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**A portfolio of work on mother-child dyad and autism: a counselling psychology perspective**

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**Declaration**

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**Abstract**

Several researchers have reported that parenting a child diagnosed with autism is linked with a high risk of presenting mental health problems such as anxiety and depression. The current study gave the opportunity to eight mothers of children diagnosed with mild or moderate symptoms of autism to voice the challenges they face in their parental role so as to better understand their needs, and to provide appropriate services for them. Semi-structured interviews were conducted with the mothers and were analysed using Interpretative Phenomenological Analysis (IPA). Three themes arose from the analysis of data. The first theme is ambiguous loss, and is concerned with mothers' way of dealing with the loss of their dreamed-for child. The second theme is identity shift, and is concerned with the change in the way mothers experienced and identified themselves after their child was diagnosed with autism. The third theme is withdrawing from others, and focuses on mothers' descriptions of their experiences of others' reaction towards both them and towards their child's condition. 'Disequilibrium' emerged as the essence of maternal experience as mothers described their difficulty in balancing their personal needs with those of their child. The information from this study may be used to provide professionals working with this population with advanced understanding about the experiences and the challenges faced by mothers in their attempt to sustain their sense of self and remain sensitive to the needs of their children.

**Section A: Introduction to the Portfolio**

## 1. Overview

The main theme of each part of this portfolio is the mother-child relationship and how the nature of this relationship affects the experiences and actions of people as they encounter, engage, and live through situations. It was through my work with my clients as a Cognitive Behaviour therapist that I developed an interest in the mother child relationship. I have come to realise that the mother-child relationship plays an important role in the development of the difficulties the client is currently facing. Cognitive Behaviour Therapy (CBT) allows adopting a historical perspective so to help the client understand the development of maladaptive beliefs and realise their adjustment value and importance in the past along with their limited effectiveness in the present (Fennell, 1992). Therefore, an understanding of the mother-child relationship can inform CBT therapeutic practice in a way that allows both the therapist and the client to have a greater awareness of the development of present difficulties and to consider the appropriate therapeutic interventions to deal with them.

Each part of this portfolio aims to explore the mother-child relationship and its impact on psychological well-being from different perspectives. The research aims to explore this relationship from the perspective of the mother. It aims to explore how the mother perceives her relationship with her child and how this relationship affects the way she experiences herself and her relationship with others. The case study aims to explore it from the perspective of the child. How the client as a child experiences her relationship with her mother and how the nature of this relationship affects current difficulties. Finally, the literature review aims to explore how the attachment style as conceptualised by Bowlby and Ainsworth, of both the therapist and the client affects the development of therapeutic relationship and the impact of that on the therapeutic outcome.

## 2. The research

During my training as a counselling psychologist, I was given the chance to work with a child diagnosed with autism as an Applied Behaviour Analysis (ABA) therapist. Apart from the therapeutic work that I had to do with the child, I also maintained a close collaboration with the parents of the child, and especially with his mother. My interaction with the child and his family triggered me to consider how mothers of children with autism experience motherhood

and motivated me to reflect on the way(s) they respond to the demands of parenting a child with autism.

The aim of my work with my clients is to explore with them the nature of the mother-child relationship from the perspective of the child, as clients reflect on their childhood experiences, so to understand the development of core maladaptive beliefs. In the work that I did as an ABA therapist I had the chance to work both with the mother and the child and to witness how the relationship a mother has with a child diagnosed with autism affects her psychological well-being. Therefore, I found it really challenging and interesting to explore the other side, meaning how mothers perceive their relationship with their child and the impact of this relationship on the maternal well-being. This approach was considered to be relevant to my work as an ABA therapist which requires to work collaboratively both with the child and the mother. Therefore, I considered that having a better understanding of the maternal experience will facilitate the work and communication of the child's therapists with the mother as well as the practice of psychologists that work therapeutically with mothers of children with autism.

After reviewing the relevant literature, I realised that the majority of the studies that have explored the impact of parenting a child diagnosed with autism on the mother are mainly quantitative. The majority of these studies have reported that parenting a child diagnosed with autism has a negative impact on the maternal well-being. Conducting a qualitative study that would allow the mothers communicate their experience and gain access into their world so to understand the essence of their experience appeared to me as the optimal approach.

## 3. The case study

The case study presents the therapeutic work that I did with a client who had difficulty to come in terms with the death of her mother. My client had to face two painful tasks: to grieve over her mother's death and to adjust to her new reality by going through an identity shift that was not welcomed. The case study explores the quality of the therapeutic relationship and considers its impact on the therapeutic outcome.

## 4. The literature review

The purpose of the critical literature review is to examine how the clients' and therapists' attachment style (as defined by Bowlby) affects the formulation of the working alliance. The idea of exploring this particular area came after the work that I did with a client who had

abusive and neglecting relationships with significant others in the past. In an attempt to better understand her difficulty to trust others, including me in the beginning sessions, I did some reading regarding the impact of past abusive and neglecting relationships on current depression problems.

According to Beck's theory of depression, early experiences lead the person to form attitudes and beliefs that will later prove maladaptive. Depression is triggered when dysfunctional assumptions are activated after critical incidents in a person's life (Fennell, 1992). Bowlby's attachment theory proposes that mental health is determined, to a large extent, by individual differences in the quality of attachment relationship between a child and the caregiver. Based on the nature of this relationship, infants develop internal working models that consist of mental representations of both themselves and the attachment figure. The attachment style of an infant is expected to be carried forward into adulthood (Wishman & McGarvey, 1995). I realised that Beck's depressotypic cognitions and Bowlby's internal working models have many similarities and actually several cognitive researchers have attempted to examine the developmental origins of depressotypic cognitions through the framework of Bowlby's attachment theory (Haaga, Yarmus, Hubbard, Brody, Solomon, Kirk, & Chamberlain, 2002; Whiffen, Kallos-Lilly, & MacDonald, 2001).

The work with this client motivated me to explore in more depth how the attachment style of the client affects the therapeutic relationship and the therapeutic outcome. While reading the relevant literature, I came across studies that also explored the therapists' attachment style and the interaction of clients' and therapists' attachment style in the formulation of the working alliance and the therapeutic outcome.

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**Disequilibrium: A qualitative study on the experience of mothers who bring up a child diagnosed with high functioning autism**

## Chapter 1: Introduction

### 1. Chapter overview

The current study is concerned with the experience of mothers who parent children with autism. A number of studies have shown that some parents are able to cope successfully with the demands of their parenting role while others are at high risk of presenting mental health problems like anxiety and depression. The goal of the present study is to contribute to the understanding of the experience of mothering a child diagnosed with autism from a psychological context so as to better understand their needs and contribute to the provision of appropriate services for them. The chapter opens with a presentation of the literature on autism and parenting, and outlines the aims of the research project. The objective of the introductory review is to gain a better understanding of how history, society, and the cultural construct of motherhood, and the extent to which these influences are both reflected in and influenced by the psychological research. The chapter begins with a general overview of the literature about autism, and follows this with a review of studies on motherhood, before presenting the literature on parenting children with autism. Particular weight is given to the role of stress. The review concludes by focusing on the impact of having a child with autism on mothers' personal and social life.

### 2. Autism

Autism is a complex neurodevelopmental disorder that is defined by the presence of social deficits, verbal and nonverbal abnormalities and a markedly restricted repertoire of activity and interests (American Psychiatric Association, 1994). Intellectual functioning, language ability, and severity of behavioural symptoms vary, although a large proportion of children with autism (50-70%) have additional learning disabilities and an IQ lower than 70. Due to the heterogeneity that characterises autism, researchers frequently use the term Autistic Spectrum Disorder to describe the different variants of autism, including Pervasive Developmental Disorder-Not Otherwise Specified and Asperger Syndrome (Pellicano, 2007).

**2.1 History of Autism**

The syndrome of autism was clinically reported and recognised for the first time by Leo Kenner in 1943 (Happe, 1994). He described a series of 11 children whom he had seen in his clinical practice, and who were characterised by what he called 'autistic disturbances of affective contact' (Happe, 1994). According to Bowler (2007), the children described by Kenner were characterised by a lack of social responsiveness, as they intended to treat other people as objects rather than human beings as themselves and appeared to be happiest when left alone. They were also characterised by what he called, an obsessive insistence on sameness, where children would attempt to prevent changes of routine or surroundings (Bowler, 2007; Happe, 1994). A related characteristic was a tendency for the behaviour of the children to be repetitive and lacking in imagination (Bowler, 2007). The children described by Kenner often displayed what he called delayed echolalia, which involves both the repetition of a phrase which was heard some time previously and that appears to bear no relation to the current context and the tendency to reverse pronouns. For example, the children would use 'you' when referring to themselves and 'I' when referring to other people (Bowler, 2007). Kenner also reported that these children had excellent rote memory, as they could memorise large amounts of effectively meaningless material, and that they had good cognitive potentialities (Happe, 1994). Kenner's observation regarding children's cognitive abilities was based on some children's outstanding memory. In particular, he believed that their good rote memory reflected a superior intelligence (Happe, 1994).

The next observer to use the term 'autistic' was Hans Asperger in 1944. He published a dissertation concerning 'autistic psychopathy' but it received notice in the English-speaking world almost 50 years after its publication (Happe, 1994). The cases described by Asperger were in some respects quite different from those described by Kenner but the common thread linking the two was the characteristic disconnectedness from other people, which both authors named 'autistic'. The term 'autistic', comes from the Greek word 'autos' which means 'self', was first used by Bleuler to describe the social withdrawal seen in people with Schizophrenia (Happe, 1994). Other common findings reported by the two authors include the children's poor eye contact, their stereotypes in word and movement, their isolated special interests often in bizarre and idiosyncratic objects, and their marked resistance to change (Happe, 1994). There are however, three main areas in which Kenner's and Asperger's reports disagree. The first is the child's language abilities. Asperger reported that his patients spoke fluently and he commented on their freedom and originality in language

use (Happe, 1994). The second area is the child's motor abilities and coordination. Kenner reported that the majority of his patients were very skilful in terms of muscle coordination. Apserger, by contrast described his patients as being clumsy (Happe, 1994). The last area of disagreement is that of the child's learning abilities. Kenner believed that his patient were best at learning rote fashion, but Asperger believed that they were good abstract thinkers and therefore, could perform best when they could produce spontaneously (Happe, 1994).

