over a longer period.

It is evident from the literature and the transactional model of stress and coping by Lazarus and Folkman (1984) that parental appraisal is an important variable in the process of adjustment in parents of children with ASD. Moreover, evidence from the meta-analysis (Chapter4) suggested the effectiveness of psychoeducation interventions in enhancing parental functioning. In addition, the qualitative exploration of maternal needs for mothers of children with ASD in the KSA (Chapter 3) revealed mothers have expressed their desire to learn more about autism, its causes, and treatment options through more intensive training. It would be imperative for interventions to provide parents of children with ASD with more on-going training opportunities that address their differing needs. One session in the intervention (Chapter 6) in this study was devoted to providing mothers with information about ASD aetiology, risk factors, causes, diagnosis, and symptoms.

**Resources.** Resources (bB factor) are considered any type of formal or informal support that parents can use during their adaptation to stressful situations (McCubbin & Patterson, 1983). These could be for example in the form of social support, government funding, and access to services. In a cross-sectional study by Sanders and Morgan (1997) that examined parental stress and family functioning in three different groups (18 families of children with ASD,18 families of children with down syndrome, and 18 families of TDC), high levels of parental stress in parents of children with ASD were found to be associated with lesser involvement in recreational, social, and cultural activities within their communities than the other two groups. Parents of children with ASD reported not having enough time to participate in social activities due to the constant demands of their children with ASD (Sanders & Morgan, 1997). Findings from that study should be interpreted with caution due to the relatively small sample size, and the cross-sectional nature of the study design that does not allow for a clear understanding of how the lack of involvement in social activities could have affected parental stress. However, a longitudinal study by Zaidman-Zait et al. (2017) that investigated the impact of social resources on parenting stress over two years in (n=283) mothers of children with ASD found that access to social resources at T1 was a strong predictor of maternal stress at T2. Mothers with high levels of social support at T1 experienced less stress at T2, and mothers with less engagement with social resources at T1 suffered from high levels of stress at T2 (Zaidman-Zait et al., 2017). The findings from this study were limited to self-report data, however, mothers' perceptions of both their stress and the available resources are essential when evaluating these variables (Zaidman-Zait et al., 2017). A strength of using a longitudinal design in that study was that it allowed for the examination of the interaction between these variables over time.

Based on the findings from the qualitative study on maternal needs for mothers of children with ASD in the KSA (Chapter 3), mothers felt isolated from their communities because of the increasing care demands for their children with ASD and due to the stigma associated with having children with disabilities. In addition, they highlighted their need to know about resources available to them in the KSA. Moreover, the findings from the meta-analysis (Chapter 4) also supported the effectiveness of psychoeducation interventions when delivered through group format. Controlled trials (Chapter 4) that delivered their interventions via group format (Samadi et al., 2013; Tellegen & Sanders, 2014; Tonge et al., 2006) were found to have a significant effect in reducing parental stress in parents of children with ASD. In contrast, the intervention in Drew et al. (2002), which was delivered in a one-on-one format, was not found to have a significant effect on parental stress. Therefore, the researcher thought it is necessary to deliver the intervention in a group format, where mothers can meet each other and be a part of a group, which might help in lessening their feelings of isolation. In addition, one session in the intervention was devoted to informing mothers of the resources available to them in the KSA.

## Development of the Intervention

The intervention was designed as a psychoeducational training programme to reduce stress and enhance psychological well-being in mothers of children with ASD in the KSA. The development of the intervention was informed by the first three studies in this thesis (Chapters 2, 3, and 4) and the psychological models of stress and coping. Below is a description of how each has contributed to the development of the intervention.

As stress and depression were the most outstanding constructs of parental well-being in the majority of the included studies in the first systematic review (Chapter 2), the researcher decided to target stress and depression in the proposed intervention, which was achieved by dedicating one session of the intervention to stress reduction techniques and another to enhancing mood.

Findings from the first qualitative study in this thesis (Chapter 3) showed that mothers of children with ASD in the KSA felt they lacked knowledge about ASD and its symptoms, causes, and treatment options. They also indicated their need for training that is not costly and in a format that does not require much travelling outside of their homes, due to the limited transportation options for women in KSA. Therefore, it was decided to design an intervention that could be delivered in a user-friendly format that required minimum face–to-face contact with therapists, which was achieved by delivering most of the intervention sessions through the WhatsApp messenger application (a further discussion of WhatsApp will be presented in Chapter 6). It was decided that a session in the intervention would be dedicated to explaining ASD to the participants, which was achieved by devoting the first session to cover ASD aetiology. One of the sub themes ″mothers' identification of their training needs‟ from the findings of the qualitative study (Chapter 3), revealed the mothers' requests for a type of training that could help them deal with their children's difficult behaviours. Therefore, it was decided that mothers would be provided with strategies to help them manage their children's problem behaviour. The third session was dedicated to cover behavioural problems and strategies that can help manage these problems.

The use of different psychological models; the Double ABCX Model by (McCubbin & Patterson, 1983) and the Transactional Model of Stress by ( Lazarus & Folkman, 1984), has informed and enriched the development of the content of the psychoeducation intervention used in the main trial (Chapter 6). Both models contributed to the development of the intervention (a detailed explanation of these two models is presented in Chapter 1). The findings from the pilot qualitative study (Chapter 3) indicated that participants expressed how dealing with their children's with ASD behaviour problems was a major stressor in their lives (factor A in Double ABCX Model), in addition to other stressors including being stigmatised by society (factor aA). They also described their limited resources (financial and training), which according to them have contributed to their distress (factor B). The proposed intervention targeted different stages of the Double ABCX Model: devoting session three to targeting child behaviour problems to help mothers cope with the initial stressor of having children with ASD; session one to informing mothers of the aetiology of ASD (aA component); session five to informing mothers of the resources available in KSA (bB component ); and session two to targeting stress in mothers, including how can they approach different stressful situations (cC component).

Moreover, the way parents attribute meaning to parenting a child with ASD may affect the level of stress they experience (Paynter, Riley, Beamish, Davies, & Milford, 2013). The intervention in this study drew on the evidence supported by the transactional model of stress that indicates parental stress is influenced by how parents appraise stressful situations and their child’s behaviour (Richard S. Lazarus, 1974). This was achieved by devoting one session in the intervention to stress reduction and another session to mood, with the aim of reducing maternal stress and enhancing mood in participants by changing the way mothers appraise stressful situation and their children’s behaviour.

Both Lazarus and Folkman's (1984) and McCubbin and Patterson's (1983) models hint at the issue of availability and access to support, such as social and financial support. This seems a crucial element in any coping process as an individual may be able to positively appraise a situation and identify strategies to cope with it, but may simply not have access to any resources to help achieve this. Session five was devoted to guiding mothers in KSA to available government and private resources. The intervention was also guided partially by the social learning theory (SLT) (Bandura, 1973). A longitudinal study by Smith, Greenberg, Seltzer, and Hong (2008) examined the impact of the quality of the relationship between mothers and their adolescents with ASD (n=149) on later child behaviour problems over an 18-months period. The study found that mothers’ perceptions of the quality of interactions with their children at T1 predicted child behaviour problems at T2; mothers who rated the quality of their interaction with their children as high at T1 were found to report fewer child behaviour problems at T2 (Smith et al., 2008). It should be noted that a limitation in that study was that their sample was mostly White, limiting the generalisability of the findings to different racial groups, however, the longitudinal design of that study provided evidence to support that child behaviour problems are related to mothers’ behaviours and interaction patterns with their children with ASD. By helping mothers control their stress, mood and children’s behaviour problems, this intervention (Chapter 6) aimed to change the way mothers approach different stressful situations, many of which are the result of their children’s challenging behaviour. Therefore, this intervention can help mothers to act as models to change other caregivers’ and family members’ behaviours towards their children with ASD. Fathers and siblings, for example, could learn and apply the strategies that mothers apply successfully to deal with the challenging behaviour of their children.

# Chapter Six: The Effectiveness of a Self-Help Psychoeducation Intervention Delivered Via WhatsApp with Minimal Therapists' Support for Mothers of Children with Autism Spectrum Disorder ASD in the Kingdom of Saudi Arabia: A Small-Scale Randomised Controlled Trial

## Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder associated with 'persistent impairment in reciprocal social communication and social interaction, and restricted, repetitive patterns of behaviour, interest, or activities' that has a worldwide prevalence of around 1% (APA, 2013, p. 53), and 0.6% in Saudi Arabia (Al Jarallah et al., 2005). Autism research shows that parents of children with autism experience intense levels of stress after having their children diagnosed with autism (V. B. Gupta, 2007; Meirsschaut et al., 2010; Patterson & Smith, 2011); much higher than stress levels in parents of children with other disabilities (Estes et al., 2009; Phetrasuwan & Miles, 2009; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). Many factors contribute to stress in families of children with ASD, including the child's challenging behaviours, financial problems, lack of medical or family support and the risk of stigmatisation (Benson, 2006b; Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; V. B. Gupta, 2007). Research also shows that parents of children with ASD suffer from higher levels of depression (Benson & Karlof, 2009; Carter et al., 2009). The impact of having a child with an ASD extends beyond the well-being of parents and affects other areas of parental life causing martial conflicts (Gau et al., 2012) ; economic burdens (Bilgin & Kucuk, 2010b; McCabe, 2010); and social isolation (Divan et al., 2012). Mothers usually experience higher levels of stress than other members of the family and often require additional support as primary care givers to help them cope with their children with ASD (Ingersoll & Dvortcsak, 2006a). Most evidence indicates a bidirectional relationship between parenting stress and childhood behaviour problems, with longitudinal evidence supporting both the influence of parenting stress on later child behaviour (Osborne & Reed, 2009); as well as the influence of childhood behaviour on later maternal stress (L. Jones, Hastings, Totsika, Keane, & Rhule, 2014; Sofronoff & Farbotko, 2002a). This indicates that mothers who experience high levels of stress will require strategies to manage their own stress levels, the additional stress that may arise from behaviour problems in their children, as well as strategies to address behaviour problems in their children that may manifest because of their mothers' stress.

Evidence based training programmes for parents of children with ASD exist (Bond et al., 2011; Sofronoff & Farbotko, 2002b), however, the majority of these interventions has been designed to teach parents to apply specific strategies that are focused on supporting the child (Ingersoll & Dvortcsak, 2006b; Patterson, Smith, & Mirenda, 2012; Stiebel, 1999). Only few studies have evaluated the efficacy of parent training interventions, where the interventions were designed mainly for the benefit of parents, focusing on parental well-being for parents of children with ASD (Bendixen et al., 2011; Ferraioli & Harris, 2013). However, most of these studies contain very small sample sizes and are often not adequately controlled (see Chapter 4).

In addition, access to support for parents of children with ASD is often limited in Western countries because of barriers that include insurance coverage, parents' time constraints, and distance from major cities (Karst & Van Hecke, 2012). Self-help parenting interventions have been shown to be effective in addressing some of these barriers in parents of children with other neurodevelopmental disorders e.g., Attention Deficit Hyperactivity Disorder (ADHD). Studies have demonstrated the positive impact of a self-help intervention alone on enhanced parental self-concept and reduced child problems (Daley & O'Brien, 2013); as well as the positive impact of self-help with minimal telephone support on reduced parental stress, depression, anxiety, and child behaviour problems (Kierfeld, Ise, Hanisch, Gortz-Dorten, & Dopfner, 2013). Self-help parent training interventions with minimal therapist support for parents of children with ASD appear to have limited evidence to date due to small sample sizes, lack of adequate controls , and poor tailoring of intervention strategies to underlying parental needs (Ingersoll, Wainer, Berger, Pickard, & Bonter, 2016). Despite increasing access to technology, researchers in mental health have also been less creative in using the opportunities afforded by technology to support the delivery of appropriate treatments (Hollis et al., 2015).

Many researchers have acknowledged the shortage of available and affordable treatment options and training services for parents of children with ASD in KSA (Al-Salehi, Al-Hifthy, & Ghaziuddin, 2009a; Almansour et al., 2013). Almansour et al. (2013) found that depression scores were significantly higher in parents of children with ASD than parents of TDC in KSA which put them in higher demand for training. A qualitative pilot study conducted by the researcher exploring the unmet needs of mothers of children with ASD in KSA (Chapter 3) found that based on mothers' perceptions, there is a lack of parental training programmes for mothers of children with ASD. A systematic review of the existing literature examining the impact of childhood ASD on parental life carried out also by the researcher (Chapter 2) has found that stress and depression were the most recurrent constructs in the literature of parental well-being to be affected by childhood ASD. However, there was a gap identified in the literature for studies evaluating the efficacy of parental training programmes in enhancing parental well-being for mothers of children with ASD in KSA. In their study focusing on ASD in developing countries, Samadi and McConkey (2011) argued that research on parenting children with ASD "has been limited largely to families in Western countries" and highlighted the need to explore the needs of families in non-Western countries" (P. 1). Therefore **the goal of this study** was to evaluate the efficacy of a self-help psychoeducation intervention with minimal therapist support that was delivered via WhatsApp for mothers of children with ASD in KSA. This study will add to the literature of ASD in KSA a psychoeducational parenting intervention that is tailored, meet the needs, and culturally sensitive to mothers of children with ASD there.

### Objectives

The main objective of this study was to examine the effectiveness of the proposed intervention on reducing stress in mothers of children with ASD in KSA.

A second objective of this study was to examine the effect of the proposed intervention on maternal well-being (depression and happiness) and child behaviour.

## Methods

This study followed the CONSORT guidelines for reporting randomised controlled trials (Schulz, Altman, & Moher, 2010).

### Trial Design

The design was a pragmatic small-scale randomised two-arm controlled trial with two conditions (intervention group IG, versus care as usual CAU) and three time points (pre- intervention T1, post-intervention T2, and approximately eight weeks follow-up T3). Assessment at T2 was conducted after completion of the programme for the intervention group IG (approximately 5 weeks) and the (CAU) group had their T2 assessment at the same time as the IG. Follow-up was conducted for both groups after approximately eight weeks, and after this final assessment, the CAU group was offered a modified version of the intervention without therapist support.

## Ethical Approval

This study's protocol and all prepared study documents were developed and submitted to the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee REC on 25th . of January, 2015 (Appendix 18). After addressing a number of minor queries from the Ethics Committee, ethical approval was granted on 29th February, 2015 (REC ref: OVS12022015 SA SoM PAPsych PhD). As this study was conducted in KSA, the researcher had to also gain ethics approval from her sponsoring University in KSA which was King Abdulaziz University KAU in Jeddah. The researcher applied to both ethics committees at Nottingham and KSA concurrently and ethics approval from KAU was obtained (Appendix 13). Considering that most of the participants might not be able to read English because their native language is Arabic, the information sheet, consent form, intervention manual, implementation fidelity questions, therapists' scripts, and interview schedule were all translated into Arabic. The Ethics Committee at KAU checked the translation for accuracy.

## Participants

Participants in this pragmatic study were all mothers of children with ASD who were in the early intervention stage (first year in the programme) at autism organisations in KSA. Children with ASD in KSA usually join autism organisations after they receive their diagnosis. This time is considered to be critical for mothers of children with ASD as they face great challenges with their well-being, but these mothers also experience a need for information about the nature of ASD and a desire to know more about how to manage their children (Karst & Van Hecke, 2012). Inclusion criteria for the study were i), mothers above the age of 18, living with their children with ASD, ii) mothers capable of reading and writing in Arabic, iii) mothers who had smart phones with a WhatsApp application, and iv) mothers of children who had received a formal diagnosis of ASD. Exclusion criteria for the study were i) mothers whose children with ASD were not attending at any of the participating organisations, ii) mothers whose children with ASD were not at the early intervention stage programmes (within the first year after diagnosis) at the participating organisations, and iii) mothers who did not have an appropriate smart phone or who were unable to download WhatsApp.

**Sample size.** This study was a feasibility trial (pilot study) to explore the utility of the proposed intervention in routine practice; therefore, a formal power calculation of sample size was not possible. This was also due to the lack of a fully powered trial of parenting interventions for mothers of ASD children in KSA. A pilot study does not require the usual sort of power calculation to calculate the minimum sample needed to detect a difference. Rather, the sample size should be adequate enough to provide key information on the utility of the intervention to facilitate preparation for a future full trial.  It was suggested that 40-60 people should be enough to provide the information required for a pilot study (Hertzog, 2008) and this number is in line with and in most cases exceeds the numbers in other similar pilot studies (Chiang, 2014; Ferraioli & Harris, 2013).

**Recruitment and Randomisation**

To explore the efficacy of the proposed intervention, mothers of children with ASD in the early intervention stage (first year programme) were recruited through four local voluntary support autism organisations that provide educational services for children with ASD and support services for their families from February 29th 2015 until March 30th 2015 (Table 6 shows the timeline of trial data collection). These autism organisations were located in the two main cities of Makkah and Jeddah in the Southern Saudi Arabia. Two of them were in Makkah and will be referred to during this study as M1 and M2, and the other two were in Jeddah will be referred to during this study as J1 and J2.

Each organisation had an administrative staff who had the job of facilitating communication between researchers and participants from their organisations. The researcher asked them to distribute study packs that included information sheets and consent forms to eligible mothers of children with ASD. Once study packs were returned to staff at the organisations, they removed the potential participants who refused to participate, placed the remaining packs in a sealed envelope and handed them to the therapists, who performed the randomisation. The therapists were not able to see the participants’ information before randomisation, therefore, allocation to trial arms was concealed from the therapists. The therapist on M2 (first organisation finished recruitment) started to put an ID code on each envelope (e.g., P1, P2, etc.) and the last code was P15. Then, the researcher was informed about the last code number and contacted the therapist from J1 to ask for the code numbers to be started from P16. This procedure was followed with all the four participating organisations. Once every envelope had received an ID code, participants were randomly allocated by the therapists to either an intervention group (IG) or care as usual group (CAU) by following the odd and even number procedure in which every participant whose envelope had an odd number code (e.g., P.5) would be in the IG and the ones that had even number codes (e.g., P.2) would be allocated to the CAU. As explained by Suresh (2011), the odd and even number method of randomisation is a simple though reliable procedure that leads to an equal number of participants allocated to study arms in trials. The reason that this randomisation procedure was administered by the therapist is that it was reliable, anonymous, simple, and previously used in the participating organisations in other research projects so the therapists were familiar with using it. After the therapists had finished putting ID codes on the opaque envelopes, they handed it to the staff members at the organisations where they were opened and lists of participants' names and contact information were created. Both the staff members at the organisations and the therapists had the lists. Allocation to trial arms was concealed from the researcher.

### Blinding

It was not possible for participants or therapists to be blinded to the intervention due to the nature of the intervention and the heavy involvement of the participants and therapists in the study. According to Winkley, Landau, Eisler, and Ismail (2006), although a double-blinded trial is methodologically superior, it is not possible in a study of a non-pharmacological intervention.

The researcher was blind to the allocation until the last data collection phase T3 when she was then given the list of participants' names and contact information to conduct qualitative interviews (Chapter 7). To ensure objectivity, as the researcher is the one who developed the intervention and drafted the intervention manual, the researcher was blind to the participants during the delivery of the intervention. The therapists were responsible for delivering the intervention and collecting questionnaire data at all times.

**Table 6. Timeline of trial data collection**

| Date | Stage of data collection |
|---|---|
| February 27th 2015 | Ethics approval letter received from the University of Nottingham |
| February 29th 2015 | Recruitment started |
| March 30th 2015 | Recruitment ended |
| April 1st–15th 2015 | Randomisation and training of the therapists and arranging suitable time and venues in the organisations for the mothers' meeting with the researcher and the first session in the intervention |
| April 21st–23rd & 27th–29th 2015 | T1 data collection and first intervention session at the four participating organisations |
| April 28th–30th 2015 & May 4th–6th 2015 | Second intervention session (start of WhatsApp training) |
| May 19th–21st & 25th–27th 2015 | End of WhatsApp training +T2 data collection |
| August 2015 | T3 data collection and intervention manual distribution to CAU group |

## Treatment Conditions

**Immediate intervention.** Mothers of ASD children in the IG attended five training sessions in four weeks starting with a face-to-face meeting at the voluntary organisations where the participants were recruited from. The four remaining sessions were delivered through the WhatsApp application on smart phones. The sessions were all delivered by trained autism therapists (see procedure section). Each meeting lasted for 30 minutes. Before each session, participants were asked and expected to read the training manual for that week's session, which would take approximately 25-30 minutes to complete. During the WhatsApp group sessions, parents discussed the topics and concerns of that week session and asked questions of the therapist (Appendix 14 for a transcript of one WhatsApp sessions on M1). At the end of each WhatsApp session, the therapists distributed and received back answers to the *implementation fidelity questions* (Appendix 15). After the end of the last training session, the therapists distributed the questionnaires to the participating mothers to collect T2 data. Mothers were asked to complete the questionnaires for the third time approximately eight weeks after the end of the last session for T3 data collection electronically.

**Care as usual (CAU).** Mothers of ASD children in the CAU group completed the same questionnaires as the mothers in the IG at all three times of T1, T2, and T3. Mothers in the IG were asked not to share any information related to the intervention with their friends' mothers at the CAU group until after T3. During the time of the intervention, mothers at the CAU group received the usual type of services that the organisations provide for all mothers of children with ASD. The organisations offer counselling services for all mothers whose children are registered with them. They also provide support to meet the individual needs of families regarding their children's educational and behavioural issues.

## Procedure

The study was conducted following these steps:

1. After the study received ethics approval from The University of Nottingham and King Abdulaziz University in KSA, the researcher contacted the organisations to start preparing for the trial. Each organisation was asked to nominate an autism therapist to deliver the intervention. The two organisations in Makkah nominated two of their therapists while the ones in Jeddah asked the researcher to hire

therapists from outside their organisations as their staffs were over-loaded. Therefore, the researcher hired one therapist to deliver the intervention to mothers in both J1 and J2. This therapist had a master's degree in psychology and four years' experience working with children with ASD and their mothers in an autism organisation. The other two therapists hired by the organisations in Makkah, had a minimum of three years' of experience working with children with ASD. The one from M1 had a graduate certificate in special education and the one from M2 was a certified clinical psychologist.

2. Study information packs (were distributed by the supporting organisations to all eligible mothers with children with an ASD diagnosis who were participating in the early intervention services provided by these organisations. Meanwhile, the researcher met each therapist for two hours to review the intervention manual with them (Appendix 19), explain the intervention process, and answer their questions. Each therapist was given *a Therapist's scripts* (Appendix 16) that was created by the researcher, and in it, there is a summary description of the important points that should and should not be covered in each training session.

3. Once study packs were returned to the organisations, mothers who consented to participate were anonymously assigned identification codes by the therapists, who then randomly allocated them to trial arms. Lists of participants' names and contact information with their allocation and ID codes were given to therapists. Following that, the organisations arranged with the therapists and the researcher suitable dates and venues for the first meeting and training session and mothers were contacted by the organisations to inform them about the dates and invited them to attend. They were also informed about their allocation and ID codes, and asked to use these codes on all questionnaires and WhatsApp conversations.

4. On the date of the first meeting in each organisation, the researcher met with the participants (mix of both IG and CAU group) to answer their questions and concerns about the study. This was required by the organisations as the researcher was not going to deliver the intervention and it is a culturally important step in research in developing countries to ensure participants' understanding of the

nature of the study even after they consent to participate (Perrey, Wassenaar, Gilchrist, & Ivanoff, 2009). It was also suggested by the organisations that mothers would usually only participate if they come to know the researcher and the aims of the research. However, the researcher was not aware of the participants' names and identification codes. At the end of the meeting, a battery of questionnaire was distributed to mothers for T1 data collection where Participants were asked to complete a battery of questionnaires (measuring parental stress, depression, happiness, ASD severity, and child problem behaviours). The therapist informed the researcher that three mothers from the IG (two from M2 and one from J1) were not able to attend the meeting due to urgent family circumstances, however, they did meet the therapists the following day at the organisations, answered T1 questionnaires, and discussed the materials of the first session. Around 12 mothers (seven from M2, one from M1, and two from J1) in the CAU group were not able to attend the meeting with the researcher, however, they only met the therapists for T1 data collection on their way to drop their children off at the organisations in the morning.

5. The researcher left after answering the concerns of the participants in each organisation and then each therapist started the first session with the IG. The remaining sessions were delivered through WhatsApp in groups created by therapists and dates for subsequent virtual meetings were set after the end of the first face to face session. Copies of the training manual designed by the researcher for this intervention were distributed to mothers before the start of the first session, mothers were expected to read the materials before each meeting as the therapist's job was only to review main points and answer questions.

6. At the end of the training programme and after the last session, therapists started collecting T2 data by distributing the same questionnaires of T1 to participants in both trial arms.

7. After approximately eight weeks, the therapist started to collect T3 data from participants in both trial arms.

8. All efforts were made by therapists to retain participants in the intervention group. If some were absent from one session, efforts were made to compensate for the missed meeting in the form of participants being encouraged to go through the manual material and

meetings' group discussion platform in WhatsApp and to contact the therapist for an explanation if they had any concerns.

9. The researcher received the lists of participants' names and contact information after the end of T3 data collection.
10. Efforts were made by the therapists and the organisations to distribute the intervention manual to participants in the CAU group after the end of the trial.
11. Only two participants in the CAU group from two different organisations requested additional help at the end of the study and they were referred to therapists working for the organisations from which they had been recruited.

## Intervention

The intervention was designed as a psychoeducational training programme to reduce stress and enhance psychological well-being in mothers of children with ASD in KSA. More information about the development of the intervention and its different components were given in chapter five.

**Development of the intervention manual.** Intervention materials were developed in the format of a booklet divided into five sections each one covering a topic corresponding to the five sessions in the intervention (Table 7)

**Table 7. Summary of the intervention sessions**

| Session' topic | Summary | Reference |
|---|---|---|
| What is Autism? | Aetiology of autism, including its causes, how it affects the lives of people with ASD, and the formal DSM-5 diagnosis criteria. | (APA, 2013; Simpson & de Boer-Ott, 2005) |
| Stress | Definition of stress, examples, causes and tips to help reduce stress in parents. | (Treacy, Tripp, & Baird, 2005) |
| Managing behaviour | Explaining behaviour, how behaviour occurs and different ways that will help parents to manage their children's behaviour problems. | (Wright & Williams, 2007) |
| Mood | Explaining mood, how can it affects the way people respond to different situations and how can different ways of thinking aggravate negative mood. | (L. Treacy, personal communication, October 10, 2015) |
| Resources for families | Listing the available resources to parents of children with ASD in KSA and contact information of ASD organisations and services in their regions. | (Al-Shodokhi & Al-Jabr, 2010) |

The manual was created in English and then translated into Arabic by the researcher who is bilingual and holds a bachelor's degree in English. A mother of a child with ASD (who was not a participant in this study) voluntarily checked the manual for clarity and usefulness and provided helpful service user involvement. Minor alterations were made based on the feedback received which included changing the font, inserting bold for some sentences, and adding more pictures and colours to make the materials more visually appealing for mothers.

The readability of the manual was assessed using Microsoft Word which calculated the *Flesch reading ease* score as 70% based on word and sentence length, and a *Flesch-Kincaid grade level* score as grade six (Flesch, 1948; Kincaid, Fishburne Jr, Rogers, & Chissom, 1975). A readability score of 70% means that the text is fairly easy to read (Flesch, 1979).

**Hosting the WhatsApp sessions.** This intervention was developed as a guided self-help (GSH) intervention that was in line with the main principles and recommendations of the NHS's *Good Practice Guidance on the Use of Self-help Materials within IAPT Services (Baguley et al., 2010).* The term GSH refers to an approach of self-help where patients receive little support from other people, but also have to engage with the content of the intervention material to achieve desirable outcomes (Lucock, Barber, Jones, & Lovell, 2007). The intervention in this study is, therefore, considered to be a GSH intervention because it requires minimal therapist interaction with the participants during the WhatsApp sessions and the participants are required to read the manual before each session.

WhatsApp is a free mobile messaging application in which people can exchange private or group messages, as well as visual and audio media (How it Works, 2016) . Four sessions in this study were delivered through WhatsApp with therapists leading the groups' discussions. The reason for doing so was because females are not allowed to drive cars in KSA, and there are no public transportations (e.g., buses and metros). According to the outcomes of a qualitative study conducted by the researchers on exploring the unmet needs of mothers of children with ASD in KSA (Chapter 3), mothers suggested the use of WhatsApp as a mode to deliver the intervention as it would encourage them to participate from their homes and they would not have to look for caregivers for their children. Another benefit of using WhatsApp to host the sessions was that participants would be able to access all the previous exchanges for they are archived; so if a participant was not able to attend a session for any reason then she could easily go through all the messages at the WhatsApp group once she went online and had the time to do so.

### Measures

Data were collected using measures to assess outcomes. Participants at both trial arms answered a battery of measures at T1, T2 and T3 (

Appendix 17).

**Parents' demographic questionnaire**. Demographic questions collected information about participants including mothers' age, child with ASD age, number of siblings with ASD and their ages, marital status, mothers' education and occupation, and fathers' occupation. The Arabic translated version, which was done by the researcher, of this questionnaire was used.

Arabic standardized versions of the following measures were administered to participants in this study as it is the official and mother language for people in KSA.

**Parent Stress Index -Short Form (PSI-SF).** The PSI-SF is a self-reported questionnaire that aims to measure the stress associated with parenting (Abidin, 1995). It includes 36 items that are divided into three subscales, each one containing 12 items: parental Distress (PD) measures the level of distress resulting from parents' perception of their role of parenting such as life restrictions due to the parenting demands ; parent–child dysfunctional interaction (PCDI) provides an indication of parents' interactions with their children ; and difficult child (DC) measures parents' perceptions of their children's temperament and compliance (Abidin, 1995). The score of most items in all subscales range between one (strongly disagree) and five (strongly agree). However, some items require a different response to answer the multiple-choice questions. Based on guidelines in the PSI-SF scoring manual, raw scores above 33 on the PD and DC subscales and above 27 on the PCDI subscale are considered clinically elevated. Raw total scores above 90 on the total score that indicates clinically significant high level of stress scores (Abidin, 1995). The PSI-SF includes a defensive responding scale (a sum of seven items) that indicates the extent to which the respondent approached the questionnaire. A mean score of 10 or less on this scale indicates that respondents are trying to cover their stress or give misleading answers, so the results should be interpreted with caution. In this study, the mean score was 26, indicating valid results for subsequent analysis.

The test–retest reliability coefficients of the PSI-SF over six months were reported to be: 0.84 for total stress, 0.85 for PD, 0.68 for PCDI, and 0.78 for the DC subscale. The following internal consistency Cronbach's alpha (ɑ) were also reported: 0.91 for total stress, 0.87 for PD, 0.80 for PCDI and 0.85 for the DC subscale (Abidin, 1995). The PSI-SF was found to highly correlate with the PSI long form with (r=.94) (Abidin, 1995). In a study by Haskett, Ahern, Ward, and Allaire (2006) in a US sample, the reported Cronbach's alpha for the total stress was .83 and the test–retest reliability coefficients of over a year was (r=.75). The PSI-SF has been previously used with mothers of children with ASD (Tomanik, Harris, & Hawkins, 2004). The PSI-SF has been successfully used in many languages with parents of children with ASD from different cultures. The Chinese version of the PSI-SF reported Cronbach's alpha values as 0.81, 0.85, 0.84, and 0.89 for the subscales of PD, PCDI, DC, and total score respectively (Ji Wang et al., 2013). The Arabic version of the PSI-SF has been used in previous research with parents of children with ASD and had reported Cronbach's alpha values for the total stress, PD, PCDI, and DC as .91, .91, .85, and .82, respectively (Dardas & Ahmad, 2013b); and .91 for total stress in a different study (Dardas & Ahmad, 2013a). The PSI-SF has also been used with mothers of children with ASD and other neurodevelopmental disorders in KSA with a reported Cronbach's alpha for the total stress, PD, PCDI, and DC as .91, .78, .82, and .83 respectively (Alquraini & Mahoney, 2015).

In this study, Cronbach's alpha for the total stress, PD, PCDI, and DC were 0.82, 0.73, 0.76, and 0.32, respectively, which indicated a good internal consistency for total stress and an acceptable reliability for PD and PCDI subscales. The Cronbach's alpha values upon item deletion were explored for the DC subscale. The largest increase in Cronbach's alpha resulted from deletion of item 33 *"Think carefully and count the number of things which your child does that bothers you"* which would increase the alpha value to 0.56. Therefore, scores for item 33 were not included in the DC subscale in this study. The low reliability of some outcome measures will be discussed in further details in the discussion section of this Chapter. The test–retest reliability coefficients of the PSI-SF in this study for the CAU group over approximately 12 weeks were found to be: 0.99 for total stress, 0.99 for PD, 0.99 for PCDI, and 0.99 for the DC subscale. The researcher acknowledged that Dardas and Ahmad (2014) proposed the use of a 30 item Arabic version of the PSI-SF , however, it was decided to use the full standardized scale in this study to be able to explore clinical significance (based on cut off scores) and to make the results comparable to other international studies.

**Hospital Anxiety and Depression scale (HADS).** This measure is used to determine the level of anxiety and depression. It has 14 items, seven of which are used to measure anxiety and seven for measuring depression. Each item has a choice of four responses that are scored from 0 to 3 yielding a maximum score of 21 for each subscale. Scores of 11 or more with either subscale are considered to indicate a significant "case" of psychiatric co-morbidity; scores of 8–10 signify the presence of a borderline case, and a score of 7 or less is considered normal. The HADS was originally designed and validated by Zigmond and Snaith (1983) in Germany, showing good internal consistency, and  a Cronbach's alpha of 0.93 and 0.90 for HADS anxiety and depression respectively. The HADS also showed a stability over six weeks with a test-retest correlation coefficient values of (0.70) for both subscales (Zigmond & Snaith, 1983).

The measure has good validity and reliability data when used with a non-clinical sample (Amr et al., 2012; Amr, Raddad, El-Mehesh, Mahmoud, & El-Gilany, 2011; Crawford, Henry, Crombie, & Taylor, 2001). A normative study with a UK sample identified two sub scales in HADS and these sub scales of anxiety and depression were found to be internally consistent with values of Cranach's coefficient being .82 and .77 , respectively (Crawford et al., 2001). HADS has found to be correlated with General Health Questionnaire-28 (r=0.68) and (r=0.66) for anxiety and depression respectively(Goldberg & Williams, 1988a); and HADS-depression to be correlated with the Beck Depression Inventory (r=0.62) (Beck, Steer, & Carbin, 1988; Caplan, 1994) .

HADS has been previously used with mothers of children with ASD (Richard P Hastings, 2003). HADS has been translated into Arabic and validated by El-Rufaie and Absood (1995), on a sample of 217 patients attending a primary health care centre in the United Arab Emirates. The Arabic version showed to be a reliable and valid measure to screen for anxiety and depression in an Arab population and an acceptable internal consistency with alpha values of 0.78 for depression and 0.87 for anxiety was identified (El-Rufaie & Absood, 1995). Al Aseri et al. (2015) validated HADS on Saudi population and showed an acceptable internal consistency with alpha values of 0.77 for depression and 0.73 for anxiety. The HADS was used previously with Saudi parents of children with ASD (Almansour et al., 2013).

In this study the Cronbach's alpha for the HADS anxiety and depression subscales were 0.32 and 0.65, respectively, which indicated a good internal consistency for depression subscale and a poor reliability for the anxiety subscale.

The Cronbach's alpha values upon item deletion were explored for the anxiety subscale. The largest increase in Cronbach's alpha resulted from a deletion of item 6 *"I get palpitations, or sensations of 'butterflies' in my stomach or chest"* which increase the alpha value to 0.55. Therefore, scores for item 6 were not included in the anxiety subscale in this study and the clinical cut off score for anxiety was adjusted to be ≥9. The test-retest reliability coefficients of the HADS in this study for the CAU group over approximately 12 weeks were found to be: 0.99 and 0.89 for the depression and anxiety subscales respectively.

**Strength and Difficulties Questionnaire (SDQ).** This is a self-report questionnaire to identify behavioural and emotional needs in children and adolescents. The SDQ can be filled out by parents or teachers. The version used in this study is the parents' version that asks about their children aged 4-12. It includes of 25 items divided into five subscales (five items each) including emotional symptoms, conduct problems, hyperactivity or / inattention, peer relationship problems, and prosocial behaviour, which asks about the child's behaviour and feelings for the past 6 months (Goodman, 1997). Parents are asked to indicate on a 3-point response scale the extent to which their child shows symptoms of behavioural difficulties (1 = not true, 2 = somewhat true, 3 = certainly true), and the total SDQ score is based on the sum of all the subscales scores except for the pro-social one (Goodman, 2001). A normative study by Goodman (2001) on a UK sample showed good internal consistency with Cranach alpha values of : 0.82, 0.67, 0.63, 0.77, 0.57, and 0.65 for total score, emotion, conduct, hyperactivity, peer, and prosocial subscales respectively. The SDQ also has been shown to correlate highly with Rutter's Child Behaviour Questionnaire Elander and Rutter (1996) (r=0.88), and to be stable over time with a test-retest correlation (r=0.62) over 4-6 months (Goodman, 2001).

The SDQ has been translated into many languages and the translated versions have been validated and widely used with many populations (Koskelainen, Sourander, & Vauras, 2001; Ronning, Handegaard, Sourander, & Morch, 2004; Smedje, Broman, Hetta, & von Knorring, 1999). The English version has been used in previous research with mothers of children with ASD (Rieffe et al., 2011); and with mothers of children with intellectual disabilities (Gallagher, Phillips, Oliver, & Carroll, 2008; Richard P Hastings, 2003). SDQ demonstrated satisfactory internal consistency with Cronbach's alpha value of 0.70, 0.82, 0.44, 0.73, 0.57, and 0.84 for total SDQ score, emotional problems, conduct disorder, hyperactivity, peer problems, and pro-social behaviour respectively (Beck, Daley, Hastings, & Stevenson, 2004). The Arabic version of the SDQ has been validated in two different studies and showed a good sensitivity (72%) and specificity (55%) (Almaqrami & Shuwail, 2004; Alyahri & Goodman, 2006).

In this study, Cronbach's alpha for the total SDQ, emotion, hyperactivity, conduct, peer, and pro-social subscales were 0.69, 0.60,0 .73, 0.49, 0.19, and 0.70 respectively which indicated an acceptable internal consistency for total SDQ, hyperactivity, emotion, conduct, and prosocial subscale ,and a poor reliability for the peer subscale . The Cronbach's alpha values upon item deletion were explored for the peer subscale. The largest increase in Cronbach's alpha resulted from deletion of item 23 *"Gets on better with adults than with other children"* which would increase the alpha value to 0.31. Therefore, it was decided to remove the peer problems subscale scores from the SDQ questionnaire in this study due to very low internal consistency and any referral to total SDQ score will be based on the sum of the three subscales of emotion, hyperactivity, and conduct. The low reliability of some outcome measures will be discussed in further detail in the discussion section of this Chapter. The test–retest reliability coefficients of SDQ in this study for the CAU group over approximately 12 weeks were found to be: 0.84 for total SDQ, 0.96 for emotion, 0.99 for hyperactivity, 0.90 conduct, and 0.95 for the prosocial subscale.

**The Indian Scale for assessment of Autism (ISAA).** Developed by the National Institute of Mentally Handicapped, this scale is used for measuring the severity of autism. It is a scale based on experts' rating of items based on parents' interviews and children's observation. It is based on Childhood Autism Rating Scale CARS by Schopler et al. (1980b). It has 40 items divided into six factors: social relationship; emotional responsiveness; speech, language, and communication; behaviour patterns; and social and cognitive component (National Institute for the Mentally Handicapped, 2009). Items are rated on a 5 point scale (rarely, sometimes, frequently, mostly, and always). According to the ISSA manual, autism is defined by a score of 70. Total scores of 70 to 106 indicate mild autism, 107-153 moderate autism, and scores of 153 and above indicate severe autism (National Institute for the Mentally Handicapped, 2009). Internal consistency yielded a Cronbach's coefficient alpha value of 0.93, which is comparable to the value on CARS of 0.94 , and an inter-rater reliability showed a good agreement between the two raters with significant ($P>0.001$) correlation ($r = 0.83$) as well as ($r = 0.89$) test-retest reliability after three months (National Institute for the Mentally Handicapped, 2009). The criterion test validity of ISAA was determined by comparison of the total scores obtained on the ISSA with those from CARS. A Pearson correlation of ($r = 0.77$) ($p<0.001$) revealed that

ISAA has a high degree of validity as that of CARS (National Institute for the Mentally Handicapped, 2009).