Most research into autism was carried out from 1950s to 1970s and aimed to refine Kenner's descriptions with the aim to gain a better understanding of underlying difficulties and to provide a richer description so to improve diagnosis and treatment (Bowler, 2007). Wing and Gould carried out and epidemiological study in 1979 and concluded that the syndrome described by Kenner is not a discrete entity with clear boundaries but represents a particular manifestation of a wider set of conditions that share certain features (Bowler, 2007). Wind and Gould suggested that autism was one of a spectrum of conditions, all of which were characterised by a triad of impairments in social, communication and imaginative and symbolic functioning accompanied by repetitive behaviours (Bowler, 2007). Asperger's Syndrome was later included in the autistic spectrum disorders (Bowler, 2007).

**2.2 Triad of impairments**

As it is mentioned at the previous section autism spectrum disorders (ASD) are characterised by a triad of impairments in the areas of socialisation, communication, and imagination. Each of these areas is itself made up of a great variety of different behaviours, which rely on different cognitive mechanisms, and which emerge at different points in normal development (Happe, 1994).

**2.2.1 Problems in socialisation**

According to Bowler (2007) the most striking feature of individuals with autism is social impairment. This can range from almost total disconnectedness from other people, to passively accepting the social approaches of others but rarely if ever initiate interaction. Some individuals with autism appear to be insensitive to the feelings of others; some appear to fail to understand other people's intentions, while others behave in a way that is repetitive and centred to their own concerns and obsessions rather than those of the person they are approaching (Bowler, 2007).

## 2.2.2 Problems in communication

The range of communication difficulties in the autistic spectrum disorders varies. Some individuals with autism are completely mute and do not even use gestures to communicate, some children might parrot whole sentences which appear to have no relation to the context, some might use single words to communicate, while others might speak fluently but pragmatically bizarre (Happe, 1994). Bowler (2007) argues that severe language difficulties appear to relate to intellectual difficulties. In particular, in the cases were language is absent and often delayed, there is present some degree of global intellectual impairment. Individuals with ASD who are not globally intellectually impaired, tend to have communication problems who are subtler and may relate more to their social difficulties rather than language difficulties per se (Bowler, 2007).

## 2.2.3 Problems in imagination

The characteristic difficulty with imaginative and symbolic behaviours seen in individuals with ASD is another important feature of this disorder. In particular, individuals with autism appear to prefer to engage in repetitive and stereotyped object related activities, appear to show little interest in imaginative activities, like fiction, and may have difficulty in following plots (Bowler, 2007). Impaired symbolic behaviours seem to be related to difficulties in generating novel approaches in solving problems. Such difficulties tend to lead to repeated attempts to use unsuccessful strategies, giving the impression of repetitive behavioural repertoire (Bowler, 2007). Repetitive behaviours in individuals with ASD manifest itself differently depending on the context of symptomatology and overall cognitive ability (Bowler, 2007).

## 2.3 Psychological theories

Psychologists have attempted to provide an explanatory framework to explain the reasons individuals with ASD experience the impairments in communication, social interaction, and imagination.

Baron-Cohen, Leslie, and Frith (1985) have suggested that the triad of difficulties in ASD result from an impairment of the fundamental human ability to "mind-read", meaning the ability to attribute mental states to oneself and others in order to understand behaviour. They supported this argument by showing that children with ASD have more difficulty than

comparison children in understanding that the beliefs that someone else holds about the world can be false, that is different from what the child knows to be truly the case. Baron-Cohen (2002) proposed the empathising-systemising theory of autism to explain both deficits and cognitive strengths in individuals with autism. This theory suggests that ASD involves deficits in the process of empathy, relative to mental age, which can occur by degrees. The term empathising encompasses a range of other terms including, theory of mind, mind-reading, empathy and taking an intentional stance. Empathy compromises the attribution of mental states to oneself and others as a natural way to make sense of the actions of oneself and others and emotional reactions who are appropriate to others' mental states (Baron-Cohen, 2002). The theory supports that deficits in empathising underlie the difficulties that children with autism experience in social and communicative development (Baron-Cohen & Belmonte, 2005). The term systemising is used to describe the drive to analyse objects and events to understand their structure and to predict their future behaviour. Empathising-systemising theory uses the concept of systemising to describe the pattern of cognitive superiorities found in individuals with autism (Baron-Cohen, 2002).

Happe (as cited in Bowler, 2007) in 1995 reviewed the published studies on theory of mind and concluded that the pass rate in false beliefs tasks ranged from 15% to 60% suggesting that a substantial minority of children with ASD perform as if they possessed a theory of mind. Bowler (1992; 1997) showed that in a group of adults with Asperger's syndrome, their performance was identical to that of two matched control groups. Bowler (2007) argues that the results of recent studies suggest that the answer to whether people with ASD have an impaired theory of mind is not straight forward but it depends on the level of functioning of the individual with ASD. Bowler (2007) further argues that it appears that many of the tasks that were thought to measure mental state understanding may have been measuring other aspects of cognition, such as specific kinds of linguistic complexity. He therefore, suggests that it is likely the mental state understanding is coordinated by the functioning of a range of diverse systems rather than by a specific component of the human cognitive system.

In a similar vein, Pellicano (2007) supports that difficulties in theory of mind explain only part of the triad of symptoms and in particular, why children with autism have difficulty with joint attention, pretended play, and understanding other's emotions. They fail however, to provide an adequate account for the presence of repetitive behaviours and limited interests. Pellicano (2007) suggests that these latter behaviours seem to be captured best by problems in

executive control. The executive dysfunction theory proposed by Ozonoff, Pennington, and Rogers (1991) suggests that autism involves a form of frontal lobe pathology leading to preservation or inability to shift focus. Pellicano, Maybery, Durkin, & Maley (2006) carried out a study with the aim to examine whether young children with autism were characterised by a single cognitive abnormality or whether several cognitive coexisting abnormalities and capabilities provided a more accurate picture of the disorder. The results of the study indicated that children with ASD performed worse on false-belief tasks and on tests of higher order planning, set-shifting, and inhibitory control; but they performed better than typically developing children on tasks necessitating a piecemeal or local processing style. The results of Pellicano et.al. (2006) study suggests that there is a profile of cognitive weaknesses and strengths in young children with ASD that happen to coexist.

As far as the strengths of individuals with ASD are concerned, these include enhanced rote memory, good visuospatial skills and perfect pitch (Pellicano, 2007). The cognitive strengths of individuals with ASD can be accounted for by weak central coherence. According to Happe (1996) weak central coherence refers to an abnormally weak tendency to bind local details into global percepts. Weak central coherence has been demonstrated in the context of superior performance on visuomotor tasks, visual discrimination tasks, and visual search as well as impaired performance on more abstract tasks such as arranging sentences from a coherent context (Baron-Cohen & Belmonte, 2005). Baron-Cohen and Belmonte (2005) argue that weak central coherence and the empathising-systemising theory suggested by Baron-Cohen in 2002, are complementary theories that can be developmentally unified. Specifically, Baron-Cohen and Belmonte (2005) argue that attention to detail described by weak central coherence may be one of the earliest manifestations of strong drive towards systemising. They argue that as cognitive capacities mature, strong "systemisers" are able to analyse complex events and systems so to understand their structure and to predict future behaviour (Baron-Cohen, 2005).

Autism is a complex developmental disorder and several theories have attempted to describe and provide an explanation for the cognitive strengths and weaknesses that characterise individuals with ASD. Bowler (2007) argues that the conditions that characterise the autism spectrum disorders are complex and multidimensional and although they exhibit the common feature of social impairments and repetitive behaviours , they often exhibit additional features that are not necessarily the defining features of the spectrum. Bowler (2007) concludes that in

order to better understand ASD it would be helpful to consider psychological functioning of individuals with autism in a wider front and put together a picture of autism spectrum that encompasses all its manifestations.

## 2.4 Neurological explanations and genetic influence

Pellicano (2007) reports that neurological abnormalities in individuals with ASD are persistent although not restricted to any one particular region of the brain. In particular, Brothers (1990) suggested that social intelligence is the function of three regions, the amygdala, orbitofrontal and media frontal cortices, and superior temporal sulcus and gyrus. She termed these interacting regions social brain. Research has shown that abnormalities in autism have been found in the amygdala, orbitofrontal and media frontal cortices, and superior temporal sulcus and gyrus (Baron-Cohen & Belmonte, 2005). In particular, physiologically, adults with ASD manifest abnormally low activation of the amygdala during tasks of inferring emotion from pictures of the eyes or the whole face and during passive processing of facial expressions of unfamiliar faces (Baron-Cohen & Belmonte, 2005). Reduced activity has also been found in left frontal cortex during a theory of mind task, in orbifrontal cortex during recognition of mental state words, and in superior temporal sulcus during passive listening to speech sounds as compared with non speech sounds (Baron-Cohen & Belmonte, 2005).

The cause of autistic spectrum disorders is not yet clear. Pellicano (2007) suggests that genetics may play an important role with multiple, interacting genes involved in generational transition of the disorder. Bailey, Le Couteur, Gottesman, Bolton, and Simmonoff (1995) conducted an epidemiological study of same-sex twins with autism found that 60% of monozygotic pairs were concordant for autism versus 0% of dizygotic pairs. When a broader phenotype was considered, 92% of monozygotic pairs were concordant versus 10% of dizygotic pairs. The high concordance in monozygotic twins indicates a high degree of genetic influence.

## 2.5 Epidemiology

According to Bowler (2007) the characterisation of autism as a spectrum of disorders has implications on how common these conditions are in the common population. Early studies gave a prevalence rate of 4 cases of autism per 10 000 children (Lotter, 1967). Rutter (2005)

reviewed recent epidemiological studies that have tested larger samples, using current diagnostic criteria and instruments, and concluded that the prevalence of autism spectrum disorders falls somewhere between 30 and 60 cases per 10 000 children.

All the epidemiological studies show a significantly greater number of boys than girls with autism as male to female ratio vary from 2:1 (Happe, 1994). In addition, it appears that most females with autism are at the lower end of the ability range, while at the more able end boys may outnumber girls (Happe, 1994).

**2.6 Diagnosis and prognosis**

Diagnosis of autism often depends upon parental recognition of developmental problems. Lord and Rissi (2000) argue that because diagnosis is based on a consideration of behavioural symptoms, some parents are left wondering whether the diagnosis is correct. The life course manifestation of autism has only recently being studied. Several studies have shown that the developmental trajectory of children with autism appears to show both continuity and change, with high-functioning adolescents improving more than low-functioning individuals not only in cognitive abilities but also in social interaction skills (McGovern & Sigman, 2005). Specifically, both social and communicative skills, and the ability to reason about mental states of others (which seem to be linked largely to children's language abilities) can improve significantly over time. On the other hand, Pellicano (2007) reports that there is little progress either in the area of restricted and repetitive behaviours, or in the ability to flexibly shift attention.

**2.7 Therapeutic approaches**

Autism treatment includes behavioural, educational, and pharmacologic therapy so to help individuals to improve overall functioning.

**2.7.1 Pharmacotherapy**

As far as pharmacologic therapy is concerned, the aim is to reduce or control behaviours associated with autism and improve response to behavioural and educational interventions as well as overall functioning (West, Brunssen, & Waldrop, 2009). In particular, medication is often prescribed for aggression, anxiety, hyperactivity, inattention, sleep problems, stereotypes and preservation (Hollander, Phillips, & Yeh, 2003). No single medication or

therapy has proven effective for treating core deficits of autism and associated symptoms (West, Brunssen, & Waldrop, 2009).

Antidepressant medication, and especially selective serotonin reuptake inhibitors (SSRIs), are often prescribed to children with autism because many of the behavioural features of autism are similar to disorders related to serotonin dysfunction, such as anxiety, obsessive compulsive disorder, and attention deficit hyperactivity disorder (West, Brunssen, & Waldrop, 2008). According to Kolevzon, Mathewson, & Hollander (2006) children with autism not only have symptoms similar to the psychiatric disorders mentioned above, but they often have altered sensory perception, motor coordination, learning ability, memory and recall, sleep patterns, eating patterns, and reward systems, all of which are influenced by serotonin. Chugani (2002 & 2005) supports that serotonin dysregulation contributes to the behavioural difficulties of children with autism and therefore, interventions to enhance serotonin activity have potential for improving function. This finding is further supported by Moore, Eichner, and Jones (2004) who found that the behavioural symptoms of autism, including compulsions, rigidity, repetitiveness, and poor social interaction often decrease with the use of antidepressant medications. A similar finding is also supported by Bodfish (2004) after reviewing the relevant literature on SSRIs.

West, Brunssen, and Waldrop (2009) reviewed the relevant literature regarding the effectiveness of antidepressant treatment on children with autism and they concluded that SSRIs are somewhat effective in treating overall autism severity as well as disruptive and repetitive symptoms, but treatment is often accompanied by side effects. The most frequently cited side effects include behavioural activation, like hyperactivity and agitation, aggression, and suicidal ideation. West et al. (2009) concluded that most of the studies were open-label observational studies or retrospective chart reviews and case reports of small cohorts of patients from a single clinical facility. As a consequence, although they provide valuable exploratory information, they have inherent limitations and therefore, the lack of controlled, randomised double-blind studies severely restricts the ability to draw conclusions about efficacy and safety of SSRIs for children with autism.

According to (Malone, Gratz, Delaney, & Hyman, 2005) antipsychotics, both the conventional and atypical agents have been found to be effective in reducing hyperactivity, aggression, self-injurious behaviour, temper tantrums, lability of mood, irritability, social withdrawal and stereotypical behaviour in individuals with autism. However, the

conventional agents have been found to be associated with the development of drug-related dyskinesias (Malone, Gratz, Delaney, & Hyman, 2005) and being poorly tolerated by many individuals (Bodfish, 2004). For this reason, current psychopharmacology treatment has focused on atypical antipsychotics (Bodfish, 2004). The atypical antipsychotics cause fewer dyskinesias (Malone, Gratz, Delaney, & Hyman, 2005) but they have been associated with weight gain and sedation in some cases (Bodfish, 2004).

Hollander, Phillips, and Yeh (2003) support that it is essential to examine the safety and efficacy of medications, particularly in very young populations such as preschool children. They argue that preschool children should be entered into drug trials only when they have severe symptoms occurring in interpersonal contexts, and symptoms such as aggression may be targets for treatment.

### 2.7.2 Behavioural and Psychoeducational treatments

Ferster (1961, as cited in Bodfish, 2004) hypothesised that some of the acquired behavioural deficits in autism might develop due to a deficiency in acquired reinforces. This was the first conceptualisation of autism within a behavioural framework and it was followed by empirical demonstrations that behaviours characteristic of each of the core domains of autism could be related in a lawful manner to certain explicit environmental changes (Bodfish, 2004). This conceptualisation is based on established scientific principles of the learning theory and supported the application of learning-based interventions as forms of treatment for both the deficit features and the expressed behavioural features of autism (Bodfish, 2004).

A key feature of the behavioural/psychoeducational approaches that have been developed for autism is an understanding of the ways children with autism tend to interact with their environment and an appreciation of how they benefit from structured, planned, and predictable presentations of events (Bodfish, 2004). Several models of behavioural treatment for autism have been established, one such model is Applied Behavioural Analysis (ABA) developed by Lovaas (Reed, Osborne & Corness, 2007).

ABA assumes that autism is a syndrome of behavioural deficits and excesses that may have neurological base, but that are amenable to change through the use of carefully controlled environments (Lovaas & Smith, 1989). The ABA approach involves one-to-one teaching of children with autism by adult tutors, a discreet trial reinforcement-based method, and an

intensive regime which involves up to 40 hours a week for approximately three years (Loovas & Smith, 1989; Lovaas, 1987). Loovas in 1987 published a study regarding the effectiveness of the ABA approach. According to this study the children that received ABA therapy made gains up to 30 IQ points, and just less than half of the children managed to overcome symptoms of autism, meaning, they were not noticeable different from normally developing children after three years of the intervention (Lovaas, 1987). The findings of this study have not been replicated and there have been a number of critiques that have mainly focused both on the internal and the external validity of this study (Reed, Osborne & Corness, 2007). As far as the internal validity is concerned, it has been noted that different IQ tests were used at baseline and at follow up to assess children's intellectual functioning, and as a consequence, this reduced the reliability of the measure (Magiati & Howlin, 2001). As far as the external validity is concerned, the reliance on IQ as a sole measure may be questioned as IQ is not necessarily the main problem in autism functioning. In addition, the participants were verbal and relatively high functioning, therefore, they may have performed equally well with any intervention of a reasonable input. Finally, the study was clinic-based and may not generalise to interventions as they are typically used in the parents' home (Reed, Osborne & Corness, 2007).

Reed, Osborne and Corness (2007) carried out a study which aimed to explore the effectiveness of ABA, special nursery placement, and portage for children diagnosed with autism. The goal of the study was to assess the effectiveness of ABA in a community setting, on a more typical sample of children, using the same instruments at baseline and follow up. Reed, Osborne and Corness (2007) utilised a wide range of instruments so not to only assess intellectual functioning, but also educational functioning and adaptive behaviour. The results showed that children who received ABA input made greater intellectual and educational gains than children in the portage programme. They also made greater educational gains than the children in the nursery program, but the nursery program produced larger gains than the portage programme in adaptive functioning (Reed, Osborne & Corness, 2007). The findings of the study reflect the effectiveness of ABA but they also suggest that this approach will not cure autism as none of the participants improved to the extent they were not noticeable different from normally developing children (Reed, Osborne & Corness, 2007). Osborne and Corness (2007) suggested that the discrepancy between their study and Lovaas' study (1987) could be due to the length of time of the intervention (at their study the intervention was nine months but at the Lovaas' study the intervention was for 36 months), the place of intervention

(community vs clinic), and the severity of the participants' symptoms (severe vs milder). In conclusion, the findings of the Reed, Osborne and Corness study (2007) suggest that ABA has a strong impact on educational and intellectual gains and this finding corroborates a number of other studies of the effectiveness of ABA approaches (Eikeseth, Smith, Jahr, & Eldevik, 2002; Eldevik, Eikeseth, Jahr, & Smith, 2006; Quinn, Larr, Carroll, & O'Sulivan, 2007; Sneinkopf & Siegel, 1998).

Behavioural interventions mainly focus on the treatment of verbal and nonverbal communication deficits, social deficits, and repetitive behaviours (Bodfish, 2004). A number of studies have indicated that the majority of children with autism who are nonverbal can learn to use verbal communication with others when behavioural interventions designed for teaching language are used before the age of five (Kern-Koegel, 2000). A key feature of the language deficits in autism is that children with autism lack spontaneous verbal and nonverbal initiations even after successful language training. For this reason researchers have developed treatments that aim to "increase the generalised use of self-initiated protodeclaratives in preliguistic children with pervasive developmental disorders and to increase the social initiations and spontaneous verbalisations in verbal children with autism" (Bodfish, 2004, p. 320). As far as the social interventions that target social deficits are concerned, research has shown that they are effective in teaching parent-child social interactions, child-other adult interactions, and child peer social interactions (Bauminger, 2002; Bodfish, 2004). There is also empirical support for the effectiveness of behavioural interventions that aim in the management of repetitive behaviours through teaching, occasioning, reinforcing alternative adaptive behaviours, promoting environmental arrangement or restructuring, and shaping or graded change (Bodfish, 2004). The majority of studies that have explored the impact of behavioural interventions on repetitive behaviours have focused on treating the simple repetitive behaviours such as stereotyped behaviours and little is known about their impact on higher-order ritualistic behaviours (Bodfish, 2004).