The ISAA has been previously used in evaluating Psych-educational intervention for parents of children with ASD (Patra, Arun, & Chavan, 2015). The Arabic version of the tool has been used with parents of children with ASD in Iraq with good internal consistency of an alpha value of 0.82 (Dawood & Khudhair, 2015); and with mothers of children with ASD in Lebanon with excellent internal consistency with an alpha value of .96 (Obeid & Daou, 2015). Two studies have been identified in which ISAA have been used with parents of children with ASD in KSA (Amr et al., 2012; Amr et al., 2011).

In the sample of this study, Cronbach's alpha yielded a value of 0.68 which indicated an acceptable internal consistency. The test–retest reliability coefficient of the ISAA in this study for the CAU group over approximately 12 weeks was found to be 0.99.

**The Arabic Scale of Happiness (ASH)***.* This is a measure that was developed originally in the Arabic language and then translated into English (Abdel-Khalek, 2013). It was designed to measure happiness in adults. It has 20 items (five items are only fillers). In a normative study on an Arab sample, two factors were identified: general happiness and a successful life (Abdel-Khalek, 2013). The ASH has been found to correlate with the five-item mental health screening test (r = 0.62) and the WHO Well-Being Index (r = 0.60) (Abdel-Khalek, 2013; Berwick et al., 1991; Topp, Ostergaard, Sondergaard, & Bech, 2015). It showed good internal consistency when used with undergraduate males and females with Cronbach's alpha values of 0.92 and 0.94 respectively and a stability over 19 days with a test-retest correlation coefficient of 0.82 and 0.86 with males and females respectively (Abdel-Khalek, 2013).

In this study the Cronbach's alpha yielded a value of 0.89 which indicated a good internal consistency. The test–retest reliability coefficient of the ASH in this study for the CAU group over approximately 12 weeks was found to be 0.99.

### Intervention Implementation Fidelity

Treatment fidelity refers to the extent to which intervention delivery adheres to the original intervention protocol (Wunderlich, Kohler, Care, Services, & Medicine, 2001). According to Wainer and Ingersoll (2013), it is essential for any parent training programme to implement strategies to ensure the fidelity in delivering the intervention. Three ways to ensure implementation fidelity were considered in this study. First, after each WhatsApp session, the therapists sent *implementation fidelity questions* to the participants asking a few questions about their involvement with the training material and the usefulness of the WhatsApp session. It asked the participants to rate the usefulness of the WhatsApp session on a scale from 0 to 10 in which zero was unhelpful and 10 was very helpful. Second, the therapists were asked by the researcher to keep records of attendance for participants on the WhatsApp sessions to explore the number of mothers who appeared committed to the sessions. Third, therapists were given *a Therapist's scripts* to remind all therapists delivering the intervention to go through the same essential topics in each session.

An examination of Table 8 shows a summary of the participants' engagement in the various aspects of the intervention. The meantime invested in all aspects of the intervention was 195.71 minutes (SD 13.00). In general, engagement with the intervention materials was high, with the vast majority of participants reporting reading each week's self-directed content. However, the amount of time participants invested reading the intervention material was relatively brief and decreased overtime. Engagement in the 30 minutes virtual therapy sessions was good with the vast majority of parents engaging each week. When mothers were unable to engage with a virtual therapy session, all mothers accessed the transcripts of the session and clarified any issues directly with a therapist. All participants rated their satisfaction with the virtual therapy sessions irrespective of whether they engaged directly in the session or accessed the transcripts afterward. Overall satisfaction with the sessions was extremely high, with a mean of 9 for most sessions and a narrow standard deviation, although satisfaction with session five was lower, it was still acceptable.

**Table 8. Participants' engagement with the intervention**

| Session no. | Reading manual<br>N (%) | Minutes reading manual<br>M (SD) | WhatsApp attendance<br>N (%) | Satisfaction score<br>M(SD) |
|---|---|---|---|---|
| Session two | 30 (93.8) | 13.30 (4.75) | 29 (90.6) | 9.22(1.00) |
| Session three | 29(90.6) | 11.69(3.37) | 27(84.4) | 9.19(0.73) |
| Session four | 31(96.9) | 10.35(3.91) | 24(75) | 9.03(1.25) |
| Session five | 31(96.9) | 6.19(1.93) | 25(78.1) | 7.38(1.33) |

### Analysis Strategy

All data analyses were conducted using IBM SPSS version 22.0. Descriptive statistics were used to explore the means and standard deviations for the primary outcomes and secondary outcomes; subscale data were also explored where appropriate. Baseline equivalence between groups was analysed using a series of one way analysis of variance ANOVA for continuous data and chi-square tests for discrete variables.

To assess for differences between groups at T2 and T3, a series of one way analysis of covariance ANCOVAS were conducted where T2 or T3 scores were entered as the dependent variable and T1 scores were entered as covariates. Effect sizes were calculated by subtracting change in the intervention arm from change in the control arm and dividing by the pooled pre-test standard deviation (Cohen, 1988), and the results were interpreted according to the traditional conventions of effect size proposed by Cohen (1988), in which small *(d* ≥0.2), medium (*d* ≥0.5), large (*d* ≥ 0.8), and very large (d≥1.3)*. P*-values ≤.05

were considered statistically significant in this trial.  No correction was made to the data to control for multiple testing (Streiner, 2015).

Internal consistency of the measures with the sample in this study has been explored using values of alpha Cronbach's coefficient at T1, and the stability of the measures overtime has been assessed using the test-retest correlation coefficient with the CAU group from T1 to T3. Internal consistency and test-retest scores for each measure in this study have been reported under each measure in the methods section of this Chapter. It should be noted that the Pearson correlation coefficient scores for reporting test-retest reliability were used for all measures in this study except for HADS-anxiety and conduct subscale of SDQ, where Kendall TAU were used due to being non-parametric.

Clinical significance was investigated for each significant parental outcome in this study to assess the practical benefits of the intervention for each individual participant in the intervention group, and this was done using two criteria for clinical significance, as  proposed by Jacobson and Truax (1991):"the return to the normal functioning"(p.13); and the Reliable Change Index RCI (Jacobson & Truax, 1991). The first criteria of Jacobson and Truax (1991) assumes that clinical significance could be achieved if participants' scores are closer to "the mean of the functional population than the mean of the dysfunctional population" post intervention( p.13). To be able to assess the clinical significance following this criteria, a cut-off point that lies half-way between the mean of the normal population and the baseline mean for participants in this study was identified for PSI-SF (101.16) and HADS depression (7.18). For a mother to experience a meaningful clinically significant change, her score should cross the cut-off point post intervention.

The second criteria used for assessing clinical significance in this study is the RCI which was the amount an outcome measure needs to change before one can be 95% assured that the change could not be attributed to a measurement error (Ogles, Lunnen, & Bonesteel, 2001). The formula used in this study to calculate RCI scores for individual participants in certain measures is the one reported by Jacobson and Truax (1991) which involve dividing the difference in participant's pre-test and post-test scores by the standard error of the difference. For a participant to achieve a reliable significance change in a certain measure, his or / her RC score should be equal to or greater than 1.96 (Jacobson & Truax, 1991). For each participant in this study, a RC score was calculated for PSI-SF and HADS depression (see the results section).

## Results

### Participants' Characteristics and Flow

One hundred and thirty eight mothers were referred into the study from participating organisations, of which 69 mothers consented to take part. It was not possible to explore whether mothers who consented were different than mothers who did not consent. Baseline data were successfully collected from 67 of these 69 consenting mothers who were consequently randomised to either an IG or CAU. See Figure 18 for the flow of participants through the trial. The demographic characteristics of the final study sample are presented in Table 9.

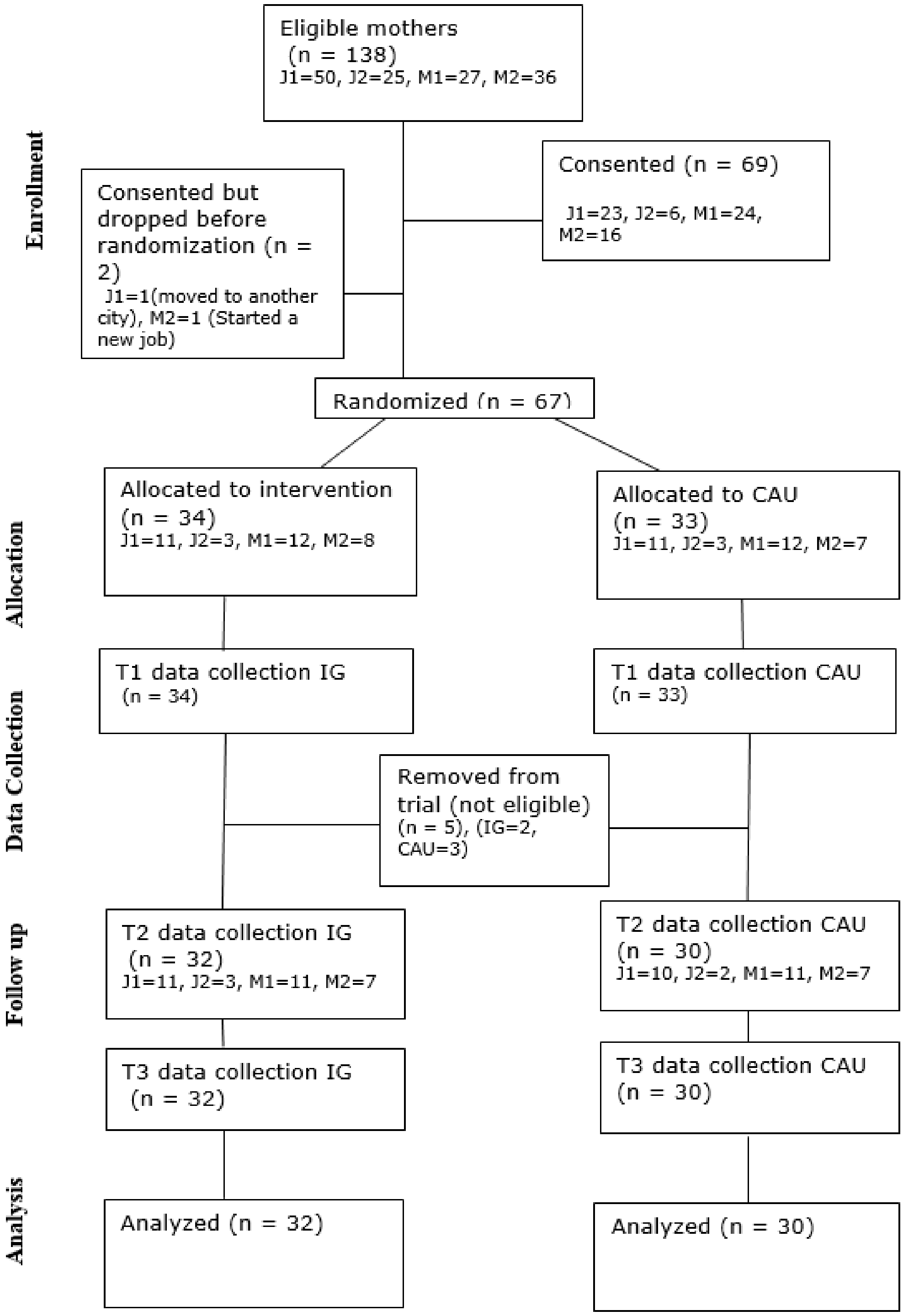


**Figure 18. Flowchart diagram showing the flow of participants through each stage of the trial**

Table 9 displays the demographic information for the sample at baseline. Children with ASD were all at preschool age. Their mothers were predominantly in their thirties. Eight percent of mothers had a second child with autism. The majority of mothers in the sample were highly educated and much more educated than the average Saudi female. The majority of the mothers were married, with the sample containing less divorced women than might be expected given the Saudi average divorce rate shown in Table 9 . A minority of the mothers in the sample were working in professions that are typical occupations for Saudi women. All fathers of children in the study were working. Fathers worked in a range of professions, with a large proportion of soldiers and policeman, however, the lack of detailed government census data for occupations made it difficult to establish whether soldiers and policeman are occupations that were over representative in the sample.

**Table 9. Demographic characteristics of study sample (n=62)**

| Characteristics | IG<br>N = 32 | CAU<br>N = 30 | Whole sample<br>N = 62 |
|---|---|---|---|
| Child age (months), M(SD) | 63.18 (13.68) | 58.73 (14.07) | 61.03 (13.94) |
| ASD symptoms$^{\Delta}$, n (%) | | | |
| Mild ASD symptoms (ISAA scores 70-106) | 20 (62.5) | 18 (60) | 38 (61.29) |
| Moderate ASD symptoms (ISAA scores 107-153) | 12 (37.5) | 12 (40) | 24 (38.7) |
| Severe ASD symptoms (ISAA scores >153) | NA$^{\diamond}$ | NA | NA |
| Mother's age (years), M(SD) | 32.90 (7.26) | 34.43 (6.65) | 33.64 (6.96) |
| Mothers with another ASD child, n (%) | 3 (9.37) | 2 (6.66) | 5 (8.1) |
| Age of another ASD child, M(SD) | 52.00 (15.62) | 71.00 (52.32) | 59.60 (30.24) |
| Education level, n (%), *[% in SA population] | | | |
| Less than high school | 5 (15.62) | 5 (16.66) | 10 (16.1), [76] |
| High school | 9 (28.12) | 11 (36.66) | 20 (32.3) ,[15] |
| Bachelor's degree | 18 (56.25) | 14 (46.66) | 32 (51.6) , [9] |

| | | | |
|---|---|---|---|
| Marital status, n (%), [% in SA population] | | | |
| Married | 29 (90.62) | 27 (90.00) | 56 (90.3), [61.04] |
| Divorced | 3 (9.37) | 3 (10.00) | 6 (9.7), [1.64] |
| Working females, n (%), [% in SA population] | 7 (21.87) | 6 (20.00) | 13 (21), [15.4] |
| Teachers | 6 (18.75) | 4 (13.33) | 10 (16.1) |
| Nurses | 1 (3.12) | 2 (6.66) | 3 (4.8) |
| Fathers' jobs, n (%) | | | |
| Soldiers | 9 (28.12) | 11 (36.66) | 20 (32.3) |
| IT | 3 (9.37) | 3 (10.00) | 6 (9.7) |
| Teachers | 6 (18.75) | 4 (13.33) | 10 (16.1) |
| Administrative work | 11 (34.37) | 8 (26.66) | 19 (30.6) |
| Business | 1 (3.12) | 2 (6.66) | 3 (4.8) |
| Physicians | 2 (6.25) | 2 (6.66) | 4 (6.5) |

* Only available information about percentages in KSA population is presented (from Saudi Central Department of Statistics and Information based on the 2010 census).

◊ None of the participants scored above 153 on ISAA.

Δ Classification of autism symptoms is based on maternal report on ISAA.

## Breach of Protocol

A visual inspection of the data after T1 data collection revealed five cases that were not suitable for inclusion in the study as they scored within the normal range (>70) in ASD symptoms on ISSA. These five cases were withdrawn from the study because of the uncertainty of whether or not they met the inclusion criteria.

## Preliminary Analysis (Equivalence)

Thirty two families were allocated to the intervention, and 30 families were allocated to the CAU. A series of chi-square tests for categorical variables (e.g., educational level) and ANOVA for numerical variables (e.g., age) revealed no significant difference between the groups on any demographic variables or baseline characteristics. An initial analysis also examined the equivalence of groups at T1 on the primary measures of outcome. Using a series of one-way analysis of variance (ANOVAS), very small but statistically non-significant differences between the trial arms at baseline across all outcomes were found (see Table 10). In general, these results indicated that intervention and control participants were well matched prior to receiving the intervention.

Results of a Kolmogorov Smirnov test indicated that although the majority of the measures were parametric, both HADS anxiety, and conduct subscale on SDQ were significantly non-normal: D (62) = .130, $p = 0.01$ and D (62) = 1.36, $p = 0.04$ respectively. However, ANCOVA is robust to the violation of the nonparametric assumption with more than 15 cases per cell (Green & Salkind, 2003).

**Table 10. Baseline ANOVA scores for IG and CAU**

| Measure | Intervention N=32 Mean (SD) | CAU N=30 Mean (SD) | F (P value) |
|---|---|---|---|
| PSI-SF | 129.86 (13.82) | 132.80 (13.07) | 0.68(0.41) |
| Parental distress | 43.84(6.74) | 45.53(6.24) | 1.04(0.31) |
| Parent child dysfunctional interaction | 40.75(6.94) | 41.500(5.59) | 0.20(0.65) |
| Difficult child(revised) | 41.28(4.21) | 41.900(4.23) | 0.33(0.56) |
| HADS (depression) | 10.68(3.56) | 10.66(3.47) | 0.00(0.98) |
| HADS (anxiety) | 7.71(2.45) | 7.63(2.77) | 0.01(0.89) |
| Happiness | 43.71(9.33) | 43.13(10.26) | 0.05(0.81) |
| ISAA | 100.500(13.60) | 101.200(14.16) | 0.03(0.84) |
| SDQ (revised) | 14.40(4.44) | 14.83(4.37) | 0.14(0.70) |

| | | | |
|---|---|---|---|
| Emotional | 4.500(2.09) | 4.500(2.31) | 0.00(1.00) |
| Hyperactivity | 6.68(2.40) | 7.00(2.21) | 0.28(0.59) |
| Conduct | 3.21(1.80) | 3.33(1.93) | 0.5(0.81) |
| Prosocial | 3.78(2.35) | 4.33(2.39) | 0.83(0.36) |

Table 11 displays the associations between the measures of the entire sample at baseline. Generally, the pattern of association presents a mixed picture with autism scores correlated positively with SDQ total, and hyperactivity, and negatively with prosocial. The lack of a significant association between autism and parental stress may be due to a truncated range for stress. Stress total score and its subscale correlated significantly with each other and with HADS depression and negatively with happiness showing mothers with high stress scores reporting higher depressive symptoms and less happiness. The difficult child stress subscale correlated with SDQ total, emotional, and conduct subscales, showing that stress in mothers is associated with greater child behaviour problems. SDQ total correlated positively with autism scores and HADS depression showing that parents with children with higher autism scores reported greater behaviour problems and higher depressive symptoms. The lack of association between SDQ conduct and hyperactivity subscales was surprising and difficult to reconcile but may be due to low internal consistency of the SDQ conduct subscale.

**Table 11. Correlations between measures**

| Measures | (1) | (2) | (3) | (4) | (5) | (6) | (7) | (8) | (9) | (10) | (11) | (12) | (13) |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 1.ISAA | - | -.018 | -.092 | .078 | .016 | .063 | __.116__ | .285* | .169 | .257* | __-.032__ | -.390** | -.243 |
| 2.PSI-SF | | - | .817** | .738** | .837** | .503** | __.327**__ | .176 | .420** | -.064 | __.012__ | -.014 | -.421** |
| 3.PD(PSI-SF) | | | - | .464** | .447** | .377** | __.356**__ | .025 | .247 | -.157 | __.023__ | .216 | -.461** |
| 4.DC(PSI-SF) revised | | | | - | .507** | .612** | __.413**__ | .427** | .641** | -.055 | __.256*__ | -.210 | -.181 |
| 5.PCDI(PSI- SF) | | | | | - | .349** | __.139__ | .126 | .295* | .049 | __-.126__ | -.140 | -.314* |
| 6.HADS-depression | | | | | | - | __.599**__ | .303* | .335** | .022 | __.266*__ | -.115 | -.336** |
| 7.HADS-anxiety | | | | | | | - | __.127__ | __.169__ | __.093__ | __-.115__ | __-.351**__ | __-.390**__ |
| 8.SDQ (revised) | | | | | | | | - | .813** | .589** | __.602**__ | -.191 | .192 |
| 9.Emotions(SDQ) | | | | | | | | | - | .136 | __.480**__ | -.163 | .207 |
| 10.Hyperactivity(SDQ) | | | | | | | | | | - | __-.059__ | -.393** | .028 |
| 11.Conduct(SDQ) | | | | | | | | | | | - | __.246__ | __.024__ |
| 12.Prosocial(SDQ) | | | | | | | | | | | | - | .025 |
| 13.Happiness | | | | | | | | | | | | | - |

**Correlation is significant at the 0.01 level (two-tailed).

*, Correlation is significant at the 0.05 level (two-tailed).

Pearson correlation coefficient is reported when both measures are parametric.

**Spearman’s rho is reported when both or either one of the measures is non parametric.**

An examination of Table 12 contrasts the baseline scores for the sample against appropriate comparison, norms or both. A closer look at the table demonstrates that parents' reported autism scores at baseline were comparable to the normative score for autism on the ISAA (National Institute for the Mentally Handicapped, 2009). For SDQ emotion, conduct, and hyperactivity, children in the sample were rated considerably higher than the UK norm for that measure. Arabic norms are not available ("SDQ: Normative School-Age SDQ Data from Britain," 2001). For the prosocial subscale, children in the sample were rated considerably lower than the UK norm. For PSI-SF, stress scores within the sample were considerably higher than the US norm according to Abidin (1995) with all parents in the sample at baseline scoring above the point of clinical concern for stress. For HADS depression, parents' self-reported levels of depression were considerably higher than the UK norm, according to Crawford et al. (2001) and 50% of the sample scored above the point of clinical concern. Although it was not possible to compare the HADS revised anxiety score against the UK norm, 40% of parents scored above the point of clinical concern for anxiety. An examination of the Arabic norm of the happiness scale indicated that parents in the sample were considerably less happy than the Arabic norms (Abdel-Khalek, 2013).

**Table 12. Baseline characteristics for outcomes (n=62)**

| Measure | M<br>(SD) | % Above cut off | Comparisons |
|---|---|---|---|
| ISAA° | 100.83<br>(13.77) | 100% | 106.09(23.5)<br>Indian ASD sample |
| SDQ1(revised) | 14.61<br>(4.38) | NA | NA |
| Emotion | 4.50<br>(2.18) | 50% | 1.9 (2.0) |
| Conduct | 3.27<br>(1.85) | 38.70% | 1.6 (1.7) |
| Hyperactivity | 6.83<br>(2.29) | 51.61% | 3.5 (2.6) |
| Prosocial | 4.04<br>(2.37) | 61.29% | 8.6 (1.6)<br>UK norm |

| | | | |
|---|---|---|---|
| PSI-SF$_x$ | 131.33 (13.43) | 100% | 71.0(15.4) |
| PD | 44.66 (6.51) | 91.93% | 26.4(7.2) |
| DC(revised) | 41.58 (4.20) | 100% | NA |
| PCDI | 41.11 (6.44) | 96.77% | 18.7(4.8)<br>U.S norm |
| HADS⌂ | | | |
| Depression | 10.67 (3.49) | 50% | 3.68 (3.07)<br>UK norm |
| Anxiety(revised) | 7.67 (2.59) | 41.93% | NA |

| | | | |
|---|---|---|---|
| Happiness | 43.43<br>(9.71) | NA | 53.7<br>(10.2)<br><br>Arab norm |

° ISAA is the Indian Scale for Assessment of Autism, ˥ SDQ is the Strength and Difficulties Questionnaire, x PSI-SF is the Parent Stress Index-Short Form- (PD is parental distress, DC is difficult child , and PCDI is parent child dysfunctional Interaction subscales of PSI-SF), ⌂ HADS is Hospital Anxiety and Depression.

## Outcomes

Primary parental outcomes are presented followed by child outcomes and then the results of the correlation between participants' implementation fidelity and outcomes are described.

## Parental Outcomes

The mean and SDs for each parental outcome measure at T1 and T2 are presented in Table 13. There was a significant effect of treatment on PSI-SF at T2 (Table 13); F [1,59 ]= 234.34, P<0.05 ) and at T3 (Table 14; F [1,59]= 131.47, P<0.05 ). An examination of the corresponding effect sizes, calculated using Cohen d, revealed the differences at T2 (d=-1.52) to be very large but this was reduced at T3 (d = -0.98) to a large but still meaningful effect size (Figure 19). All three PSI-SF subscales demonstrated a significant effect of intervention at T2 (*PD* F [1,59] = 195.71, P < 0.05; *PCDI* F[ 1,59] = 206.68, P < 0.05; *DC* F [1,59] = 44.25, P < 0.05) and also at T3 (*PD* F [1,59] = 64.39, P < 0.05; *PCDI* F [1,59] = 137.92, P < 0.05; *DC* F [1,59] = 28.95, P < 0.05). An examination of the corresponding effect sizes at T2 (Table 13) exhibited a very large effect size difference for the PCDI subscale (d=-2.01), a large effect size for the parental distress subscale (d= -0.80) and a small effect size for the difficult child subscale (d= -0.47) in favour of intervention. At T3, the magnitude of the effect sizes in favour of intervention were attenuated for all three subscales, although the PCDI subscale remained very large (d= -1.51), and the difficult child subscale remained small (d= -0.28) but the parental distress scale reduced from a large to a small effect size (d= -0.33). There was also a significant effect of treatment group on HADS depression at T2 (F [1,59]= 195.70, P < 0.05 ) and T3 (F [1,59 ]= 183.58, P < 0.05 ) but not on HADS anxiety (Table 14). An examination of the corresponding effect sizes revealed the differences at T2 (d= -2.14) and T3 (d= -2.05) to be very large and therefore meaningful (Figure 20). Unsurprisingly, there were no meaningful differences in the effect sizes at T2 and T3 for HADS anxiety which corroborated the lack of statistical significance between the groups. There was also a significant effect of the treatment group on the Arabic happiness scale at T2 (F [1,59 ]= 121.32, P < 0.05 ) and T3 (F [1,59]= 95.46, P < 0.05 ) although the corresponding effect sizes were small (d= 0.35 ).

## Child Outcomes

There was a significant effect of treatment group on the Indian Scale for Autism Assessment at T2 (F [1,59]= 21.85, P < 0.05 ) and T3 (F [1,59]= 23.23, P < 0.05 ), although the corresponding effect sizes were small (d= -0.23 ). There was a significant effect of treatment group on the SDQ total at T2 (F [1,59]= 100.63, P < 0.05 ) and T3 (F [1,59]= 41.80, P < 0.05 ) and the hyperactivity scale at T2 (F [1,59 ]= 133.66, P < 0.05 ) and T3 (F [1,59]= 115.85, P < 0.05 ). However, no significant effect was shown for emotions, conduct, and prosocial subscales either at T2 or T3. A close examination of the corresponding effect sizes for SDQ revealed a large effect size at T2 and T3 for SDQ total (d= -0.98) and a very large effect size for the hyperactivity subscale at T2 (d= -1.54) and T3 (d= -1.47). Not surprisingly, there was no effect on SDQ emotions, conduct, and prosocial subscales at T2 and T3 which mirrors the lack of statistical significance from the ANCOVA.

**Table 13. Means and SDs for outcomes at T1 and T2**

| | Intervention N=32 M (SD) | | CAU N=30 M (SD) | | | |
|---|---|---|---|---|---|---|
| Measure | T1 | T2 | T1 | T2 | F (P value) | Cohen's d T1 to T2 |
| PSI-SF | 129.96(13.82) | 116.18(12.65) | 132.80(13.07) | 139.400(13.34) | 234.34(<0.001) | -1.52 |
| Parental distress | 43.84(6.74) | 41.46(6.43) | 45.53(6.24) | 48.36(5.75) | 195.71(<0.001) | -0.80 |
| Parent child dysfunctional interaction | 40.75(6.94) | 30.59(5.48) | 41.5(5.95) | 44.30(5.91) | 206.68(<0.001) | -2.01 |
| Difficult child(revised) | 41.28(4.21) | 40.12(4.20) | 41.90(4.23) | 42.76(4.26) | 44.25(<0.001) | -0.47 |
| HADS (depression) | 10.68(3.56) | 3.84(2.49) | 10.66(3.47) | 11.36(3.42) | 195.70(<0.001) | -2.14 |
| HADS (anxiety) | 7.71(2.45) | 7.59(2.09) | 7.63(2.77) | 7.83(2.64) | 3.76(0.057) | -0.12 |

| | | | | | | |
|---|---|---|---|---|---|---|
| Happiness | 43.71(9.33) | 47.50(8.56) | 43.13(10.26) | 43.46(9.80) | 121.32(<0.001) | 0.35 |
| ISAA | 100.50(13.60) | 91.71(12.76) | 101.20(14.16) | 95.66(13.82) | 21.85(<0.001) | -0.23 |
| SDQ (revised) | 14.40(4.44) | 10.40(3.60) | 14.83(4.37) | 14.76(3.89) | 100.63(<0.001) | -0.89 |
| Emotional | 4.50(2.09) | 4.50(2.09) | 4.50(2.31) | 4.56(2.29) | .69(0.40) | -0.03 |
| Hyperactivity | 6.68(2.40) | 2.84(1.95) | 7.00(2.21) | 6.70(2.26) | 133.66(<0.001) | -1.54 |
| Conduct | 3.21(1.80) | 3.21(1.80) | 3.33(1.93) | 3.43(1.85) | 2.20(0.14) | -0.05 |
| Prosocial | 3.78(2.35) | 3.78(2.35) | 4.33(2.39) | 4.60(2.12) | 7.03(0.10) | -0.11 |

Note: effect sizes were calculated based on change scores.

**Table 14. Means and SDs for outcomes at T1 and T3**

| Measure | Intervention M (SD) | | CAU M (SD) | | | |
|---|---|---|---|---|---|---|
| | T1 | T3 | T1 | T3 | F (P value) | Cohen's d T1 to T3 |
| PSI-SF | 129.96(13.82) | 116.50(12.46) | 132.80(13.07) | 132.56(12.86) | 131.47(<0.001) | -0.98 |
| Parental distress | 43.84(6.74) | 41.50(6.42) | 45.53(6.24) | 45.36(6.13) | 64.39(<0.001) | -0.33 |
| Parent child dysfunctional interaction | 40.75(6.94) | 30.96(5.32) | 41.5(5.95) | 41.50(5.78) | 137.92(<0.001) | -1.51 |
| Difficult child(revised) | 41.28(4.21) | 40.03(4.12) | 41.90(4.23) | 41.83(4.29) | 28.95(<0.001) | -0.28 |
| HADS (depression) | 10.68(3.56) | 4.12(2.49) | 10.66(3.47) | 11.33(3.39) | 183.58(<0.001) | -2.05 |
| HADS (anxiety) | 7.71(2.45) | 7.65(2.00) | 7.63(2.77) | 7.86(2.67) | 1.69(0.19) | -0.11 |
| Happiness | 43.71(9.33) | 47.62(8.47) | 43.13(10.26) | 43.56(9.63) | 95.46(<0.001) | 0.35 |

| | | | | | | |
|---|---|---|---|---|---|---|
| ISAA | 100.50(13.60) | 91.68(12.72) | 101.20(14.16) | 95.66(13.84) | 23.23(<0.001) | -0.23 |
| SDQ (revised) | 14.40(4.44) | 14.75(4.21) | 14.83(4.37) | 19.53(4.09) | 41.80(<0.001) | -0.98 |
| Emotional | 4.50(2.09) | 4.56(2.03) | 4.50(2.31) | 4.63(2.25) | 0.28(0.59) | -0.03 |
| Hyperactivity | 6.68(2.40) | 3.09(1.85) | 7.00(2.21) | 6.80(2.34) | 115.85(<0.001) | -1.47 |
| Conduct | 3.21(1.80) | 3.25(1.77) | 3.33(1.93) | 3.46(1.81) | 1.14(0.28) | -0.05 |
| Prosocial | 3.78(2.35) | 3.84(2.39) | 4.33(2.39) | 4.63(2.15) | 3.63(0.06) | -0.10 |

Note: effect sizes were calculated based on change scores

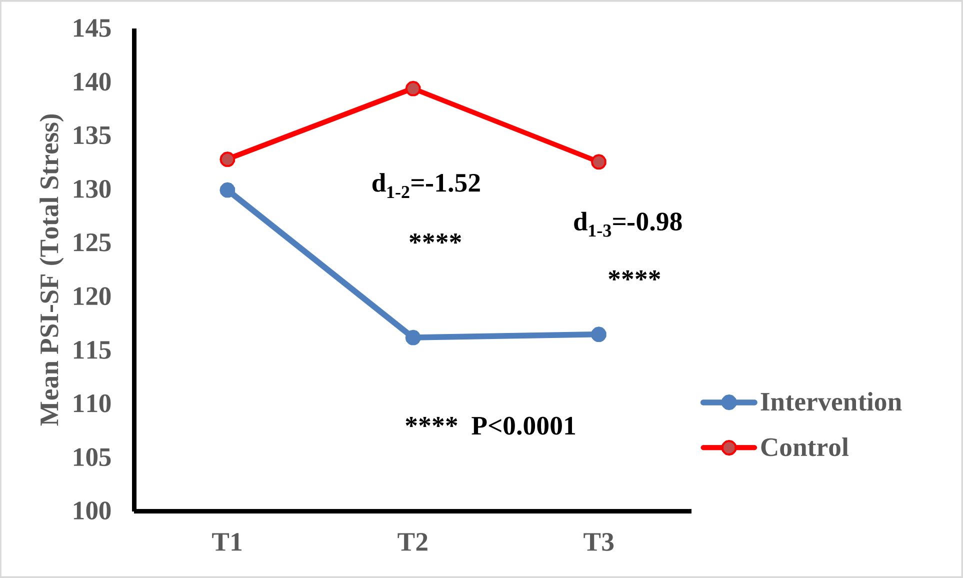


Figure 19. Change of PSI-SF effect size across the study

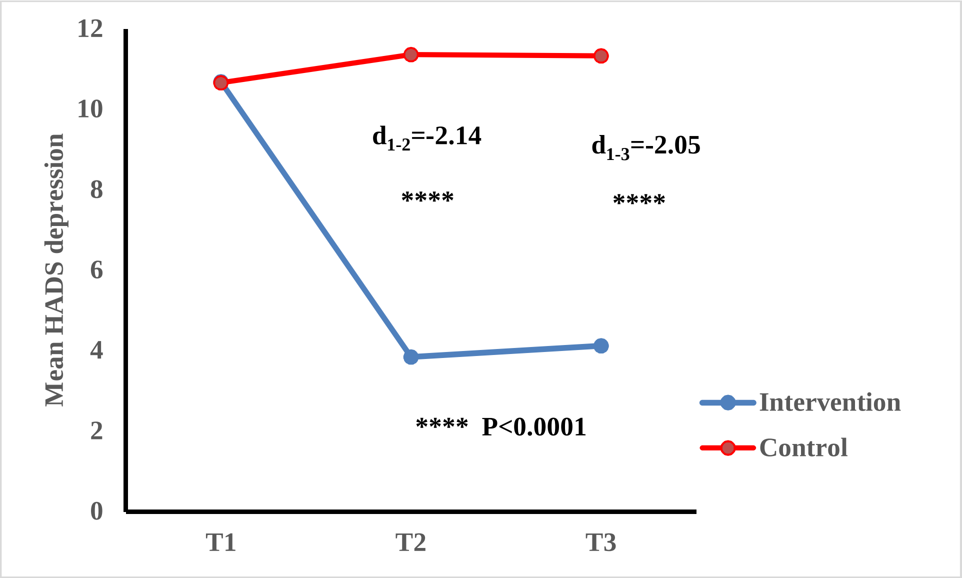


Figure 20. Change of HADS depression effect size across the study

An exploration of the relationship between participants' implementation fidelity and change in outcomes between T1 and T3 revealed two marginally significant effects regarding the total number of minutes spent reading the manual HADS depression (r=-0.32, P=0.09) and happiness (r=0.35, P=0.07).

**Clinical Significance**

Clinical significant change was examined in this study for the significant parental outcomes of PSI-SF and HADS depression. Using Jacobson and Truax (1991) criteria of achieving clinical significance by being closer to the mean of the normal population (see the methods section), a close examination of participants' mean scores on PSI-SF revealed that three mothers (9.37%) in the intervention group experienced clinical significant changes compared to no one (0 %) in the CAU group following the training at T2, and three mothers (9.37%) in the intervention group compared to one mother (3.33%) at T3. An examination of participants' mean scores on HADS depression revealed that 30 mothers (93.75%) in the intervention group experienced clinical significant change compared to three mothers (10 %) in the CAU group following the training at T2, and 29 mothers (90.62%) in the intervention group compared to three mothers (10 %) in the CAU group at T3.

Analysis of clinical significance using RCI criteria indicated that the intervention was associated with improvement in 12 mothers (37.5%) in the intervention group at T2 on PSI-SF scores, and an improvement in 11 mothers (34.37%) at T3. However, none of the participants in the CAU group experienced a significant reliable change in their PSI-SF scores at T2 nor T3. The intervention was also found to cause significantly reliable change in participants' HADS depression scores as 24 mothers (75%) in the intervention group had improved at T2 and this improvement was maintained at T3. However, none of the participants in the CAU group experienced significant reliable change in their HADS depression scores at either T2 or T3.

For a participant to be considered as recovered after the course of an intervention, he or / she should achieve clinically significant change on both criteria: becoming close to the functional rather than dysfunctional population; and experiencing RC in their scores on the same measure (Jacobson, Roberts, Berns, & McGlinchey, 1999). A thorough inspection of the data in this study showed that no participant in this sample had recovered after the intervention (based on their PSI-SF scores). Even though three mothers in the intervention group had experienced clinically significant change on their PSI-SF scores by moving to the side of the normal population, these three participants did not experience any reliable significant change. However, Jacobson and Truax (1991) noted that the aim for participants to be recovered after a course of an intervention might be too strict for people with pervasive and serious conditions. Therefore, as the participants of this study were mothers of children with ASD, It was not peculiar that they did not fully recover at the end of training. Twenty three mothers (71.87%) in the intervention group had recovered at T2 and 22 (68.75%) at T3 based on their HADS depression scores.

## Discussion

This study was an addition to the evidence based supporting the effectiveness of parent training interventions in enhancing parental well-being in mothers of children with ASD. The main aim of this study was to evaluate the efficacy of a self-help psychoeducational intervention with minimal therapist support delivered via WhatsApp. The results of this study indicated that the proposed intervention was effective in reducing maternal stress, depression, parent reported ASD symptoms, and child behaviour problems, and in increasing maternal happiness in mothers of children with ASD in KSA.

Even though the baseline stress level of the participants in this study were high and all mothers' stress scores fell within the clinical range for PSI-SF, other studies in the literature have showed similar elevated level of parental stress at baseline (Dardas, 2014; Hoffman et al., 2008). The parental mean total stress score was significantly reduced in mothers at the IG and this result was maintained after a 12 weeks follow-up. This finding is consistent with other studies that reported a significant reduction in parental stress after parental intervention (Bendixen et al., 2011; Chiang, 2014; Ferraioli & Harris, 2013). Mean scores for all PSI-SF subscales including PD, DC, and PCDI in this study were significantly reduced post intervention, a finding supported by Bendixen et al. (2011) who found that maternal stress was significantly reduced for PD and DC subscales of PSI-SF post intervention but not for the PCDI subscale. The non-significant reduction of PCDI subscale in Bendixen et al. (2011) could be explained due to the fact that the intervention was delivered mainly to fathers who were supposed to train mothers, which could have lessened the efficacy of the intervention in targeting the dysfunctional interactions between mothers and their children. The findings of Ginn et al. (2015) indicated that neither parental total mean stress scores, nor any of the mean scores for the three subscales of the PSI-SF were significantly reduced post intervention, which contradicts the findings of this study. However, this could be due to the fact that the intervention used in Ginn et al. (2015) was a *Child-Directed Interaction Training* aiming to enhance communication and social learning between parents and their children with ASD and there was nothing in the intervention to target parental well-being.

The mean score for depression and anxiety was high at baseline with the majority of the participants' scores above the clinical cut-off for HADS depression and anxiety. These elevated levels of depression and stress has also been reported in other studies of parents of children with ASD (Almansour et al., 2013; Carter et al., 2009). This study showed a significant reduction in maternal depression post intervention with a very large effect size and this result was maintained at follow-up. This finding is consistent with (Bristol et al., 1993) who explored the effectiveness of a psychoeducational intervention to reduce maternal depression for mothers of children with ASD. Surprisingly, there was no reduction in mothers' mean scores of anxiety in this study, which contradicts the majority of the literature in which depression and anxiety scores are usually correlated (Almansour et al., 2013; Lee, 2009 b). This result might be because of the low internal consistency of the HADS anxiety when used with the sample in this study or because the proposed intervention was not sufficient to reduce anxiety in mothers of children with ASD. This was expected, for the anxiety was not a specific target at any of the training sessions. Another explanation is that it might be that one aspect of depression, including the positive affect of how mothers enjoy their environment in this particular sample, was reduced post intervention, which according to Watson, Clark, and Carey (1988), is different than the negative affect of depression that is related to feeling sad, angry, and tired, symptoms usually correlated with anxiety. A longitudinal study of maternal well-being by Barker et al. (2011) for mothers of adolescents with ASD over a 10 years period found that maternal anxiety improved over time while maternal depression remained stable even during events when mothers were experiencing high levels of stress, indicate that depression and anxiety were not highly correlated over time.