Although there is no proven cure for autism, the goal of treatment is to improve overall functioning of the child by helping him/her to develop communication, social, adaptive, behavioural, and academic skills (Committee on Children with Disabilities, 2001). According to Seltzer, Shattuck, Abbeduto, and Greenberg (2004) most individuals do not attain normative outcomes in adulthood and continue to manifest significant degrees of symptomatology and dependency.

## 3. Motherhood

A large number of studies about mothers who raise either typical children or children with special needs indicate that women consider themselves to be primarily responsible for their children's current and future psychological well-being (Bull & Whelan, 2006; Chesler & Parry, 2001; Gray, 1997; Kingston, 2007; Lam & Mackenzie, 2002; Mercer, 1995; Milo, 2007; Paris & Helson, 2002; Raphael-Leff, 1983). Psychological research provided suggests the optimum condition for effective motherhood and the ways in which mothers interact with their children. Dally (1982) emphasises the centrality of the work of John Bowlby in establishing the link between a mother's effective and sensitive interactions with her progeny and the child's subsequent ability to live an independent life. In 1948, the Social Commission of the United Nations commissioned Bowlby to carry out a study about homeless children who were orphaned or separated from their families and living in institutions. Bowlby (1951) believed that the child should experience a warm, intimate, and continuous relationship with its mother in which both should find satisfaction and enjoyment. He contended that mothers need to feel that they belong to their children so to easily devote their life to them (Bowlby, 1951). Bowlby's ideas continue to inform the understanding that continuous maternal love is essential to a child's mental health (Dally, 1982).

Subsequently, Bowlby (1973; 1977; 1979) carried out extensive research on the mother-child dyad. His theory argued that children's ties to caregivers vary according to the quality of the attachment. Children who are securely attached to the caregiver perceive them as a safe base in times of high distress, and as a secure base to support exploration and play in times of low distress. Responsive and sensitive care from the caregiver is the prerequisite for secure attachment. Kerns et al. (1996; 2000) report that attachment has significant implications outside the parent-child relationship with more securely attached children being more confident, experiencing less difficulty in social interactions and having better emotional and school adjustment (Kerns, Klepac, & Cole, 1996; Kerns, Tomich, Aspelmeier, & Contreras 2000). In addition, several studies have shown that securely attached children have parents who are responsive to their children's needs and concerns, and are able to support them (De Wolff & van IJzendoorn, 1997; Kerns, Tomich, Aspelmeier, & Contreras 2000;). Suess, Grossmann, and Sroufe (1992) hypothesise that mother-child attachment has a greater impact on children than does father-child attachment (maternal primacy hypothesis). However, research findings on maternal primacy are mixed as some studies from early childhood have

supported this finding, while others have not (Youngblade, Park, & Belsky, 1993), and some studies have reported that the situation may shift across childhood (Cohn, Patterson, & Christopoulos, 1991; Kerns, Tomich, Aspelmeier, & Contreras, 2000).

Psychological research highlights the importance of the mother's role in the development of children and suggests that in order to achieve this goal mothers should carry out their role in a sensitive way. Sensitive mothering has been defined as the mother being responsive at every stage to what the child needs. The mother must understand and know when the child is ready to distance itself, and when it is feeling unable to be distant or separate. Chodorow (1999) states that the continuity of care from the mother enables the child to develop a sense of self. Phoenix & Woollett (1991) report that mothers are widely expected to demonstrate strong feelings of attachment, to take major responsibility for their children's care, and to be sensitively responsive to children's behaviour and individuality.

In conclusion, this brief review suggests that psychological research demonstrates the importance of sensitive mothering for children's present and future smooth integration into society. However, mothering a child diagnosed with autism has been linked with a high risk of presenting mental health problems such as depression and anxiety (Duarte, Bordin, Yazigi, Mooney, 2005).

## 4. Stress and adjustment

Hill (1949) defines stress as a process between the environment, the availability of resources, and individual patterns of appraisal and coping. Similarly, Antonovsky (1987) argues that it is impossible to foresee the consequences of a specific stressor without knowing something about the person's views of himself/herself and the world. Friedrich, Wilturner, and Cohen (1985) assert that while having a child with Intellectual Disabilities (ID) increases the probability of stress in the parents, this factor does not assist in predicting how an individual will respond to this event as raising a child with special needs may have a positive impact on the family. Friedrich, Wilturner, and Cohen (1985) and other researchers find that the presence of a chronic disability in a child is a stressor that requires an ongoing coping response from the parents. The inconsistency of findings regarding parental response to this stressor implies that some parents have the ability to successfully adjust, while others find it more difficult to do so. Therefore, it can further be hypothesised that it may be the

psychosocial implications of the disability rather than the disability itself that are more significant for maternal adjustment (Woolfson, 2004).

Adjustment is a psychological concept that emphasizes individuals' struggle to negotiate the social and physical environment. It consists of two kind of process. The first involves assimilating oneself into given circumstances, while the second involves accommodating the circumstances to fit one's needs. Lazarus (1976) argues that in the psychological study of adjustment, focus should be placed on the adjustive commerce between the person and the environment as we live interdependently with other people.

According to Lazarus (1976) the adjustment process does not involve only cognitive processes, like problem solving, but emotional processes as well. Strong emotions of anger, fear, anxiety, guilt, and shame are also generated. Stress is considered to be very important in the adjustment process as it implies a change from simple problem solving to a strong emotional situation. Stress is considered to arise when the demands exceed the resources of the person. Manifestations of adjustive failure include actions that seem peculiar because they deviate from societal standards and frequent or continuing subjective distress, like anxiety, anger, depression, and guilt. Successful adjustment can be considered when the individual can tolerate all or some of the attendant distress, when he/she can maintain a sense of personal worth despite defeats as well as rewarding interpersonal relationships, and when one can meet specific requirements of the stressful task (Lazarus, 1976).

Recent studies have examined the role of cognitive appraisal in families of disabled children and have found it to be an important outcome in parental adaptation (Beresford, 1996; Pelchat, Bouchard, Perreault, Saucier, Berthiaume, & Bisson, 1999; Woolfson, 1999). The results of these studies indicate that a focus on the psychological strategies employed by family members dealing with stress is an area of potential importance. An understanding of how family members perceive and interpret the experience of raising a child with intellectual difficulties has implications for the family's well-being and for the provision of services to the parents (Woolfson, 2004).

**5. Common themes in the literature on parenting a child with developmental disabilities**

There are several common themes that result in reviewing the studies on parents and families of children with disabilities: parental stress, the role of support, the effect on mother's employment and adjustment.

**5.1 Parental stress**

A finding that is consistent across the literature is that greater stress, higher levels of depression, and more adjustment problems are reported by parents who raise a child with autism in comparison to parents that raise children with Down's Syndrome (Feldman, McDonald, Serbin, Stack, Secco, & Yo, 2007; Eisenhower, Baker, & Blacher, 2005; Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murhy, 2004; Beck, Daley, Hastings, & Stevenson, 2004; Olsson & Hwang, 2002; Cahill & Glidden, 1996; Rodrigue, Morgan, & Geffken, 1990; Donovan, 1988). Factors that are associated with parental stress include uncertainty of the child's capability (Gowen, Johnson-Martin, Goldman, & Appelbaum, 1989), future health, growth, and the family's ability to meet the child's needs (Harris & McHale, 1989). Moreover, parental distress seems to increases when questions about the cause of the disability and their expectations for the future are unanswered (Feldman, McDonald, Serbin, Stack, Secco, & Yo, 2007). The type of behaviours displayed by children diagnosed with autism also seems to affect the experience of stress in parents' life. In a qualitative study conducted by Gray (1997) it was found that the presence of aggressive behaviours seem to affect in a negative way parents' perception of smooth family life as they interfere with typical family activities like going out in public and eating meals. Burrows, Adams, and Spiers (2008) have also reported that the unpredictable and volatile behaviour displayed by children with autism creates stress for their parents.

Several researchers have attempted to examine how the type of the disorder relates to maternal well-being. It has been suggested that mothers that raise children diagnosed with autism tend to report poorer psychological well-being when compared to mothers that raise children with other types of ID. Researchers have suggested that this finding relates to the negative and unpredictable behaviours displayed by children with autism, including impulsivity, hyperactivity, and irritability (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murhy, 2004; Maes, Broekman, Dosen, & Nauts, 2003; Kasari & Singman, 1997; Rodrigue, Morgan, & Geffken, 1990).

In particular, Rodrigue, Morgan, and Geffken (1990) conducted a study to examine the impact of a child with autism on the psychosocial function of their mothers. The experience of mothers of children with autism was compared with the experiences of mothers of children with Down syndrome and normally developing children. The participants of this study who had children with autism reported lower perceived parenting competence, frustration, anxiety, and tenseness, and tended to rely more on information seeking, wish-fulfilling fantasy, and self blame as coping strategies. The authors suggested that raising a child who does not interact socially or often resists physical contact may precipitate feelings of anger or rejection, which may lead to subsequent feelings of self blame.

Kasari and Sigman (1997) also examined the experience of mothers who bring up children with autism, Down syndrome, and developmentally normal children, and the findings of their study are consistent to the study of Rodrigue, Morgan, and Geffken (1990). Kasari and Sigman (1997) examined both the perceptions of caregivers of children with autism, children with Down syndrome, or normally developing children and the correlation between caregivers' perceptions and caregivers' feelings and nature of interaction with the child. It was found that parents of children with autism reported their children to be more difficult temperamentally and reported greater stress associated with child characteristics than the parents of normally developing children and parents of children with Down syndrome.

Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, and Murphy (2004) conducted a study to explore the psychological well-being and coping in mothers of youths with autism, Down syndrome, of Fragile X syndrome and found that mothers of children with autism reported higher levels of pessimism, more distant relationships with their children, and higher levels of depressive symptoms than did the mothers of children with Down syndrome. The strongest and most consistent predictor of maternal outcomes was the extent and severity of the behavioural symptoms of the adolescent as measured by the Autism Behaviour Checklist, which is a list of questions about a child's behaviors. In particular, it was found that high scores on this measure significantly predicted greater maternal pessimism and depressive symptoms and more distant relationship with the child.

Similar findings have been reported by a study contacted by Blacher and McIntyre (2006). In particular, they examined whether behavior problems and adaptive behavior of low functioning adults and well being of their mothers varied by diagnostic syndrome. The participants of this study had children diagnosed with intellectual difficulties, cerebral palsy,

Down syndrome, or autism. The results indicated that autism was associated with the highest scores in multiple behavior problem areas as well as maternal reports of lower well being and higher parenting stress.

Some researchers however, have not managed to find a relationship between the nature of disorder, the severity or of the symptoms, and maternal adjustment. Greenberg, Seltzer, Krauss, Chou, and Hong (2004) carried out a study which aimed to investigate the effects of the quality of the relationship between maternal caregivers and their adult child with disabilities on maternal well being. Their sample included mother caring for adult children with Down syndrome, schizophrenia, or autism. Their findings indicated that mothers of adults with autism had better psychological well-being when they had a better quality relationship with their child. It was found that the quality of the relationship was totally or partially mediated by optimism and that the behavioural problems of the child did not appear to affect the well-being of their mothers. The authors hypothesized that Inventory for Client and Agency Planning (ICAP), the instrument they used to measure the behavioural problems of the children, did not capture the range of behaviours that are most distressing to the parents of children with autism. When they rerun the regression analysis using the Autism Behaviour Checklist they found that a higher level of behavioural symptoms was predictive to a higher level of depression and lower levels of maternal well-being. The authors concluded that their finding of no relationship between behaviour problems and maternal well-being should be interpreted with caution as it might reflect limitations in the use of ICAP for capturing the range of behavioural problems in adult with autism.

**5.2 Support**

Woolfson (2005) states that western societies tend to view disability as a tragedy and that parents of disabled children are likely to experience additional parenting challenges, such as coping with family and friends' responses to disability. Support can be multidimensional, and can be provided by the spouse, the family, the extended family, friends, religious groups, statutory services, and/or voluntary services (White & Hastings, 2004). Support can be both helpful and unhelpful. Brewer, Smith, Eatough, Stanley, Glendinning, and Quarrell (2007) have found that the characteristics of helpful support involve listening, honesty, flexibility, and consistency. On the other hand, unhelpful support is characterised by a tendency not to listen or not to believe the family, inflexibility, and inconsistency. Perceived satisfaction with support is considered to be a fundamental dimension of social support and is considered to be

related to well-being (Dunst, Trivette, & Cross, 1986). A study conducted by Dunst, Trivette, and Cross (1986) revealed that satisfaction with social support was associated with protection. In particular, parents of children with ID reported being less overprotective of their children when they perceived their social networks as being supportive.

Herman and Thompson (1995) inter alia, indicate that marital satisfaction amongst parents with a child with special needs is associated with lower levels of stress. Other studies have shown that perceived maternal satisfaction with family members' support in care giving for an adult with intellectual disability is associated with lower levels of depression and higher maternal well being (Blacher & McIntyre, 2006; Magana, 1999). Support from extended family members, especially grandparents, and friends and religious groups has also been found to mediate and/or moderate parental stress (White & Hastings, 2004). Specifically, support from grandparents has been found to be an important resource for families of children with intellectual disabilities (Sandler, Warren, & Raver, 1995; Hastings, Thomas, & Delwiche, 2002).

Studies express a wide range of views about the impact of professional support for children with autism on parental well being. White & Hastings (2002), reveal that professional support was not associated with improved parental well-being, and that it appeared to be more strongly associated with the child's needs, rather than with parents' needs. The authors suggested that the results could be affected by the instrument chosen to measure the impact of professional support. In particular, the properties of the Professional Services Support Scale (PSSS) are unknown and it might not be a valid measure of important dimensions of support form professionals and services.

Other studies however, have shown that intervention programmes for children have a positive impact on maternal well-being. Baker, Landen, and Kashima (1991) carried out a study which aimed to examine the broader impact of parent training on parents and families of children with intellectual difficulties. The researchers examined the changes on a variety of parent, family, and marital measures before and after parents completed an 11-session parent training programme focused on skill teaching and behaviour problem management one year later. The results indicated that there were small but statistically significant decreases in reports of symptoms of depression, parent and family problems, and overall family stress.

Trudgeon and Carr (2007) conducted a qualitative study which aimed to examine the impact of home-based early behavioural intervention programmes on families of children with autism. The results present a picture of mixed impacts: specific sources of anxiety and stress on families through the programme's demands were accompanied by significant sources of support provided through the programmes benefits. Hastings and Johnson (2001) conducted a quantitative study to explore predictors of stress in parents participating in intensive home-based behavioural intervention for young children with autism and the results indicated that there is no relation between parental intervention involvement and family stress. Schwichtenberg and Poehlmann (2007) build on the Hastings' and Johnson's study and conducted a study which aimed to assess maternal depression and home-based behavioural intervention intensity. The results of their study indicated that the mothers who spent more hours per week involved in their child's behavioural programme reported more feelings of personal strain. Differences in the results of these studies could be due to differences in sample size and sample characteristics, as the study conducted by Schwichtenberg and Poehlmann (2007) had a small sample size consisted only by mothers.

The literature reviewed indicates that social support is well documented as being a significant factor in family coping and adjustment to a child's disability. However, O'Brien (2007) observes that if we take into consideration the different ways that families respond to the child's disability, we can conclude that social support does not provide an explanation for the initial variation in distress. Duarte, Bordin, Yazigi, and Mooney (2005) found that a decreased motivation to be involved with other people rather than a lack of resources available is more related to stress. In similar vein, Woolfson (2004) argues that how a parent perceives and interprets the stresses involved in parenting a child with ID can be an area of potential importance for the family's well being.

## 5.3 Adjustment

The review of the literature indicates that raising a child with autism imposes a number of hardships on family life. There are however, a number of studies that report that families of children with ID are able to adjust to the demands of parenting a child with special needs. Stainton & Besser (1998) report that there is a positive impact of raising a child with ID including autism, and that further, in terms of personality, marital adjustment, and family interactions, mothers of children with autism do not differ significantly from mothers raising children with normal intelligence. Similar findings have been reported in other studies where

marital satisfaction and adjustment in families with children with autism were measured (Akerley, 1984). A study conducted by Hastings, Allen, McDermott, and Still (2002) found a positive association between a mother's perception of the child as a source of happiness, fulfilment, and personal growth and both her positive perception of social support and her ability to devise coping strategies. The findings of this study imply that there is an association between coping and positive perceptions.

Tunali and Power (1993) argue that it is difficult to determine whether the variables that are considered to affect parental adjustment are predictors for successful coping or the outcome of successful coping. It appears however, from a number of qualitative studies that have been conducted that the process of adjustment involves the interplay between parents' beliefs regarding the child's disability and the management of child's disability. In particular, Knafl and Deatrick (2002) suggest that the families who are able to normalise childhood chronic illness, recognise the seriousness of the illness while continue to view their child and the family as unchanged in important ways. As a consequence, they are able to adopt a flexible approach carrying out the treatment regimen, one that emphasises incorporating the illness into the usual routines of the family and child. In a similar vein, May (1997) in her study of low birth weight infants, described searching for normalcy as the process through which mothers achieved a family lifestyle not centered on infant vulnerability and caregiving burden.

Similarly, King, Zwaigenbaum, King, Baxter, Rosenbaum, and Bates (2006) in their study of children diagnosed with autism or Down's Syndrome, reported that it was important for the parents not to let autism dominate the family life. Parents reported that in order to sustain their own sense of self as well as the family's sense of self had to set priorities so to develop a life style that was not solely focused on helping the child diagnosed with autism. They also emphasised the importance of both accepting that the child would experience milestones in his or her own development completely different than the same-aged, normally developing children and acknowledging that there were certain situations associated with their child's disorder that could not always change. Lassetter, Mandleco, and Roper (2007) argue that finding positive meaning in the challenge of raising a child with disabilities has been found to be a process that requires passage of time rather than a spontaneous event.

**6. Qualitative studies on families that parent children diagnosed with autism**

The majority of the studies that have been conducted are quantitative. These studies have provided information regarding the variables that seem to affect the parental experience of raising a child with disabilities. A small number of qualitative studies have attempted to understand the meanings parents assign to having a child with autism. Gray (1993; 2002) carried out two sociological qualitative studies that aimed to examine the perception of stigma among parents of children with autism. In both studies the results indicated that parents of children with autism experience stigma but mothers were more likely to do so than fathers. The author attributed the results of his studies to the disruptive nature of symptoms of autism, the normal physical appearance of children with autism, and the lack of public knowledge and understanding regarding the nature of autism. In both studies the type of the symptoms of autism was related to stigmatization, as parents of aggressive children were more likely to experience stigma than parents of children with more passive behaviour.