Studies have found that parental programmes that included strategies to manage children's behaviour problems did enhance the well-being of parents (Bristol et al., 1993; R. L. Koegel et al., 1992); this is in line with the findings from this study in which the intervention included strategies to help mothers manage their children's with ASD behaviour problems and also enhanced maternal well-being. Remington et al. (2007) found that there was not significant effect on the parental well-being of an intensive parent behavioural intervention for parents of children with ASD. The lack of significant change of parental stress and depression in Remington et al. (2007) could be explained by the fact that their intervention was focused mainly on modifying children's behaviour and nothing was offered to parents to help them deal with their psychological well-being. In addition, an intervention that required parents to intensively use behavioural strategies for 25.6 hours per week for two years with their children might be demanding and stressful, considering those parents challenging responsibilities in dealing with their ASD children.

This study showed a significant increase in participants' happiness level post intervention and results were maintained at follow-up. This finding is consistent with other studies that showed an increase in parental level of happiness after parental intervention (L. K. Koegel, Stiebel, & Koegel, 1998; Robert L. Koegel et al., 1996; Steiner, 2011).

This study revealed that parental reported ASD symptoms were significantly reduced post intervention, and that these results were maintained after follow-up. The theoretical explanation for why mothers reported reduced ASD symptoms post intervention is not clear, as strategies to directly target ASD were not included in the intervention. The complex relationship between parental well-being, child behaviour, and the putative role of potential mediating variables were beyond the scope and statistical power of the current study. Child behaviour problems were also found to significantly decrease post intervention, a finding that is consistent with the results of other studies evaluating interventions for parents of children with ASD (Tellegen & Sanders, 2014; Whittingham et al., 2009). However, it was only the hyperactivity subscale of the SDQ that was significantly reduced post intervention, with the conduct, prosocial, and emotional subscales remaining unchanged overtime. Surprisingly, hyperactivity was significantly reduced when conduct remained stable overtime, which contradicts the majority of the literature where hyperactivity and conduct problems in children with ASD were highly correlated (Mulligan et al., 2009). However, E. A. Jones and Feeley (2007) stated that when controlling for conduct problems , hyperactivity in children with ADHD was significantly reduced based on parents' report after receiving a parental intervention. The stability of conduct subscale scores could be due to the low reliability for that particular subscale which also could be explained due to the small number of items (only five items).

## Strengths

This study has many strong points. This study used a RCT design to evaluate the efficacy of the intervention, which is considered to be the golden design for programme evaluation (Akobeng, 2005). The CONSORT statement guidelines for reporting RCTs were used in this study, which ensured a clear and comprehensive reporting of RCTs. Moreover, a follow-up data collection was used in this study to test the stability of findings overtime. In addition, there was zero-dropout rate in this study, which is very rare in studies that evaluate psychological interventions. This might be due to the fact that the training was delivered in a user friendly format that was accessible to participants from the comfort of their homes. This study also had an evaluation of the participants' level of engagement with the intervention, which showed high level of engagement.

## Limitations

Despite the strengths of this study, it also had limitations. The lack of objective measures of maternal well-being and child behaviour problems was one of the limitations, however, the main intention behind the intervention was to evaluate the effectiveness of the intervention on maternal well-being which could be hard to obtain from fathers or other caregivers. It was thought that mothers would be the best informants about their own well-being. Other physiological measures of stress (e.g., saliva or cortisol level) have not proved to be reliable measures of stress and can fluctuate throughout the day time. Using an objective measure to evaluate children's behaviour problems was also not possible and hard to access in this study as children moved from one class to another during the course of the intervention. However, it also should be noted that it was not the main intention of this intervention to change children's behaviour and that measuring it in this study as a secondary outcome was only for the purpose of evaluating the change in mothers' reports on their children's behaviour problems from T1 to T2. Another limitation of this study was that it did not examine moderations; because of the small sample size, the study was not powered and the sample was simply not large enough to explore potential moderators of the outcome. The design of this study did not allow for exploring the differences in outcomes if the intervention was delivered face to face compared to WhatsApp (dismantling design). This study did not provide any information about health economics, even though the intervention was brief, self-administered, and delivered via WhatsApp, which could likely be cost-effective. Another limitation is that the study did not provide information about the impact of the intervention on fathers. This was because of the cultural restrictions that make it inappropriate for fathers to access the WhatsApp discussion and communicate with other women.

Finally, exploration of Cronbach's alpha values at baseline revealed a relatively low Cronbach's alpha value for the HADS anxiety 0.55 and conduct subscale of SDQ 0.49. Although some variation is expected when measuring psychological constructs (Kline, 2013), this low alpha value could indicate that the measure was unreliable in this sample. F. B. Davis (1964) indicated that an alpha value of 0.5 is acceptable when the number of participants in a study is more than 50. However, Nunnally (1967) argued that the minimum acceptable alpha value in a preliminary research is between 0.6 and 0.5, however, he changed that value to 0.7 in Nunnally (1978) without any justification. Therefore, it was decided in this study to remove SDQ peer subscale because it showed a very low internal consistency alpha value of 0.19 which could be due to the fact that mothers of children with ASD did not understand the actual peer relationships between their children and others as interaction with peers is considered to be one of the main deficient of the disorder. It was noted that the conduct subscale in the Arabic version of the SDQ was low in sensitivity (35%) in detecting conduct problems in children, therefore, interpreting results from this subscale should be done with caution when used with an Arab population (Almaqrami & Shuwail, 2004). Despite the low alpha value of 0.49 for the conduct subscale in this study, it is comparable to the value of 0.44 reported in (Beck et al., 2004).

The Arabic version of the SDQ for children aged 4-12 was used with all participants, even though six children, three in the IG and three in the CAU, were below the age of four. The only difference between the 4-12 version and the 2-4 one is in two items. Item 22 in the 4-12 version is "*Steals from home, school or elsewhere" where it is* "*Can be spiteful to others* "in the 2-4 version. Moreover, item 18 in the 4-12 version is "*Often lies or cheats" where it is* "*Often argumentative with adults*" in the 2-4 version. The two different items are from the conduct-subscale and therefore, the result from this subscale of SDQ in this study should be interpreted with caution. It was decided to use the 4-12 version of the SDQ in this study with all participants as it is the only available version of the SDQ in Arabic, and it was beyond the scope of this thesis to translate and validate the 2-4 version. This was also considering the aim for using the SDQ with this sample to evaluate if mothers' perceptions of their children's behaviour have changed from T1 to T2 after the intervention.

The low value of alpha in some of the measures in this study (HADS anxiety, conduct subscale of SDQ) could be explained due to the fact that despite being translated and validated to many languages, these measures were originally created in the West which would be difficult to apply Western culture and values to non-Western population. However, all the measure used in this study has been successfully used in previous research.

## Implications and Future Recommendations

Future explorations in this topic area should address the following important issues

- As this was a small-scale study, it would be important in the future to replicate the study within a larger sample, especially because there is now information to inform a full power calculation.
- To conduct a study on implementation to be able to explore additional barriers to the use of the intervention in routine clinical practice within ASD organisations in KSA. Moreover, to explore the relationship between mode of delivery, intervention intensity and outcome. For example, would better outcomes be achieved if the intervention was delivered face to face, even though this would be difficult to achieve in KSA. Would the same outcome be achieved if this study was replicated without the WhatsApp therapeutic support?
- It will be important in future studies to explore the cost-effectiveness of this intervention as a greater understanding of costs and benefits of the intervention could be used to build a business case for its implementation.
- Once the results of this study have been confirmed through replication, a larger study powered for mediation and moderation would help inform clinical servicers about why the intervention leads to change in outcomes and for whom the intervention is best suited.

## Generalisability

The study was conducted in the two cities of Makkah and Jeddah which are two of the largest cities in KSA, each with diverse cultural values, therefore, it would be possible to generalize the findings to other cities within the country. However, it would be important for future research to explore the generalisability of the findings to other Middle Eastern countries.

## Conclusions

In summary, the results of this study support the efficacy of the self-help parent training with minimal therapist support delivered via WhatsApp for mothers of children with ASD. It was demonstrated that the intervention led to significant changes in mothers' reports of stress, depression, happiness, child ASD symptoms and behaviour problems. Given the lack of research in the given area of self-help parenting interventions for parents of children with ASD in KSA, the results of this study are a significant contribution literature

## Registration

This trial was registered with clinicaltrial.gov, and the study ID code is NCT02384486.

# Chapter Seven: "It was like a life raft": A Qualitative Study Exploring Participants' Experiences and Acceptability of a Psychoeducation Intervention for Mothers of Children with ASD in KSA

## Introduction

Parent training is essential to fostering and assisting parents in developing the necessary skills to manage their children's behaviour and some other aspects of their children's development (Wyatt Kaminski, Valle, Filene, & Boyle, 2008). The training becomes of special importance to parents of children with neurodevelopmental disorders (e.g., ASD or ADHD) or behavioural disorders (e.g., conduct problems), who require extra effort in managing their children's behaviours that interfere with the normal daily routine of parents and families (Kane, Wood, & Barlow, 2007; McConachie & Diggle, 2007).

Despite the importance of these interventions to parents, there is a paucity of studies evaluating the effectiveness of parenting interventions for parents of children with neurodevelopmental disorders (McConachie & Diggle, 2007; NICE, 2013). Moreover, few trials exist that have quantitatively evaluated the effectiveness of parenting interventions for parents of children with ASD (Samadi et al., 2013; Whittingham, Sofronoff, Sheffield, & Sanders, 2014). Even, fewer studies have evaluated the acceptability and experience of interventions for parents of children with ASD (Ferraioli & Harris, 2013; Grahame et al., 2015a; Tellegen & Sanders, 2014). Ferraioli and Harris (2013) and Tellegen and Sanders (2014) used quantitative methods (questionnaires) to gather information about parents' involvement and satisfaction, while Grahame et al. (2015a) used a qualitative method (focus groups) to evaluate the acceptability and participants' experiences regarding participating in an intervention that is aimed to train parents using strategies to manage their children's restricted and repetitive behaviours. Even though satisfaction questionnaires have been used to provide some indication about participants' acceptability of self-help interventions for disruptive child behaviour (O'Cathain, Thomas, Drabble, Rudolph, & Hewison, 2013) , quantitative measures of participant satisfaction do not provide in-depth feedback from participants about their experiences.

There has been a recognition over the past decade that evaluating the effectiveness of evidence-based parenting interventions should not be restricted to randomised trials, and should include findings from qualitative studies (Dixon-Woods & Fitzpatrick, 2001; Goldsmith, Bankhead, & Austoker, 2007). A systematic review by Kane et al. (2007) of qualitative studies evaluating parenting interventions for children with emotional and behavioural problems indicated a lack of qualitative studies evaluating the RCT’s of parenting interventions. Campbell et al. (2000) highlighted the ability of qualitative methods to provide detailed relevant information that may be missed by quantitative outcome measures. Qualitative methods provide an opportunity to complement quantitative findings (Lewin, Glenton, & Oxman, 2009). Although intervention acceptability is usually related to treatment outcome, this relationship is not bi-directional. Positive significant change in a variable may or may not indicate treatment acceptability (Kazdin et al., 1997). This emphasizes the necessity of supplementing the investigation of change in outcomes with explorations of participant’s qualitative input.

In light of previous research indicating that parents of children with ASD are at an increased risk for experiencing poorer well-being compared to parents of typically developing children and because of the discussion above (B. L. Baker et al., 2003; Richard P Hastings, 2003), it is of greater importance that parenting interventions be qualitatively evaluated for their effectiveness and usefulness to parents. These interventions could be then further modified to encompass parents’ various demands and concerns. To the author’s best knowledge, no study has previously evaluated the acceptability and experience of participants with a self-help psychoeducational intervention delivered through the virtual environment in KSA. Grindle, Kovshoff, Hastings, and Remington (2009) have qualitatively evaluated the experiences of parents of children with ASD after implementing an intensive home intervention based on the principles of applied behavioural analysis, which is different in nature and implementation than the proposed intervention in this thesis. This study, therefore, has three aims. First, is to explore participants’ experiences and the acceptability of the self-help psychoeducational intervention with minimal therapist support and the participants’ views on using WhatsApp as a mode of delivery. Second, is to gauge an understanding about the components of the intervention that mothers particularly liked and components that could be improved to help guide the future development of self-help parenting interventions in the management of ASD in KSA. Third, is to explore the practicality of involving therapists in delivering the intervention and whether their involvement did facilitate mothers’ involvement with the different component of the intervention. This qualitative study formed part of a larger study that comprised of a small-scale (pilot) RCT evaluating the effectiveness of a proposed psychoeducational intervention to enhance maternal functioning in mothers of children with ASD in KSA (Chapter 6). The results from that trial showed significant improvements in quantitative measures of parental well-being and child ASD symptoms and behaviours.

## Methods

### Procedure

All participants in the intervention group IG (n=32) consented at the beginning of the trial to take part in the qualitative interviews after T3 follow-up data collection. However, when contacted at that time to arrange a suitable time for the interviews, 20 mothers were willing to take part (62.5%). Ten of the mothers in the IG were not willing to take part for numerous reasons (e.g., busy with a new job, moving into a new home), and it was also the beginning of the school year in KSA. Two mothers did not respond despite several attempts to reach them, and they finally replied at the start of the qualitative study and were both unwilling to be interviewed (one was on vacation outside of the city, and the other one was grieving the loss of her father). Semi-structured telephone interviews were conducted with 20 recipients of the intervention within one month of the end of T3 data collection. Telephone interviews are used as a method of collecting qualitative data and an effective format of interviewing participants when face-to-face interviews are not feasible (Britten, 2007; Holstein & Gubrium, 2004).

The interviews took place over the telephone. Eighteen of the interviews were digitally recorded and transcribed verbatim. For the remaining two participants who refused a digital recording of the interview, efforts were made to ask them to slow down while they answered the questions so that the researcher would have the chance to write down and capture everything. It is very common in studies conducted in Arab countries and within female communities that participants do not accept the use of technology, including recorders, during interviews (Opdenakker, 2006a). The mothers were asked to answer questions as honestly as possible and in as much detail as possible. Interviewees were advised that their comments would remain confidential and identifiable data would be removed from any records. Participants' real names and all other identifiable information were removed from the data and participant's IDs given to them at the beginning of the trial study, were used to refer to them throughout this study. Interview length varied between approximately 5 and 21 minutes, with a mean interview length of approximately 8 minutes.

An examination of baseline demographic differences and outcome variables for participants who were willing to participate in the intervention versus those who were not indicated no significant difference between the two groups except for marginally elevated anxiety levels for participants who were interviewed compared to those who were not ( F [1,30]=3.20, p =0.08) . Therefore, mothers who engaged with the intervention were representative of the IG as a whole.

### Interviews

Interview data provided a deeper understanding of the experiences of mothers involved in the intervention. Using telephone interviews was a useful tool in collecting information from mothers because it allowed them to disclose a wide array of information and provide honest opinions about their involvement with the intervention. The main aims of the interviews were to elicit parents’ feelings about their experiences with the intervention and the acceptability of it. The interview schedule (Appendix 20) was developed using open-ended questions to give the participants the opportunity to explain their experiences when attending the training programme. The interview schedule covered four main areas: participants’ experiences with the training sessions; their evaluation of the therapist delivering the training; the training manual and their overall experiences participating in the study; and also how things can be improved in future research. Prompts were used throughout the interviews to enable the researcher and the respondents to engage more in the dialogue of the topics and to further explore participants’ answers.

Interviews were conducted in Arabic as it is the mother tongue language of people in KSA. The researcher is bilingual in both Arabic and English, and she also holds a bachelor’s degree in English. The second supervisor (NA) who assisted in the data analysis in this study is fluent in both Arabic and English and holds a postgraduate degree in linguistics. All the interviews were transcribed in Arabic by the researcher, while all subsequent analysis was performed in English.

### Participants

According to (Charmaz, 2006), sample size depends on the purpose of the study. It is suggested that a sample of as small as 10 participants could be sufficient in qualitative data to establish a reliable conclusion in the topic of interest (Atran, Medin, & Ross, 2005). Moreover, in their recent guidelines for qualitative research using thematic analysis, Braun and Clarke (2013) indicated that the sample size depends on the type of data collected and the size of the project, so 6 to 10 participants are recommended for small projects. Therefore, it was thought that conducting interviews with 20 mothers to assess their experiences with the intervention was sufficient in terms of the assessment of a small-scale trial. A second criterion widely used in qualitative research for assessing the suitability of a sample size is the term *data saturation* (For a definition, see Chapter 3). Data saturation was achieved in this study after 15 interviews, in which no new themes or subthemes emerged.

The interviews were conducted with 20 mothers who had received the intervention as part of the RCT. The demographic characteristics of interviewed parents are presented (Table 15). The mothers’ mean age was (M=31.55) years, with the children’s mean age (M= 62.80) months. Two mothers (10%) had another child with ASD, and 18 (90%) were married, while only two (10%) were divorced. The sample was considered to be highly educated as 13 mothers (65%) held bachelor’s degrees, four (20%) were high school graduates and only three (15%) had less than high school education. Only four mothers were employed in this sample (20%), which is slightly higher than the percentage of working mothers in KSA (15.4%).

**Table 15. Demographic characteristics of interview participants**

| Participant’s ID | Age (years) | Child’s age (months) | Another ASD child | Interview length (minutes) |
|---|---|---|---|---|
| P1 | 30 | 48 | 0 | 21.33 |
| P5 | 30 | 60 | 0 | 7.06 |
| P7 | 30 | 64 | 0 | 5.50 |
| P9 | 37 | 72 | 0 | 8.27 |
| P15 | 30 | 60 | 0 | 8.22 |
| P17 | 35 | 75 | 0 | 9.23 |
| P19 | 40 | 74 | 0 | 7.28 |
| P21 | 31 | 76 | 0 | 9.40 |
| P23 | 33 | 72 | 1 | 8.57 |
| P29 | 30 | 78 | 0 | 9.03 |
| P33 | 25 | 55 | 0 | 5.08 |
| P37 | 27 | 65 | 0 | 17.16 |
| P39 | 25 | 36 | 0 | 7.09 |
| P41 | 36 | 65 | 0 | 7.42 |
| P49 | 34 | 54 | 1 | 7.48 |
| P51 | 34 | 66 | 0 | 4.50 |

| | | | | |
|---|---|---|---|---|
| P53 | 45 | 49 | 0 | 5.59 |
| P55 | 29 | 60 | 0 | 4.20 |
| P63 | 23 | 50 | 0 | 8.50 |
| P67 | 27 | 77 | 0 | 5.28 |

## Analysis

Thematic analysis is a qualitative analysis method that is widely used in healthcare research (Fugard & Potts, 2015). This was chosen as the most appropriate approach for this study as it allowed for the analysis of inductive data (emerging directly from the data), which was considered suitable in addressing the main aims of this study. The analysis followed the six stages to thematic analysis proposed by Braun and Clarke (2006) (see Chapter 3 for more details).

By applying thematic analysis to the data collected from the interviews in this study, the researcher used an inductive analysis approach to code relevant data and identify emergent themes and subthemes. The transcripts were first read and re-read many times to become familiar with the ideas and concepts then the data underwent initial coding, wherein segments of data were labelled with codes. The coded data then were searched to identify similar codes. Subsequently, themes and subthemes emerged from the analysis. Moreover, once themes and subthemes had been established, a codebook was developed to describe each one (Appendix 21). For each theme in this study, five elements were described in the created codebook, as outlined by Boyatzis (1998) (see Chapter 3 for more detail about these elements). Each subtheme that was included in the codebook was defined in detailed and both positive and negative examples were provided.

To enhance the credibility of the data, the consistency of the themes' identification among the researcher and NA were explored. Quotes belonging to each theme were selected randomly and given to NA to identify codes using the codebook and the detailed descriptions of the themes and subthemes through discussion with the researcher. In this study, inter-rater reliability refers to the degree to which two individuals agree on the codes assigned to the qualitative data (Marques & McCall, 2005). The extent of agreement between the two coders was calculated using a percentage agreement index formula (agreements divided by agreements plus disagreements and multiplied by 100). An agreement was defined as when both ratters assigned the same codes, themes, and subthemes to the same quote. The percentage agreement between the two coders was established at 83%, indicating that the themes were consistent and reliable to a recommended standard. Boyatzis (1998) recommended that percentage agreement between the two coders above 70% demonstrates acceptable reliability. This process resulted in minor adjustments to descriptions of themes in the codebook, merging of two themes to best reflect mothers' opinions about the intervention and merging of two similar subthemes. Once the codebook had been modified to include the suggested amendments, all previously coded transcripts were reviewed to ensure they were consistent with the changes.

**Trustworthiness**

Trustworthiness in qualitative research can be achieved through ensuring credibility, dependability, and transferability (more details are provided in Chapter three) (Miles & Huberman, 1994). Credibility was ensured in this study through the utilisation of different procedures. First, the researcher spent extended periods of time reading the transcripts and engaging with the data before any analysis was conducted, which allowed for a good understanding of participants' answers. Second, negative cases (what is not considered to belong to a specific theme or subtheme) were identified when creating the codebook, which allowed the readers to get a hint of the differences between what should belong to the theme and what should not. Third, transcripts of the interviews were sent to participants for validation to ensure that the researcher did not misinterpret what had been said, a criteria named by Lincoln and Guba (2002) as *member check.* However, only six mothers were able to check the accuracy of transcription, and the remaining participants' apologised for not having the enough time and efforts to do so. Fourth, a reflexive statement about the role of the researcher in the study has been described in details (at the end of this section). Fifth, *analyst triangulation* as a method of ensuring credibility was employed in this study. The term refers to a situation in which multiple analysts review the findings of the research (Patton, 2002).The accuracy of assigning codes to data and the development of themes and subthemes has been checked by a second supervisor N A and inter-rater percentage was calculated and reported on the previous section.

Transferability in qualitative research refers to the extent to which readers are able to generalise the findings of a study to their own context (Miles & Huberman, 1994). This could only be achieved when the researcher provides sufficient information about the self (the researcher as instrument), the research context, and participant to enable the readers to decide how the findings may or may not apply to them. (Lincoln & Guba, 1986); Morrow (2005) noted that transferability is more the responsibility of the person wanting to transfer the findings to another context or apply it to different population than it is that of the researcher of the original study. They argued that as long as the original researchers present sufficient descriptive data to allow for comparison, then they have addressed the problem of applicability. To ensure transferability in this study, the researcher provided a detailed account of the participants' characteristics, and information about the researcher herself (reflective statement below) to allow readers to decide on whether the findings could be generalised to their participants, if they have similar characteristics for example. However, it should be noted that despite all the measures of ensuring objectivity in qualitative research that have been suggested by many scholars above, qualitative research is still subjective in the sense that the researchers' life experiences and surrounding situations do have an enormous impact on the way she or / he views the world, and this in no sense is considered to be a weakness as it is of an essence in qualitative research (Lincoln & Guba, 1985; Patton, 2002).

On the other hand, dependability refers to the extent that a given study could be replicated to attain similar results (equal to reliability in quantitative research) (Patton, 2002). This could be achieved by keeping records of data collection and analysis processes. In the present study, the researcher provided in detail the procedures of data collection and analysis (an example of a coded transcript is provided in Appendix 22).

**Reflexive statement.** Reflexivity involves being "attentive to and conscious of the cultural, political, social, linguistic, and ideological origins of one's own perspective and voice as well as the perspective and voices of those one interviews and those to whom one reports" (Patton, 2002, p. 65). A H is a female postgraduate student who has been through undergraduate education in KSA followed by postgraduate education (Master) in Canada. She is married and a mother of two children. Prior to starting her PhD, she was working as an academic lecturer at a University in KSA for two years, and part of her job involved supervising graduate students during their training at autism organisations. She described herself to the participants at the beginning of the study (before the start of the trial) before introducing the study and its requirements so that mothers would be familiar with the researcher. This is considered an essential part of research with vulnerable population in KSA, and the researcher was requested by the organisations to do so as though it would be more acceptable by participants to be involved in studies where they are not distanced from researchers. As a mother, there were some moments during the interviews in which the researcher did sympathise with mothers and the stressful parenting situation they were going through, however, she stayed objective, so as to not let any of these feelings impact her interpretation of the data, by taking extensive notes about the interviews, including impressions of the interview (e.g., “P1 and I engaged well in the interview”) and other points of interest (e.g., “I was feeling bad about her not being able to find child support early after the diagnosis of her child with ASD”). Rennie (2004) argued that taking extensive notes during the process of interviews could allow researchers to distance themselves from the interviewee and look more objectively at the data later on. It should be noted that being a female researcher in KSA interviewing women could have impacted the study in a positive way because mothers might have felt more comfortable discussing their experiences with a female, rather than a male researcher, resulting in more insights and descriptions of their involvement. This is necessary to highlight, specifically in a country such as KSA in which people are considered to be conservative in dealing with the other sex (Alqahtani & Salmon, 2008). Finally, an important factor that could have impacted the researcher during the interview is her training as a qualitative researcher in Canada and familiarity with interview skills such as appropriate language, active listening, and paying attention to a participant’s tone of voice to gain more insight about the data.

## Findings

Six overarching themes and six subthemes were identified in the data through thematic analysis (Table 16). Each theme and subtheme is described below, alongside illustrative participant’s quotes.

**Table 16. Main themes and subthemes**

| Themes | Subthemes (If Available) |
|---|---|
| Broadening mothers' knowledge of how to deal with themselves and their children with ASD | • Understanding their stress and mood<br>• Perceptive about their children's behaviour |
| Satisfaction with therapist interaction and the length of the intervention (duration) | |
| Differing opinions on the mode of delivering the intervention | |
| Perception of the intervention manual as a document written for their use | |
| Apprehension of the advantage of group therapy | • Realisation of loneliness and healing their way<br>• Facilitating the giving and receiving of support |
| Suggestions for intervention improvement | • More behavioural strategies<br>• Continuous training for mothers |

### Broadening mothers' knowledge of how to deal with themselves and their children with ASD

This theme captured how mothers felt taking part in an intervention that helped them to expand their understanding of themselves and their children with ASD. Two subthemes emerged from this main theme.

**Understanding their stress and mood.** Mothers believed that the intervention had helped them in understanding and analysing their reactions to different stressful situations and recognizing that being angry or depressed is not always about the child with ASD but can be related to their own states of well-being. P49 explained:

> As a mother of two children with ASD, you can imagine the pressure I am going through in my life including financial pressure which is causing a big psychological stress for me and my husband that sometimes, for example, I shout at my kids when they laugh loudly where it is not about their laugh more than me thinking how are we going to pay the rent at the end of this year. (P49)

Some mothers highlighted the demanding tasks of child care as contributing to their poor mental health, as P33 mentioned that " having a child with ASD, you can never have a vacation as it is a demanding 24-7 job so you never have peace in your mind". However, all mothers indicated that they felt that the intervention helped them in managing their anxiety, mood, and stressful situations. "It taught me how to hold my nerves" (P5). According to mothers, the techniques that the intervention provided for them to manage their stress and mood have widened the possibilities for them when handling difficult situations. P1 described how taking part in the training has helped her deal with different emotions:

> To be honest with you, sometimes I have fearful moments when I couldn't deal with my kid and I feel sorry for him, so I became nervous myself, and as a result of that all, is when I'm getting nervous he became nervous too and sad, so this programme has trained me to use some tips like how not to be anxious and how to control myself, to be calm, to take a breath and to ask for the nearest possible help in order to keep calm once I face any problem while dealing with my kid. I personally did benefit from everything on it. (P1)

All mothers mentioned being pleased with the stress and mood sessions in this training, an area that is, according to them, rarely addressed in training programmes for ASD where the focus is mainly on the children. P15 explained that "this training is one of its kind and different than anything else I attended previously because it helped me to change and think about my own well-being, I am more tolerant to stress now".

**Perceptive about their children's behaviour.** Mothers confided that the training increased their awareness about different ASD symptoms, behaviours, behavioural management techniques, and their roles in modifying their children's behaviours; before the majority of them felt that they were lacking information about the nature of ASD and its manifestation in different children with ASD. "We needed that training badly as there are a lot of things that we can't understand about dealing with our kids and their behaviours" (P1). Another mother expressed that "I did not know previously that ASD was behind my kid not being able to play and interact with other kids" (P9). Moreover, some mothers indicated that they thought that ASD is different than autism in that "the word spectrum was confusing so you think it is less severe than autism while now I am glad I know what is ASD is all about" (P15).

Some mothers explained how not having knowledge about the different techniques for managing behaviour problems for their children with ASD has impacted the way they interacted with their children and how the intervention helped them to realize what should or should not be done in certain situations. P37 explained:

> I used to distract my kid's attention from something when he really insists on having it and I could not give it to him, I thought that distraction is a wrong thing to do with my child as ASD children get distracted easily so I stopped using that, however, after the session on behaviours It was a surprise for me to know that this is a behavioural strategy actually so I started using it again and confidently. (P37)

Another mother confided that after taking the session on behavioural strategies, "I realized the value of my role as a mother in fostering my child progress". This is because some mothers mentioned they thought that using behaviour management techniques was only for teachers and therapists, not for parents.

The majority of the mothers mentioned that they applied the behavioural strategies they learned from the training, and two mothers provided examples about how they successfully used these strategies with their children. P63 described:

> My child daily sleeping routine used to be that his father would put him in his car seat every day evening and buckle him very well before they start going around the city many many times until he fall asleep. That made me very sad. I applied a technique I learned in one session called desensitization, so I started by locking the door really well every evening which used to be unlocked previously and hugging him because he likes to be hugged then I took him to his bed room without putting him on bed just turning off the lights, for sure the first day he panicked and went to the door to find it locked so he returned to his bedroom crying but the second day he went to his room straight after he saw me turning the lights off but then I had to wait for him until he fall asleep on the floor then I carry him to bed, after three days of doing so he actually started going straight to bed just after I turn the lights off. I feel like a one million riyal winner. (P63)

Another mother provided an example of how using pictures has helped her prevent her child's tantrums (her child was non-verbal);  she used to offer him pictures of different types of food before his meal time so that he could choose what he prefers for his meal "rather than throwing himself on the floor every time I offer him food" (P67).

### Satisfaction with Therapists Interaction and the Length of the Intervention (Duration)

This theme captured mothers experience with the therapists and the mothers' varying opinions on the length of the training they received.  All mothers expressed their contentment with their communication with the therapists who delivered the intervention. They indicated that the therapists helped them in understanding each session's content and answering their questions clearly. P1 exemplified that her therapist "was very enthusiastic and she was understanding, she was very occupied and immersed with us and she explained to us everything in the manual that we asked about, it was a magnificent interaction between her and the mothers". Another mother described the style of the therapist as "very nice and convincing, there is no going around things as she was straightforward and clear" (P7).  One of the therapists was a mother of a child with ASD herself, and mothers felt that they established a sense of community with her during the training and they valued her attribution to the sessions. One mother expressed that the therapist “ was very interactive and positive about ASD and I think that this is because of her experience that she could feel our sufferings and needs, and I am also encouraged because If she was able to handle the situation then we can also do” (P5).

Mothers had differing points of views regarding the length of the training. Although the majority of the mothers were satisfied with the length of the training, five mothers argued that the training was short and that it should have lasted for many months and or more than one session should be provided per week. One mother who felt happy with the length of the training stated that “it was neither short nor long as you might know people are busy and if you make it longer many of them could have dropped” (P19). Another mother said that “I am one hundred percent satisfied with it being five sessions that was never long but interesting” (P17).

Mothers who thought that the training was short indicated that they were desperate to know more about ASD and they sensed their need for more information. “I wish it never ended and I think that if more than one session were provided each week then we could have learned more and more (P55). Another one stated that “it was very good but short like a shot” (P15). One mother suggested that providing a day long training session in which the therapist is available to answer questions “is a good idea so whenever you have a concern or question you can just join the session and ask the therapist” (P67).

### Differing Opinions on the Mode of Delivering the Intervention

This theme depicted the contradicting views towards delivering the training using the WhatsApp application. Although the majority of the mothers felt that attending sessions through WhatsApp was very useful for various reasons, seven mothers discussed their mixed feelings about it and how they preferred face-to-face sessions. However, six of those seven mothers stated very clearly that it would have been impossible for them to attend if it was face-to-face training due to several limitations. All mothers indicated that they were familiar with using WhatsApp but not for training as P17 stated “I use it all the time for rubbish stuff like exchanging things and social chats and never thought that it could be used for training purposes, that’s interesting”.

Mothers who felt that WhatsApp was a useful means for delivering the intervention believed that the use of this application has made it easier for them to attend from the comfort of their own homes and without worrying about “who will take care of your children or the house" (P9). They also referred to difficulties in transportation and how WhatsApp has relieved them from arranging transportation and finding someone "who will drop and pick you from training" (P5). Moreover, mothers discussed how providing the sessions through WhatsApp made it easier for them to continue participating in the intervention. According to P17, this is because "you can go back to the transcripts of the sessions anytime you like, so if you happened to miss a session then you can still find all the information Stored there, nothing will be gone". Another mother explained that WhatsApp has helped her to access information from the session she missed because she "did not have access to the Internet being in the emergency room with him [her son]" (P37). One mother explained that the use of technology in this training has "brought people closer so that you can meet other mums who work full time and miss mothers' meeting all the time" (P15).

Conversely, mothers who preferred face-to-face sessions recognised that even though they prefer to interact directly with mothers and the therapists during the training, they realised that would put more strain on them due to difficulties in arranging transportation and childcare. According to P51 who indicated that she preferred the face-to-face session "you kind of have this sense of connectedness with others that you will not have in the virtual thing but in term of practicality forget about it because of transportation, you know the issue". Another mother explained that she preferred the face-to-face as "I am not a technology person and prefer to do everything by hand even writing my letters which does not make sense these days but it is just me" (P49).

### Perception of the Intervention Manual as a Document Written for their Use

This theme displays mothers' feelings and thoughts about the manual, its uniqueness, usefulness, and clarity. All mothers explained how they felt about the manual as a document that helped them find answers to their questions and focused on them and their well-being. P55 described her satisfaction with the topics and examples included in the manual and how it matched what they were looking for, "it is like someone was reading your head and knew exactly what you need". According to the mothers, most of the books and manuals they have dealt with previously have focused mainly on the child with ASD, and they had never come across any written document that paid attention to their needs. This is because, according to what P5 stated "nobody cares about us they think it is only the children". P1 described the manual:

> It was magnificent, and everything was just clear enough, however the only thing that surprised me that it wasn't only concerned about the kids but about the mothers as well and the whole family in general, actually I liked it very much. I have not seen any negative thing at all.

Mothers described their thoughts about the manual and its utility. The majority of the mothers mentioned considering it as a reference. They reflected in the information provided on the manual as being very useful and handy to them. According to P7, "this manual is better than most books I read before so I am keeping it as a reference and I always find myself going back to it when I do not know how to deal with my kid's behaviour". Another mother asserted "that I keep reading it all the time specifically the stress and mood section where I refer to the techniques every time I am not in a good mood" (P15).

Mothers also conveyed to the researcher their contentment with the manual's clarity in terms of the simplicity of the language used to express the information, the representative examples, and the attractive graphics. All mothers felt that the language that was used to present the different ideas throughout the manual was simple. According to P49 "any mother can understand it even if she is not highly educated". Another mother stated that "you do not need to have a degree to understand what's there" P9. The majority of the mothers reflected on how valuable and useful the examples provided in the manual were and how much the examples assisted them in understanding the different ideas. P 33 explained that:

> I lived a different experience with this manual as it helped me to understand myself through the different examples provided in the stress and mood Chapters, I mean we all think that we know what stress is all about, however, reading the examples about stressful situations made me realize that most of my previous behaviours were related to real stress specifically that these examples were real life ones, I mean you can just feel it". P33

Another mother described the manual as "a state of art that is clear, short, and to the point" (p53). Moreover, some mothers also referred to the pictures displayed beside some terms as beneficial in aiding them to comprehend the meaning of it. P73 demonstrated that "the picture of the mother putting the oxygen mask for herself before her child in the mood section has helped me to understand what mood is and I also realized that I will never be able to help my child if I did not help myself first".

### Apprehension of the Advantage of Group Therapy

This theme explicates the mothers' reflections and opinions on the benefits of group meetings throughout the training. Two subthemes emerged from this main theme.

**Realization of loneliness and healing their way.** This subtheme reflected the mothers' positive expressions of the benefits of group meetings, which helped them to realize that they were lonely before the training and how it provided them with a sense of relief and hope. Mothers expressed that joining a group of other mothers of children with ASD helped them recognise that they were isolated and lonely before joining the group which according to them, contributed to their poor well-being. P9 described the following

> When I joined the group and heard the sufferings of other mothers through their stories about their kids I realized that I was wrong thinking that I was the only one in this world who suffered with a child with ASD which affected my mood badly at that time. (P19)

Another mother explained how joining the group "has given me a sense of community that I was missing before as if I were living alone on my own planet" (P19).

Mothers also believed that joining group training assisted them in healing from their negative feelings associated with having children with ASD, and it provided them with hope. P33 explained "I was helpless, depressed, and lonely and these group meetings gave me a sense of relief and hope as I now know that other people are suffering but surviving". The phrase "you gave us hope" was stated by many mothers during the interviews referring to the researcher as giving mothers hope by arranging group training for them (P1, P5, P9, P19, and P33). Another mother believed that group training helped in changing her negative feelings and views towards children with ASD as she said "It [group training] changed the way I look at things and I feel that there is hope so I am not the negative person anymore with my child and I want to be like other positive mums, I feel so much better" (P21). P15 described that group training was like "a life raft" for her as she explained:

> I was drowning on all of these things happening around me from having a child with ASD starting with the diagnosis, organisations, social pressure etc and I did not know what to do or where to go so even if my child was having training at the organisation I was totally lost until I joined this

> programme, it was like a life draft for me as I now know that it is ok to feel sad or angry as other mothers are also feeling the same but that’s does not mean that I should gave up on everything else in life so I have more hope to move forward now and I am relieved. (p15)

**Facilitating the giving and receiving of support.** This subtheme describes the mothers’ positive opinions on the value of group training in enhancing the information they shared about their children with ASD with other mothers. Mothers felt that joining a group discussion has enabled them to exchange ideas and examples about applying different behavioural strategies. P23 expressed that

> It was really beneficial for me to read about each mother’s successful achievement with her child, it was good so that you can learn new skills from others’ experiences or you can also learn how to use a behavioural technique to manage your child’s annoying behaviour for example you can see how different mothers were able to control their children’s tantrums then you can end up with having different ways to deal with it. (P23)

Mothers also indicated that group discussion with other mothers during the sessions inspired them to ask many questions. According to P7 “you feel that everyone is interested and responding so why not ask as many questions as I like”. Many mothers recognised how the questions that were asked by other mothers during group sessions was an opportunity for them to learn new information, which held their interests and motivated them to join the sessions. According to P15 “people were asking lots of good questions that sometimes never come to your mind like one mother who asked about where you can submit the paperwork applying for government financial support for your child, believe me you do not want to miss these meetings”.

It should be noted that two mothers mentioned that they felt they were “losing hope” after joining the group as they anticipated the other mothers would help them find a cure for ASD (P41, P39), however, the researcher pointed out for them that this intervention was never aimed to provide a cure for autism. They asserted to the researcher that they were aware of the intervention aims but nevertheless decided to join searching for a cure that “might be hidden somewhere” (P41).

## Suggestions for Intervention Improvement

This main theme captured the suggestions mothers thought would help to improve the design and delivery of information in future interventions for mothers of children with ASD. Two subthemes emerged from this theme.

**More behavioural strategies.** This subtheme reflected the mothers' demands for more intensive and in depth training to help them manage their children's behaviour problems. Many mothers indicated that despite the focus in one of the sessions about behavioural strategies, "that was never enough to meet our needs" (P7). P 49 demonstrated the following

> As mothers of children with ASD, we suffer a lot from behavioural problems and as you might know each child is different and therefore we need a focused behavioural training for us as non professionals that can help us somehow to manage the majority of our children's behaviours. (P.49)

Moreover, some mothers expressed that they felt it would be more useful to provide example models for behavioural strategies to help them better understand how to apply these strategies in the actual world. P9 explained that "it could have been very useful if the therapist in this session displayed the strategies with children from the organisation so as it give us better idea about how to use them". Another mother suggested that "including example models of behavioural strategies on a CD that is attached to the manual and discussing these examples with the therapist during the session could have been more helpful and productive" (P37).

**Continuous training for mothers.** This subtheme revealed the mothers' call for constant need for training to help them meet the challenging and changing demands of raising their children with ASD. P 19 explained that:

> As mothers of children with ASD at the early intervention stage I can assure you that we are totally lost but very smart so we just need a non-stop training that can help us with our difficult task as you might know we face endless troubles raising children with ASD and therefore we need endless training. (P19)

Moreover, some mothers indicated that it is not always an easy and straightforward task for them to read and understand books or brochures about ASD that are given to them by professionals. Therefore, they suggested that they felt continuous training lead by therapists or professionals would be useful because they would have the chance to ask questions and seek further explanations for anything they need. P 21 described that

> it is very hard sometimes for poor mothers to understand anything about ASD from books as they are very complicated, even if they are trained by therapists they will sometimes complain about not being able to understand things, which is ok at least the therapist can simplify things for them so I wish we have very intensive and constant training that can assist us along the way as we face new challenges every day as our children grow older. (P21)

This subtheme also captured the mothers’ thoughts and requests of training that focus mainly on them and their well-being. According to them, they felt that continuous training on stress reduction techniques and mood management could help them deal with their own difficulties. According to P15:

> I think there is a need for constant training that focus on maternal well-being, this is something that is unfortunately being dismissed in most training groups while in reality the problem lies mainly within the mother and not the child as she goes through tough times where her psychological peace is totally damaged but when she gets involved with such good training focusing on her issues and her mental wellness then I can assure you that she will survive, we desperately need training of that kind and on an ongoing basis. (P15).

## Discussion

The importance of supplementing the quantitative assessment of intervention outcomes with a qualitative analysis of the intervention experiences in health care research has been stressed (Campbell et al., 2000). Therefore, this study had the aim of complementing the results of the main quantitative trial presented in the previous Chapter with a qualitative exploration of participants’ experiences of the intervention and its mode of delivery. Second, this qualitative study also had an aim of exploring which components of the intervention participants valued and which they did not to help inform the design of future interventions. Finally, it had the aim of exploring how useful supplementing self-help manuals with therapist help was.

Overall, the participants felt satisfied with the intervention with the majority of them describing their positive experiences with the intervention’s duration, manual, mode of delivery, interaction with therapists, and collaborating with other mothers during the sessions. Six overarching themes have emerged from the data, including broadening mothers' knowledge of how to deal with themselves and their children with ASD, satisfaction with therapists interaction and the length of the intervention (duration), differing opinions on the mode of delivering the intervention, perception of the intervention manual as a document written for their use, apprehension of the advantage of group therapy, and suggestions for intervention improvement.

One of the main findings in this study was that mothers felt that the intervention helped them in broadening their knowledge and being more perceptive about their own well-being as well as their children's behaviours. According to the mothers, they were distressed and under continuous pressure when raising their children with ASD prior to the intervention. This was validated in previous qualitative studies that indicated that parents in several parts of the world including India, Australia, and Ireland face emotional and psychological distress raising their children with ASD (Divan et al., 2012; D. E. Gray, 2002, 2003). In addition, studies indicated that children's behaviour caused distress in parents who require strategies to manage them, a finding that was also reported by mothers in this study (Aylaz et al., 2012; Dillenburger et al., 2010; Safe, Joosten, & Molineux, 2012).

Another main theme within the findings in this study was participants' satisfaction with their interaction with therapists. They also acknowledged how their therapists' knowledge and experiences have impacted them positively by encouraging them to attend the sessions and participate in the discussion. This finding is in line with the results of Koerting et al. (2013) review that highlighted the importance of a positive experience with therapists and how it helped in retaining participants in interventions for parents of children with behaviour problems, including ADHD. In addition, the finding is also in concordance with Connell, Sanders, and Markie-Dadds (1997) who designed an intervention to use with families of oppositional children. The parents in this study used a self-directed manual to learn behaviour strategies and they also participated in weekly telephone consultations with therapists about their children's oppositional behaviours. The results of their study indicated more positive outcomes for the families that received phone consultations than those who did not (Connell et al., 1997). The majority of the participants in this study reported feeling satisfied with the duration and length of the intervention, while few of them thought it should have lasted longer. According to Polster, Dangel, and Rasp (1987), training for parents of children with ASD becomes challenging for trainers and parents when a training programme lasts longer than eight weeks. This is because, according to

Prinz and Sanders (2007), due to time pressure on parents which might lead to increased mental health problems.

Despite having differing opinions about using WhatsApp as a mode of delivering the intervention, participants acknowledged the flexibility of the intervention in terms of their ability to attend the sessions at home, which they stated was convenient because they did not have to worry about transportation and childcare. The finding about mothers' positive experiences with WhatsApp supports previous findings from Owens et al. (2002), who suggested that the development of self-help interventions was initiated to overcome practical barriers to accessing parenting interventions such as transportation and childcare issues (Owens et al., 2002). In addition, Moran, Ghate, Van Der Merwe, and bureau (2004) emphasized an intervention design that can accommodate different modes of delivery and therefore an ability to respond flexibly to parental needs. Kolko, Parrish, and Wilson (1985) found that inadequate transportation was a main reason for missed appointments at a child behaviour management clinic. Moreover, in a systematic review of qualitative studies evaluating parenting interventions for parents of children with behavioural problems by Koerting et al. (2013), situational barriers ( e.g., transportation) were found to prevent parents from attending and continuing on with parenting interventions.

This study found that participants perceived the usefulness of the intervention manual in terms of simplicity of language, clarity of examples, and its focus on their well-being. They indicated that the manual was better than many books and other sources of information they had previously encountered. This is in concordance with Kisely, Ong, and Takyar (2003), who argued that accessible information provided on the Internet may be questionable in terms of its quality and usefulness, therefore, self-help manuals from reputable sources are recommended as information available online for parents was found misleading for parents of children with ADHD for example.

Participants in this study recognized the importance of group therapy as they felt that being part of a group helped them to heal and feel less distressed and also to realise that they were feeling lonely before joining the intervention. The finding was also depicted by Bristol (1984), who found that a support network that provides emotional and practical guidance, can act as a buffer against stress, anxiety, and depression for some parents of children with autism. Moreover, Mandell and Salzer (2007) found participation in a self-help group for parents of children with ASD resulted in feeling less distressed and reduced isolation. Kane et al. (2007) in their results of a systematic reviews of qualitative studies evaluating parental experiences of parental programmes for parents of children with behavioural and emotional problems, indicated that parents felt less isolated, a greater sense of support from other parents, and more confident in managing their children's behaviour.

Mothers in this study also emphasised the usefulness of the intervention regarding meeting with other mothers and sharing their experiences with them, a finding that was in concordance with findings from other studies that evaluated trials' experiences with parents of children with ASD (Ferraioli & Harris, 2013; Grahame et al., 2015a). However, Koerting et al. (2013) found that parents felt being outsiders in group sessions, and they disliked group sessions. This could be due to cultural differences between parents included in the groups and differences in the severity of the child problems, which is not the case in this study.

The final finding of this study was participants' suggestions for intervention improvement. Mothers felt that adding more sessions on behavioural training could help in providing them with more behavioural strategies that would address their children's problems. Some mothers suggested using behaviour modelling to help them better understand the strategy. This was also highlighted in Hupp and Reitman (2000); (Ingersoll & Dvortcsak, 2006), who found behavioural modelling to be an important component in effective training programs. This is because modelling allows the therapist to transfer information visually to the participant in person or through video (Hupp & Reitman, 2000).

### Limitations

The findings of this qualitative study should be considered in light of some limitations. Firstly, although attempts were made to interview all mothers who received the intervention as part of their involvement in the trial, mothers who refused to take part or those who could not be contacted, were not interviewed. Since mothers may be more likely to drop out if they had unacceptable views of the intervention or experienced situational barriers, the analysis may be missing their vital viewpoints. Nonetheless, an analysis was conducted that compared mothers who did and did not take part in qualitative interviews, and it showed no significant differences between the two groups neither in demographics nor in outcome measures at T1 or T2. Secondly, for practicality, interviews had to be conducted over the telephone. It has been argued that face to face interviews allow for a more natural conversation and visual cues, which may encourage participants to elaborate further and provide more detailed data (Gubrium & Holstein, 2002). However, in a review by Miller (1991) comparing telephone and in-person interviews, it was reported that although people tend to give short responses over the telephone, they disclose as much personal information and express the same views as when given different interview methods. Moreover, the results of telephone interviews are comparable to face-to-face ones (Holt, 2010; Opdenakker, 2006b). Third, the mothers did not talk as much as expected but there was no obvious relationship between the length of the interviews and the quality of information provided. It should also be noted that mothers of children with ASD are vulnerable to high levels of stress, which could have prevented them for spending too much time talking about their experiences with the intervention. Finally, although mothers were asked to answer questions as honestly as possible, it is conceivable that mothers' awareness of the interviewer's role as the main researcher in this trial could have led to response bias. The use of an independent interviewer may have overcome this, but was not possible in this study.

### Suggestions for Future Research

- Greater effort is needed to qualitatively explore the experiences of participants with interventions in addition to quantitative analysis.
- More interventions should include elements that focus on maternal well-being in interventions for mothers of children with ASD.
- Interventions that aim to reduce maternal stress should add more behavioural elements that could help mothers better understand and deal with their children's behaviours.
- It is recommended, based on the findings of this study, to use group sessions when delivering the interventions since this could add to the benefits of group support.
- Integration of technology to help in delivering interventions to parents of children with ASD. This should help to retain parents in the intervention and remove barriers to engagement.
- Interventions should include material that can aid parents during interventions and provide a reliable source of information for them.

Supplementing self-help materials with therapists support is recommended for parents of children with ASD as it might help in answering their concerns and questions.

# Chapter Eight: General (Overall) Discussion

## Overview

Assessing the needs of parents of children with ASD and developing interventions to help enhance their well-being and their interactions with their children is recommended (NICE, 2013). The main aims of this thesis were; I) to understand the impact of having a child with ASD on parental functioning both internationally and for Saudi Arabian mothers, and II) to then develop and evaluate both quantitatively and qualitatively the effectiveness of a brief psychoeducation intervention for mothers of children with ASD in KSA. To address thesis aims, initially, a systematic literature review was undertaken investigating the impact of having children with ASD on parental life. Next, a qualitative pilot study exploring the unmet needs of mothers of children with ASD in KSA was conducted. Following that, a meta-analysis of trials examining parental interventions for parents of children with ASD was presented. This thesis presents findings from a small-scale (pilot) RCT of a self-help psychoeducation intervention with minimal therapist support that was delivered through WhatsApp for mothers of children with ASD in KSA. Finally, given the relative novelty of self-help interventions for mothers of children with ASD in KSA, this thesis aimed to qualitatively examine parents' views and acceptability of the intervention of interest. This general discussion Chapter begins by giving a summary of the main findings of the different studies reported in this thesis, before moving on to a discussion of the methodological strengths and challenges. Finally, directions for future research are presented. The clinical implications of the findings presented herein are also discussed. A detailed discussion of the findings and limitations of each of the five studies conducted for this thesis have been described in detail within their respective Chapters  and, therefore, will not be repeated in this overall discussion. Only overarching methodological considerations and findings across the different studies or outstanding issues within some studies in this thesis will be discussed in this Chapter.

## Summary of Findings

Parents of children with ASD experience numerous challenges when caring for their children due to the pervasive nature of the disorder and its impact on family life. The aim of the systematic review in this thesis (Chapter 2), was to systematically investigate the literature related to the impact of ASD on parental life. A systematic search was conducted covering the period of January, 1994–January, 2014 in Pub Med, PSYC INFO, and Web of Knowledge, augmented by a search of key autism journals by hand. The systematic search generated a total of 6,792 citations for initial screening. Two investigators assessed the relevance of the studies identified using predefined selection criteria. Fifty three articles were included in the final review. A narrative approach was used to describe the findings. Six major ways in which ASD impacts parental life areas were identified: i) response to ASD, ii) parental well-being, iii) relationships, iv) positive perception, v) financial problems, and iv) future worries. The importance of social support to parental adjustment was also highlighted in the findings; parents surrounded by strong social support were found to have less negative perceptions of their children with ASD than those who did not. Few studies examined quality of life for parents of children with ASD and its relationship to other parental constructs. The studies were mostly cross-sectionals, with very few qualitative studies being found, and the majority of the studies focused on exploring parental well-being. Differences in findings between mothers and fathers were identified; mothers were found in most of the studies to suffer from poorer well-being than fathers. In conclusion, this review supported the majority of the literature, demonstrating that parents of ASD children suffer high levels of stress and depression. It was recommended that the effect of socioeconomic status, culture, and child's age on parental functioning needs to be explored further. Because one of the main aims of this thesis was to develop and evaluate the effectiveness of a proposed intervention for mothers of children with ASD in KSA, and as no studies were identified in the international literature to address the needs of mothers of children with ASD in KSA, this led to the development of the second study in this thesis.

The second study (Chapter 3) was a qualitative pilot study to explore the unmet needs and experiences of mothers of children with ASD in KSA. This study employed a one-to-one semi-structured telephone interviews with eight Saudi mothers raising children with autism. Questions from a researcher-developed interview guide elicited responses about challenges and unmet needs while asking questions about the mother's daily living experiences with their children. Results indicated that the majority of the respondents felt that they had little to no knowledge of ASD prior to and after the child's diagnosis. Mothers expressed a range of issues and needs that were categorised into six major themes: (a) mothers' identification of their lack of information about their children with ASD, (b) mother's perceptions about their mental and physical well-being, (c) mothers' recognition of their constant challenges raising their children with ASD, (d) suggestions to increase public awareness about ASD, (e) mothers' identification of their training needs, and (f) mothers' perceptions of their children's educational needs. Important findings within the subthemes suggested that mothers felt that they needed training and that using WhatsApp as a mode of delivering parental interventions would be useful in reducing barriers to attendance and engagement. In addition, mothers complained about the long waiting lists for ASD organisations and the burden associated with waiting because they had to find alternative solutions that sometimes included sending their children to surrounding countries. Moreover, mothers insisted that cultural issues, such as a lack of transportation, the stigma associated with having a child with ASD, and a lack of fathers involvement added to their burden. It was recommended that professionals and academics in KSA should take into consideration the unmet needs of mothers of children with ASD when designing interventions and services for ASD to ensure these programmes and services are tailored to the cultural context and needs of those mothers. Because of the gap in the literature of sufficient Saudi studies evaluating parenting interventions for parents for children with ASD in KSA, this led to the need for the third study in this thesis that evaluated the effectiveness of parenting interventions for parents of children with ASD. This was helpful in identifying the weakness and gaps in current available interventions and addressing them in the main trial in this thesis.

The third study in this thesis was a meta-analysis (Chapter 4) conducted to quantitatively evaluate the effectiveness of parenting interventions on parental functioning for parents of children with ASD. Interventions of interest were any parental intervention that delivered strategies to parents to enhance their parental functioning whether these strategies targeted elements in the parents themselves (e.g., stress reduction techniques) or in the parents' relationships with their children (e.g., behavioural management techniques). The following databases were searched: Pub Med, PSYCINFO, and Web of Knowledge from 1994 until 1st August 2015. The literature search identified 11 eligible studies. Included studies were controlled studies and pre- to post- studies. Analyses revealed that parenting interventions are significantly effective in enhancing parental well-being (stress, depression, and anxiety) and parenting practices, and in increasing parents' sense of competence (SOC). However, the significance of treatment effects was not upheld during sensitivity analyses removing non-randomised studies of depression and anxiety. Effect sizes ranged from large (SOC in pre- and post- studies), medium (stress and parenting styles and SOC in controlled studies), and small (depression and anxiety). The included studies displayed an overall high quality using the MMAT tool but an unclear risk of bias using the

Cochrane collaboration risk of bias tools for RCTs and NRS mostly due to studies lack of sufficient information reported.

Chapter 6 presented the fourth study in the thesis, a small-scale RCT piloting the effectiveness of a self-help psychoeducation intervention for mothers of children with autism spectrum disorder ASD in KSA with minimal therapists' support delivered via WhatsApp. Sixty two mothers (*23-52 years*) of young children (*26-78 months*) were recruited to a multi-site RCT of the psychoeducation intervention. The intervention consisted of a brief five session self-directed Psychoeducation manual that was supplemented by one face-to-face therapy session (60 minutes) and four virtual therapy session (30 minutes each). Parenting stress was the primary outcome, with secondary outcomes focusing on maternal well-being, child behaviour problems and ASD symptoms. Data were collected at baseline T1, post intervention T2 and 8 week follow-up T3. A one way ANCOVA was used at T2 and T3, with T1 scores entered as a covariate. Intervention related improvements were found at T2 maternal stress and maternal depression, which was significantly reduced while anxiety was not reduced; these results were maintained at T3. Changes in child behaviour problems were limited mainly to improvements in hyperactivity at T2 and maintained at T3. There was also a significant reduction in maternal report of ASD symptoms at T2, which was maintained at T3. An examination of clinical significant change for both stress and depression suggested that although the intervention led to considerable statistical improvement in both stress and mood, clinical significance change was minimal and limited to HADS depression. This indicated that the brief self-directed intervention with virtual therapy support was beneficial but may need to be augmented with other forms of support for mothers of children with ASD.

There is increasing recognition of the need to include qualitative studies as part of intervention research. This led to the fifth study (Chapter 7), a qualitative study with a sample of 20 mothers from the IG arm of the trial. Semi-structured telephone interviews were conducted to investigate participants' views and acceptability of the self-help intervention. Six overarching themes were identified from the interviews: I) broadening mothers' knowledge of how to deal with themselves and their children with ASD, II) satisfaction with therapists interaction and the length of the intervention (duration), III) differing opinions on the mode of delivering the intervention, IV) perception of the intervention manual as a document written for their use, V) apprehension of the advantage of group therapy and VI) suggestions for intervention improvement. The majority of the mothers were satisfied with using WhatsApp for delivering the sessions, with only few mothers preferring the traditional face-to-face meetings. Moreover, mothers felt that the intervention helped them change the way they perceive their stress and how they appraise stressful situations. Overall, mothers had positive views of the intervention. Many mothers were actively engaged in the intervention and discussed the new parenting skills and behaviours that they had acquired.

## Methodological Strengths

The key methodological strengths of this thesis are explored and discussed in this section.

**Using a mixed-method approach to data collection.** Both qualitative and quantitative approaches to collecting data were used separately in different studies within this thesis. Mixed-method approaches have become increasingly useful in mental health research, for quantitative methods alone may not adequately explore people's experiences and views (Fossey, Harvey, McDermott, & Davidson, 2002; Rice & Ezzy, 1999). This thesis employed a series of qualitative and quantitative studies, and the main trial used what is referred to as an *embedded mixed-method* approach by (Creswell & Clark, 2011). The purpose of using the embedded design with the main trial in this thesis was to collect different types of data (quantitative and qualitative) to answer different questions, allowing further qualitative exploration of participants' acceptability and views on the trial.

The need to include qualitative methods when assessing intervention outcomes has been stressed (Campbell et al., 2000). Qualitative studies can provide information that helps capture information about treatment outcomes that are missed by psychometric outcome data (Campbell et al., 2000). The qualitative interviews that followed the trial, for examples, revealed positive parental views of the mode of intervention delivery, which could explain the high level of participant adherence to the intervention. To the best of the author's knowledge, few published studies have yet explored parental views of the acceptability of self-help parenting interventions for parents of children with ASD.

**Participants' compliance.** One of the strengths within this thesis was participants' compliance to the studies. This was evident for example in the first pilot study (Chapter 3), where all participants who were invited to take part consented to participate and adhered to the time arranged for the interviews, with few changes being made to the interviews' timing to facilitate participants' wishes. Moreover, there was no attrition in the main trial (Chapter 6), which was at odds with the literature in parenting interventions in which a moderate dropout rate is expected as not all participants usually can be retained (C. N. Baker, Arnold, & Meagher, 2011). However, this could be due to two reasons. First, participants might have been motivated and recognised the importance of the intervention as parents of children with ASD in KSA have very limited access to support due to high demands and a shortage of services. Second, the mode of delivery for the intervention via WhatsApp could have contributed to participants' compliance as it lessened the burden usually associated with dropout in parental interventions (e.g., transportation, childcare) (C. N. Baker et al., 2011). The majority of the participants in the trial (N=20) participated in the qualitative study, which explored participants' perceptions and views on the intervention (Chapter 7). The reaming (N = 10) participants did not take part was due to their inability to find suitable times (e.g., new job commitments), but there was no evidence that a lack of engagement in the intervention was related to a lack of motivation or interest, and those who participated did not differ from those who did not participate based on key outcome or demographic variables.

**Adhering to international guidelines for conducting and reporting studies.** Another strength is the adherence of different studies within this thesis to scientific guidelines and checklists for conducting the studies and reporting their results. First, the *Preferred Reporting Items for Systematic Reviews and Meta-Analyses* (PRISMA) by Moher, Liberati, Tetzlaff, Altman, and The (2009) has guided the planning, conduct, and reporting of the systematic review (Chapter 2) and meta-analysis (Chapter 4). Second, study eligibility criteria have been reported in accordance with the PICOS principles for reporting systematic reviews and meta-analyses by (Petticrew & Roberts, 2008); Population, Intervention, Comparison, Outcomes and Study designs. Third, the main trial study (Chapter 6) followed the CONSORT guidelines for reporting RCTs (Schulz et al., 2010). Finally, both qualitative studies in this thesis (Chapter 3) and (Chapter 7) followed the Braun and Clarke (2006) model for analysing qualitative research.

**Using theoretical models related to parenting children with ASD.** The use of three different models; the *Double ABCX Model* by (McCubbin & Patterson, 1983); the *Transactional Model of Stress* by (Lazarus & Folkman, 1984); and the *Social Learning Theory* by (Bandura, 1973), informed and enriched the development of the content of the Psychoeducation intervention used in the main trial (further details were given in Chapter 6). In addition, findings from the qualitative study (Chapter 7) indicated that participants felt that the intervention had helped them better understand and recognize their stress and mood as they became more aware of situations that cause them distress and also more aware of the impact of their disturbed well-being when appraising different life events, including their children's behaviours (*The Transactional Model of Stress* and factor cC in the *Double ABCX Model*). In addition, they thought that using the intervention ,manual has provided them with clear and beneficial information about ASD that were not available to them elsewhere as they were looking for resources to help them address their concerns (factor bB in the *Double ABCX Model).*

**Cultural context of participants was taken into consideration.** The cultural context of participants as citizens in KSA was taken into consideration when designing the different studies within this thesis. First, a pilot qualitative study was conducted (Chapter 3) to explore the unmet needs of mothers of children of ASD in KSA as it was not possible to generalize the needs of mothers of children with ASD from Western countries to those in KSA due to language, religious, and cultural differences. For example, according to (Bilgin & Kucuk, 2010a), mothers in Turkey were considered to be the main caregiver for children with ASD and fathers' roles were mainly connected to providing financial support for the family. It is not known yet how useful research from Western countries is in helping gain a better understanding of parenting of children with ASD in KSA; and whether transcultural issues modify the applicability of Western research findings to the Arabic culture. Second, the intervention (Chapter 6) was designed to be delivered via WhatsApp which was recommended by mothers of children with ASD. The mothers clearly indicated (Chapter 3) that it would not be possible for them to find someone to drive them to group face-to-face sessions. This is due to the fact that women do not drive in KSA, and there is very limited public transportation for women. Third, the fact that the researcher is herself a woman interviewing women in both trials (Chapter 3 and 7) was an important cultural factor; it could have been impossible for a male researcher to interview women in these studies due to cultural restrictions that prohibit free communication between males and females in private and religious restrictions that do not allow women to talk freely to men.

**Investigation of intervention effects for multiple outcomes**. A large focus of this thesis has been the evaluation of the effectiveness of the proposed psychoeducation intervention for a number of maternal well-being outcomes. Consequently, the main trial (Chapter 6) included outcome measures incorporating measurements of parenting stress, depression, anxiety, and happiness, and also a measurement of child symptoms and behaviours. A parental well-being outcome, parenting stress, was chosen as the primary outcome for the main trial. Stress is a key component of parental well-being and has important implications for child well-being, particularly in relation to dealing with difficult behaviour. Even though it was never the aim of the trial in this thesis to reduce ASD symptoms or difficult behaviour in children with ASD, the inclusion of a measurement for these constructs was to assess any change in maternal perception of child ASD symptoms and behaviours pre- to post- intervention. The results of the trial did indicate a significant change in maternal perception of their children's ASD symptoms and behaviours.

**Inclusion of a long-term follow-up assessment.** The main trial (Chapter 6) also included a long-term follow-up assessment at approximately eight weeks post-intervention. The inclusion of longer-term follow-ups is important to ensure that treatment effects are maintained. When assessing intervention effects with parents of children with ASD, long term outcomes may be especially important given evidence of continued improvement from immediate post-intervention to follow-up (Tonge et al., 2006).

### Methodological Challenges

**Lack of father involvement.** The lack of father involvement in parenting interventions for parents of children with ASD was evident throughout the different studies in this thesis. First, it was found in the systematic review (Chapter 2) that fathers participation in research concerning their children with ASD was very minimal. Second, the studies included in the meta-analysis (Chapter 4) also highlighted that the majority of participants in interventions for parents of children with ASD were mothers. Third, fathers were intentionally not included in the studies conducted in KSA (Chapter 3, 6, and 7) because it was not practical and their inclusion in the intervention could have prevented mothers from participating due to cultural restrictions. However, it was thought that excluding fathers from the studies conducted in KSA within this thesis was less problematic than if these studies were conducted in Western countries; as fathers are not the caregivers of children with ASD in KSA and their roles in care giving could be described as very limited. In conclusion, it seems that the limited involvement of fathers in research concerning parents of children with ASD is a universal issue across many cultures and continents as fathers are often dramatically underrepresented in parenting programmes (Flippin & Crais, 2011).

**Self-report measures.** The majority of parental outcomes across the different studies in this thesis (Chapter 2, 4, and 6) utilised self-reported measures. An independent observation of child behaviour could not be included in the outcome measures of the main trial (Chapter 6) for practicality and feasibility reasons. It is possible that parent-reported outcome measures are prone to expectancy bias following their involvement and effort in parenting interventions (Sonuga-Barke et al., 2013). Although, it is also possible that parental reporting of behaviour reflects real changes in the child's behaviour at home that are not apparent in artificial time limited observations. It is thought that successfully reducing mothers' perceptions of their levels of stress and depression in the main trial is beneficial considering their high levels of stress at T1 and limited access to services. The differences between outcomes in self-reported measures and objective ones are as yet unclear in the area of parenting children with ASD, however, in other neurodevelopmental disorders such as ADHD, for example, the impact of interventions on ADHD self-reported symptoms is considerably different than those obtained from objective measures (Daley et al., 2014). The inclusion of more objective and appropriate measures will be an important consideration for future trials.

**Small sample size.** Limited sample size is an issue highlighted across the different studies in this thesis. It was also acknowledged by other studies conducted with parents of children with ASD (Drew et al., 2002b; Hastings & Brown, 2002). It was possible that this could be due to the demanding tasks of raising children with ASD which could have prevented their parents from participating in research. The high levels of stress and depression among mothers of children with ASD makes them a vulnerable group. It may also be that this vulnerability will limit a mother's ability or opportunity to engage in research studies. The lack of good moderators of outcome for interventions in this area makes it impossible to understand how maternal factors may impact on engagements with research and intervention. However, it is plausible that mothers of children with ASD who were already very stressed might consider the additional burden of engaging with a research project to be just another potential source of stress. The main issue concerning sample size in RCTs is the power to detect significance in the outcomes. Luckily, this was not an issue with the trial in this thesis, and the results showed significant outcomes with large to very large effect sizes despite the modest sample size recruited.

**Confirmation of ASD assessment for children.** Even though the children of the mothers who were involved in the different studies within this thesis (Chapter 3, 6, and 7) received a double diagnosis (one from a psychiatrist or a clinical psychologist and another from the organisation), it was neither acceptable nor practical to confirm their diagnosis. The researcher is confident in the accuracy of the diagnosis for most of the cases; there was a 92 % concordance between diagnosis and scoring above the cut off on the Indian Scale for Autism Assessment. Five cases were removed from the main trial analysis due to maternal ratings of behaviour that fell below the required cut off score on the *Indian Scale for Assessment of Autism.* While this discrepancy may be due to poor understand or literacy on behalf of the mother, or changes in context of behaviour in the child, it was thought to be prudent to remove these cases from the trial.

**Burden within families.** Even though this thesis evaluated the effectiveness of the intervention both quantitatively and qualitatively, the additional impact of participating in the intervention on the mother was beyond the scope of the evaluation (Chapter 6 and 7). For example, participating in the intervention may have limited mothers' engagement in other social events such as visiting neighbours for example, or could have impacted negatively on martial relationships; although these issues were not spontaneously noted by participants during the qualitative interviews. While participation in all interventions for mothers come with an opportunity cost that is not possible to estimate, the high levels of stress and depression among the sample, and the many barriers when seeking help in KSA, make it highly likely that the cost of taking part in the intervention would outweigh the opportunity cost.

**Limited validated measures in Arabic.** Another issue that faced the researcher in the main trial was identifying Arabic validated measures that were designed and validated for Arab populations. The majority of the measures used in the trial, with the exception of the *Arabic Scale of Happiness*, were developed originally in Western, English speaking countries and then translated into Arabic. Even though they were validated with an Arab population, there is still the risk of using translated measures that were originally designed for people with different sets of cultural values, (see Chapter 6) (Sousa & Rojjanasrirat, 2011).

**Limited long-term follow-up assessment.** The lack of longitudinal studies of parenting interventions for parents of children with ASD was highlighted within the different studies in this thesis (Chapter 2 and 4). Very little is known about the impact of ASD on parents as children grow and develop. For example, as children with ASD develop, the nature of their disorders and their demands could also change. The key issue for interventions is not only to provide psychoeducation and strategies to modify behaviour at the time the intervention is delivered, but also to help parents understand how they can modify those strategies as their children develop.

**Data Collection.** The widespread recruitment approach in this study also meant that data collection was reliant on parents completing and returning information sheets and consent forms (Chapter 3, 5, and 7). This approach could have led to sample bias, since motivated and organised parents may be more likely to consent. Similarly, parents experiencing significant levels of a low-mood may be less likely to participate. However baseline levels of parental well-being were lower in this trial sample which suggests that parents with higher levels of stress and depression were not excluded from the study.

**Adjustments for multiple testing**. There is a debate regarding the appropriate use of adjustments for analyses with multiple outcome measures (Cabin & Mitchell, 2000). The analyses of outcomes in the main trial study did not apply adjustments for multiple outcomes (e.g., Bonferroni adjustments). This was considered justified for two reasons. Firstly, since the investigations were somewhat exploratory, the author did not want to increase the risk of a Type II error, particularly given the small sample size. In addition, it was unclear how the constructs assessed in the outcome measures were related, and to what extent they should be treated as related constructs. For example, even mothers reporting of ASD symptoms and behaviours at T1 and T2 could be considered independent if child behaviour or intervention effects varied between settings. However, even if an adjustment had been applied, the majority of the results would not have changed as the significance levels for most of the outcomes were far below ($p< 0.05$). Despite this, there is a possibility that the significant effects reported in the trial were the result of multiple testing.

## Clinical Implications

The findings presented in this thesis could have several implications for clinical practice and service providers.

First, it was evident from the different studies within this thesis that parents of children with ASD suffer from high levels of stress and poor well-being. The findings from the systematic review (Chapter 2) showed that stress and depression were the most prominent constructs affecting parental well-being as highlighted in the literature. It also showed that mothers of children with ASD suffer from higher levels of stress compared to fathers. Moreover, the initial assessment of participants in the trial at T1 (Chapter 6) revealed that stress scores for all the participants in that sample were in the clinical range. Therefore, clinicians should consider maternal stress and signpost mothers who display high levels of stress to counselling services or stress reduction interventions.

Second, clinicians and service providers should be aware that there is growing evidence that psychoeducation interventions are beneficial for parents of children with ASD suffering from high levels of stress (Karst & Van Hecke, 2012; Samadi et al., 2013). The promising outcomes reported in this thesis (Chapter 6 and 6) should be of interest to service providers seeking to improve parental outcomes in families of children with ASD. Based upon our current findings from the meta-analysis (Chapter 4), that parental interventions that focused on educating parents about ASD and provided strategies for them to enhance their well-being, were successfully significant in reducing parental levels of stress and depression and enhancing their parental functioning. In addition, the results from the trial (Chapter 6) reported promising outcomes in term of significant mother-reported enhanced well-being and decrease child behaviour problems. Therefore, specialist ASD services (ASD organisations in the case of KSA) may want to consider using Psychoeducation parenting interventions as a preliminary intervention for parents on waiting lists. It would also be recommended for clinicians and service providers to provide parental interventions that focus mainly on parental well-being.

Third, the qualitative exploration in this thesis of maternal needs for mothers of children with ASD in KSA (Chapter 3) and mothers’ experiences and acceptability of the proposed intervention (Chapter 7) revealed some clinically relevant findings. All the mothers who were interviewed in both studies expressed their desire to learn more about their children’s disorder through more intensive training, and mothers at the second qualitative study (Chapter 7) indicated their need for a more focused intervention that addressed their well-being. It would be beneficial for ASD service providers to provide parents of children with ASD with more on-going training opportunities that address their differing needs as their children develop. Mothers (Chapter 7) also felt that the information in the intervention manual was useful to them in contrast to all the other books and sources of information about ASD in KSA, most of which is written for professionals. It may, therefore, be important for clinicians and service providers to be able to signpost parents to sources of information if parents request it.

## Direction for Future Research

- Studies should focus on encouraging and actively involving fathers of children with ASD to participate in parenting interventions. However, researchers conducting studies in KSA should take gender barriers into considerations when fathers are to be involved in parenting interventions regarding children with ASD. A suggestion would be, for example, to assess the needs of fathers and design separate interventions for them. This raises several potential challenges; it would require a male workforce skilled and able to deliver a father focused intervention, and it is unclear if there are such male therapists available.  It is also unclear whether fathers of children with ASD in KSA would access a father specific intervention, given their cultural views about their roles in childrearing. Consideration would need to be given to overcoming important barriers to engagement to ensure fathers would participate if an intervention was offered.
- It would be advisable for future studies, where possible, to include objective measures or independent assessments when evaluating intervention outcomes to avoid relying solely on self-reported measures. However the lack of reliable and valid objective measures and the cost implications associated with collecting additional independent assessments are both additional considerations. Using other informants within the family may be the most realistic way to achieve this aim
- Long-term follow-up assessments of the outcomes is recommended in future studies evaluating parenting interventions for parents of children with ASD. This would allow researchers to assess the maintenance of desired outcomes over longer periods of time which could demonstrate the stability of intervention related effects as well as allow for sleeper effects to emerge.
- Intervention studies of parents of children with ASD should aim to recruit more participants and include larger sample sizes to be able to accurately evaluate significance and have the power to accurately detect intervention related change. Studies with large sample sizes would allow researchers to assess mediators and moderators of outcomes that could be helpful when designing future interventions. In assessing moderators of an intervention that aims to reduce depression in parents of children with ASD, for example, the researchers might discover that

gender was a moderator variable in which mothers were less affected by the intervention than fathers, so their depression scores were higher than fathers. Based on that example, researchers could design parenting interventions that would address the specific needs of mothers by providing them with different intervention materials than fathers or condensed sessions for example.

- Including stress reduction techniques and providing positive ways and examples to appraise stress in training programmes for mothers of children with ASD would be advisable. The results of this intervention have demonstrated the value of stress reduction strategies but more intensive methods may be required.
- It is recommended that Arab researchers develop and validate measures of parental well-being that can suitably address the cultural and social aspects of parents living in Arabic speaking countries. Although the steps necessary to translate and validate Western measures into Arabic are considerable, the lack of valid and culturally appropriate measures will limit future research in this area.
- It is suggested that future studies evaluating the effectiveness of parental interventions for parents of children with ASD should take into account the financial cost of implementing such interventions and whether using different modes of delivery could help in increasing or reducing that cost. A health economic evaluation of future studies will help to illuminate this issue and guide policy makers in KSA on the costs and potential future cost savings of providing additional support for mothers of children with ASD.