Gray (1994) has also examined the perception of stressors and the coping strategies employed by parents of children with autism. According to this study the most serious stresses that parents reported included problems with the lack of normal language, disruptive and violent behaviour, inappropriate eating and toileting, and inappropriate sexual behaviour. The parents who participated in this study reported using a variety of coping strategies including the use of service agencies, family support, social withdrawal, religion, normalization, and activism. The author concluded that although no single strategy appeared to provide better outcome for parents' adjustment, the use of services and family support appeared to be most effective for a substantial number of parents. Finally, Gray (1997) examined the sociological construction of "normal" life among the parents of children with high functioning autism or Asperger's syndrome. The results indicated that parents' understanding of "normal" life was linked to factors such as their ability to socialise, the emotional quality of their interactions among family members, and the rituals and routines that comprised their perceptions of what "normal" families do.

King, Zwaigenbaum, King, Baxter, Rosenbaum, and Bates (2005) conducted a qualitative study that aimed to examine the changes in the belief systems of families of children with autism or Down syndrome and the way this is related to the adaptation and resilience of the families. The results indicated that the participants of this study were able to adapt and eventually gain a sense of coherence and control through changes in their world views, values

and priorities that involved different ways of thinking about their child and their parenting role, and the role of the family. Woodgate, Ateah, and Secco (2008) explored the experiences of parents who have a child with autism. The parents of this study reported a sense of isolation to be dominant in their lives which was found to be mainly the result of external factors like society's lack of understanding regarding autism. The participants of the study dealt with their isolation through valuing the accomplishments of their child with autism and receiving support from other families of children with autism. Cashin (2004) explored the existential mechanisms through which parents experience a shrinking of their selves as a result of parenting a child diagnosed with autism.

It is clear that there are few qualitative studies about the maternal experience of parenting a child diagnosed with autism, and even fewer that focus specifically on mothers. Kingston (2007) conducted a study of mothers living in Ireland who parent children diagnosed either with Down's Syndrome, Autism, or Attention Deficit Hyperactivity Disorder, and explored how women's gender and the social construction of motherhood affect their experience of parenting their child. She provided a rich description of maternal coping strategies and the nature of mothers' relationship with family members, professional, and the society in general (Kingston, 2007). O' Brien (2007) conducted a mixed methods study to explore the presence of ambiguity in mothers' experience of parenting a child diagnosed with autism. O'Brien's qualitative analysis revealed that mothers experience conflicting realities and emotions as a result of variability in day-to-day functioning and the uncertainty about child's prognosis; whilst the quantitative analysis revealed that the higher the ambiguity, the higher the maternal depression. Magana and Smith (2006) conducted a mixed methods study to examine how co-residence with a youth or an adult with autism affects the emotional well-being of Latina and non-Latina White mothers. Latina mothers were less likely to report negative aspects of co-residence and consequently they were less distressed and had higher levels of psychological well-being than non-Latina White mothers. The authors conclude that culturally related attitudes can be protective for mothers' emotional well-being as other studies have documented that strong feelings of loyalty, reciprocity, and solidarity among family members are important factors with respect to Latinos and caregiving (Magana & Smith, 2006).

**7. Conclusion and emergent research areas**

This brief review has shown that there are a limited number of studies that seek to understand and explore in depth the meanings that parents assign to having a child diagnosed with

autism. There are even fewer studies that have focused solely on mothers. Mothers are considered to be primarily responsible for their children and act as their primary caregivers. Therefore, there is a need for more studies that provide mothers with the opportunity to voice the challenges they face while parenting a child diagnosed with autism so as to better understand their experience and their needs, and to provide appropriate services for them. The majority of the studies that seek to explore maternal experience have not been conducted by psychologists. At the same time, a great number of quantitative studies highlight that this population is at significant risk of developing mental health problems mental such as anxiety and depression. As the burden of help in dealing with mental health issues falls on psychologists and therapists, it may be reasoned that their understanding would be enhanced by a study that aims to describe and interpret experience of mothers who parent children diagnosed with autism and discuss the essence of their experience through the framework of psychological theories.

The following two broad research topic areas emerged from the review of the literature. The first concerns mothers' own sense of identity and whether the experience of parenting a child diagnosed with autism affects the way they experience themselves, their character, their goals and aspirations in life. The second concerns the impact of parenting a child diagnosed with autism on mothers' personal and social life. Both research areas engage the meanings and beliefs that mothers have about themselves and others as a result of parenting a child diagnosed with autism, and how their cognitions affect their life choices and their consequent psychological well being.  It may be argued that only a qualitative methodology will achieve this objective.

# Chapter 2: Methodology

## 1. Chapter overview

This chapter presents a rationale for the use of Interpretative Phenomenological Analysis (IPA) through a discussion of the epistemological position of the researcher, and the relevance of IPA both to the research topic and the questions to be addressed. Finally, the chapter gives an account of the methods and the procedures used in the current study.

## 2. Research design

The study employed a cross sectional research, small sample design incorporating a qualitative methodology.

### 2.1 Research Rationale - Definition of the research question

The majority of the studies that have been conducted with mothers who parent children with autism are quantitative, with a main focus on identifying variables associated with parents adaptation. These studies have attempted to compare groups of mothers who have children with different types of intellectual difficulties, and have examined the levels of stress and adjustment problems in each group. In contrast, some qualitative studies have adopted a non-categorical approach in order to focus on commonalities across chronic conditions. The researcher reasoned that although there are some commonalities among different conditions in terms of the features that characterise them, it would be beneficial to adopt a diagnostic-specific approach so to gain a more in-depth understanding of the condition's impact on the mothers, and therefore promote the development of more specialist services (Brewer, Eatough, Smith, Stanley, Glendinning, & Quarrell, 2008). For similar reasons, the researcher decided to focus only on mothers and not on both parents as several studies have shown that gender influences the experience of parenting a child and as a consequence the construction of meaning and the needs of each parent differ. Furthermore, it has been reported that mothers typically provide the majority of the care given to children with autism (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murhy, 2004; Gray, 1997; Kingston, 2007).

The aim of this study is not to explain why mothers respond in certain ways to the demands of parenting a child with autism, but to understand how the world appears to them and to explore how their understanding relates to their behaviour (Maxwell, 1996). According to Willig (2001), each individual brings to the situation different resources that are influenced

by their experiences of past events, their life history, or their social environment. As a consequence, reality can be constructed in many different ways, depending on the resources that each individual brings to the situation. Therefore, the accounts of the participants of this study are part of the reality that the researcher aims to understand. This study is concerned with the subjective nature of parenting a child with autism, and attempts to explore the beliefs and feelings that mothers bring to the experience. In particular, the study explores the meanings attached to the phenomenon of parenting. It considers how the participants' experience affects their view of themselves both as women and as mothers, as well as the way they perceive their relationship with others. The questions that emerge from these considerations are: What does it mean to be a mother who parents a child diagnosed with autism? How do mothers think and feel about themselves and others as a result of this experience?

Since the aim of these research questions is to explore the meanings and perceptions of participants' experience, it seems appropriate to use a research methodology that enables an exploratory approach. Qualitative methodologies regard researchers as participating in a process of data generation (Smith, 1996). This emphasis on reflexivity lies at the heart of the philosophy of counselling psychology (BPS, 2005). Therefore, the adoption of qualitative methodology is also congruent with the researcher's role as a practitioner. The researcher considers that questionnaires with limited and specific questions may prevent the exploration of meanings and emotions (Smith, 1995). Therefore, a semi-structured interview has been chosen as a means for the collection of data. Qualitative research methods regard interviews as essential for obtaining scientific knowledge (Kvale, 1996). The goal of qualitative research methods in psychology is to develop understandings of a particular phenomenon. These understandings should be based on the perspective of the participants as much as possible (Elliot, Fischer & Rennie, 1999).

## 2.2. Philosophical Paradigm

The choice of the research method as well as the choice of the approach within the particular research method is based on the epistemological position of the researcher. Epistemology is concerned with ways of knowing and learning about the world (Snape & Spencer, 2003). A philosophical paradigm can be defined as "a set of assumptions about the social world which provides a philosophical and conceptual framework for the organised study of that world" (Filstead, 1979, p.34). According to Ponterotto (2005), the selected philosophical paradigm

guides the researcher to philosophical assumptions about the research and to the selection of tools, instruments, participants, and methods used in the study.

The paradigm that the researcher has adopted in order to develop this present study is the constructionist paradigm. According to Ponterotto (2005), the constructionist paradigm adheres to a relativist position that assumes multiple, apprehendable, and equally valid realities.  In particular, relativism proposes that there is no single social reality, only a series of alternative social constructions (Snape & Spencer, 2003). The constructionist paradigm holds that reality is constructed in the mind of the individual and that it is not an externally singular approach. Proponents of the constructionist approach emphasise the goal of understanding the 'lived experiences' from the point of view of those who live it day by day (Ponterotto, 2005).

At the same time, constructionist approach supports that reality is influenced by the context, the participant's experience and perceptions, the social environment and the interaction between the researcher and the participant. Therefore, it is through the interaction between the researcher and the participant that the meaning of the participant's experiences can be understood. Interpretation plays a central role in this process (Ponterotto, 2005).

There are several constructionist approaches. The constructionist approach that was adopted for the development of the present study is the contextual constructionist. Contextual constructionist proposes that all knowledge is contextual and stand-point dependent. As a consequence different perspectives generate different insights into the same phenomenon. As a result contextual constructionist is concerned with completeness rather than accuracy of representations (Willig, 2001).

## 2.3 Methodological Considerations

As already mentioned, the philosophical paradigm adopted by the researcher guides him/her to the selection of methods for the development of the study (Ponterotto, 2005). The contextual constructionist philosophical paradigm rejects the idea of an unequivocal, real world. As a consequence it rejects the positivistic, philosophical paradigm (Ashworth, 2003). Positivism adheres closely to the hypothetico-deductive method and aims to verify a prior hypothesis that is most often stated in quantitative methods (Ponterotto, 2005). Therefore, a qualitative method was adopted for the development of the present study. Qualitative

methods are designed to describe and interpret the experiences of participants in a context-specific setting (Ponterotto, 2005).