## General Conclusion

Collectively, these studies have provided evidence for the effectiveness of parenting interventions when they included components of psychoeducation training. The meta-analysis presented in this thesis provided evidence that parenting interventions that included elements in their training to enhance parental knowledge of ASD and their children’s behaviour were effective for improving parental well-being and parenting practices in parents of children with ASD. Furthermore, the main trial indicated that self-help psychoeducation intervention with minimal therapist support delivered via WhatsApp was successful for enhancing well-being in a sample of mothers of children with ASD in KSA and in reducing their rating of ASD symptoms and behavioural problems. Parenting interventions delivered via the virtual medium have the potential to overcome barriers that often prevent attendance or adherence at parenting programmes conducted within ASD organisations. Large effect sizes favouring the intervention arm were evident for reduced stress, depression, child behaviour problems and ASD symptoms, and increasing happiness. In addition, qualitative interviews revealed participants' positive views of the intervention. Parents viewed the intervention as an important, convenient and highly accessible recommended form of treatment. All the interviewed mothers felt that the intervention should be routinely offered when parents access ASD organisations for their children. The results of the pilot qualitative study in this thesis suggested there might be merit in addressing mothers�given needs, time and transportation constraints, and lack of support when designing an intervention so as to increase the acceptability and adherence to the intervention. Overall, this thesis provides evidence that self-help psychoeducation interventions with minimal therapist support that are delivered via the virtual environment may have a place in routine care and should pave the way for larger clinical trials of parental interventions for mothers of children with ASD in KSA

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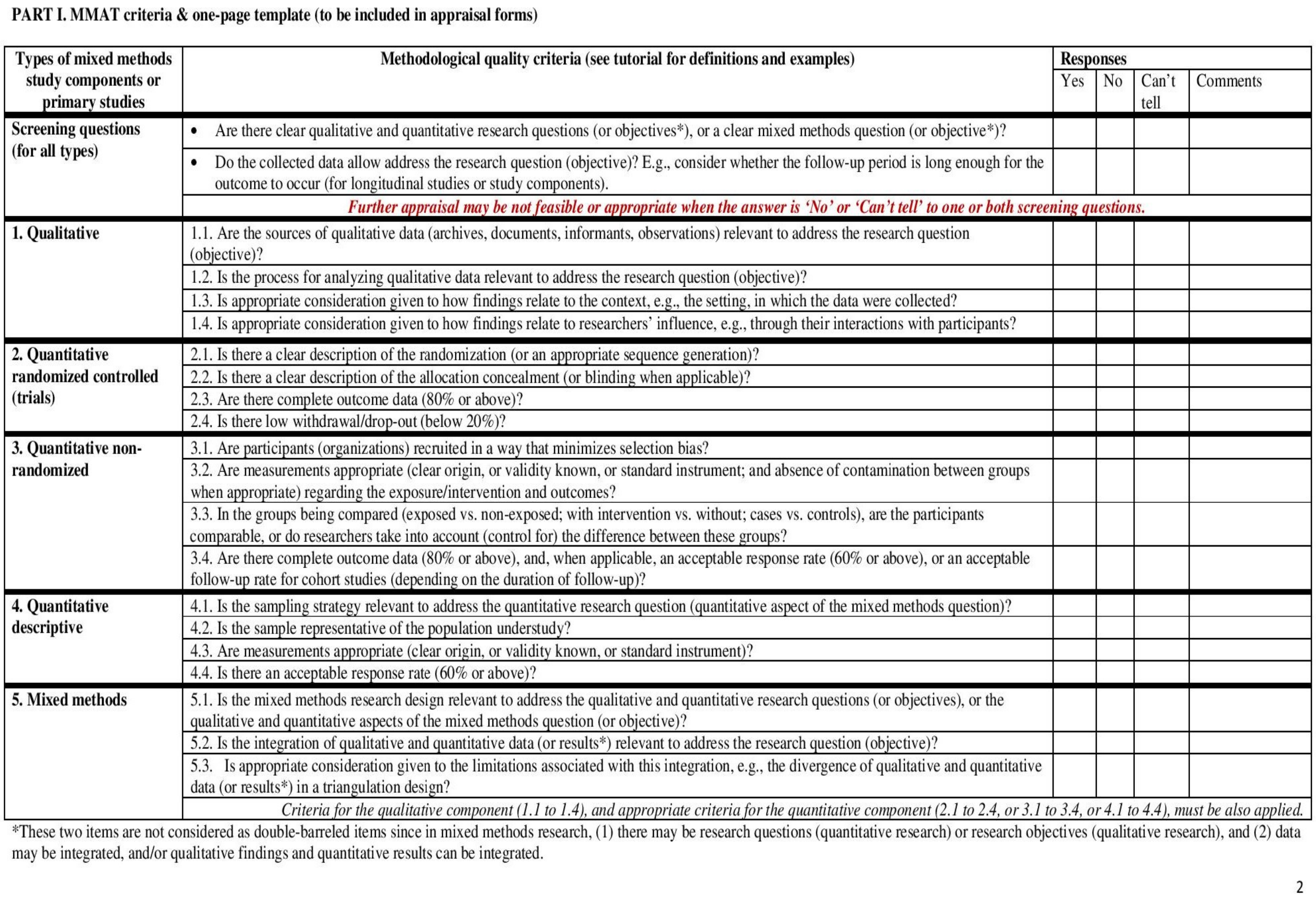
Zigmond, A. S., & Snaith, R. P. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica, 67*(6), 361-370. doi:10.1111/j.1600-0447.1983.tb09716.x

## Appendix 1. Excluded studies with reasons (Chapter 2)

| Study (Reference) | Reasons for exclusion |
|---|---|
| (Benson, 2006a; Freedman, Kalb, Zablotsky, & Stuart, 2012; Giallo, Wood, Jellett, & Porter, 2013; Gill & Liamputtong, 2009, 2011; Hall & Graff, 2010; Harper, Dyches, Harper, Roper, & South, 2013; Hill-Chapman, Herzog, & Maduro, 2013; Hock, Timm, & Ramisch, 2012; Hodgetts, Nicholas, & Zwaigenbaum, 2013; Kayfitz, Gragg, & Orr, 2010; Khanna et al., 2011; Michael D. Kogan et al., 2008; Ludlow, Skelly, & Rohleder, 2012; Lyons, Leon, Phelps, & Dunleavy, 2010; Matthews, Booth, Taylor, & Martin, 2011; Myers, Mackintosh, & Goin-Kochel, 2009; Phelps, McCammon, Wuensch, & Golden, 2009; Quintero & McIntyre, 2010; Ryan & Cole, 2009; Sayyed Ali Samadi, McConkey, & Kelly, 2012; Seymour, Wood, Giallo, & Jellett, 2013; Shu, 2009; Tehee, Honan, & Hevey, 2009; Twoy, Connolly, & Novak, 2007; Vidyasagar & Koshy, 2010; Walsh, Mulder, & Tudor, 2013; Woodgate, Ateah, & Secco, 2008; Zablotsky, Bradshaw, & Stuart, 2013) | No confirmed diagnosis of ASD |
| (Apicella et al., 2013; Beversdorf et al., 2005; Bitsika & Sharpley, 2000; Dolev, Oppenheim, Koren-Karie, & Yirmiya, 2009; Ingersoll & Hambrick, 2011; Ivey, 2004; N. L. Johnson & Simpson, 2013; O'Brien, 2007; Patterson & Smith, 2011; Rocque, 2010; Samios, Pakenham, & Sofronoff, 2008; Whitaker, 2002) | Did not explore the impact of ASD on parental life |

| | |
|---|---|
| (Boyd, 2002; Langan, 2011; Norton & Drew, 1994) | A review, not a study |
| (Cadman et al., 2012) | Included parents of adolescents (age 14-24)- Included children with different neurodevelopmental disorder (ADHD) |
| (Corman, 2009) | Children average age 14 years |
| (Benjak, 2011) | Children mean age 15 years |
| (Farrugia, 2009) | Included children and adults with ASD |
| (D. E. Gray, 1997) | Most participants were adolescents |
| (Lambrechts, Van Leeuwen, Boonen, Maes, & Noens, 2011) | Parents of children younger than 8 excluded |
| (Luong, Yoder, & Canham, 2009) | Mean age not available to all children |
| (M, Sweeney, & Doody, 2013) | Children mean age 13 years |
| (McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013) | Children mean age 13 years |
| (Rao & Beidel, 2009) | Children under 8 were not included |
| (Jungbauer & Meye, 2008) | Not in English |
| (Mahani, Rostami, & Nejad, 2013) | Different neurodevelopmental disorders |

## Appendix 2. Mixed Methods Appraisal Tool (Chapter 2 & 4)



**PART I. MMAT criteria & one-page template (to be included in appraisal forms)**

| **Types of mixed methods study components or primary studies** | **Methodological quality criteria (see tutorial for definitions and examples)** | **Responses** | | | |
|---|---|---|---|---|---|
| | | Yes | No | Can't tell | Comments |
| **Screening questions (for all types)** | • Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)? | | | | |
| | • Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components). | | | | |
| | ***Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.*** | | | | |
| **1. Qualitative** | 1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)? | | | | |
| | 1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)? | | | | |
| | 1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected? | | | | |
| | 1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants? | | | | |
| **2. Quantitative randomized controlled (trials)** | 2.1. Is there a clear description of the randomization (or an appropriate sequence generation)? | | | | |
| | 2.2. Is there a clear description of the allocation concealment (or blinding when applicable)? | | | | |
| | 2.3. Are there complete outcome data (80% or above)? | | | | |
| | 2.4. Is there low withdrawal/drop-out (below 20%)? | | | | |
| **3. Quantitative non-randomized** | 3.1. Are participants (organizations) recruited in a way that minimizes selection bias? | | | | |
| | 3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes? | | | | |
| | 3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups? | | | | |
| | 3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)? | | | | |
| **4. Quantitative descriptive** | 4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)? | | | | |
| | 4.2. Is the sample representative of the population understudy? | | | | |
| | 4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)? | | | | |
| | 4.4. Is there an acceptable response rate (60% or above)? | | | | |
| **5. Mixed methods** | 5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)? | | | | |
| | 5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)? | | | | |
| | 5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design? | | | | |
| | *Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.* | | | | |

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

## Appendix 3. Quality scores for Included Studies (Chapter 2)

| Study ID | scoring | note |
|---|---|---|
| Allik 2006, Al-Mansour 2013, Baker-Ericzen 2005, Benson 2009, Bishop 2007, Carter 2009, Davis 2008, Ekas 2009, Epstein 2008, Faso 2013, Gau 2012, Hall 2011, Hastings 2003, Hastings 2005, Hoffman 2008, Lickenbrock 2011, Meltzer 2011, Mori 2009, Pakenham 2005, Rivard 2014, Sivberg 2002, Wang 2013, Wisessathorn 2013 | 100% | Satisfied all criteria |
| Altiere 2009 a, Huang 2013, Osborne 2009 (study1), Osborne 2009 (study2) | 75% | Unavailable response rate |
| Baeza Velasco 2013, Estes 2013, Kaniel 2011, Simon-Tov 2011 | 75% | Not clear selection method |
| Altiere 2009 b ,Belgin 2010, Divan 2012, Kuhaneck 2010, McCabe 2010 | 75% | not clear how findings relate to researchers' influence on findings |
| Bundy 2009 | 75% | not clear how findings relate to context- Low response rate- no clear integration of qualitative and quantitative data and the limitation associated with that integration |
| Dardas 2013, Dunn 2001, Ekas 2011, | 75% | Low response rate |

| | | |
|---|---|---|
| Phetrasuwan 2009 | | |
| Hoffman 2009, Lee 2009 a, Lee 2009 b, Maltzer 2008 | 75% | Selection bias |
| Kapp 2011 | 75% | not clear how findings relate to researchers' influence on findings- no clear integration of qualitative and quantitative data-Low response rate |
| Lin 2008, Safe 2012 | 75% | not clear how findings relate to context |
| Wang 2012 | 75% | Sample not representative of the population |
| Meirsschaut 2010 | 50% | not clear how findings relate to context and researchers' influence on findings was not clear-recruitment did not minimise selection bias- no validation information for all measures used- no clear integration of qualitative and quantitative data and the limitation associated with that integration |
| Aylaz 2012 | 50% | not clear how findings relate to context and researchers' influence on findings was not clear |
| Cidav 2012 | 25% | No clear description of outcome measures-unclear selection method |

## Appendix 4. Interview Schedule (Chapter 3)

**The researcher will start the interview by saying**: The recording will now begin and I am pressing the on button. Are you still happy to do this interview? (**Participant will be given the chance to respond)**. I will stop recording immediately if you asked me to do so .
Please note that if you said something and then changed your mind then I will erase it from the recording at your request.

**Opening statement**

I am interested in finding out more about your experiences of having a child with autism. I have a number of questions to use as a guide to help you think about your unmet needs and issues parenting your child with ASD.

Q1: Tell me about yourself? (Age, Education, marital status, employment, number of children)

Q2: Could you explain to me your experience of having a child with autism

Prompts:

- How has having a child with autism affected your…
    - Family relationships, siblings, extended family?
    - Social/community involvement?
    - Working life?
    - Self-perceptions?

Q3: If I ask you to describe your child day. What would you say?

Prompts:

- Difficult behaviours
- Adaptive behaviours
- Communication

Q4: Tell me more about your experience of the available services to mothers of children following the diagnosis of ASD?

Prompts:

- What did you hope to receive at that point?
- What kind of support do you expect you could offer to your child at home?
- How do you see your child’s future in the light of the available services?

Q5: What types of services/support that you would find most useful? (Emotional support, day care services, educational interventions, etc.)?

Q6: What are barriers that interfere with you obtaining services (e.g., Childcare, not aware of services, transportation, difficulty acknowledging need for help, etc.)?

Closing question

- How was the experience for you talking to me today?
- Is there anything else that you think is important that we haven’t talked about?

**Thank you for your time.**

**End of interview.**

## Appendix 5. Ethics Approval Letters from The University of Nottingham and KAU (Chapter 3)

The University of Nottingham

Direct line/e-mail
+44 (0) 115 8232561
Louise.Sabir@nottingham.ac.uk

**Faculty of Medicine and Health Sciences**

Research Ethics Committee
Division of Respiratory Medicine
D Floor, South Block
Queen's Medical Centre
Nottingham University Hospitals
Nottingham
NG7 2UH

27th November 2013

Alyaa Hemid
PhD Student
c/o Professor David Daley
Division of Psychiatry and Applied Psychology
School of Medicine
Institute of Mental Health
Triumph Road
Nottingham
NG7 2TU

Dear Alyaa

**Ethics Reference No:** OVSA14112013 SoM Psychiat & App – please always quote.
**Study Title**: Exploring unmet needs of mothers of children with Autism Spectrum Disorder (ASD) in Saudi Arabia.
**Academic Supervisor in Charge:** Professor David Daley, Division of Psychiatry and Applied Psychiatry, School of Medicine.
**Student Investigator** Alyaa Hemdi, PhD Student, Division of Psychiatry & Applied Psychiatry, School of Medicine
**Duration of Study:** 10/12/2013-30/2/2014 3mths **No of Subjects:** 8

Thank you for your recent application which was considered by the Committee at its meeting on 14th November 2013 and the following documents were received:

1. UoN FMHS Med Sch Research Ethics Application form dated 23/7/2013.
2. Mother's needs: Study Proposal, version 2, 27/11/2013.
3. Mother's needs: Information letter v2. 27/11/2013
4. Mother's needs: Appendix A, Interview Schedule, v1.2, 28/10/2013.
5. Mother's needs: Consent form, Final V2. 27/11/2013
6. Letter of approval from Prof Ammar Amin, Supervisor General of the Joint Supervision Program, Postgraduate Studies & Academic Research, King Abdulaziz University, Kingdom of Saudi Arabia dated 18/11/2013

These have been reviewed and are satisfactory and the study is approved.

A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are sought for each overseas project in accordance with all local laws, and that the host organisation involved also gives their permission where applicable.

Approval is given on the understanding that the Conditions of Approval set out below are followed.

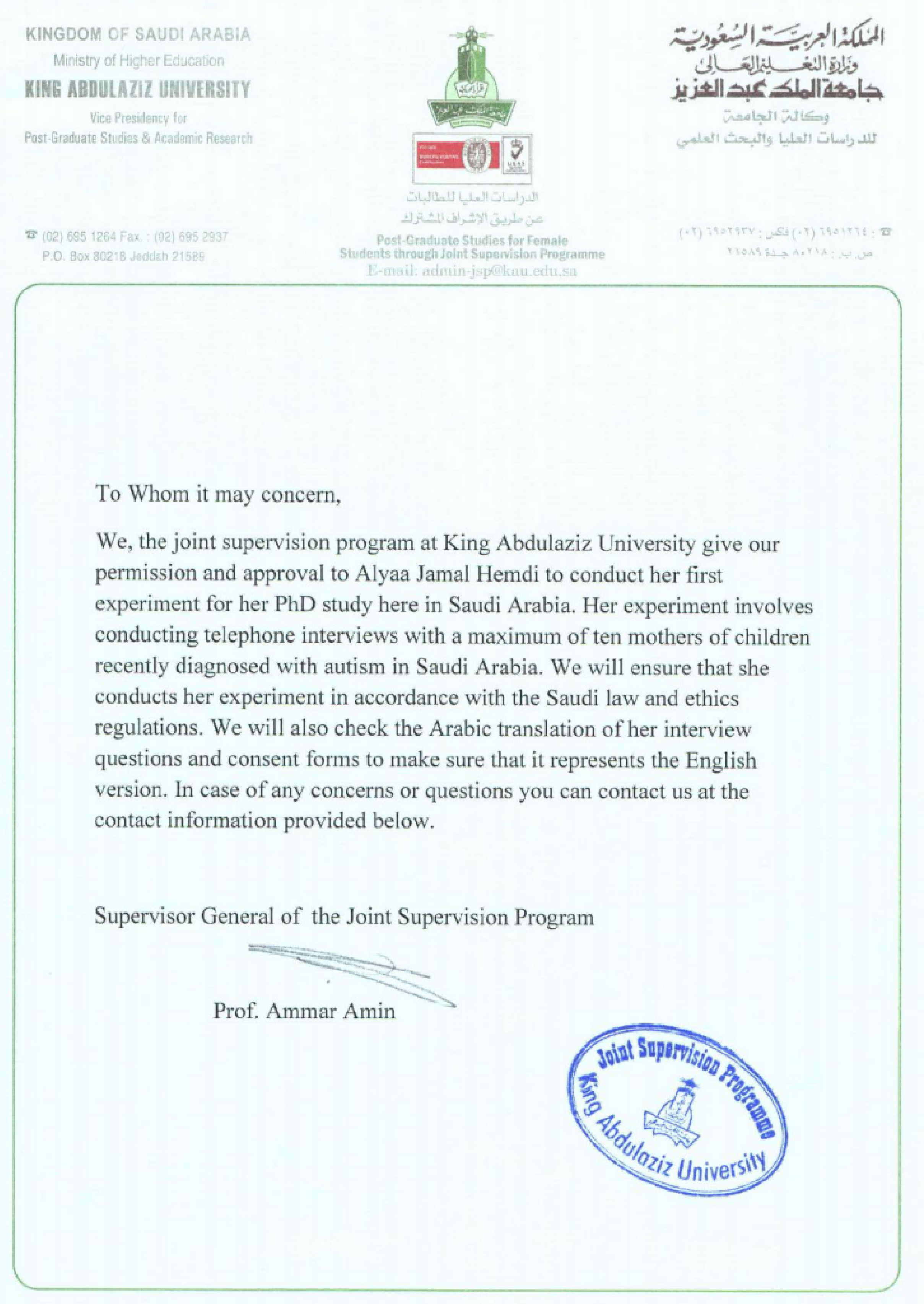
1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).
2. You must notify the Chair of any serious or unexpected event.

3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

**Dr Clodagh Dugdale**
**Chair, Nottingham University Medical School Research Ethics Committee**



KINGDOM OF SAUDI ARABIA
Ministry of Higher Education
**KING ABDULAZIZ UNIVERSITY**
Vice Presidency for
Post-Graduate Studies & Academic Research

☎ (02) 695 1264 Fax : (02) 695 2937
P.O. Box 80218 Jeddah 21589

الدراسات العليا للطالبات
عن طريق الإشراف المشترك
Post-Graduate Studies for Female
Students through Joint Supervision Programme
E-mail: admin-jsp@kau.edu.sa

المملكة العربية السعودية
وزارة التعليم العالي
**جامعة الملك عبد العزيز**
وكالة الجامعة
للدراسات العليا والبحث العلمي

☎ : ٦٩٥١٢٦٤ (٠٢) فاكس : ٦٩٥٢٩٣٧ (٠٢)
ص. ب : ٨٠٢١٨ جدة ٢١٥٨٩

To Whom it may concern,

We, the joint supervision program at King Abdulaziz University give our permission and approval to Alyaa Jamal Hemdi to conduct her first experiment for her PhD study here in Saudi Arabia. Her experiment involves conducting telephone interviews with a maximum of ten mothers of children recently diagnosed with autism in Saudi Arabia. We will ensure that she conducts her experiment in accordance with the Saudi law and ethics regulations. We will also check the Arabic translation of her interview questions and consent forms to make sure that it represents the English version. In case of any concerns or questions you can contact us at the contact information provided below.

Supervisor General of the Joint Supervision Program

Prof. Ammar Amin

## Appendix 6. Information Sheet and Consent Form (Chapter 3)

The University of Nottingham

School of Medicine

Division of Psychiatry

Institute of Mental Health

Triumph Rd

Nottingham

NG7 2TU

### Exploring the unmet needs of mothers of children with Autism Spectrum Disorder (ASD) in Saudi Arabia

**Name of Investigators**: Alyaa Hemdi and Professor David Daley

### Healthy Volunteer's Information Sheet

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you like. This study is being undertaken by **Alyaa Hemdi**, PhD student, as part of the degree of Doctorate of Philosophy in Psychiatry & Applied Psycholgoy at the University of Nottingham. Professor David Daley is supervising Alyaa in this study. Please contact Alyaa to ask about anything that is not clear or if you would like more information. Alyaa's contact information is provided below. Take time to decide whether you wish to take part or not. If you decide to take part you may keep this leaflet. Thank you for reading this.

### Background

This study aims to identify what mothers of children with ASD in Saudi Arabia want and need following the diagnosis of their children. Your experience parenting your child can be very informative for research because it shows the concerns of mothers of children with ASD in Saudi Arabia. It is hoped that the results of this study will provide information about how services for mothers of children with ASD can be improved.

**What does the study involve?**

We aim to recruit at least eight mothers of children recently diagnosed with ASD from a voluntary sector organisation in Saudi Arabia. Mothers will be asked to consent for us to interview them over the telephone for 35-45 minutes. The interviews will be digitally recorded. Each mother will be asked a similar set of questions around their needs parenting their child with ASD. The interview will focus on your experience having a child diagnosed with ASD; your needs as a mother of a child with ASD in Saudi Arabia; your child behaviour and how do you deal with it; your hope for the future of your child. It is your choice as to how much you like to talk about each question and you are free to avoid answering any one if you find it difficult to discuss.

**Why have you been chosen?**

You have been chosen because you are a mother of a child recently diagnosed with ASD in Saudi Arabia.

**Do you have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

**What do I have to do**?

If you wish to be involved in this study, complete the enclosed ‘consent form’ and return it in the pre-paid envelop or handed it to the secretary of the organisation (whatever is convenient for you). You will then be contacted by Alyaa to arrange a convenient time for the interview. You will be interviewed over the phone and the interview will be digitally recorded. If you said something at the interview and then changed your mind then I will erase it from the recording at your request The data collected from the interview will be anonymised and all the audio files will be destroyed. You will be given a copy of this information sheet and a signed consent form to keep for yourself.

**What are the side effects of any treatment or procedures received when taking part?**

There are no real side effects of taking part in this study.

**What are the possible disadvantages and risks of taking part?**

While we do not envisage any risks or disadvantages in taking part in this study we do however appreciate that you will be giving up 35-45 minutes of your time to assist me with my research. We are aware that the topics covered in the interview may be sensitive and if the interview causes you any distress, Alyaa will stop the interview for a while and you will have the choice weather to continue or not. However, if you require any further support, you will be redirected to the voluntary organisation to provide advice regarding further appropriate support.

**What if something goes wrong?/Who can I complain to.**

In the first instance please contact Mrs.Omaima Olaqy, Joint Supervision Program, King Abdulaziz University, Jeddah, 21589, Saudi Arabia. Telephone XXXXXXXXXX. Email: XXXXXX.edu.sa. She will pass your concerns to Professor David Daley, Division of Psychiatry, Institute of Mental Health, Triumph Road, Nottingham University Innovation Park, Nottingham, NG72TU.Telephone 0115XXXXXX, Email:XXXXXXX@nottingham.ac.uk. and Mrs. Louise Sabir, the Ethics Committee Secretary (Division of Therapeutics and Molecular Medicine, D floor, South Block, Queens Medical Centre, Nottingham, NG7 2UH) Telephone 0115 XXXXXXx. Email XXXXXXX@nottingham.ac.uk

**Will my taking part in this study be kept confidential?**

Yes. All the information you share with us during the interviews will be anonymised and treated as highly confidential. This data will only be seen and analysed by the researcher conducting the telephone interviews (Alyaa Hemdi) and the researchers' supervisor (Professor Daley). If your information is seen, analysed or transported by other research members, your personal details such as name and address will be destroyed. Data will be made anonymous and securely stored in a secure database belonging to the University of Nottingham.

**What will happen to the results of the research study?**

The results will provide the evidence required to explore the need of mothers of children recently diagnosed with ASD in Saudi Arabia. The results of this study will likely be published once it is ready for publication. The researcher will notify you once it is published and if you wish to obtain a copy of the published results then arrangements will be made with the researcher to deliver it to you. You will not be identified in any publication.

**Who is organising and funding the research?**

The University of Nottingham.

**Who has reviewed the study?**

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee.

This study will be conducted in Saudi Arabia under the supervision and approval of King Abdul Aziz University.

**Contact for Further Information**:

**The researcher**: Alyaa Hemdi,Division of Psychitry, Institute of Mental Health, Triumph Road, Nottingham University Innovation Park, Nottingham, NG7 2TU. Telephone: XXXXXXXXXXX, Email: XXXXXX@nottingham.ac.uk (Correspondence in English or Arabic)

**Researchers' supervisor**:Professor David Daley, Division of Psychiatry, Institute of Mental Health, Triumph Road, Nottingham University Innovation Park, Nottingham, NG7 2TU. Telephone XXXXXX, Email: XXXXXX@nottingham.ac.uk. (correspondence in English only)

The University of
Nottingham

UNITED KINGDOM · CHINA · MALAYSIA

***University of Nottingham,***
***School of Medicine,***
***Davison of Psychiatry and Applied Psychology***

**Title of Project**: Exploring the unmet needs of mothers of children with Autism Spectrum Disorder (ASD) in Saudi Arabia

**Name of Investigators**: Alyaa Hemdi and Professor David Daley

## Healthy Volunteer's Consent Form

Please read this form and sign it once the above named or
their designated representative, has explained fully the aims
and procedures of the study to you

- I voluntarily agree to take part in this study. ☐
- I confirm that I have been given a full explanation by Alyaa Hemdi and that I have read and understand the information sheet given to me which is attached. ☐
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result. ☐
- I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports ☐
- I agree to the above investigators contacting my general practitioner [and teaching or university authority if appropriate] to make known my participation in the study where relevant. ☐
- I agree to comply with the reasonable instructions of the supervising investigator and will notify him immediately of any unexpected unusual symptoms or deterioration of health. ☐
- I authorise the investigators to disclose the results of my participation in the study but not my name. ☐
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published. ☐
- I understand that I can ask for further instructions or explanations at ☐

any time.

- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing. ☐
- I confirm that I have disclosed relevant medical information before the study. ☐

**Name:**

…………………………………………………………………………………………

**Address:** ……………………………………………………………………………

**Telephone number**: …………………………….

**Signature:**…………………………………………………………………………….

**Date:** ………………………………………….

I confirm that I have fully explained the purpose of the study and what is involved to:

……………………………………………………………………………………………….

I have given the above named a copy of this form together with the information sheet.

**Investigators Signature:** ……………………….. **Date**: …………………………….

**Investigators Name:**… ………………

**Study Volunteer Number**: ………………………………………………………

## Appendix 7. An Example from the Codebook for Qualitative Analysis (Chapter 3)

### Mothers’ identification of their lack of information about their children with ASD

This theme reflects how mothers felt taking part in the intervention has helped them to identify their lack of information about ASD and its causes, diagnostic process, and treatment options. This includes insufficient information about ASD and inconsistent diagnosis of ASD.

**Subthemes:**

**Insufficient information about ASD**
This subtheme describes mothers’ identification of their lack of sufficient information about ASD and its aetiology. It also includes mothers’ descriptions about relying on searching the Internet and other mothers’ experiences to find more about treatment options for children with ASD. Moreover, mothers’ feelings of fear about their children’s future and the lack of services for adults with ASD in the country were also included.
**Positive example**: “A mother needs someone to explain to her what is ASD, how can ASD affect her child and her relationship with him, she needs to know what she can do to be able to communicate with him, it is never enough to tell the mother that her child is autistic, nobody ever told what ASD is all about.” (P2)
**Exclusions:** participants did not identify their lack of information about ASD.
**Negative example**: “It’s very good to find someone who asks about you. We have many problems here and there many problems related to children harassment and no one knows and no one cares. It’s good to ask and care about us.” (P4 - did not identify her lack of information about ASD)

**Inconsistent diagnosis for children with ASD**
This subtheme describes mothers’ feelings of confusion during the diagnosis process of their children. It also includes description of mothers’ confusion from receiving double diagnosis sometimes.

**Positive example**: “I received three different diagnoses for my child. One doctor told me that he has mild autism, another doctor told me that he has moderate autism, and a third doctor told me that he only has mental retardation and therefore I decided to take him to X hospital and I told them that we have three different diagnosis for the child and they evaluated him and we are waiting for their report.” (P2)

**Exclusions:** Mothers did not describe their feeling during or regarding the diagnosis of their children.

**Negative example**: “My child is suffering from a touch of autism.”(P3- did not relate the diagnosis with her feeling of confusion or non satisfaction)

## Appendix 8. An Example of Coded Transcript (Chapter 3)

**P4**
**The recording will now begin and I am pressing the on button. Are you still happy to do this interview? (***yes go ahead***). I will stop recording immediately if you asked me to do so.**
**Please note that if you said something and then changed your mind then I will erase it from the recording at your request.** *No worries*

**Opening statement**
**I am interested in finding out more about your experiences of having a child**
**with autism. I have a number of questions to use as a guide to help you think about your unmet needs and issues parenting your child with ASD.**

**Q1: Tell me about yourself (age, education, marital status, work, no of children)**

*I'm 29 years old. I have 3 children (a boy and a girl and a baby boy). My last certificate was secondary school. Married since 14 years. My eldest son is 10 years old and he is an autistic child.*

*I have another girl, 3 years of age, and was diagnosed by XXXXXX Centre. I don't go to any other centre. She was diagnosed there after displaying some autism symptoms. I have another 5 months baby boy; thanks for God.*

**Do you have a work?** *No, I don't.*

**What's your educational status?** *Secondary school.*

**Q2: Tell me about your experience of having a child with autism**

**Prompts:**
- **How has having a child with autism affected your…**
    - **Family relationships – marital, siblings, extended family?**
    - **Social/community involvement?**
    - **Working life?**
    - **Self-perceptions?**

*Do you mean what's happening with me. my family, my husband, my husband's family, etc?*

**Yes, sure. Tell me everything**.

*Regarding my daughter, she doesn't have hyperactivity, only simple symptoms not to be mentioned. The only main problem is the speech. She is good and everything is Ok except for pronunciation, she has a delayed speech. This is her problem.*

*As for XXX, my elder son, he had ADHD and a high percentage of autism, around 70% roughly and his autism level is very severe. I was annoyed because of this hyperactivity and distraction and was very depressed.*

> *No one was visiting me as no one now would tolerate him. Also I couldn't go to my relatives and my husband's family. Even I couldn't go to anyone's home.* [ **Mothers' recognition of their constant challenges raising their children with ASD (The stigma associated with having a child with ASD].**
> *Sometimes, when I had something to do, such as cooking, going to toilet, taking shower, etc), I had to tie him because he hurt himself a lot; like he climbs on the cupboards, touches hot things and does other dangerous things and there was an incident when he burned his hands. His situation was very very very bad and so was his social status. This urged me to take him to educational centers, but unfortunately as soon as he enters the center, he accommodates himself, however, when he gets out, everything is upside down and life is disrupted. He doesn't learn from the center to apply at home. Why he doesn't have the same order at home?* [ **Mothers' recognition of their constant challenges raising their children with ASD (Lack of support and assistance)].**

*As for me, I'm a mother and a wife; I have many tasks at home and tasks with my husband and with other relationships. I couldn't provide him everything he needed. Even home maids don't accept to come to my home because he destroys everything and attacks them. So I had a very bad relationship with my family and my neighbors. It is like I was living alone in a separate world that has me and my son only. Even my husband, I was living away from him. He usually leaves me at home and goes to his relatives and friends and only comes back to sleep at home. I'm lonely with my son. No one with us. No one feels or cares about us. God helps.* [ **Mothers' recognition of their constant challenges raising their children with ASD (Lack of support and assistance)].**

*I took a decision and told my husband that I would not continue with him as a wife except if we took the boy to an environment where he could learn. The boy can find people who could take care of him the whole day long,day and night, he also needs to see people . He needs a complete schedule, he needs learning. I mean he needs somebody to take care of him over the whole year. During vacations and weekends, oh my God, the situation was so bad. That's why, I had to take him to Jordan.* [**Mother's perceptions about their mental and physical well-being (Wanting their own time)].**

*In Jordan, the whole year is learning from morning to night. He follows a schedule from the time he wakes up until dinner. He receives physical therapy, pronunciation training, occupational therapy and whatever you imagine he is learning it there. His time is fully occupied and the teachers take consequent shifts to care for them.* **[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*One of my friends took her son to this center in Jordan. That's why I studied the subjects studied there and took my son to learn there as well. Unfortunately, I would love to take care of him myself but was unable to do it alone. Also because I had other children, frankly speaking I couldn't do that.*

**Do you visit him in Jordan or not?**

*Yes, we visit him every three months. We take him for a walk, we have fun together, he sleeps with us in the flat. Thanks God, in the beginning, he was depressed then he accepted the situation and everything is good, thanks God.*

**Q3: If I ask you to describe your daughter's day. What would you say?**

**Prompts:**

*Now it's a month and a half since we knew XXXXX Centre. My daughter had a bad luck that time as I was pregnant and she was crying. Her father's relatives were in Jeddah and we had to spend most of the time with them , so we didn't go frequently. Most of her time was spent on her IPAD and about 4-5 hours watching TV in addition to the time on IPAD. The whole time was spent on these devices.* [ **Mothers' recognition of their constant challenges raising their children with ASD (Lack of support and assistance)]**

*Now it's getting better, we decreased it to 2 hours per day, 1 hour in the morning and another hour in the evening. Once at 11 am and in the afternoon i.e. 2pm, I let her watch TV for about 2 hours. I tried my best to take the mobile and IPAD from her and she is doing better.*

**Prompt: Does she go to the centre or not?**

*Now she has had 3 sessions because they are very busy. She takes 3 sessions per month. There's improvement in comprehension, in dealing with people, in social interactions. Her brother was so aggressive, was hurting himself and others as well. However, she is calm; she loves people and communicates with them and with me.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

**Prompt: Does she have eye to eye contact with you?**
*Yes she has eye contact. Her words are not understandable and I don't get what she says. She speaks to me and tries to tell me something but I don't understand her words. She plays with other children.*

**Prompt: Does she have difficult behaviours?**
*When we go out, she displays difficult behaviours. If we go to the market or for a walk, she does some disturbance like her brother. I don't know this is a baby behaviour or normal behaviour.* **[Mothers' identification of their lack of information about their children with ASD (insufficient information about ASD)].**

**Prompt; She attacks her brothers at home?**
*No she doesn't but she wants to do anything she likes. She doesn't want us to control her.*

**Prompt: Does she break things?**
*No no no she doesn't. This habit was in her brother not her.*
*So what do you think of my daughter's situation. May be she is bormal. Because I have a complete experience and my son stayed with me for 7 years. I have experience in dealing with people with autism. I noticed that she only has a problem in her pronunciation . Her problem is like her brother's problem. The same way of talking but she is normal.* **[Mothers' identification of their lack of information about their children with ASD (insufficient information about ASD)].**
*She plays normally with children. She has the ability to eat by herself earlier in her life not like her brother. She dresses herself. With regards to going to toilet I think she need a little more time. She recognizes persons and tries to talk and communicate with them and with me as well.*

**Prompt: Does she have a routine behaviour? Like repeated waving hands?**

*No no no not at all, she does not have any repetitive behaviour, her problem is in pronunciation. She understands and brings all things I need. When the doctor diagnosed her case, I was surprised.*

**Could you please raise your voice?**
*I'm surprised with the diagnosis of her doctor. How did the doctor took that decision , I'm not sure of this diagnosis. I'm afraid my daughter is normal. I'm not saying this because I'm her mother. What I care about the most is that I need her to talk and I want her to overcome any problems before school age.* **[Mothers' identification of their lack of information about their children with ASD (Inconsistent diagnosis for children with ASD)].**

**Prompt: Then, you can diagnose her in another place if you have doubt?**
*You know what, when my daughter was diagnosed I was postpartum and I had just delivered my new born and stayed for 2-3 weeks after that diagnosis. I was depressed saying to myself that is enough. Enough to have an autistics boy? Now the girl as well? I had hypertension at that time as a result then I decided to get her diagnosed at another place.* [**Mother's perceptions about their mental and physical well-being (Understanding their poor well-being and the need for help)].**

*People advised me to diagnose her case and let her take intelligence tests then to approach the centers. Centers don't do diagnosis but doctors.*

*I told the doctor about all symptoms she had. What I see in her is the problem in speaking and some food that she doesn't prefer; other than that, she is a normal girl who communicates and interacts with you and that's what gives me patience. Even if they say that she has a mild case, it is ok as long as she interacts. But speaking is not yet developed, she has a problem there.*

**Prompt: You might consider taking her to a psychiatrist to get a confirmed diagnosis if you still have a doubt**
*I'm doing now my search. They have told me about the national guard hospital in Jeddah.* **[Mothers' identification of their lack of information about their children with ASD (Inconsistent diagnosis for children with ASD)].**

**Prompt: Yes, I heard about Dr. XXX, a psychiatrist there. Is that the one you have been told about ?**
*I talk to them 1 week ago and was informed that he left the clinic and they don't know the number of the new clinic. Then there is still remaining the military hospital. There should be a well know doctor somewhere who can diagnose the case.* **[Mothers' identification of their lack of information about their children with ASD (Inconsistent diagnosis for children with ASD)].**

*Please let me know if you have any idea to help, on the same time, I want you to benefit from my experience as well during this interview.*

**Prompt: Thank you very much. I am really benefitting from your experience with your daughter and your son as well.**
*Oh yes, my son was a separate story, thanks God. I want you to take every thing that benefit your research.*

**Prompt: Please feel free. When I ask you any question, you can talk about your son or your daughter. Every this you will be saying at this interview is valuable and will benefit this research and add to it and this will in return benefit this category of children when we develop something for them in the future.**

*We hope that because we have problems here with all centers. For example XXXXX Centre, it's the only one that covers MAkkah's region and is overloaded. They give only 2 hours sessions (from 8: 30 am to 12 noon time) and the children are back to home with no benefit.*

*I was talking with Jordan and told me your son improved but the problem is when he is back to home. This is the main problem here. God helps.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

**Q4: Tell me more about your experience of the available services to mothers of children following the diagnosis of ASD?**
*First thing, the centres are very bad. No benefit and you do not find many centres and if you find one, it is only three hours per day and the fees are quite high around 20,000 Saudi Riyal not including transportation.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*So, the problems are regarding centres, transportations and money (fees). Our flat is rented and we have to pay about 25,000 per year. The government does not do us anything and they pay us only 1,200 SAR. What this 1,200 SAR and what could it do? My son also has over electricity in his brain and other problems and we have to pay for him from our pocket around 1000 SAR for medications. A medication called Risperidal which calms him down costs us around 300 SAR per month.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*So, the problems are related to centres, transportations, medications, fund(money) and hospitals for sure.*

**Prompts: Which services did you hope to receive at that point and you didn't?**
*My son had been waiting for 3 years to join a centre as there were no place , when a student goes out, another one takes his place. What I was hoping that the nearest center was good and perfect in everything. I wanted it to be an academic( learn) or may be some programs in the afternoons, things like that. I needed a center that served my son in all aspects like treatment, training, movement, pronunciation etc. XXXX Centre offered us pronunciation sessions for some amount of money.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*What I needed is to have a highly qualified centre for my son. A centre that serves all his needs. He should make use of all his time because autistic children do many troubles and bad things if their time is not fully occupied.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*When he comes back to home, i have other issues at house and with my husband. So the time won't be enough for him. Even if I give him time, he needs more. He needs to be more busy and he needs more time. What I want is a highly qualified centre near our home.*

*I hope that the same centre in Jordan is here beside us instead of being far away and we go there few times. I hope there would be a centre with athletic clubs, pronunciation sessions, speech therapy, behaviour modifications, occupational therapy and everything.*

*They (Jordan centre) would know what are his gifts and abilities. They communicate more with parents. Now, there is less communication with parents. I need my child to be near me, see him and communicate with him more frequently, even I can dedicate a full day or two to him every week.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*In Jordan, they have a clinic inside the centre in case it is needed, it is like a hospital, so it's a complete and perfect centre and it is the same as school environment. Some children don't want this atmosphere but my child does because he loves learning and school environment.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

**Prompts: How do you see your child's future in the light of the available services?** *First of all, I believe in God and I am quite sure my son will be healed.Second, he became completely independent, he eats and drinks by himself. He goes to toilet and combs his hair by himself. They CAUght him good things and how to take shower and to tie his shoes; he became perfect in all of this.I told them that my priority is for teaching him how to be independent and the studying comes later. I needed him to, at least, take care of himself.Then, he is speaking better now, thanks God. In spite of being late to take him to this centre, he is getting better and there are many good things now after 2 years.*

**Prompts: How do you see your daughter's future in the light of the available services?**
*I may take her to any kindergartens or any centre in Jeddah. She may get better soon hopefully, God help. Her problem is very mild and she will get better soon with God help, there was a teacher that admired her telling that she knows colors and has social communication and loves many things. I expect her future will be way better than her brother.*

*Her brother needs long time and his problem is harder and will improve but I think after longer time but my draught I think in the very near future*

**Q5: What types of services/support that you would find most useful? (emotional support, day care services, educational interventions, etc.)?**
*My son needs daily care but my daughter needs learning. My son needs attention and someone who accompanies him taking care of him day and night. The girl needs frequent pronunciation sessions and learning as she understands many things and thinks properly.* **.[ Mothers' perceptions of their children's educational needs (Need of ASD organisations with quality services)].**

*However, my son needs someone who shows him and teaches him. He needs everything an autistics child might need. The girl needs a small modification then she can go to school.* **.[ Mothers' perceptions of their children's educational needs (The inclusion of children with ASD in the general education classroom)].**

**Prompts: I mean the mothers? What services needed by you and any mother of an autistic child? Because no one focuses on mothers' needs?**

*First, any mother will tell you that she needs a home maid.* [ **Mothers' recognition of their constant challenges raising their children with ASD (Lack of support and assistance)].**

*Then, secondly the autistic child should have a place in hospitals. They should give him a card with all his information stating that he is autistic so that any hospital sees it should give his medications without such complications, it is really unfair.*

*Then, there should be lab tests that show us the hereditary things and whether this disease comes from the father or the mother. This way, if the disease comes from mother, she should stop giving birth to more babies who will suffer and the mother will suffer too, any bold test anything that will tell us.* **[Mothers' identification of their lack of information about their children with ASD (Inconsistent information about ASD)].**

**Prompts: Nothing in science now can tell us. Nobody knows the reason. There is no scientific reason for autism till now.**
*We, as mothers, need education, courses and learning*. [ **Mothers' identification of their training needs** *The fathers also need the same as well as some fathers don't understand nor cooperates*. [ **Mothers' recognition of their constant challenges raising their children with ASD (Lack of support and assistance)].**

*They need to understand that this is from God and they need to cooperate.*

*The mother needs home maid. Also, needs education, teaching, support and encouragement as there are many mothers who are very depressed and take depression medications.*

*This is because the mother is completely separated from the surrounding world, the people and everything. I have been living such life and no one feels neither relatives nor others. Thanks God any way.* [**Mother's perceptions about their mental and physical well-being (Understanding their poor well-being and the need for help)].**

*They should educate the community and all people should know such category of patients should be appreciated and people need to understand specifically that some people could not tolerate autistic children.***[ Suggestions to increase public awareness about ASD].**

*Still the most important things for the mother are education, learning and a home maid.*

**Prompts: Do you think that if there are educational courses and sessions for mothers, will they attend?**
*If they have a home maid, they can attend. Others, i know them, can't attend as they don't have a home maid. How can she go and take her children with her?*

*There was one time when I asked the centre to have their maids to take care of my children to attend the courses but they refused. They told me that they are overloaded and (squeezed). They even refused to take care of my daughter only during one session.*

*However, I need to attend these sessions to understand more and know how to deal with my children.* .[ **Mothers' identification of their training needs (Removing barriers to engagment)].**

**Prompts: Can't you leave them with your relatives?**
*Ohhhhh, unfortunately, no one cooperates, they did not cooperate from the beginning do you want them to cooperate now? The same is happening with one of my colleagues. She has autistic children with ADHD and her family doesn't*

*accept neither tolerates her children as they hit and destroy things; no one would offer help.* [ **Mothers' recognition of their constant challenges raising their children with ASD (Lack of support and assistance)].**

*Even mothers when they are at home, they have many things to do; should they clean the house, or see their husbands' requirements, take care of their children, take care of themselves, could somebody tell me what can the mother do to herself??* **[Lack of support and assistance].**
*So, the home maid is so important to serve as maid and as a nurse. She shouldn't be a normal maid and should be aware of everything and well educated. This way the mother will take care of the home and the nurse will take care of the autistic child and take the role of a nanny.* [**Mother's perceptions about their mental and physical well-being (Wanting their own time)].**

*In this way, the mother will retain her rights to go out everywhere anywhere she likes. God knows how I was dealing with my son and how was the efforts and pain I was having in taking care of him as he was a man (her words is referring to his physical body as a big boy).* **[Wanting their own time].**

*Mothers should have rights in the community and should have maids and training sessions. This is my suggestion.*

**Q5: What are barriers that interfere with you obtaining services (e.g., Childcare, not aware of services, transportation, difficulty acknowledging need for help,
etc.)?**
*Child care during sessions so we can attend. Also the transportation because my husband's work is so far. It took him 2 hours to go to his work and 2 hours back as well. This means 18 hours outside home; almost full day except for the 4 hours at home with me.*[ **Mothers' identification of their training needs (Removing barriers to engagment)].**

**Prompts: Awareness with courses and sessions? Does anyone tells you about that**?
*Yes, because I am a member in mothers' group (the mothers' meeting) and in another group of autistic children named ( children, the source of our happiness),it is a Whatsapp group*

**Prompts: How do you meet?**
*The mothers' group is in Riyadh. They teach mothers many things and I benefit from chatting with those mothers. In these groups they show you how to deal with children and everything about autism, especially in this (mothers' group).[* **Mothers' identification of their training needs].**

**Prompts: How did you know about this group? WhatsApp group I mean?**
*Via one of the mothers in XXXXX Centre, I knew her for long time and our children were together. She worked on this group and invited me to this group on WhatsApp. Many benefits and we know everything from this group*

**Prompts: Who made this group?**
*Her name is XXXXX.*

**Prompts: Can you please talk to her to invite me to this group as I would love always to talk to mothers?**

*Yes sure, this will be an honour for us*
*This group is of high benefit and you can take anything any experience from this group.*

**Closing question: How was the experience for you talking to me today?**
*Thanks God, the questions were really good and I felt comfortable that I talked to you today. I feel lighter* **[Arabic expression meaning that by finding somebody to talk to about your worries and concerns then some of these worries are not there anymore within you]***It's very good to find someone who asks about you. We have many problems here and there many problems related to children harassment and no one knows and no one cares. It's good to ask and care about us.* [**Mother's perceptions about their mental and physical well-being (Understanding their poor well-being and the need for help)**].

**Prompts: There are many good things coming; if you to put your hand with others something good will be achieved hopefully. Please pray for me to be able to serve this category of children and their parents which I chose them from many other categories because I love to serve them and their parents**
*God bless and help you in your way and your research and degree as well. We females suffer a lot to get Education and considering that you are a mother and you have to leave your kids and dedicate your time to do research, ah this is something that God is going to bliss you for.*

**Is there anything else that you think is important that we haven't talked about?**
*Transportation, education, courses, and sessions. The community should have more awareness about this category of people.* **.[ Suggestions to increase public awareness about ASD].**
*Father also should have a role. Hospitals should help us as well.*

**Thank you for your time.**

**End of interview.**

## Appendix 9. Excluded Studies with Reasons (Chapter 4)

| Study (reference) | Reasons for exclusion |
|---|---|
| Karst et al. (2015) | Child mean age 14 |
| Stuttard et al. (2014) | Children with different disabilities+ no formal diagnosis of ASD |
| Bearss et al. (2015); (Dababnah & Parish, 2015; Frankel et al., 2010; Hastings & Symes, 2002; Pillay, Alderson-Day, Wright, Williams, & Urwin, 2011a; J. A. Weiss, Viecili, Sloman, & Lunsky, 2013) | No measurement of included outcomes |
| Inalegwu P. Oono, Emma J. Honey, and Helen McConachie (2013) | A review |
| Vismara, McCormick, Young, Nadhan, and Monlux (2013) | Single-subject design |
| Blackledge and Hayes (2006); (Farmer & Reupert, 2013; Fava & Strauss, 2011) | No formal diagnosis of ASD |
| Dykens and Lambert (2013) | Children with different disabilities |
| Ferraioli and Harris (2013); (Solomon, Necheles, Ferch, & Bruckman, 2007) | No enough statistical information |

## Appendix 10. Outcomes of included studies (Chapter 4)

| | Stress | Sense of competence | Parenting practices | Depression& | Anxiety |
|---|---|---|---|---|---|
| **Randomised controlled studies** | | | | | |
| Drew 2002 | X | | | | |
| Ginn 2015 | X | | | | |
| Grahame 2015 | | X | | | |
| Tellegen 2014 | x | x | x | x | x |
| Tonge 2006 | x | | | x | x |
| Whittingham 2009 | | x | x | | |
| **Non randomised controlled studies** | | | | | |
| Sofronoff 2002 | | X | | | |
| Samadi 2012 | X | | | X | x |
| **Pre to post studies** | | | | | |
| Bendixen 2011 | X | | X | | |
| Chiang 2014 | X | X | | | |
| Keen 2010 | X | X | | | |

# Appendix 11. Characteristics of Included Studies (Chapter 4)

| **Study** | **Design** | **Country** | **Sample size** | **Gender F M** | **Child age M(SD)** | **Summary of main conclusions** | **Measures** | **Quality scores** |
|---|---|---|---|---|---|---|---|---|
| Bendixen 2012 | Pre-post | USA | 19 parents | 19 F<br>19 M | 4.41 yr (1.36) | Significant reduction in mothers but not father stress post intervention | PSI-SF<br>FACES II | 75% |
| Chiang 2014 | Pre-post | USA | 9 Families | 9 F<br>2 M | Range 3-11 yr | Significant reduction in parents' stress and increase in parental confidence post intervention | PSI<br>*CDQ* | 75% |
| Drew 2002 | RCT | UK | 24 parents (12 intervention- 12 control) | NR | 22.5 mon. (3.4) | No difference in stress scores over time | PSI-SF | 75% |
| Ginn 2015 | RCT | USA | 30 mothers (15 intervention- 15 control) | 30 F | 4.32 yr (1.16) intervention<br>&<br>5.12 yr (1.39) control | No significant reduction in parental stress | PSI-SF | 50% |
| Grahame 2015 | Mixed methods (RCT+focus group) | UK | 45 families (25 intervention -20 control) | NR | 60.44 mon.(13.44) intervention<br>&<br>62.75 mon.(16.89) control | Significant increase in self efficacy | Parent Self-Efficacy Questionnaire | 50% |
| Keen 2010 | Pre-post | Australia | 39 families ( 17 intervention + 22 another treatment) | 17 F<br>16 M<br>(Intervention) | 36.38 mon.(7.54) | Child related stress reduction and increase in self efficacy | PSI<br>PSOC | 75% |

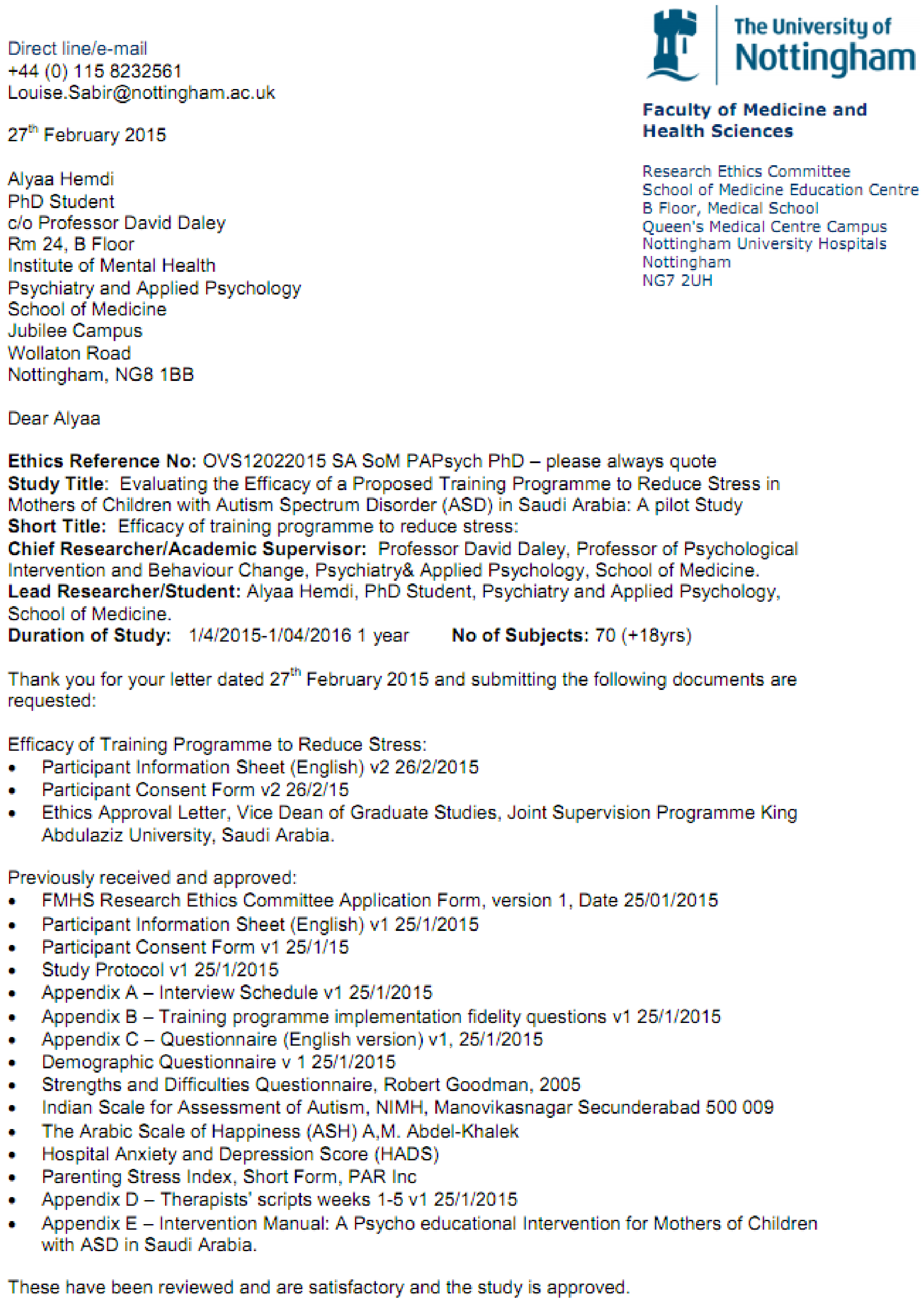
| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | 22 F<br>21 M<br>(another) | | | | |
| Sammadi 2012 | Non randomised controlled trial | Iran | 37 parents | 24 F<br>13 M | 8.2 yr | Significant reduction in stress, Psychological distress, and family functioning | PSI-SF<br>GHQ (depression and anxiety) | 100% |
| Sofronoff 2002 | Non randomised controlled trial (3 groups) | Australia | 45 mothers<br>+<br>44 fathers | 17 F<br>16 M<br>(intervention1)<br>18 F<br>18 M<br>(intervention2)<br>10 F<br>10 M<br>(control) | 8.3 yr | Significant increase in self efficacy | Parental self-efficacy in the management of Asperger Syndrome questionnaire | 25% |
| Tellegen 2014 | RCT | Australia | 64 parents (35 intervention + 29 control) | 34 F<br>1 M<br>(Intervention)<br>27 F<br>2 M<br>(another) | 5.66 yr (2.18) intervention<br>&<br>5.69 yr (2.12) control | Significant improvement in stress, confidence, adjustment, parenting styles but no reduction in depression and anxiety | DASS-21 (stress, depression, and anxiety subscales)<br>The Parenting Tasks Checklist | 100% |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | | | | | | | The Parenting Scale | |
| Tonge 2006 | RCT (3 groups) | Australia | 35 parents intervention+ 35 Different treatment+ 35 control | NR | 45.3 mon.(8.9) intervention &<br>45.3 (8.5) Different treatment control<br>& 49.4 (10.0)control | Significant reduction in stress, Psychological distress at T3 only | The Parenting Stress Thermometer<br>GHQ (depression and anxiety) | 100% |
| Whittingham 2009 | RCT | Australia | 59 parents (29 intervention + 30 control) | 54 F<br>4 M | 5.91 yr (1.90) | Significant increase in parenting styles | PSOC<br>The Parenting Scale | 100% |

## Appendix 12. Quality Scores for Included Studies (Chapter 4)

| Study ID | Rating | Note |
|---|---|---|
| Sammadi 2012, Tellegen 2014, Tonge 2006 , Whittingham 2009 | 100% | |
| Bendixen 2012, Chiang 2014 , Keen 2010 | 75% | Response rate not available |
| Drew 2002 | 75% | No description of allocation concealment or blinding |
| Ginn 2015 | 50% | Dropout rate 24% and completion rate of 76% |
| Grahame 2015 | 50% | No description of how findings relate to context or researcher-no description of randomisation or allocation concealment-no integration of qualitative and quantitative findings. |
| Sofronoff 2002 | 25% | No description of recruitment-no validity information for all measures-no comparison between groups |

# Appendix 13. Ethics Approval Letters from The University of Nottingham and KAU (Chapter 6 + 7)



The University of Nottingham

**Faculty of Medicine and Health Sciences**

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27th February 2015

Alyaa Hemdi
PhD Student
c/o Professor David Daley
Rm 24, B Floor
Institute of Mental Health
Psychiatry and Applied Psychology
School of Medicine
Jubilee Campus
Wollaton Road
Nottingham, NG8 1BB

Dear Alyaa

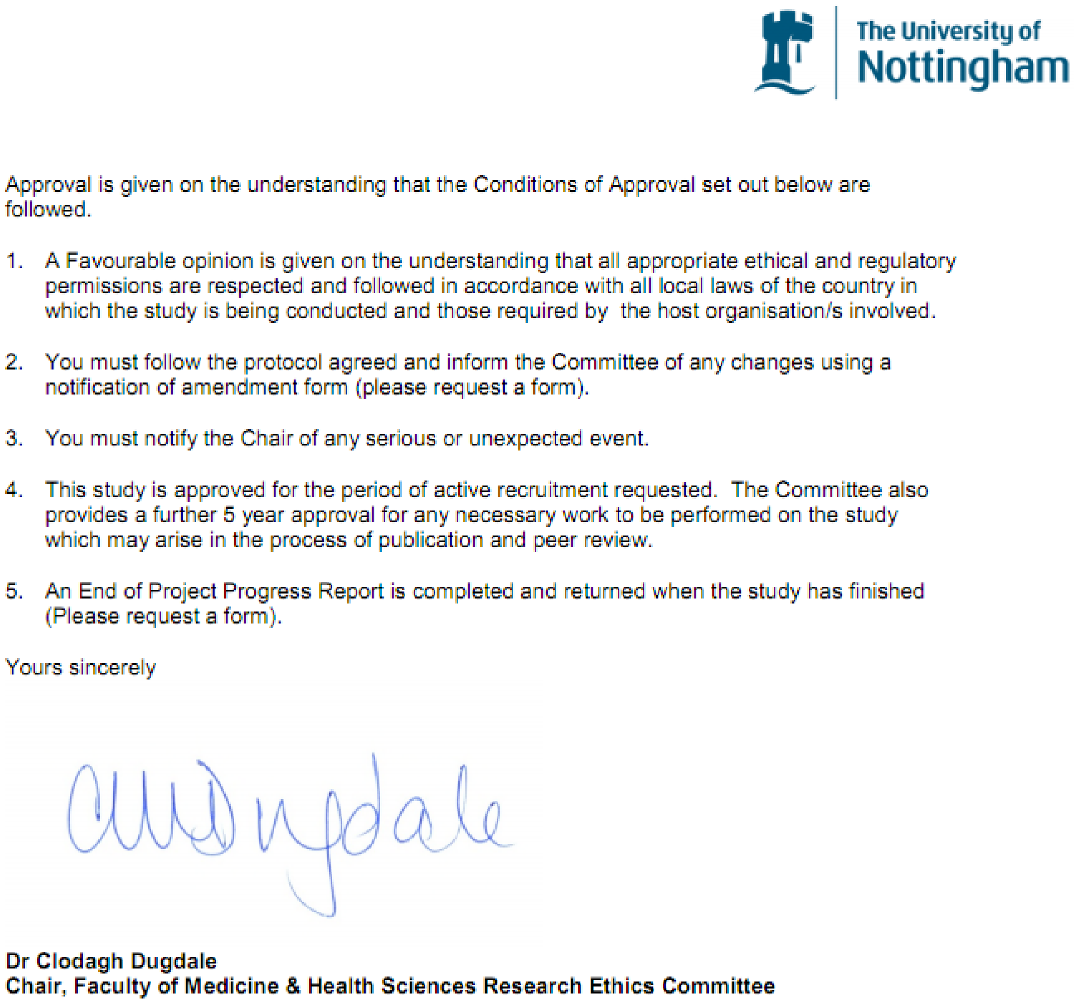
**Ethics Reference No:** OVS12022015 SA SoM PAPsych PhD – please always quote
**Study Title:** Evaluating the Efficacy of a Proposed Training Programme to Reduce Stress in Mothers of Children with Autism Spectrum Disorder (ASD) in Saudi Arabia: A pilot Study
**Short Title:** Efficacy of training programme to reduce stress:
**Chief Researcher/Academic Supervisor:** Professor David Daley, Professor of Psychological Intervention and Behaviour Change, Psychiatry& Applied Psychology, School of Medicine.
**Lead Researcher/Student:** Alyaa Hemdi, PhD Student, Psychiatry and Applied Psychology, School of Medicine.
**Duration of Study:** 1/4/2015-1/04/2016 1 year **No of Subjects:** 70 (+18yrs)

Thank you for your letter dated 27th February 2015 and submitting the following documents are requested:

Efficacy of Training Programme to Reduce Stress:
- Participant Information Sheet (English) v2 26/2/2015
- Participant Consent Form v2 26/2/15
- Ethics Approval Letter, Vice Dean of Graduate Studies, Joint Supervision Programme King Abdulaziz University, Saudi Arabia.

Previously received and approved:
- FMHS Research Ethics Committee Application Form, version 1, Date 25/01/2015
- Participant Information Sheet (English) v1 25/1/2015
- Participant Consent Form v1 25/1/15
- Study Protocol v1 25/1/2015
- Appendix A – Interview Schedule v1 25/1/2015
- Appendix B – Training programme implementation fidelity questions v1 25/1/2015
- Appendix C – Questionnaire (English version) v1, 25/1/2015
- Demographic Questionnaire v 1 25/1/2015
- Strengths and Difficulties Questionnaire, Robert Goodman, 2005
- Indian Scale for Assessment of Autism, NIMH, Manovikasnagar Secunderabad 500 009
- The Arabic Scale of Happiness (ASH) A,M. Abdel-Khalek
- Hospital Anxiety and Depression Score (HADS)
- Parenting Stress Index, Short Form, PAR Inc
- Appendix D – Therapists' scripts weeks 1-5 v1 25/1/2015
- Appendix E – Intervention Manual: A Psycho educational Intervention for Mothers of Children with ASD in Saudi Arabia.

These have been reviewed and are satisfactory and the study is approved.



The University of
Nottingham

Approval is given on the understanding that the Conditions of Approval set out below are followed.

1. A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are respected and followed in accordance with all local laws of the country in which the study is being conducted and those required by the host organisation/s involved.

2. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).

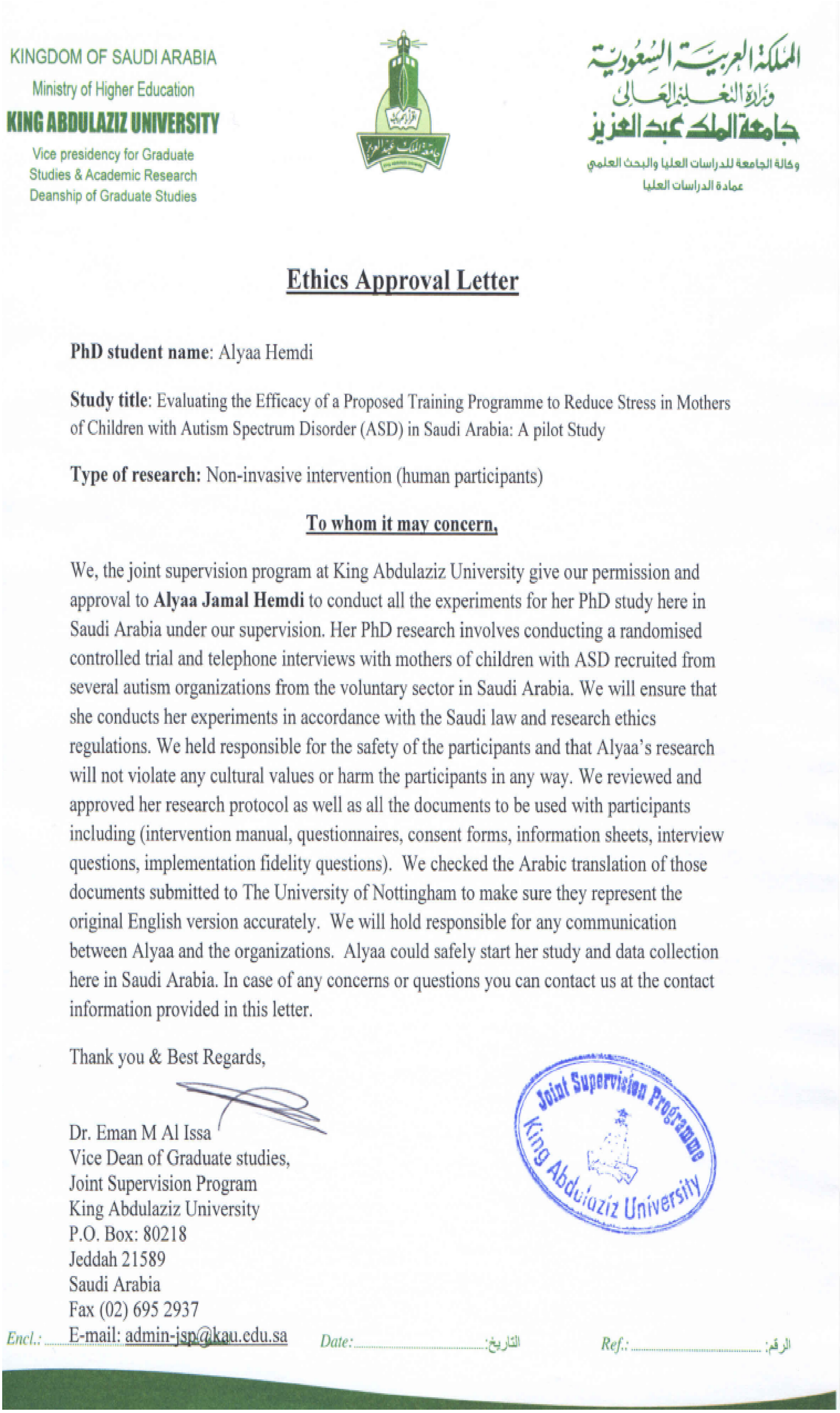
3. You must notify the Chair of any serious or unexpected event.

4. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.

5. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

**Dr Clodagh Dugdale**
**Chair, Faculty of Medicine & Health Sciences Research Ethics Committee**



KINGDOM OF SAUDI ARABIA
Ministry of Higher Education
**KING ABDULAZIZ UNIVERSITY**
Vice presidency for Graduate
Studies & Academic Research
Deanship of Graduate Studies

المملكة العربية السعودية
وزارة التعليم العالي
جامعة الملك عبد العزيز
وكالة الجامعة للدراسات العليا والبحث العلمي
عمادة الدراسات العليا

## Ethics Approval Letter

**PhD student name**: Alyaa Hemdi

**Study title**: Evaluating the Efficacy of a Proposed Training Programme to Reduce Stress in Mothers of Children with Autism Spectrum Disorder (ASD) in Saudi Arabia: A pilot Study

**Type of research:** Non-invasive intervention (human participants)

**To whom it may concern,**

We, the joint supervision program at King Abdulaziz University give our permission and approval to **Alyaa Jamal Hemdi** to conduct all the experiments for her PhD study here in Saudi Arabia under our supervision. Her PhD research involves conducting a randomised controlled trial and telephone interviews with mothers of children with ASD recruited from several autism organizations from the voluntary sector in Saudi Arabia. We will ensure that she conducts her experiments in accordance with the Saudi law and research ethics regulations. We held responsible for the safety of the participants and that Alyaa's research will not violate any cultural values or harm the participants in any way. We reviewed and approved her research protocol as well as all the documents to be used with participants including (intervention manual, questionnaires, consent forms, information sheets, interview questions, implementation fidelity questions). We checked the Arabic translation of those documents submitted to The University of Nottingham to make sure they represent the original English version accurately. We will hold responsible for any communication between Alyaa and the organizations. Alyaa could safely start her study and data collection here in Saudi Arabia. In case of any concerns or questions you can contact us at the contact information provided in this letter.

Thank you & Best Regards,

Joint Supervision Programme
King Abdulaziz University

Dr. Eman M Al Issa
Vice Dean of Graduate studies,
Joint Supervision Program
King Abdulaziz University
P.O. Box: 80218
Jeddah 21589
Saudi Arabia
Fax (02) 695 2937
E-mail: admin-jsp@kau.edu.sa

Encl.: ........ Date: ........ :التاريخ Ref.: ........ :الرقم

## Appendix 14. An Example from one WhatsApp session transcript (Chapter 6)

[First WhatsApp session in M1 (second session in intervention). The therapist created a group called "Mothers' training programme" and added all the participating mothers to the group asking each one to use her study ID during group discussion].

19:15 PM, Apr 27 - [Therapist] added p1, p3, p5, p7, p9, p11, p13, p15

19:18 PM, Apr 27 - :I am [ therapist' name] the autism therapist who will be running the group. I added all the participating mothers to this group.

19:19 PM, Apr 27 - : Dear mothers, would you please respond to my message to ensure that you were added to the group. As we all agreed on the first face to face session, we will meet on WhatsApp every Tuesday for the coming four weeks at 19: 00 PM. Please read the second session section about stress from the manual.

19:20 PM, Apr 27- [p 5]: Added p5.

19:20 PM, Apr 27 - [p 13]: Hello p13

19:20 PM, Apr 27 - [p 1]: Hi p1

19:30 PM, Apr 27 - p 9[]: Hi dear sisters , with you p9

22:20 PM, Apr 27 - [p 11]: Hi p11

22:30 PM, Apr 27 - [p 3]: With you all p3

10:00 AM, Apr 28 - [p 15]: Hi I just checked my WhatsApp with you all p 15

11:00 AM, Apr 28 - [p 7]: Hi me too p 7

19:00 PM, Apr 28 - [therapist]: How are you everyone. Today we begin the first WhatsApp session and the second session in the training programme. I want every mother to write her study ID before e start the discussion as I need to take attendance.

19:01 PM, Apr 28 - [p 5]: Evening everyone, this is p5

19:01 PM, Apr 28 - [p 1]: P1 present

19:01 PM, Apr 28 - [p 7]: Hello everyone, this is p7

19:03 PM, Apr 28 - [p 11]: P11

19:03 PM, Apr 28 - [p13]: Hi, p13

19:04 PM, Apr 28 - [p 9]: Welcome, p9

19:04 PM, Apr 28 - [p 15]: P15 is here

19:05 PM, Apr 28 - [therapist]: Welcome everyone, I think p3 is missing?

19:05 PM, Apr 28 - [p 3]: Here I am p3

19:05 PM, Apr 28 - [therapist]: Good that everyone is present in the first session, may God bless your evening my dear mothers.

19:06 PM, Apr 28 - [therapist]: As you all know this session topic is about stress, I hope that you all had the chance to read the manual.

19:06 PM, Apr 28 - [p 5]: P5, I read it and it was about solving tension for mothers and methods to help in dealing with tension.

19:07 PM, Apr 28 - [therapist]: Ok, that's good. Did everyone understand the examples in the manual?

19:07PM, Apr 28 - [p11]: P11, I got the point that the mothers' psychological state does affect the way she perceives her ASD child.

19:08PM, Apr 28 - [p 1]: P1, simply speaking stress is to think nervously

19:08PM, Apr 28 - [therapist]: True

19:08PM, Apr 28 - [therapist]: But what else?

19:09PM, Apr 28 - [p 9]: P9, stress or tension is common in all the things surrounding us or in most situations.

19:09PM, Apr 28 - [therapist]: Stress actually is the reaction to the situation and the feeling associated with it rather than the situation itself.

19:10PM, Apr 28 - [p 5]: P5, also undesirable feelings result from psychological pressure

19:10PM, Apr 28 - [p 3]: P3, it is a reaction

19:11PM, Apr 28 - [therapist]: True

19:11PM, Apr 28 - [therapist]: Can every mother write for us what are the situations that made her tense and stressed.

19:12PM, Apr 28 - [p 5]: P5, for me dealing with my child behaviour.

19:12PM, Apr 28 - [p 9]: P9, me too

19:13PM, Apr 28 - [p 11]: P11, we are all creatures of God and if God loved someone then he will test that person and I think that God is testing my patience with my son.

19:13PM, Apr 28 - [p 7]: P7, I was scared to travel with my child on a plane, and was afraid from the reactions of people in the plane.

19:13PM, Apr 28 - [p 7]: P7, however, I went through the experience, was simple and my child behaviour was not bad and everything went well, the people were normal.

19:13PM, Apr 28 - [p 1]: P1, If I attended a social occasion and my kid saw anything with the other kids and asked for it, I sometimes became tense.

19:14PM, Apr 28 - [therapist]: Ok what do you usually do?

19:14PM, Apr 28 - [p 1]: P1, I am usually ready for that and with iPad , toys and chocolate.

19:14PM, Apr 28 - [p 11]: P11, my child gets angry when visiting some neighbours or going to the market.

19:14PM, Apr 28 - [p 11]: P11, adults may understand the situation, but the tension and stress is not from my son but from his peers.

19:15PM, Apr 28 - [p 11]: P11, I try to dismiss it but I cannot when they stare at my kid.

19:15PM, Apr 28 - [therapist]: But p1 who took toys with her has found that to be helpful in the situation. Did you try something similar?

19:15PM, Apr 28 - [p 11]: P11, sometimes I submit to his requests.

19:16PM, Apr 28 - [therapist]: And does he become less stressed if you submit to his request?

19:16PM, Apr 28 - [p 11]: P11, if we knew what he wanted then the problem comes to an end.

19:16PM, Apr 28 - [p 5]: P5, yesterday I had a situation with my kid at the hospital.

19:16PM, Apr 28 - [therapist]: Go on.

19:17PM, Apr 28 - [p 5]: P5, when his father was filling out the appointments papers, my kid left my hands and went out running , out of the building and I ran after him to the extent that he stopped the road, I was in the position that nobody can imagine and when I caught him, he threw himself on the ground and cried, I was completely incapable of making him quiet, until his father came and helped me. That situation was really stressful.

19:17PM, Apr 28 - [p 5]: P5, the question here is how to deal with him if I was alone?

19:18PM, Apr 28 - [therapist]: You do not go out before taking your precautions. May be you tie his hand with yours.

19:18PM, Apr 28 - [p 5]: P5, will try next time.

19:19PM, Apr 28 - [therapist]: God help you.

19:19PM, Apr 28 - [p 9]: P9, most of my tension with my son when we are at public places.

19:19PM, Apr 28 - [therapist]: Has anyone tried the five steps plan of getting rid of stress from the manual?

19:20PM, Apr 28 - [p 13]: P13,my son don't like anyone to hold his hand in any place, I am going to follow the steps proposed in the manual later.

19:20PM, Apr 28- [p 15]: P15, I feel like I'm on the edge, and I have stress and frustration because my son refuses to learn due to continuous tantrums.

19:21PM, Apr 28 - [therapist]: Ok p15 can you be more specific, what are the things that causes tension to you and how did you try to address it?

19:21PM, Apr 28 - [p 15]: P15, I can't do anything with him from frequent seizures and continuous screaming for a long time.

19:22PM, Apr 28 - [therapist]: Your child could learn but will take a long time, be patient my dear.

19:22PM, Apr 28 - [therapist]: Do you know that children with ASD love routine and may be he is frustrated because he is looking for that, did you try to organise his time and make a schedule for him?

19:23PM, Apr 28 - [p 15]: P15, I did the schedule even with his brothers but it did not help.

19:24PM, Apr 28 - [therapist]: As you might know, children with ASD are different and you can not compare one to another, however, you should keep trying with the available strategies until you find something that work for your child.

19:24PM, Apr 28 - [p 1]: P1, I did like the part in the manual that discusses mediation and prayers and I think that was helpful in relieving my stress.

19:25PM, Apr 28 - [p 5]: P5, the examples also were good as I never looked at my stress from this side until I read it in the manual.

19:26PM, Apr 28 - [therapist]: Glad that you find the manual helpful and beneficial.

19:27PM, Apr 28 - [therapist]: Does anyone has anything more to add to the discussion?

19:28PM, Apr 28 - [p 15]: P15, not me

19:28PM, Apr 28 - [p 11]: P11, I think we covered the main things.

19:29PM, Apr 28 - [therapist]: Well our discussion is finished, will send you all the intervention fidelity questions and rating of the session, please answer them and send them back to me in private. Thank you and see you next session.

10:33AM, May 4 - [therapist]: Good morning everyone, tomorrow, will be our second meeting at WhatsApp, Please read the Third Session from the manual about child behaviour, my best wishes for you all.

### Appendix 15. Implementation Fidelity Questions (Chapter 6)

# Training programme implementation fidelity questions

**Please tick the box that represents the answer to your question:**

1- Did you have the chance to get engaged with the manual material for this week's session before the meeting? ☐Yes ☐ No

**If you answer with Yes to the first question then proceed to question no. 2. If you answered with No then proceed to question no.3**

2- How much time (in minutes) did you spend engaging with the manual material? ☐

3- On a scale of 1-10 with 1 being unhelpful and 10 very helpful, how helpful you think was today's session? (circle the number)

0 1 2 3 4 5 6 7 8 9
10

Thank you

### Appendix 16. An Example of Therapists' scripts (Chapter 6)

## Week 1 script

Good morning ladies I am very pleased to welcome you to our first session. Alyaa and I are very happy that you have managed to make time to engage with our intervention. We hope you will find it helpful

The aims of this session are for you to have an opportunity to meet me before we carry on supporting you via WhatsApp. It is also an opportunity to help you understand ASD better so that you know why your child with ASD behaves in the way they do. Specifically we are going to discuss

1) We want you to understand about Autism
2) We want you to understand what children with Autism find difficult and why do they behave in the way they do?
3) What causes Autism
4) What is special about Autism
5) The 5 senses
6) The differences between ASD and Asperger

**Questions?**

**Things we don’t want to cover in this session**

Behavioural strategies, stress & coping, practical financial information, and mood.

Things we would prefer not to cover at all. Marital problems, difficulties or concerns about other children in the family unless the parent is concerned that they may have ASD.

## Appendix 17. Measures (Chapter 6)

### Demographic Questionnaire

**Please answer the following questions about yourself**

**1-What is your age?**

**2-What is your child age?**

**3-Do you have children other than the ASD child?**

A-Yes

B-No

If yes then please specify how many and their ages?

**4-Do you have another ASD child?**

A-Yes

B-No

**5-What is the highest level of education you have completed?**

A-Lower than high school

B-High school

C-Bachelor degree

D-Master degree and higher

**6-What is your marital status?**

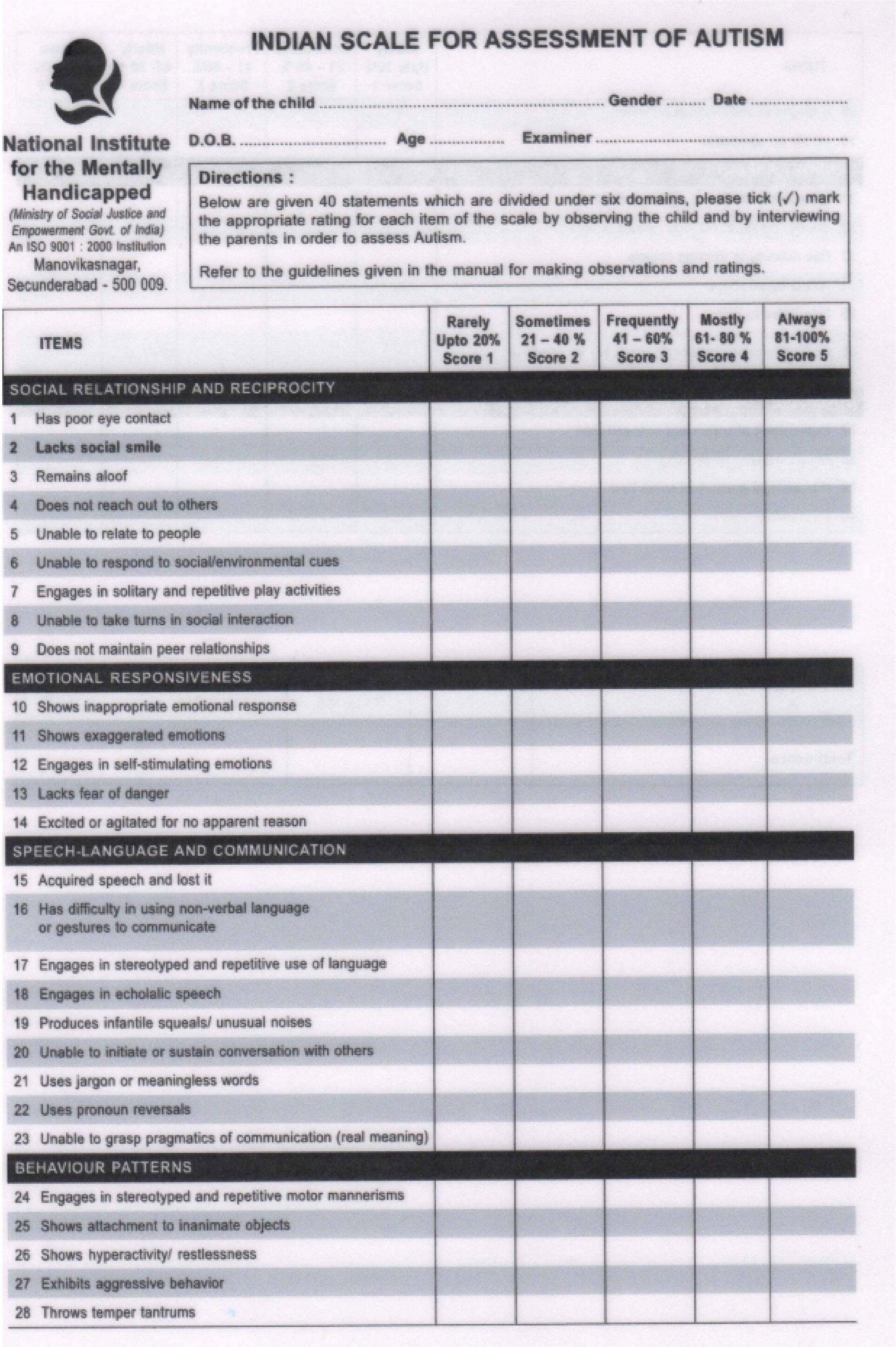
A-Married

B-Divorced

C-Widowed

**7-Do you work? If yes then what is your occupation?**

**8-What is the occupation of the father?**



**National Institute for the Mentally Handicapped**

*(Ministry of Social Justice and Empowerment Govt. of India)*
An ISO 9001 : 2000 Institution
Manovikasnagar,
Secunderabad - 500 009.