Interpretative Phenomenological Analysis (IPA) and the social constructionist version of Grounded Theory are two qualitative methods that take a contextual constructionist approach (Willig, 2001). Therefore, in order to decide which method would be appropriate for the development of the present study, the researcher considered to examine what kind of knowledge these methods aim to produce and what kind of assumptions they make about the world.

Grounded Theory and IPA share many features. According to Willig (2008) both aim to produce a cognitive map of a person's world view and both start with individual cases which are then integrated to obtain a composite picture of the phenomenon. Moreover, both IPA and Grounded Theory use categorization in order to achieve data reduction leading to a general understanding of the fundamental process or the essence that characterised the phenomenon of interest (Willig, 2008). The difference between Grounded Theory and IPA is that Grounded Theory aims to identify and explicate contextualized social processes which account for phenomena (Willig, 2008). On the other hand, IPA is concerned with gaining a better understanding of the quality and the texture of individual experiences, and is interested in gaining an insight into individual's life world (Willig, 2008).

According to Willig (2008), IPA assumes that individuals can experience the same condition in different ways, and that this happens because experience is mediated by the thoughts, beliefs, judgements, and expectations that the individual brings. As a consequence, IPA aims to obtain an insight into another person's thoughts and beliefs in relation to the phenomenon under investigation. In particular, it aims to create knowledge about the way people think about this phenomenon. This study attempts to explore the beliefs that mothers of children with autism bring to the experience of parenting their child. In particular, it explores the meanings that they attach to this phenomenon and how the experience of parenting their child has affected the way they perceive themselves and their interaction with others. IPA tends to deal with significant life-transforming events (Brewer, Smith, Eatough, Stanley, Glendinning, & Quarrell, 2007). Therefore, it is reasoned that IPA is the most appropriate methodology to gain an insight into mothers' life world.

At the same time, IPA acknowledges that interpretations of events are affected by the social interactions and processes between people in their role as social actors. This implies that IPA

adopts a symbolic interactionist perspective (Willig, 2008). Symbolic interactionism perceives the individual's social world as involving the interplay of symbols and meanings embedded within a particular social context (Richardson, 1996). The present study aims to gain a greater understanding on how mothers of children with autism make sense of their experiences within both their personal and social world. The mother is a person who is relative and three dimensional. She is relative because she is thought of in relation to the father and the children. She is three dimensional because, in addition to this two-fold relationship, the mother is also a person, who often has nothing in common with her husband's thoughts or her children's desires (Badinter, 1981). Therefore, it is reasoned by the researcher that it is not possible to discuss one member of the family without taking into account the other members as well. It is further reasoned that the symbolic interactionist perspective of IPA provides the space to explore how mothers' social interactions affect the way they interpret the experience of raising a child diagnosed with autism.

## 2.4 Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) aims to explore in detail how participants make sense of their personal and social world (Smith & Osborn, 2003). There are two main theoretical underpinnings for IPA. The first is phenomenology. Husserl developed the core principle of phenomenology according to which there is nothing more fundamental than experience. Therefore, the investigation of a phenomenon should start with what is experienced because what appears is to be taken as 'reality' (Ashworth, 2003). According to McLeod (2001) phenomenology seeks to set aside any assumptions of the object of inquiry and aims to produce an exhaustive description of the phenomenon until its essential features reveal themselves. The goal is to builds up a comprehensive description of the object itself. (McLeod, 2001). The phenomenological emphasis of IPA is reflected in the way the researcher approaches the data. According to Larkin, Watts, and Clifton (2006), the IPA researcher should try to understand the participant's experiences of a specific phenomenon, and to describe what it is like. However, the researcher should always take into consideration that access to experience is both partial and complex because it depends on the researcher's own perceptions (Smith & Osborn, 2003).

The emphasis that IPA places on the active role of the researcher in the research process connects it intellectually with the theory of interpretation or hermeneutics (Eatough & Smith, 2008). Hermeneutics is concerned with the interpretation of the texts. In the context of

qualitative research in counselling and psychotherapy, hermeneutics can be understood as an act of interpretation that attempts to make sense of an object of study. The aim is to bring to light an underlying coherence or sense, within the actions, behaviour or utterances of a person or a group (McLeod, 2001). A recognised early discussion of hermeneutic method is found in the work of Heidegger. Heidegger claimed that humans live in an interpreted world as we are ourselves hermeneutic interpreters (Ashworth, 2003). Hermeneutics can be defined as a theory of interpretation (Ashworth, 2003). There are two types of hermeneutics: (1) the hermeneutics of meaning recollection which aims at faithful disclosure of an instance, and (2) the hermeneutics of suspicion which aims to discover a further reality behind the experiences analysed in order to facilitate a much deeper interpretation to be made.

IPA aims to understand what the particular respondent thinks or believes about the topic of discussion, therefore, IPA is concerned with cognition. Understanding of cognitions allows comprehension of participants experience and actions (Willig, 2001). For this reason, IPA combines an empathic hermeneutic with a questioning hermeneutic. As far as the empathic hermeneutic is concerned, IPA attempts to understand what it is like from the point of view of the participants. At the same time, IPA involves asking critical questions so as to understand what the participant is trying to achieve or whether there are issues that the participants are less aware of. In other words, the goal of the researcher is to understand and interpret participants' meaning of a particular experience. This can lead to a richer analysis of participants' experience and can allow consideration of how meanings are constructed by individuals within both a social and a personal world (Smith & Osborn, 2003).

## 3. Procedure

The rationale for the sampling and for using semi-structured interviews is presented, as well as methods of data collection, interview context and procedure, and process of transcribing the interviews.

### 3.1 Participants

### 3.1.1 Sampling Criteria

IPA studies are conducted on small and fairly homogeneous samples. The basic logic behind that is to find a closely defined group for whom the research question will be significant (Smith & Osborn, 2003).

The sample of the present study was criterion based so to ensure homogeneity (Morrow, 2005). Therefore, the criteria for the selection of the participants for the present study included: (1) women that are mothers of children diagnosed with autism, (2) a family constellation of two biological parents living at home. Single mothers parenting a child with autism were not be included in this study as research has shown that single mothers experience higher levels of psychological distress than married mothers due to greater exposure to stress and strain (Crosier, Butterworth, & Rodgers, 2007; William, Ali, & Walters, 2007). Crosier, Butterworth, and Rodgers (2007) found that single mothers are more likely to experience poor mental health than partnered mothers, and the primary factors associated with this are the presence of financial hardship in particular, as well as perceived lack of social support. (3) Children should have received a diagnosis of autism between two or eight years ago. The reason for that is because the aim of the present study is not to explore the immediate response of the mother to the diagnosis itself. When a child receives a diagnosis of autism, this is a change in the family that demands an immediate response. Parents must learn to come in terms with how newly realised reality contradicts with their past perception of their child (O'Brien, 2007). As a consequence they have to consider how family patterns of behaviour should alter so as to accommodate the new child and his/her behaviour needs (Cahill & Glidden, 1996). Moreover, they have to face a confusing and sometimes conflicting array of choices regarding the type of intervention for their child (Domingue, Cutler, & Tarnaghan, 2000). (4) The children should not have entered adolescence as this is a transition period that is characterised by uncertainty. As a consequence this might require mothers to deal with new challenges (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murhy, 2004). Finally (5), children should have mild or moderate symptoms of autism, as several studies suggest that severity of autistic symptomatology can have an impact on parental adjustment. In specific, in a study contacted by Holmberg (2007) it was found that parents of children with a higher severity of autistic symptoms reported higher levels of child-related stress than parents of children with a lower severity of autistic symptoms. Moreover, parents of children with a higher severity of autistic symptoms also reported using more coping strategies than parents of children with a lower severity of autistic symptoms. Severity of autistic symptoms accounted for the greatest amount of variance in predicting the overall level of stress.

Although a number of selection criteria were employed in order to ensure homogeneity of the sample, it should be noted that the sample of the present study is a diverse convenience

sample as the participants represent a volunteer sample of people who were willing to talk about their experience. It is suggested by some researchers (Rodrigue, Morgan, & Geffken, 1990) that people who do not participate in research tend to differ systematically from those who do and therefore, the results of the present study may be biased because of the characteristics of the sample. One should be cautious therefore, about interpreting the relative weight of each emergent theme in relation to the wider population.

### 3.1.2 Sample size and demographic information

IPA does not set any criteria about the size of the sample. The requirement set by IPA is that the sample provides rich data to examine similarities and differences between cases (Smith & Osborn, 2003). The current study had eight participants. The age range of the participants ranged from 35 to 45 years old and the mean age was 39. All participants were married and living with their spouse and their children. Except one mother who had three children, all mothers had two children. Two mothers had two children diagnosed with autism in the family. All children diagnosed with autism were boys and their age ranged from five to 12 years old, with the children's age of initial diagnosis ranging from 2.5 to 4.5 years. Only one child received the diagnosis when he was six years old. All mothers reported that their children have mild or moderate symptoms of autism and described them as being high functioning. As far as the ethnic background of the participants is concerned, half of the participants were Asians, two were White British, one French, and one half White British, half Iraqi. All but one mothers lived their whole adult life in the United Kingdom. Half of the mothers held a postgraduate diploma and half of them worked part time, one worked full time, while the rest had no employment. A full summary of demographic information can be found in Appendix 9.