# INDIAN SCALE FOR ASSESSMENT OF AUTISM

**Name of the child** .................................................................. **Gender** ......... **Date** ........................

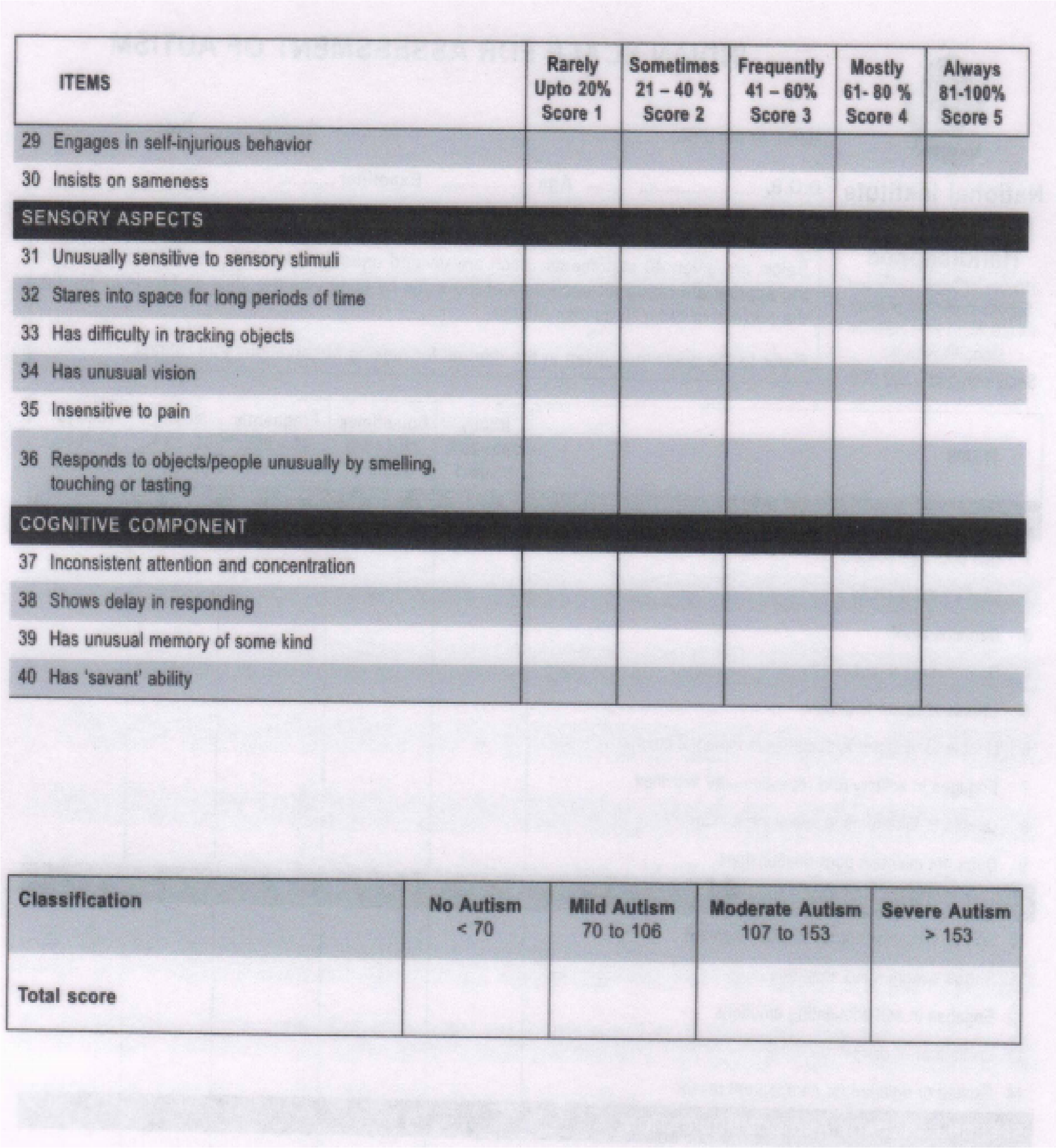
**D.O.B.** .................................. **Age** ................. **Examiner** .........................................................

**Directions :**

Below are given 40 statements which are divided under six domains, please tick (✓) mark the appropriate rating for each item of the scale by observing the child and by interviewing the parents in order to assess Autism.

Refer to the guidelines given in the manual for making observations and ratings.

| ITEMS | Rarely Upto 20% Score 1 | Sometimes 21 – 40 % Score 2 | Frequently 41 – 60% Score 3 | Mostly 61- 80 % Score 4 | Always 81-100% Score 5 |
|---|---|---|---|---|---|
| SOCIAL RELATIONSHIP AND RECIPROCITY | | | | | |
| 1 Has poor eye contact | | | | | |
| 2 **Lacks social smile** | | | | | |
| 3 Remains aloof | | | | | |
| 4 Does not reach out to others | | | | | |
| 5 Unable to relate to people | | | | | |
| 6 Unable to respond to social/environmental cues | | | | | |
| 7 Engages in solitary and repetitive play activities | | | | | |
| 8 Unable to take turns in social interaction | | | | | |
| 9 Does not maintain peer relationships | | | | | |
| EMOTIONAL RESPONSIVENESS | | | | | |
| 10 Shows inappropriate emotional response | | | | | |
| 11 Shows exaggerated emotions | | | | | |
| 12 Engages in self-stimulating emotions | | | | | |
| 13 Lacks fear of danger | | | | | |
| 14 Excited or agitated for no apparent reason | | | | | |
| SPEECH-LANGUAGE AND COMMUNICATION | | | | | |
| 15 Acquired speech and lost it | | | | | |
| 16 Has difficulty in using non-verbal language or gestures to communicate | | | | | |
| 17 Engages in stereotyped and repetitive use of language | | | | | |
| 18 Engages in echolalic speech | | | | | |
| 19 Produces infantile squeals/ unusual noises | | | | | |
| 20 Unable to initiate or sustain conversation with others | | | | | |
| 21 Uses jargon or meaningless words | | | | | |
| 22 Uses pronoun reversals | | | | | |
| 23 Unable to grasp pragmatics of communication (real meaning) | | | | | |
| BEHAVIOUR PATTERNS | | | | | |
| 24 Engages in stereotyped and repetitive motor mannerisms | | | | | |
| 25 Shows attachment to inanimate objects | | | | | |
| 26 Shows hyperactivity/ restlessness | | | | | |
| 27 Exhibits aggressive behavior | | | | | |
| 28 Throws temper tantrums | | | | | |



| ITEMS | Rarely<br>Upto 20%<br>Score 1 | Sometimes<br>21 – 40 %<br>Score 2 | Frequently<br>41 – 60%<br>Score 3 | Mostly<br>61- 80 %<br>Score 4 | Always<br>81-100%<br>Score 5 |
|---|---|---|---|---|---|
| 29 Engages in self-injurious behavior | | | | | |
| 30 Insists on sameness | | | | | |
| SENSORY ASPECTS | | | | | |
| 31 Unusually sensitive to sensory stimuli | | | | | |
| 32 Stares into space for long periods of time | | | | | |
| 33 Has difficulty in tracking objects | | | | | |
| 34 Has unusual vision | | | | | |
| 35 Insensitive to pain | | | | | |
| 36 Responds to objects/people unusually by smelling, touching or tasting | | | | | |
| COGNITIVE COMPONENT | | | | | |
| 37 Inconsistent attention and concentration | | | | | |
| 38 Shows delay in responding | | | | | |
| 39 Has unusual memory of some kind | | | | | |
| 40 Has 'savant' ability | | | | | |

| Classification | No Autism<br>< 70 | Mild Autism<br>70 to 106 | Moderate Autism<br>107 to 153 | Severe Autism<br>> 153 |
|---|---|---|---|---|
| Total score | | | | |

# Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

Child's Name ...................................................................................... Male/Female

Date of Birth........................................................

| | **Not True** | **Somewhat True** | **Certainly True** |
|---|---|---|---|
| Considerate of other people's feelings | ☐ | ☐ | ☐ |
| Restless, overactive, cannot stay still for long | ☐ | ☐ | ☐ |
| Often complains of headaches, stomach-aches or sickness | ☐ | ☐ | ☐ |
| Shares readily with other children (treats, toys, pencils etc.) | ☐ | ☐ | ☐ |
| Often has temper tantrums or hot tempers | ☐ | ☐ | ☐ |
| Rather solitary, tends to play alone | ☐ | ☐ | ☐ |
| Generally obedient, usually does what adults request | ☐ | ☐ | ☐ |
| Many worries, often seems worried | ☐ | ☐ | ☐ |
| Helpful if someone is hurt, upset or feeling ill | ☐ | ☐ | ☐ |
| Constantly fidgeting or squirming | ☐ | ☐ | ☐ |
| Has at least one good friend | ☐ | ☐ | ☐ |
| Often fights with other children or bullies them | ☐ | ☐ | ☐ |
| Often unhappy, down-hearted or tearful | ☐ | ☐ | ☐ |
| Generally liked by other children | ☐ | ☐ | ☐ |
| Easily distracted, concentration wanders | ☐ | ☐ | ☐ |
| Nervous or clingy in new situations, easily loses confidence | ☐ | ☐ | ☐ |
| Kind to younger children | ☐ | ☐ | ☐ |
| Often lies or cheats | ☐ | ☐ | ☐ |
| Picked on or bullied by other children | ☐ | ☐ | ☐ |
| Often volunteers to help others (parents, teachers, other children) | ☐ | ☐ | ☐ |
| Thinks things out before acting | ☐ | ☐ | ☐ |
| Steals from home, school or elsewhere | ☐ | ☐ | ☐ |
| Gets on better with adults than with other children | ☐ | ☐ | ☐ |
| Many fears, easily scared | ☐ | ☐ | ☐ |
| Sees tasks through to the end, good attention span | ☐ | ☐ | ☐ |

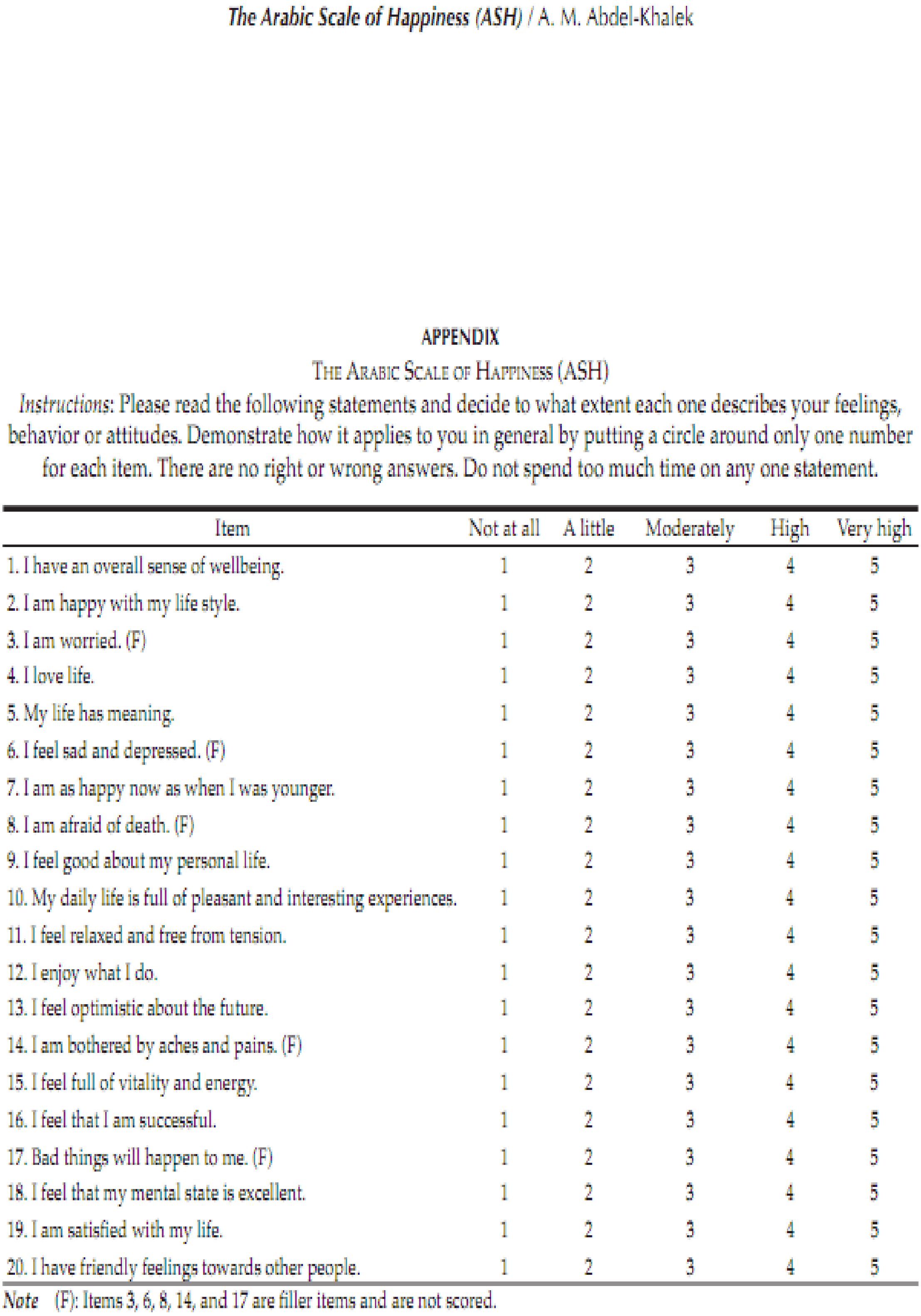
Signature ............................................................................ Date ............................................................................

Parent/Teacher/Other (please specify:)

**Thank you very much for your help**

# Parent stress index-short form (PSI-SF)

# Hospital Anxiety and Depression Scale (HADS)



*The Arabic Scale of Happiness (ASH)* / A. M. Abdel-Khalek

## APPENDIX

### THE ARABIC SCALE OF HAPPINESS (ASH)

*Instructions*: Please read the following statements and decide to what extent each one describes your feelings, behavior or attitudes. Demonstrate how it applies to you in general by putting a circle around only one number for each item. There are no right or wrong answers. Do not spend too much time on any one statement.

| Item | Not at all | A little | Moderately | High | Very high |
|---|---|---|---|---|---|
| 1. I have an overall sense of wellbeing. | 1 | 2 | 3 | 4 | 5 |
| 2. I am happy with my life style. | 1 | 2 | 3 | 4 | 5 |
| 3. I am worried. (F) | 1 | 2 | 3 | 4 | 5 |
| 4. I love life. | 1 | 2 | 3 | 4 | 5 |
| 5. My life has meaning. | 1 | 2 | 3 | 4 | 5 |
| 6. I feel sad and depressed. (F) | 1 | 2 | 3 | 4 | 5 |
| 7. I am as happy now as when I was younger. | 1 | 2 | 3 | 4 | 5 |
| 8. I am afraid of death. (F) | 1 | 2 | 3 | 4 | 5 |
| 9. I feel good about my personal life. | 1 | 2 | 3 | 4 | 5 |
| 10. My daily life is full of pleasant and interesting experiences. | 1 | 2 | 3 | 4 | 5 |
| 11. I feel relaxed and free from tension. | 1 | 2 | 3 | 4 | 5 |
| 12. I enjoy what I do. | 1 | 2 | 3 | 4 | 5 |
| 13. I feel optimistic about the future. | 1 | 2 | 3 | 4 | 5 |
| 14. I am bothered by aches and pains. (F) | 1 | 2 | 3 | 4 | 5 |
| 15. I feel full of vitality and energy. | 1 | 2 | 3 | 4 | 5 |
| 16. I feel that I am successful. | 1 | 2 | 3 | 4 | 5 |
| 17. Bad things will happen to me. (F) | 1 | 2 | 3 | 4 | 5 |
| 18. I feel that my mental state is excellent. | 1 | 2 | 3 | 4 | 5 |
| 19. I am satisfied with my life. | 1 | 2 | 3 | 4 | 5 |
| 20. I have friendly feelings towards other people. | 1 | 2 | 3 | 4 | 5 |

*Note* (F): Items 3, 6, 8, 14, and 17 are filler items and are not scored.

## Appendix 18. Information Sheet and Consent Form (Chapter 6)

University of Nottingham

School of Medicine

Division of Psychiatry

Institute of Mental Health

**Triumph Rd**

**Nottingham**

**NG7 2TU**

### Evaluating the Efficacy of a Proposed Training Programme to Reduce Stress in Mothers of Children with Autism Spectrum Disorder (ASD) in Saudi Arabia: A pilot Study

**Name of Investigators**: Alyaa Hemdi and Professor David Daley

Participants' Information Sheet

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends and relatives if you like. This study is being undertaken by **Alyaa Hemdi**, PhD student, as part of the degree of Doctorate of Philosophy in Psychiatry & Applied Psycholgoy at the University of Nottingham. Professor David Daley is supervising Alyaa in this study. Please contact Alyaa to ask about anything that is not clear or if you would like more information. Alyaa's contact information is provided below. Take time to decide whether you wish to take part or not. If you decide to take part you may keep this leaflet. Thank you for reading this.

### Background

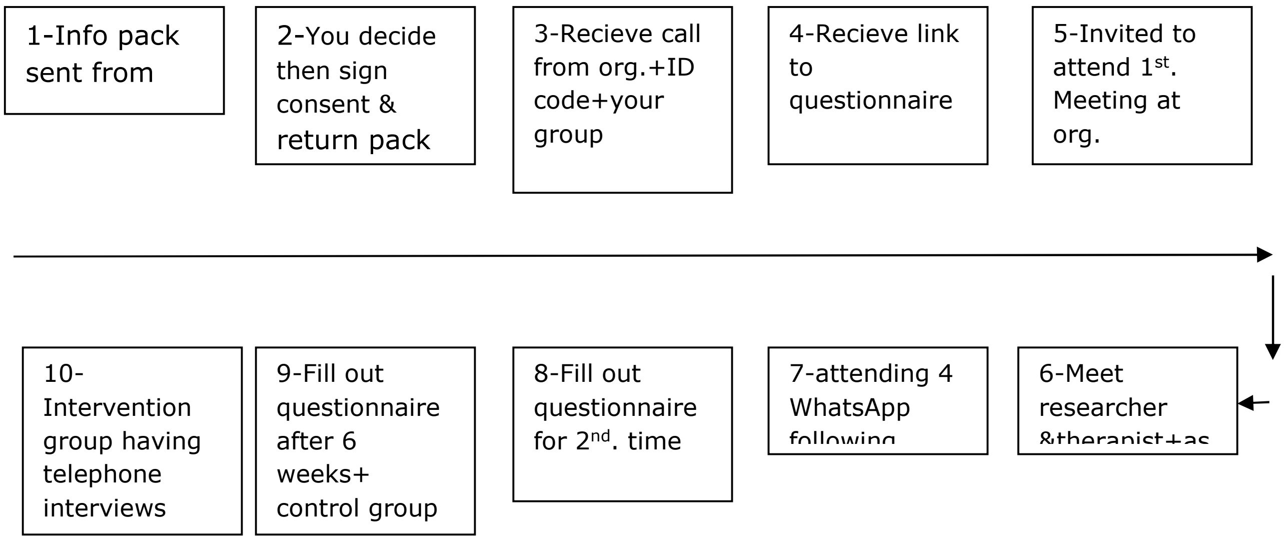
Parenting a child with ASD can be very stressful for mothers. This study aims to evaluate the effect of a proposed training programme in reducing stress in mothers of ASD children in Saudi Arabia SA. Your experience as a mother of a child with ASD can be very informative for research and it is hoped that the results of this study will provide information about how training for mothers of children with ASD can be improved.

**What does the study involve?**

We aim to recruit at least 70 mothers of ASD children from four different voluntary sector autism organisations in Saudi Arabia whose children are at the early intervention stage programme at the organisations. This research study will last for a year; however, each participant's involvement will last for ten weeks starting from the first training session and ending with the follow-up phase of data collection. Because we do not know the usefulness of the proposed training programme for participants, therefore, participants will be put into two groups and then compared (one group is called intervention group who will receive the training first and the other group is called control group which will eventually receive the same training when the intervention group finishes their involvement in the study). The participants will be selected to join either groups are selected randomly without knowing their names. Your chance to joint the intervention group is one in two chance.

Participants in the intervention group will attend five training sessions in four weeks starting the first session as face to face meeting with an autism therapist at the voluntary organisations participants were recruited from. The other four sessions following the first one will be through whatsapp application on smart phones. Therapists at the first face to face session will discuss the time for the whatsapp meetings. Each meeting will last for 30 minutes. Participants will be asked to fill an online questionnaire (measuring parental stress, depression, happiness, ASD severity, and child problem behaviours) before they join the first session. Before each session participants will be expected to read the training manual for that week's session which will take approximately 25-30 minutes to finish reading. When they join the whatsapp group, they can discuss the topic and concerns of that week session and ask questions to the therapist if they have any. At the end of each whatsapp session, therapists will send few questions to participants about their involvement with the training material and the usefulness of the session. This will be answered on whatsapp and sent back to the therapist. After the end of the last training session, therapists will send link to the questionnaire to be filled out. This is the same questionnaire that participants completed at the beginning of the study. They will also be asked to fill it for the third time after six weeks from the end of last session. This will help the researcher to see the maintenance effect of the training participants received. If the participant does not want to fill out the online version of the questionnaire, they can ask the therapist to provide them with a paper version. The use of the questionnaire is never intended to give any clinical diagnosis for the mother or her child, it will be used only be the research to see the differences in parental outcomes and evaluate the usefulness of the training programme.

Mothers will then be interviewed by the researcher over the telephone for 25 minutes asking them about their experiences with the training sessions; their evaluation of the therapist delivering the training; the training manual and their overall experiences participating in the study and how things can be improved in future research . The interviews will be digitally recorded. It is your choice as to how much you like to talk about each question and you are free to avoid answering any one if you find it difficult to discuss.



**Why have you been chosen?**

You have been chosen because you are a mother of a child with ASD in Saudi Arabia whose child is attending an early intervention class at the autism organisation. The researcher will aim to recruit 70 participants for this study.

**Do you have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you

decide to take part you are still free to withdraw at any time during the study and without giving a reason.

**What do I have to do**?

If you wish to be involved in this study, complete the enclosed ‘consent form’ and return it in the pre-paid envelop or handed it to the secretary of the organisation (whatever is convenient for you). You will then be contacted by a personal from the organisation to give you an ID code that you will use during whatsapp meetings and when filling out the questionnaire. This step has been taken to ensure your confidentiality. The organisations personal will let you know if you will be part of the intervention group or the control waiting group (you have been randomly allocated). If you are one of those participating in the intervention group then you will be invited to attend the first session. You will also be asked to fill out a questionnaire by sending you an online link for it (if you do not want to fill the online version, a paper one can be provided to you upon request). At the first session, you will meet Alyaa briefly at the beginning as she will introduce the study and answer participants’ questions. After that,Alyaa will leave and the therapist will start the first session. The therapist will arrange for a suitable time to arrange a convenient time for the following whatsapp meetings. You will be expected to spend sometime reading the manual material before each session which will take around 25 minutes of your time. During the session, you can ask questions and contribute to discussion. At the end of each meeting, the therapist will send you few questions about your involvement with the manual materials and evaluating the usefulness of the session. You will answer the questions and send them back to the therapist on the same day after the end of the session. At the end of the training programme, the therapist will send you a link of the same questionnaire you filled out at the beginning of the study. You will be asked by the therapist to fill out the same questionnaire for the third time after six weeks following the end of the last session. Once you submit your questionnaire, you will be contacted by Alyaa to arrange for a suitable time for a telephone interview. You will be interviewed over the phone and the interview will be digitally recorded. If you said something at the interview and then changed your mind then I will erase it from the recording at your request. The data collected from the interview will be anonymised and all the audio files will be destroyed. You will be given a copy of this information sheet and a signed consent form to keep for yourself.

**What are the side effects of any treatment or procedures received when taking part?**

There are no real side effects of taking part in this study.

**What are the possible disadvantages and risks of taking part?**

While we do not envisage any risks or disadvantages in taking part in this study we do however appreciate that you will be giving up some of your time to assist me with my research. We are aware that the topics covered in the study may be sensitive and if any part of the study causes you any distress, you can ask the therapist to stop for a while and you will have the choice weather to continue or not. However, if you require any further support, you will be redirected to the voluntary organisation to provide advice regarding further appropriate support.

**What if there is a problem?**

In the first instance please contact Mrs.Omaima Olaqy, Joint Supervision Program, King Abdulaziz University, Jeddah, 21589, Saudi Arabia. Telephone 012XXXXXX. Email: XXXXXXX.edu.sa. She will pass your concerns to Professor David Daley, Division of Psychiatry, Institute of Mental Health, Triumph Road, Nottingham University Innovation Park,Nottingham,NG72TU.Telephone0115XXXXXX,Email:XXXXXX@nottingham.ac.uk. and Mrs. Louise Sabir, the Research Ethics Committee Administrator, c/o The University of Nottingham, School of Medicine Education Centre, B Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH. E-mail: XXXXXXX@nottingham.ac.uk

**Will my taking part in this study be kept confidential?**

Yes. All the information you share with us during the study will be anonymised and treated as highly confidential. This data will only be seen and analysed by the researcher (Alyaa Hemdi) and the researchers' supervisor (Professor Daley). If your information is seen, analysed or transported by other research members, your personal details such as name and address will be destroyed. Data will be made anonymous and securely stored in a secure database belonging to the University of Nottingham.

**What will happen to the results of the research study?**

The results will provide the evidence required to evaluate the efficacy of the proposed training programme on reducing stress for mothers of ASD children in SA. The results of this study will likely be published once it is ready for publication. The researcher will notify you once it is published and if you wish to obtain a copy of the published results then arrangements will be made with the researcher to deliver it to you. You will not be identified in any publication.

**Who is organising and funding the research?**

The University of Nottingham.

**Who has reviewed the study?**

This study has been reviewed and approved by the University of Nottingham Medical School Ethics Committee. It has been also approved by the ethics committee at King Abdulaziz University in Jeddah.

This study will be conducted in Saudi Arabia under the supervision and approval of King Abdul Aziz University.

**Contact for Further Information**:

**The researcher**: Alyaa Hemdi,Division of Psychitry, Institute of Mental Health, Triumph Road, Nottingham University Innovation Park, Nottingham, NG7 2TU. Telephone: XXXXXXXXXXx, Email: XXXXXXX@nottingham.ac.uk (Correspondence in English or Arabic

**Researchers' supervisor**:Professor David Daley, Division of Psychiatry, Institute of Mental Health, Triumph Road, Nottingham University Innovation Park, Nottingham, NG7 2TU. Telephone XXXXXXXXX, Email: XXXXXXXX@nottingham.ac.uk. (correspondence in English only)

***University of Nottingham,***
***School of Medicine,***
***Davison of Psychiatry and Applied Psychology***

**Title of Project**: Evaluating the Efficacy of a Proposed Training Programme to Reduce Stress in Mothers of Children with Autism Spectrum Disorder (ASD) in Saudi Arabia: A pilot Study

**Name of Investigators**: Alyaa Hemdi and Professor David Daley

## Participants' Consent Form

Please read this form and sign it once the above named or their designated representative, has explained fully the aims and procedures of the study to you

- I voluntarily agree to take part in this study. ☐
- I confirm that I have been given a full explanation by Alyaa Hemdi and that I have read and understand the information sheet given to me which is attached. ☐
- I have been given the opportunity to ask questions and discuss the study with one of the above investigators or their deputies on all aspects of the study and have understood the advice and information given as a result. ☐
- I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports ☐
- I understand that whatsapp group discussion is a shared domain and that all other participants will be able to see the discussion but not my name as I will use my ID code ☐
- I understand that online questionnaire are not totally anonymous but I will use my ID code so my questionnaire will not have my name or any identification information ☐
- I understand that I might be either in the intervention group who will receive the training immediately or the waiting group which will receive the training at the end of the study 10 weeks after the other group has received it. ☐
- I agree to the above investigators contacting my general practitioner [and teaching or university authority if appropriate] to make known my participation in the study where relevant. ☐

- I agree to comply with the reasonable instructions of the supervising investigator and will notify him immediately of any unexpected unusual symptoms or deterioration of health. ☐
- I authorise the investigators to disclose the results of my participation in the study but not my name. ☐
- I understand that information about me recorded during the study will be kept in a secure database. If data is transferred to others it will be made anonymous. Data will be kept for 7 years after the results of this study have been published. ☐
- I understand that I can ask for further instructions or explanations at any time. ☐
- I understand that I am free to withdraw from the study at any time, without having to give a reason for withdrawing. ☐
- I confirm that I have disclosed relevant medical information before the study. ☐

**Name:**

……………………………………………………………………………………………

**Address:**

…………………………………………………………………………………

……….. **Telephone number**: ……………………………….

**Signature:**…………………………………………………………………………….

**Date:** ………………………………………….

I confirm that I have fully explained the purpose of the study and what is involved to:

…………………………………………………………………………………………………….

I have given the above named a copy of this form together with the information sheet.

**Investigators Signature:** ……………………….. **Date**: ………………………………

**Investigators Name:**… ………………

**Study participant Number**: …………………………………………………………

**Appendix 19. Intervention Manual**

# Intervention Manual

## A Proposed Intervention to reduce Stress for Mothers of Children with ASD in Saudi Arabia

**By**

**Alyaa Hemdi**

# Content page

# A Proposed Intervention to reduce stress for Mothers of Children with ASD in Saudi Arabia

## Introduction

***Parents who used the strategies that we have included for you in our brief intervention have found that when they work hard to apply them they are very helpful.***

**This intervention will be delivered in five sessions through a Whats app group that will be managed and run by an ASD therapist. Please take your time before each session to read the handouts for that session and be prepared to share your thoughts and questions with other group members during the session.**

## The five sessions will focus on

1) **What is Autism Spectrum Disorder (ASD)?**
2) **Stress and coping**
3) **Behaviour problems and modification strategies**
4) **Mood**
5) **Resources for families and intervention summary and conclusion**

# Session 1: What is Autism?

## About autism

There are many people with autism in Saudi Arabia. About 0.6% of children in the country have autism[2].

You cannot always tell that someone has autism just by looking at them. Because of this autism is sometimes called a hidden disability.

Autism lasts for all of a person's life. But they can still do a lot of things and learn a lot of skills.

Autism is a complex neurodevelopmental disorder, marked by multiple symptoms that include difficulties in:

1. Social interactions (i.e. children with autism would often find it difficult to understand others' mental states and emotions [mind blindness], and respond accordingly).

**Example of mind blindness**

*Ahmad is a child with autism. His teacher shows him a crayon box and asks Ahmad what he thinks is inside. He will usually say 'crayons!' The teacher then reveals that it is full of pins-not crayons. The teacher then invites another child whose name is Ali in the class and says to Ahmad, 'What will Ali say if I ask him what is inside the crayon box?' Because Ahmad has mind blindness due to ASD, he will say 'pins' as Ahmad does not appreciate the fact that Ali does not know about the content of the crayon box as himself. Ahmad sees the crayon box from his point of view and has difficulty viewing it from Ali's*

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[2] Al Jarallah, A., Al Waznah, T., Al Ansari, S., & Al Hazmi, M. (2005). Studying autism and related developmental disorders (G. p. g. section, Trans.). Riyadh: King Saudi University.

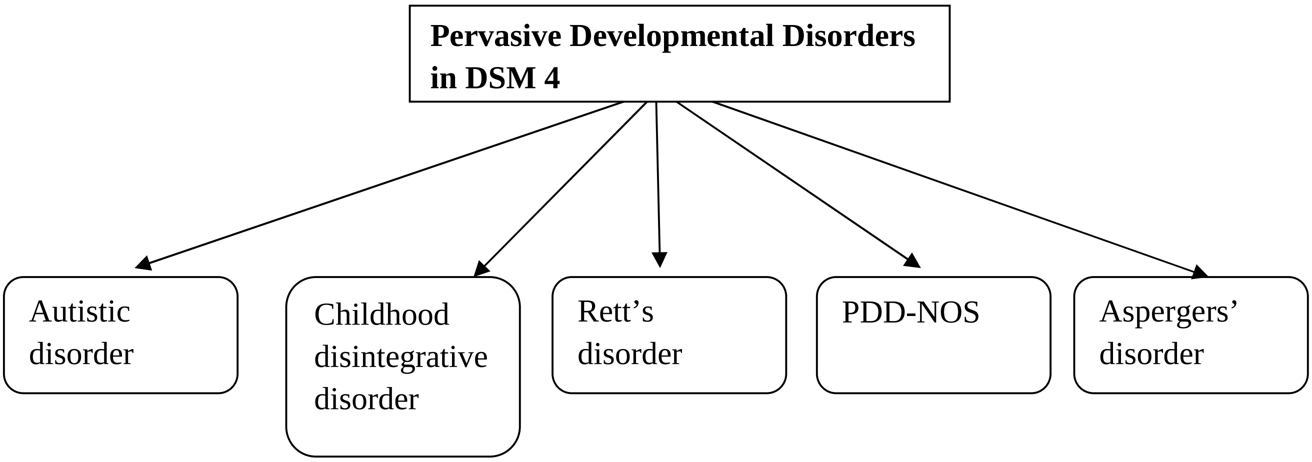
2. verbal and non-verbal communication (i. e. people with autism may have poor use of gestures and understanding of other people emotions, and some may echo words and phrases or use unusual tone or accents).

3. Repetitive behaviour and restricted interest (i.e. people with autism might repeat certain words or actions over and over, usually in a rigid rule-governed manner; some children get really attached to certain toys or cloth).

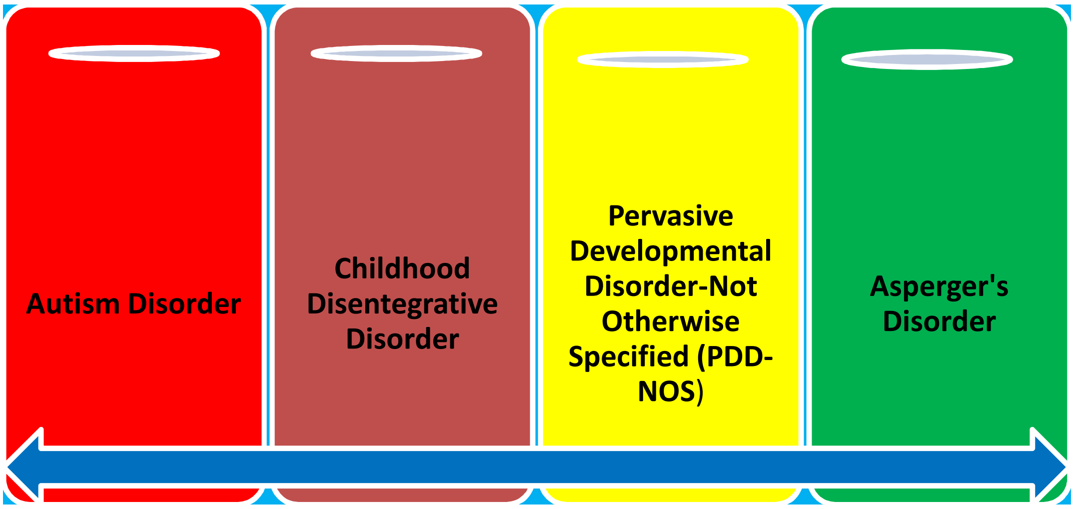
4. Autism might or might not be accompanied by language delay.

5. May or may not be accompanied by intellectual disability.

According to the previous diagnosis in the Diagnostic and Statistical Manual DSM 4 (a manual used by professionals to diagnose several psychiatric disorders), autism was under pervasive developmental disorders together with childhood disintegrative disorder, Rett's disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger's disorder.



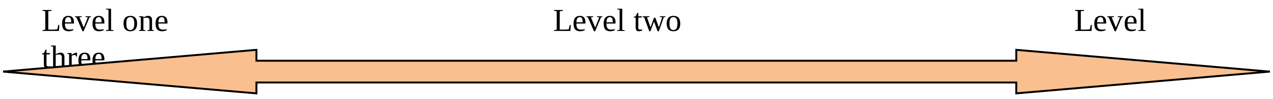
However, in the new manual DSM-5 published in 2013, autism together with childhood disintegrative disorder, (PDD-NOS), and Asperger's syndrome were all grouped under one broad category called 'autism spectrum disorders' (ASD).



Autism spectrum disorder in DSM-5

There is a wide variability in the degree to which autistic symptoms manifest themselves, leading to the use of the term 'autism spectrum disorders' (ASD). There are three severity levels of ASD in DSM-5:

- Level one: requiring support
- Level two: requiring substantial support
- Level three: Requiring very substantial support



Severity levels of ASD

## DSM-5 Criteria for diagnosing ASD (APA, 2013)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

   1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
   2. Deficits in nonverbal communicative behaviours used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
   3. 
   4. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify* current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behaviour.**

B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

   1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify* current severity:

**Severity is based on social communication impairments and restricted, repetitive patterns of behaviour**.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

**APA, A. P. A. (2013). *Diagnostic and Statistical Manual of Mental Disorders: Dsm-5*: Amer Psychiatric Pub Incorporated.**

## What causes autism?

No one knows why children develop autism.

**If your child has autism, it is not because you are a bad parent**.

More than 1 person in a family may have autism. One of the explanations is that Autism is genetic. This means the risk of autism can pass from parents to their children.

However we still don't really know which genes are important and there is very little we can do about the genes we get from our parents, except live with what we have received.

## What we now know about the causes of autism?

Research studies show Autism is in part genetic. However the genetics of ASD is very complex and it wouldn't be possible to conduct genetic testing to identify whether a child was at risk of developing ASD or not.

The causes of autism are still unknown. Experts believe that autism is caused by an interaction between several complex genetic and environmental factors. However, at present these factors are not properly understood.

However what is known now is that Autism is not caused by giving your child the MMR vaccination. Also while environmental factors many influence your child's ASD symptoms, Dietary factors such as supplementary omega 3 and 6 (pumpkin diet for example) are not yet evidenced based and so are not recommended at present.

## Things that children with autism find difficult

- They find it difficult to tell their parents what they need, and express their feelings.

- They find it difficult to make friends, and pleasure with others.
- They find it difficult to understand what other people think, and how they feel (for example, they can not tell when people are angry).
- They find it difficult to start a conversation with people or carrying it on.
- They find it difficult to imagine and role play (i.e. a child with autism may not be able to play with medical kits toy and imagine himself to be a physician).

Not all children with autism will find these things difficult. This is because all children with Autism are different. Each and every child is unique with different abilities and needs.

## How do people with autism behave?

- They may not speak. But they may use things like pictures or sign language to communicate.
- They may not understand what other people are saying or tend to take things literally (i.e. when somebody asks you about the weather and you say ‘I am boiling’ they may think that you are literally boiling like a water boiling on the stove).
- They may copy what other people say.
- They may only talk about their favourite subject.
- They may not like to socialize with other people.
- They may like to play the same game every day.

## What else is special about autism?

- They may find muscle co-ordination difficult. This means that they may find it difficult to do things like use scissors, or ride a bike.
- They may be very good at something. For example, they may be very good at maths or art.
- They can be good at learning how to do something when they see someone else doing it.
- They may be good at concentrating on one activity.
- They may have learning disabilities and or ADHD.
- They may have other difficulties. For example, they may have dyslexia( reading difficulty).

## How can autism affect someone's senses?

**Sight**
Some people with autism may or may not like bright lights and colours.

**Sound**
Some people with autism may not like loud noises. Other people with autism might like certain noises (like door bill ring).

**Smell**
Some people with autism may or may not like some smells.

**Touch**
Some people with autism may or may not like being touched.

**Taste**
some people with autism may like to eat the same food every day. Other people with autism may refuse to eat certain food types.

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## Asperger's disorder:

There is a type of autism called Asperger's disorder.

People with Asperger's disorder do not have significant delay in language development and cognitive abilities but they share with people with autism their repetitive and restricted behaviours. Some people with Asperger syndrome find these things difficult.

- They may find it difficult to tell people what they need, and how they feel.
- They may find it difficult to meet other people and to make new friends.
- They may find it difficult to understand what other people think, and how they feel.
- They may find it difficult to change routines (i.e. they need to go to bed every day on the same time, hearing the same story and holding the same doll and be covered with the same blanket).
- They may show repetitive body movements.
- They may be obsessed with patterns.

**End of session one**

# Session 2: Stress and coping

## WHAT IS STRESS?

- Stress is a word that we commonly use to describe the variety of often-unpleasant emotions that we feel when we feel we are under pressure. This pressure can come from a variety of sources, including:
- The work place (e.g., when your workload becomes too high for you to possibly cope)
- Home (e.g., financial difficulties, child behaviour)
- We may even exert pressure on ourselves (eg ensuring your child does well in life).

As you can see, stress can arise both out of different events/situations (e.g., the workplace) while it can also arise from our feelings about different events/situation, (e.g., trying always to ensure your child succeeds).

Therefore, it is not always just the situation that causes us to feel stressed. If this were the case, we would expect everyone to respond to the same stressful situation in exactly the same way, all of the time. It is our

*Ali is a child with autism who usually has tantrum. His mother is expecting her in laws visit shortly. They are going to stay in their house for few days and she is busy arranging the house. At the same time she is worried that Ali would have a tantrum in front of her in laws and embraces them. Suddenly and while Ali is playing he started to knock the door but he is calm, however, his mother gets really upset and started*

**understanding of and response** to the situations that leads to stress.

We have probably all had times where we have reacted to exactly the same situation in completely different ways .

Our reaction depends on what is happening around us, but will also depend on how we are feeling at the time. The way that we think about a particular situation will also influence how we react to it.

## Try this exercise:

Think about what stress means to you. "What do you mean when you say you are stressed"

Feelings (e.g., feeling on edge)

Thoughts (e.g., I can't cope)

Behaviours (e.g., talking faster)

Events (e.g., battles with my child’s school)

Physical Responses (e.g., muscle tension, shakiness)

Generate a list of definitions on a piece of paper. Highlight which of these responses are *thoughts*, *feelings*, *behaviours* and *physical responses* to stress

*Halah is a university student who did not perform well in her midterm exams . She is in a very low mood as she can not do anything about the situation except waiting for the results. Her phone is ringing, she answered and it is her sister asking her what dress is she going to wear in their cousin’s wedding next week, she got really frustrated and told her sister that she does not care about what she is*

## Why are we stressed: Fight or flight?

- We all need to understand why we are stressed. Over thousands of years, we have developed a response to danger called fight or flight. When we experience threats or danger, either we fight it or we flee (run away).
- However, in a modern context we usually can not fight or flee. Imagine you are on your way to the airport and your car is stuck in a large traffic jam. You can't fight (i.e. shout at your driver) and there is nowhere to flee, so the only alternative is to sit in the car in the traffic jam and get stressed as you worry about missing your flight and the cost and inconvenience that this will cause.

- We also know that stress can affect the way we parent, and our ability to deal with problem situations with our children (especially when we become so stressed that we deal with problem situations in unproductive ways that make stressful situations worse).

**Here is a five steps plan to help deal with stress as a parent**

## Step One: Defining the Problem

- Try not to accuse or blame others
- Try to see it not as a problem but as a challenge

## Step Two: Generating a Variety of Alternative Solutions

- Brainstorm possible solutions
- List as many solutions as possible

- Don't evaluate solutions at this stage

### Step Three: Evaluating Ideas and Selecting the Best One

- Evaluate each solutions one after the other
- Are your solutions practical?
- Sometimes the best thing to do is nothing except say a prayer!
- Sometimes the best thing is to accept the situation
- Rank solutions from best to worst.

### Step Four: Planning to Implement the Selected Solution

- Look in more detail at chosen solution.
- Decide upon a solution
- Implement the solution.

### Step Five: Did your solution work?

- How could you make further Improvements

- Do you need to do something else such as seek advice from someone you trust

**Remember there are other ways in which you can reduce your stress levels**

- Reading Qur’an and pray
- Relaxation
- Health diet
- Exercise

- Sleep

# Session three

# Managing behaviour

- All children display behaviour problems in different situations which would affect their parents and let them doubt their parenting abilities.
- For children with ASD the situation is different in that sometimes children display the behaviour to express their unmet needs as they might not, because of their mind blindness (refer to session one), understand that they have to ask for something (i.e. a child with ASD will have tantrum at the dinner table because he is hungry and wants food immediately but does not know that he has to ask his mother which forces him to go into tantrum).

In order for you to know how to manage your child behaviours, it will be helpful to understand first the reasons why the child is displaying that behaviour in the first place.

Behaviours occur within context. Things that happen before, during, and after the behaviour will have an impact on whether the behaviour will happen again in the future or not.

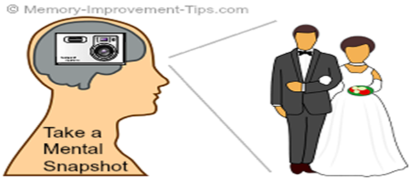
*Ahmad is a typically developing child, he sees some candies at the checkout in the supermarket. He picks some sweets and his mother told him to put it back and she said 'No sweets Ahmad'. He starts crying then his mother says o.k. just this time'.  It might be that Ahmad was hungry at that time so he asked for the sweets or he just likes sweets. The mother reaction to his crying by allowing him to have the sweets may reinforce his crying behaviour for anything he will ask for in the future because he knows it works! Just ignoring his cry might have*

As all ASD children are different it would be impossible to tell you exactly which strategy to use and when.  Instead we encourage you to look closely at your child and their behaviour and select the strategy that you think is most appropriate **( you know your child better than anyone else!)**

We strongly encourage you to experiment, try strategies in different contexts and don't be afraid of **<u>getting things wrong</u>**

## Behaviour management strategies:

### Snap shotting



Before you can do anything else you need to being to understand your child and their behaviour.  This we call snap shotting and you will be pleased to hear it is very easy to do!

To snap shot all you need to do is

- Take a brief moment to look at your child
- Ask yourself what are they doing/feeling/asking
- Take a picture in your mind of  what they are doing/feeling/asking

If you do this fequently throughout the day you will find it easier to understand how your child thinks and feels and why they behave in the way that they do.

## Distraction

We all know how difficult and distressing child tantrums are.  Therefore if and when you notice that your child is about to get upset or have a tantrum, it is much better to distract them at as early stage as possible. The earlier you use distraction the greater the likelihood that upset and distress will be avoided.

| **Verbal Distractions distractions** | **non-verbal** |
|---|---|
| Ask them a question | Play some music |

Point out something them

tickle them

Offer them a drink
you like

Give them a hug if

Offer them a soft toy

Or anything that you know will work for them

## Preparing your child for change (giving reminders)

Lots of children with ASD do not notice the clues that an event is about to happen. For example they won't notice that their mum is wearing her Abaya in prepation to leave the house. Parents therefore need to help to prepare their child with ASD for little changes such as leaving the house or staying at home while their mum goes out.

What we recommend is that children with ASD get three reminders before any event. The reminders can be verbal like one in the example below or non-verbal using picture cards. For example

i) We are going to the shopping mall in five minutes,

ii) We are going to the shopping mall in three minutes

iii) We are going to the shopping mall in one minute please put on your sandals.

This strategy like all strategies doesn't work all of the time, but if your child does have a tantrum before they don't want to go to the shopping mall, at least the tantrum happens five minutes before you need to leave the house.

## Praise

Praising your child is very very important. As a parent you need to recognise and praise behaviours that you would like to see your child engage in more often, and never praise behaviours that you don't want your child to display (hitting, spitting etc).

Praise can be verbal or non verbal

| **Verbal praise** | **Non-verbal praise** |
|---|---|
| Well done | Thumbs up |
| Good job | High five |
| Good boy | hugs |
| I am really pround of you | Smiles |
| | Small food treats |

Or anything that you know will work for them

- A wonderful way to increase the amount of praise that your child receives is to ear shot. I know that sounds like a strange term but it is very easy to understand! To ear shot means to say good things about your child to someone else when you know they are able to hear you. For example when your husband come home make sure you tell him while your child is listening something wonderful that your child has done that day (e.g., the child sat and listened to a story, drew a lovely picture etc).

# Reward charts

I BELONG TO A SPECIAL PERSON CALLED

| | Cleaning my room | Picking up my toys | Completing my chores | Sharing my toys | Special rewards |
|---|---|---|---|---|---|
| MONDAY | | | | | |
| TUESDAY | | | | | |
| WEDNESDAY | | | | | |
| THURSDAY | | | | | |
| FRIDAY | | | | | |
| SATURDAY | | | | | |
| SUNDAY | | | | | |

10 stars means this special treat! ____________

Reward charts are small tables onto which you stick stars or stickers that you child has won for engaging in a specific behaviour, once your child has gained an agreed number of stars or stickets they receive a reward. Rewards charts are very helpful and powerful ways to shape your child's behaviour. Rewards chart really do work if you follow these few simple rules

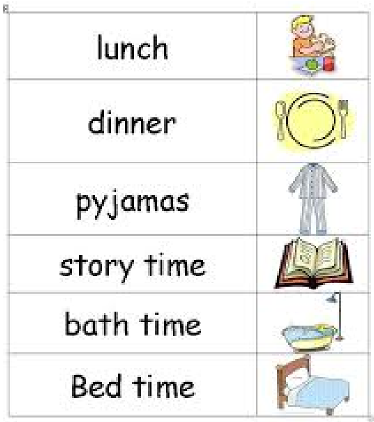
- Agree on the behaviour that is going to be focused on with your child such as sitting quietly at the table or brushing their teeth.
- Make the behaviour very specific such as brushing teeth rather than very general such as being good all day long!
- Keep the reward chart short, no more than 5 days
- Make sure the rewards at the end of the chart is agreed with the child, and is desirable to the child
- When the child get the right number of stars to claim their rewards, make sure the reward is made available straight away

*As a parent think carefully about what sort of reward you are going to promise, for example don't promise to bake your child's favourite cake, if in 5 days time you might not feel like baking.

*Remember that reward chart is for a specific behaviour such as brushing teeth or sitting nicely at the table. If you child engages in the behaviour then they get a star or sticker on their chart. If they are badly behaved in other ways then you should give them a punishment of some kind but do not take away stars or stickers as a punishment

## Visual timetables

A visual timetable uses pictures or words to break down steps of a task or the daily routine. Each item is usually placed in a row or a coloum. This strategy is widely used in autism organisations. There is a way to show that the child have finished the task and is moving to something else. It may be by crossing the finished activity or removing the picture card from the row of activities.



| | |
|---|---|
| lunch | |
| dinner | |
| pyjamas | |
| story time | |
| bath time | |
| Bed time | |

**Benefits of visual timetables for ASD children:**

- ASD children with language difficulties may benefit greatly from visual timetables because of the extra time they allow them to think and process the information.
- It helps in reducing anxiety in children with ASD as they will know in advance what to expect
- It helps in building independence as children are capable of reading their own charts and moving from one actibity to the other.

## Calm down

- Lots of parents use a strategy called “time out” with their children with ASD. Time out is when you want to stop undersirable behaviour so you put the child in a corner or separate room for several minutes to reflect on their bad behaviour. We don’t advise this strategy for children with ASD as it tends not to work and parents and children find it very stressful.

- Instead we would recommend calm down where mothers can identify signs that their child is becoming distressed immediately encourage their child to come and sit on a calm down spot that the child has. This calm down spot can be a small rug, blacket or whatever the mother has that the child likes. You know your child best, work with them to identify their calm down spots.

- When you identify that your child is getting upset or angry and needs to calm down. Take them by the hand and lead them to their calm down spot. Encourage them to sit on their calm down spot, relax and calm down. For young chidlren the mother may need to reamin with the child while them calming down, quietly reassure them, sooth them and even stroke their hair or skin. It it very important that everyone else in the home knows what the child’s calm down spot is, and respects the time the child spends calming down.

## Desensitisation

This is a strategy that can be used to help you help your child to develop skills or cope with experiences they are fearful of. The key to denensitisation is to break down the situation into very small steps so the child very gradually is able to tolerate the situation.

For example if you are trying to teach your child to brush their teeth by themseles. You might break that task down into the following small steps

- You put your hard on their hand while they brush their teeth
- You put your hard on their shoulder while they brush their teeth
- You stand by the bathroom door while they brush their teeth
- You wave to them from the living room, reassuing them while they brush their teeth
- They are now able to brush their teeth on their own

How long it takes your child to move from one step to another will vary from child to child. Like all strategies, this strategy may not work for all children or all skills that you may wish to teach your child.

**Things that you should not do when dealing with your child with ASD behaviours:**

- Do not Use praise and approval statements (i.e. 'mom will be happy if you put your cup on the table after finishing'). A child with ASD will not be able to get the concept, however, the child needs praise but in a more clear and direct way (i.e. 'would you please put your cup on the table' and if he put it them the mother will say ' wow good boy').

- Try not to associate the child's behaviour with guilt and blame (i.e. the mother will tell her child 'you lost your toy because you did not returned it to the toybox yesterday' this statement might be meaningless for an ASD child and he would not be able to draw the conclusion between loosing his toy and outting it on the toy box).

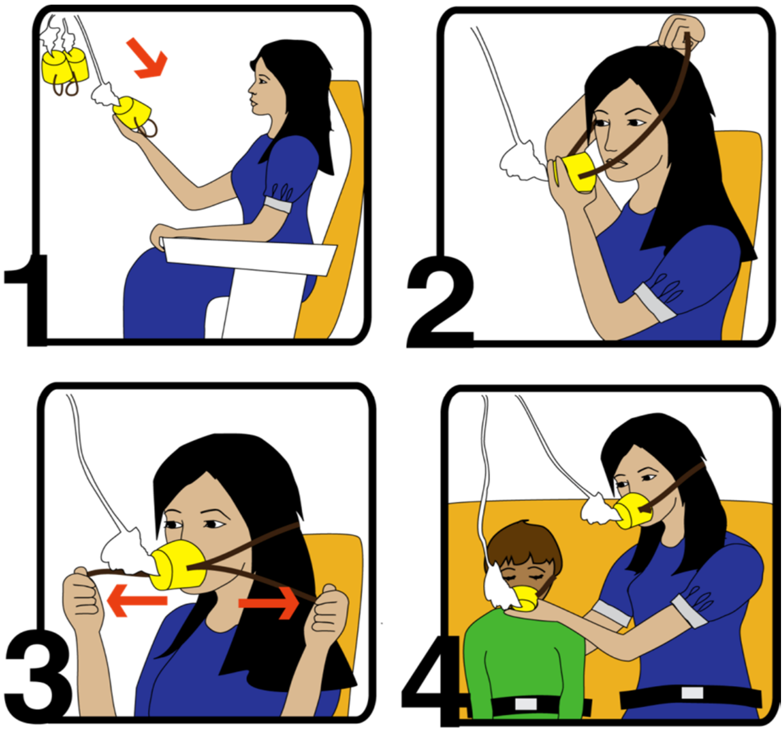
- Do not Use abstract language trying to manage the child's problem behaviour (i.e. if the child is spitting when the family is outside home and the mother told him'I will not take you out with us next time' this phrase looks abstract and complicated for an ASD child to understand as he might not be able to make the association between spitting and not being able to go out next time. Abetter alternative would be saying 'stop spitting please, this is not good, stop'.

# Session 4: Mood

- We know that many parents of children with ASD may also from time to time experience some difficulties with mood and or have some worries. This to be expected as parenting a child with ASD can be a very hard work as we discussed in week 1.

- We know that you have worked hard to apply the behavioural strategies that we discussed last week. We now like this week to focus more on strategies that may be helpful for you.

While you are very motivated to help your child with ASD, often it is very difficult to help your child unless you first help yourself. Think about the last time you were on an airplane you may have noticed on the safety card the advice in an emergency to always help yourself first before helping others (see figure below). We would like you to think about what we are saying.



# Mood

This week we are focusing on how we think about situations/events, and how this can affect the way we feel about and react to those events. This is important because the way that we think about situations will often influence how we react to them, both in terms of what we feel and how we behave.

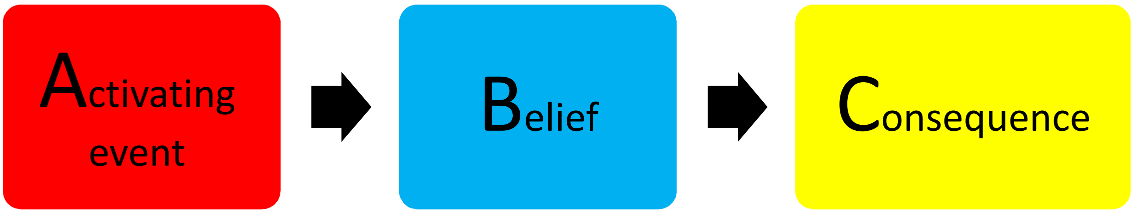
**EXERCISE:** Imagine you are at home alone during a thunderstorm and you hear a loud crash in the next room.

**How would you respond to this?**

- **How would you feel?**
- **How would you behave? (i.e. what would you do?)**

- One way of responding to the "loud crash" is to think that someone is attempting to break into your home. This way of thinking will probably result in fear and panic. Another person may respond by thinking that they forgot to close the window in the room, and the wind has blown it shut. This line of thinking may allow the person to calmly go and close the window, before returning to sleep.

As you can see, the same situation (**A** Activating event) can be thought of in different ways (**B** Belief System/Thoughts), and can lead to different feelings and behaviours (**C** Consequence).



If this were not true, then each of us would respond to the same situation in exactly the same way. It is important to not to forget that the way that we each think about events and situations can influence our feelings and actions.

For a real life example, *one parent told us that every time the phone rings during the day, they immediately think the worst (i.e. that their child has done something terrible at school) and start to feel wound up and stressed. However if the phone rings during the evening it does not bother them particularly*. You can see from this example, that it is not the situation (i.e. the phone ringing) that causes the parent to feel worried, but rather their <u>thoughts</u> about the situation (i.e. that something has gone wrong at school). Once again, our thoughts about the situation affect how we feel and behave.

## AUTOMATIC THOUGHTS

- Our initial reactions to situations are usually automatic, thoughts pop into our heads, and tell us what to feel (e.g., when you receive a phone call at 6am you immediately assumes that something is wrong).

- All of us tend to think negatively at times. The purpose of this session is to make you more aware of how your thinking affects the way that you feel and behave. It takes practice to learn to recognize and challenge negative thoughts.

> *For instance, you may always go to the same hair salon often without thinking. There may be other hair salons nearby, but you may tend to use the same way each time. In order to take a use a different hair salon, you may need to actively remind yourself to try a new one.*

- Likewise, in order to recognize and challenge our automatic thoughts, we have to actively remind ourselves to look out for and challenge our negative thoughts so that our new thoughts may become automatic.

The first step in this process will be to identify those negative aspects of our thinking. To begin with, we are going to look at some common errors in thinking.

# COMMON ERRORS IN THINKING

## (1) **Overgeneralization**

This occurs when you take one fact or event and make a general rule about it.  For example if your child did not learn to walk at the same age as your other children and friends' children, you might have thought they would never learn to walk.

Likewise, some of us may have encountered difficult teachers at our child's school.  *If you were to over generalize, you could conclude that not all teachers are helpful*.  Despite the fact that we have heard of some teachers who have been helpful, this sort of thinking/expectation will set you up to have negative experiences with your child's teacher and school.

## *(2)* **Filtering**

This occurs when you focus on the negative things around you, and

*For example, you would have enjoyed the family party if it wasn't for the burnt chicken. In this example, you focus on the negative aspects of the situation (the burnt chicken), while filtering out the positive aspects (such as getting together with family members that you have not seen in a long time), which results in negative feelings about the party in general.*

filter out all of those positive things that are happening.

In terms of parenting, engaging in thinking that involves filtering may mean that it is easy to fall into a cycle of only noticing poor behaviour, while failing to notice the positive things that your child does (e.g., showing affection toward a parent or sibling,). One other danger of filtering (focusing on bad thing and filtering out good things) is that your negative problems can often appear worse and bigger than they actually are.

### *(3)* All or Nothing Thinking

- This occurs when you lump things into absolute, black and white categories, with no middle ground. With this line of thinking, you have to be perfect, or you are worthless.

*For instance, you may have been unsuccessful when dealing with a problem situation with your child. The all-or-nothing thinker would conclude that they are a failure as a parent, even if they had had some success in dealing with other problems during the week.*

- What we recommend in these situations is to *challenge these thoughts* (e.g., by asking yourself would it really be the end of the world if we were not the best at everything).

- You may also view others in "all-or-nothing" terms. *For instance, you may conclude that because a child deliberately misbehaves on one occasion, that all of their behaviour must be deliberate and purposeful.*

We know that this is not true for children with ASD, and in fact is not true for most children.

As you can see, this type of thinking can prevent us from generating realistic expectations about others and ourselves.

### *(4)* Self Blame

This occurs when you consistently blame yourself for everything that happens around you, even those things that may not be your own fault. *For instance, many parents of children with ASD blame themselves for their children's poor behaviours, despite the fact* *that we know parents do not cause ASD.* Thinking like this will prevent you from seeing the good parenting that you are doing.

### *(5)* Mind reading

This occurs when you think that you know what everyone else is thinking, and may happen more often with people we know well (e.g., partners, family members, close friends).

*For instance, you may assume that someone does not like you when they pass by you in the street without saying hello, when in fact they were in a hurry and did not see you at all.*

## HOME PRACTICE EXERCISE:

(1) Consider any negative thoughts you may have, and search for alternatives that are more balanced by asking logical questions. The following questions may be useful to challenge your negative thoughts and replace them with more helpful thoughts:

- What evidence is there for what I am thinking?
- Am I confusing a thought with a fact?
- Do I really know what is happening in this situation?
- Am I being honest with myself? Is it possible I am denying the truth, or misplacing the blame?
- Are my information sources reliable? Is the information I am basing my thoughts on reliable and truthful?
- How would someone else feel about this situation?
- Am I thinking in all or nothing terms? "If I cant do this then I am a failure"
- Am I overestimating how bad a situation is? What would be so bad about this? Is this the worst thing that could happen today?
- How will things be in a few hours, a week, or a month or so from now? Try to put things in perspective.

- Be specific. Think in terms of specific behaviour, or a specific problem. Instead of saying “my child never behaves”, say “my child is not behaving at the moment, which is frustrating for me because I know he can behave better than this”.

- Seek balance. Include the positive as well as the negative (e.g., even if you are unsuccessful in your problem solving this week, try to recall all of those times when you have successfully resolved problems).

- Where possible, test out your new thoughts to see whether they are true (e.g., just because the phone rings during the day does not always mean that your child has been in trouble at school).

# Week 5: Resources for families and intervention summary and close

There are many resources and services available to ASD children and their families in Saudi Arabia. You may already know some of them

- Do you know that your ASD child is entitled to a yearly income from the government through the Ministry of Social Affairs . You can claim that money by visiting the office of the *Saudi society for families of children with ASD* in Jeddah and filling out the required paper work. You name will be sent then to the Ministry of Social Affairs and they will decide after checking your child profile on the amount you should receive every year. Each family will receive different amount depending on their income and the severity of their child's autism. More information about the location of *Saudi society of families of children with ASD* and their contact information will be provided later in this session.

- Do you know that your ASD child is entitled to a 50% discount on air tickets as well as one accompanying person for up to three tickets per year. This could be claimed through the airlines. Please make sure to have your child card that have his name and information with you.

- If your doctor feels your child would benefit from a specific piece of equipment then it may be possible to get that piece of equipment paid for by the Government.

- Access to early intervention services for ASD are provided by one government organisation for female students and some private not for profit organisations. These organisations charge for the intervention services they provide. If you are not able to afford these costs then please do discuss this with the organisations, as they are often able to access Government subsidies and private donations to support their work if parents are unable to pay.

- Around the age of six years when it is time for your child to go to school, any child with ASD who does not have any specific cognitive problems may enter mainstream education if it is felt they will benefit from the experience . A child with ASD who also have cognitive problems may be offered a place in a special education class within a mainstream school or a place at a special education school. All children's progress will be monitored for the first six months to ensure that they have been placed in the correct educational setting for their specific needs.

## Contact information for autism organisations in Jeddah and Makkah:

### In Makkah city:

- *Al-amal al manshoud* organisation
  Tel: 012 5402411
- *Umm-Al Qura* organisation for morning care services
  Tel: 012 5506641

### In Jeddah city:

- Saudi Autistic society organisation.
  Tel: 012 6622513
- Jeddah Autism Centre
  Tel: 012 6622513
- *Acaemiyat Al tawahod Al Raedah*
  Tel: 012 2574053
- Government female organisation
  Tel: 012 6727868

- Saudi society of families of children with ASD
  Tel: 012 6511414

## Helpful websites:

- http://www.childguidanceclinic.com/

  This is an Arabic website that has many useful resources for parents and professionals.

- http://www.gulfkids.com/ar/index.php?action=show_res&r_id=4

  This is an Arabic website which provides information about ASD, online books, and update on ASD conferences.

- http://www.gulfkids.com/ar/index.php?action=show_res&r_id=4

  This is the Autism Research Centre in Riyadh website. It has many links to the latest research on ASD.

- http://www.t7di.net/vb/forumdisplay.php?f=15

  This is a blog for parents of children with ASD in the Arab countries

- http://www.autism-society.org/

An English website that provides information about ASD and the lates research

- http://www.autism.org.uk/

  This is an English website that provides information about ASD for parents and professionals.

## Suggested reading in Arabic:

- Al-Shami, Wafaa .(2004).*Khafaya Al Tawahud* (Autism secrets). Riyadh
- Al-Sa'd, Samira. (1997*). Muánati wa al tawahud* (my experience with autism). That al salasel publisher. Kuwait
- Al-Fuzan, Muhammad. (2000). *Tayf Al tawahud bayn al haqiqah wal gumoud* (Autism Spectrum between the real and unknown). Alam al kutub publisher. Riyadh.

## Summary and conclusion:

The main aim of this intervention is to reduce stress in mothers of children with ASD in Saudi Arabia. The intervention is divided into five sessions.

- Session one is about the etiology of autism including its causes, how it affects the lives of people with ASD, and the formal diagnosis criteria.
- Session two is about stress including its definition, examples, causes, and tips to help reduce stress in parents.
- Session three is about behaviour management and how behaviour occurs and different ways that will help parents to manage their children's problem behaviour.

- Session four is about mood and how can it affects the way people respond to different situations
- Session five is about the available resources to parents of children with ASD in Saudi Arabia

We hope that you benefited from the information and strategies this manual provided.

## Appendix 20. Interview Schedule (Chapter 7)

**The researcher will start the interview by saying**: The recording will now begin and I am pressing the on button. Are you still happy to do this interview? (**Participant will be given the chance to respond)**. I will stop recording immediately if you asked me to do so .
Please note that if you said something and then changed your mind then I will erase it from the recording at your request.

**Opening statement**

I am interested in finding out more about your experience with the proposed training programme. I have a number of questions to use as a guide to help you think about the content of the training manual and sessions, the therapist who delivered the intervention, and your overall experience participating in this study as a mother of a child with ASD.

Q1: Tell me about your experience participating in the training programme

Prompts:

- What do you think about the usefulness and use of
    - Whatsapp group meeting?
    - Discussion of manual material during each meeting?
    - Information discussed in each session?
- What did you like/did not like about the training programme?

Q2: If I ask you to describe the therapist that delivered the programme. What would you say?

Prompts:

- How would you describe her
    - Performance during training sessions?
    - Style of presenting information?
    - Response to participants' questions?

Q3: What do you think about the training manual?

Prompts:

- How useful was
    - The printed materials(formats, colours, font, pictures)
    - The organisation and clarity of the ideas and examples presented under each week's session
    - The information, skills and strategies for you as a mother of a child with ASS

Q4: Tell me about your overall experience participating in this study?

Prompts:

- How would you describe your satisfaction participating in the study?
    - Study length- meeting times
    - Answering questionnaire
    - Acquired skills
- What would you change or do differently?

Q5: Do you like to add any additional feedback?

Prompts:

- Is there anything else that you think is important that we haven't talked about?

Thank you for your time.

End of interview

## Appendix 21. An Example from Codebook for Qualitative Analysis (Chapter 7)

### Main theme: Broadening mothers' knowledge of how to deal with themselves and their children with ASD

This theme reflects how mothers felt taking part in the intervention has helped them to expand their understanding of themselves and their children with ASD. This includes their increased awareness of their well-being and their children's behaviour.

**Subthemes:**

### Understanding their stress and mood

This subtheme describes how the intervention has helped them in understanding and analysing their reactions to different stressful situations. This subtheme also includes
participants' description of how being angry or depressed is not always about the child with ASD but can be related to their own state of well-being.
**Positive example**: "Sometimes I have fearful moments when I couldn't deal with my kid and I feel sorry for him, so I became nervous myself, and as a result of that all, is when I'm getting nervous he became nervous too and sad, so this programme has trained me to use some tips like how not to be anxious and how to control myself." (P1)
**Exclusions:** participants did not describe how the intervention has helped them in understanding their stress and mood.
**Negative example**: "I am not accepting the fact that my child has ASD." (P41 - did not describe having a child with ASD in relation to her well-being or participation in the intervention)

### Perceptive about their children's behaviour

This subtheme describes how the training has increased mothers' awareness about different ASD symptoms, behaviours, and behavioural management techniques. It also includes description and examples of the different behavioural techniques they learned and how did they apply it.
**Positive example**: "I did not know previously that ASD was behind my kid not being able to play and interact with other kids" (P9).
**Exclusions:** participants did not describe how the intervention has helped them in understanding ASD symptoms, behaviours, and behavioural management techniques.
**Negative example**:"The sessions were really helpful and I consider it a complete training programme about autistic children."(P17

## Appendix 22. An Example of Coded Transcript (Chapter 7)

**(P1)**
**The researcher will start the interview by saying**: The recording will now begin and I am pressing the on button. Are you still happy to do this interview? (**Participant will be given the chance to respond)**. I will stop recording immediately if you asked me to do so.
Please note that if you said something and then changed your mind then I will erase it from the recording at your request.

**Opening statement**

I am interested in finding out more about your experience with the proposed training programme. I have a number of questions to use as a guide to help you think about the content of the training manual and sessions, the therapist who delivered the intervention, and your overall experience participating in this study as a mother of a child with ASD.
**Q1: Tell me about your experience participating in the training programme.**

- **What do you think about WhatsApp groups? What do you think about the training? Generally.**

*Actually at the beginning I wasn't that aware of the programme and its benefits, I didn't know anything about my kid's problem, Sometimes I couldn't deal with my own kid, however after we read and raised the problems one by one to be discussed, for the first time, the programme could be generalized and applied to every mother not only the mother who has a child suffering from autism but also to any mother who is raising a normal child who goes to school and is herself suffering from pressure. I can see that any mother who has kids is in need of such programme's provided information, as any mother will need to take a course and learn how to deal with her kids whether they are suffering from autism or any other problems.*

**Prompts:**
- **What do you think about the usefulness and use of WhatsApp group meeting**?

*For me, I prefer group face to face meeting where mothers are gathered in the organisation than what's app, however, WhatsApp group meetings were good, as it saved time and transportation efforts where you don't have to plan for a meeting and go out of your home,***[AH: Differing opinions on the mode of delivering the intervention**] *and the good thing about those meetings that the therapist was accurate in her appointments* **[AH: Satisfaction with therapists interaction]**, *all mothers attended, I was sooo excited when I saw other mothers attending, I could not miss it.*

- **What did you like/did not like about the training programme?**

*Actually there are a lot of things that I really liked, it gave us a chance to express ourselves, be patient with our kids, express our suffering dealing with our ASD kids and how we could treat our kids right and approach their difficult behaviour problems.* **[ AH: Broadening mothers' knowledge of how to deal with themselves and their children with ASD]** *You gave us hope, it made me think that even though we face a lot of pressure, we must take care of ourselves as well* **[AH: Apprehension of the advantage of group therapy(realization of loneliness and healing their way)]**

- **That's right**.

*Sometimes, I have a breakdown for my own self when I became nervous dealing with my kid, in order to get the problem solved and figuring out a way to deal with it.* **[ AH: Broadening mothers' knowledge of how to deal with themselves and their children with ASD]**, *and I think I started gaining wisdom because of all of that.*

- **That's right.**

*To be honest with you, sometimes I have fearful moments when I couldn't deal with my kid and I feel sorry for him, so I became nervous myself, and as a result of that all, is when I'm getting nervous he became nervous too and sad, so this programme has trained me to use some tips like how not to be anxious and how to control myself, to be calm, to take a breath and to ask for the nearest possible help in order to keep calm once I face any problem while dealing with my kid. I personally did benefit from everything on it.* **[ AH: Broadening mothers' knowledge of how to deal with themselves and their children with ASD]**

- **Have you faced anything that you didn't like?**

*No, actually I don't have any negatives, it's just perfect.*

- **Thank you very much.**

*There is just one problem that it's a month long course and merely one session per week so there is a long time between sessions, it is a long period to wait one week for the next session that I would forget about the date of the next session* **[AH: Satisfaction with the length of the intervention]** *and there was not even a phone call from the therapist during that time.*

- **We planned it that way in order to give the mother a chance to read the manual and to have an opportunity to apply the strategies mentioned on it.**

*That's right however at that period I was studying at the college (online study) , I was stressed out a little bit because of exams' period and that's why I couldn't spend that much time to read the manual but I managed to read it every time before the session.*

**Q2: If I ask you to describe the therapist that delivered the programme. What would you say?**

*God bless her, she was a very helpful, and she used to listen to mothers' opinions, and to listen well to all of us, and the other good thing about her is that she is not rude like other therapists who ask you not to go off the subject of the session as there are some subjects that may lead to another related sub-discussion and mothers may discuss problems that are related to the main problem so this therapist allowed the conversation to go anywhere as long as it discussed something relative to the session' topic. She was very nice and adorable.* **[AH: Satisfaction with therapists interaction]**

**Prompts:**

- **How would you describe the therapist, her performance during training sessions?**

*She was very interactive, she responded to our concerns, may be because she herself has a kid suffering from autism, that's why she can understand what we are going through.* **[AH: Satisfaction with therapists interaction]** *So if there was a very frustrated mother for example with no positive attitude she would tell her that one day she was in her place where she could not find any spark of hope,* however, *thanks God she did survive and kept going on life learning how to manage her kid and deal with his behaviour, and that having a child with ASD is like anything you do not like in life but you must accept and deal with it.* **AH: Apprehension of the advantage of group therapy (Facilitating the giving and receiving of support)]**
*She was very enthusiastic and she was understanding, she was very occupied and immersed with us and she explained to us everything in the manual that we asked about, it was a magnificent interaction between her and the mothers*. **[AH: Satisfaction with therapists interaction]**

- **Style of presenting information?**

*First, she talked about the manual parts, then she started the discussion and allowed mothers to talk she was very knowledgeable in the topic.*

**Q3: What do you think about the training manual?**

- **This manual is a part of the intervention so I would be interested to know about your opinion, was it clear or not, has you gained anything from the information included**.

*The manual was astonishing and the study was good, what I liked about it the most was that it was one of its kind, as not too many people has discussed that topic, there are lot of researches but most of them are concerned about kids and how to deal with them, but there was none of them who were concerned about the mother and her suffering.***[AH: Perception of the intervention manual as a document written for their use]** *That's why I've said that it was a very good idea and I hope that a lot of* *people would follow you lead  as I've not come across any study in which stress and well-being in mothers were a concern.*

- **That's why I was concerned about the mother in the first place.**

*It was very good.*

- **How did you find the manual, was it clear, unclear or has vague terms? The organisation of the material presented?**

*It was magnificent, and everything was just clear enough, however the only thing that surprised me that it wasn't only concerned about the kids but about the mothers as well and the whole family in general, actually I liked it very much. I have not seen any negative thing at all.* .**[AH: Perception of the intervention manual as a document written for their use]**

- **Tell me in general about your own experience as a participant at this programme, how far are you satisfied with the experience, are you happy or not?**

**Prompts:**

- **How useful was the printed materials(formats, colours, font, pictures)**

*It was all clear*. .**[AH: Perception of the intervention manual as a document written for their use]**

- **The organisation and clarity of the ideas and examples presented under each week's session**

*I was surprised that it was talking about the mother as well as the whole family.*

- **The information, skills and strategies for you as a mother of a child with ASD?**

*I have not seen anything negative.*

**Q4: Tell me about your overall experience participating in this study?**

**Prompts:**

- **How would you describe your satisfaction participating in the study**

  *I was happy in fact, but the thing is that, I was having my exams by that time, so the timing didn't suit me and I was hoping to be totally free and to attend more sessions in my free time. I used to read the manual, even if I was stressed; however, I forced myself to read it in order to understand what's going on at the sessions.*

- **Even though you had your exams at the time, you did consent to participate in the study?**

*For sure I consented to participate, and why not, this is an opportunity that I did not want to miss, we needed that training badly as there are a lot of things that we can't understand about dealing with our kids and their behaviours.* **[AH: Suggestion for intervention improvement (continuous training for mothers)]**

- **What would you change or do differently?**

*I don't want to change anything. It's just if you could personally contact the mothers even if it is for an hour per week, each mother, one by one.*

- **I really wanted to do so but because this is part of my study and I am the main researcher so it would not be objective to deliver the intervention? It is the formality of doing research you know.**

*Or even every couple of weeks. You may choose certain cases of mothers who really suffer dealing with their kids , as in my case for example, I used to have depression a year ago, but thanks God and many thanks to my friends who were very optimistic, they helped me a lot. I was in a great need to find someone who can understand me such as a psychologist or a therapist or family counsellor who could understand such cases, to get us some ideas on how to deal with them. So if you could personally meet the mothers even for an hour every couple of weeks during the intervention that would be great.*

*Yes, but I do get your point of being objective as a researcher because of the evaluation etc.*

*How far is your research?*

- **Actually, we need more time as we are still gathering information and other things.**

*I'm very happy because of you and others who are from our own country, who are concerned about these issues, as I've previously told you that I was depressed especially because of educating my child. I used to be a member of three groups in WhatsApp, each of which there are mothers from all surrounding regions , you must be depressed while observing all those negative people interacting , I was very depressed that I was thinking about quitting these groups but I couldn't, even my husband advised me to quit them too . I'm talking about my own experience that I was spending each day of my life along with depression until I started to depend on God and I remembered the prophet Muhammad who advised us to "Be optimistic in order to have better things" and I discovered the things that can make me optimistic, is to live my life beside my kid and nothing to worry about the future, I have nothing to do with it as no one could expect what would happen in the future. So thanks God I started to be serious and let nothing negative affects me or allow myself to be depressed again such as in the past year, I always think about the best things. I'm convincing myself that my kid might be better one day and I seek motivation , there are sometimes when I feel broken and defeated but thanks God it's going away and I ask Allah to support me.*

- **It's a very good thing to be positive in thinking.**

**Q5: Do you like to add any additional feedback?**

**Prompts:**

- **Is there anything else that you think is important that we haven't talked about?**

*No, this training somehow covered all issues but it was me who was very busy and I hoped I was free in order to dedicate myself more to it. But I can reassure you that I have not seen anything wrong at all.*

- **Thank you for participating in the programme despite being busy and thank you for your time today.**

**End of interview.**