### 3.1.3 Recruitment

The recruitment of the participants took place by networking and using the researcher's contacts in the field of behaviour treatment for autism. Moreover, contacts were sought with four charities that provide support to children diagnosed with autism and their families. The administration staff of these charities were approached by telephone and it was agreed that the research flyer of the present study would be advertised within the newsletters of these organizations. However, only one of them, Peach (a charity that promotes early behavioural intervention for young children with autism) actually advertised the present research within its newsletter. Moreover, the Director of External Affairs of Disabilities Trust (a charity that

provides services to people with disabilities in United Kingdom) contacted a mother that was believed to meet the research criteria and provided her with information about the research. In addition, an advertisement was placed on a magazine specialised in autism, 'Autism file' and a post was uploaded on an internet site for parents with children diagnosed with autism 'ASD Friendly'. The administrator of the site was contacted by the researcher via email, and he gave his approval for the post to be uploaded. Finally, the researcher contacted the Special Educational Needs Coordinator (SENCO) of Aylward First and Middle School, a mainstream school in north London that accepts children with developmental difficulties like autism. Approval was gained and the SENCO of the school wrote a letter to introduce the researcher and the aims of the research. This letter was sent by the SENCO along with the information sheets constructed by the researcher to parents that met the sampling criteria. The researcher decided to contact this particular school as she used to work there for eight months as a learning assistant supporting a child diagnosed with autism. Evidence of contacts related to recruitment can be found in Appendix 8.

## 3.2 Interviews

### 3.2.1 Selection of interview type

Qualitative researchers consider interviews as essential for obtaining scientific knowledge. The main goal of qualitative researchers is to obtain data that will enable them to interpret meaningful relations (Kvan, 1996). For the purposes of the present study, semi structured interviews were designed and conducted. This form of interview facilitates rapport and empathy and allows a greater flexibility of coverage. Moreover, it allows a greater flexibility to enter novel areas, and it tends to produce richer data. The IPA interview schedule generally addresses a range of issues to be explored by using neutral, open-ended questions and a 'funnelling' approach, starting at a general level and then probing more specific issues (Smith & Osborn, 2003). The researcher reasoned that this type of interview is consistent with the aims of the present study as the goal was to encourage participants to feel safe and comfortable to explore sensitive issues without feeling guided by the researcher.

### 3.2.2 Interview questions

Due to the demands of the Doctorate in Counselling Psychology, a research proposal was submitted and a critical review of the relevant literature carried out. The interview questions were stimulated both by the theoretical literature reviewed and by the clinical experience of

the researcher. An interview schedule was constructed to make sure that the questions addressed the researcher's areas of interest. Questions were constructed in a way that were neutral rather than value-laden, and did not include any jargon language (Smith & Osborn, 2003) Nevertheless, the researcher was open to novel views that might have emerged from the interviews and was flexible about introducing new questions to the interview (Smith & Osborn, 2003).

Questions were open-ended so to allow participants to elaborate on their story and to encourage them to talk more about their experiences with as little prompting from the researcher as possible. The goal was to examine participants' attitudes to meet the demands of parenting a child diagnosed with autism and to explore participants' experience rather than making assumptions about them (Smith & Osborn, 2003). In addition, participants were asked to fill out a questionnaire on demographics. The purpose of this questionnaire was to help the researcher define the sample in terms of demographic characteristics. Appendix 1 provides detail of the interview schedule.

### 3.2.3 Interview context and procedure

The interviews on average lasted between 45 minutes and 75 minutes. The interviews were recorded on a digital voice recorder. Participants were asked to fill out a sheet on demographic characteristics (Appendix 2). The researcher completed a field notebook throughout the data collection period in order to record her reflections of the process. All interviews took place at the house of the participants so to minimise inconvenience. In some occasions, there were interruptions during the interview process for several reasons, the most common being children's need for the mother's attention. On all occasions and for safety reasons, the researcher notified a person in her close environment about where the interview was taking place and how long the interview would approximately last.

All participants were encouraged to ask questions about the study. Most of the participants expressed their enthusiasm about the study as they believe that there is lack of information and understanding about mothers' experience of parenting a child diagnosed with autism. Some of the mothers felt upset and cried during the interview. They were encouraged to ask if they wished to stop the interview, and were offered the opportunity to stop at any time. The researcher also used her clinical judgement to monitor participants' levels of distress. None of the mothers who participated in face-to-face interviews stopped the interview process because of feelings of distress, nor did anyone withdraw from the study.

Two mothers who were interested in this study asked to have an e-mail interview because of the considerable distance between their base and researcher's base. Several IPA researchers use e-mail interviews as a method of collecting data (Murray, 2008). The advantages of this method include being time and cost effective, allowing for contact with a wide range of participants, and allowing time for participant reflection. Additionally, e-mail interviews might help people to disclose things that would be difficult to say face-to-face, as well as allow the researcher to work with a set of interviews simultaneously. A further advantage is that this method might help overcome the interviewer effect (Hunt & McHale, 2008). A major disadvantage of e-mail interviews is the fact that they narrow bandwidth of communication as the researcher misses the nonverbal cues that are present during a face-to-face interview (Evans, Elford & Wiggins, 2008). Having considered all these factors, the researcher decided to use e-mail interviews as they were appropriate and compatible with the methodology employed. The first participant who requested to have an e-mail interview signed the consent form and sent it to the researcher via post,  but then never replied to the researcher's email that informed her she had received the consent form and invited her to start the interview process. Therefore, she withdrew from the study without providing any information about her experience. The second participant sent the consent form via post and responded to the researcher's first set of questions, but never responded to the second set and subsequently withdrew from the study without providing any reason. Due to this the data of the second participant has not been used for analysis.

## 3.3 Transcription

All interviews were transcribed by the researcher. Identifying features such as names of the mother and the family members have been replaced in the transcript with pseudonyms. Names of professionals who work with the child, names of organisations, or names of schools have been removed. IPA transcribing does not require prosodic features of talk but according to the IPA criteria for transcription all words spoken should be transcribed including false starts, pauses, laughs, crying and other behavioural expressions that are worth recording (Smith, 2003).

## 4. Analysis of data

### 4.1. Analytical method

IPA analysis requires the researcher to carry out detailed and interpretative work on a case-by-case basis. The transcripts were read through several times. At the initial stage of the analysis, the entire transcript was treated as data and there was no attempt to select particular passages for special attention. The aim was to understand the content and complexity of participants' comments, and as a consequence, to gain a greater understanding of their psychological world. In subsequent readings, comments were made in the left hand margin regarding interesting and significant passages. The initial themes derived by reading through the highlighting data and the comments in the left hand margin were noted in the right hand margins. These initial thematic codes that derived from the highlighted data were phenomenological and attempted to describe the essence of participants' experience. The emerging themes were listed in order of presentation, and the researcher tried to understand the connections between the themes and to cluster them. Super-ordinate themes derived from this process. During this process the analysis moved from the descriptive to the interpretative level. At each stage the emergent themes were strongly supported and grounded in the data. (Smith & Osborn, 2003).

This type of data analysis was adopted for each interview. The researcher engaged in an interactive process by identifying repeating patterns among interviews but at the same time being aware of new issues that emerged. After all the data was analysed transcript by transcript it was re-analysed across all interviews. Only themes that were strongly supported from the data of all or the majority of the interviews were extracted, and a table of super-ordinate themes was constructed (Smith & Osborn, 2003). Super-ordinate themes were reviewed and reorganised so that the final table of super-ordinate themes to capture the essence of participants' experience.  The following master table of themes as well as details of each theme and sub-themes were developed by the researcher:

**Master table of themes**

**<u>Theme 1: Ambiguous loss</u>**

Sub-theme 1: Loss of the child I thought I had
Sub-theme 2: Ambiguity
Sub-theme 3: Making Sense of the loss
Sub-theme 4: Growth

## Theme 2: Identity shift

Sub-theme 1: Maternal Identity
2.1.1 Responsibility for the child
2.1.2 Devotion to child's progress

Sub-theme 2: Integrating maternal identity to the self system
2.2.1: Integrating maternal identity and wife identity
2.2.2: Change in priorities

## Theme 3: Withdrawing from others

Sub-theme 1: Lack of understanding
Sub-theme 2: Feeling judged
Sub-theme 3: Affiliation with people that accept autism

### Theme 1: Ambiguous Loss

| Participants | Loss of the child I thought I had | Ambiguity | Making sense of the loss | Growth |
|---|---|---|---|---|
| Mary | 11.14-20 | 3.27-31, 4.1-12 | 23.5-15, 3.8-13 | 12.31 |
| Angela | 2.6-8, 3.18-26 | 3.27-28, 17.14-16 | 2.2-5, 4.17-21 | |
| Nicole | 3.8-9 | 9.19-29 | 4.20-21, 6.6-9 | 7.26, 8.1 |
| Adriana | 1.1, 1.19-21, 4.8 | | 2.16-17 | 7.1-6, 9.17-22 |
| Paulina | 7.1-3, 7.10-12 | 6.13-17 | 2.3-4, 5.4-6 | 4.21-23, 5.1-4 |
| Rosie | 1.7-9, 1.20-22, 15.13-15 | 7.13 | 12.21-26 | 13.21 |
| Jacqui | 9.14 | 2.28, 7.22-26 | 1.3-6 | 6.24-27, 7.1-2 5.22-27 |
| Laura | | 2.9-10, 9.9, 13.10-12, 14.7-9 | 4.25-26 | 14.24-27, 15. 1-3 |

### Theme 2: Identity shift, Subtheme 1: Maternal identity

| Participants | Responsibility for the child | Devotion to child's progress |
|---|---|---|
| Mary | 7.25, 19.17-30 | 7.25, 10.10-16 |
| Angela | 6.26-29, 8.11-14, 11.28-29, 16.27-31, 17.1-2 | 4.22, 7.9-10, 7.15 |
| Nicole | 4.15-16, 10.15-17, 10.23-26 | 7.17-27 |
| Adriana | 5.28-30 | 5.19-20 |
| Paulina | | 4.7-10 |
| Rosie | 5.2-4 | 7.4-8 |
| Jacqui | 1.26-27, 2.1, 2.27-28, 10.23-27 | 3.19-26, 4.1-4, 8.11-14 |
| Laura | 9.7-11 | 2.2-10, 6.14-18, 7.21, 13.19 |

**Theme 2: Identity shift, Subtheme 2: Integrating maternal identity to self system**

| Participants | Integrating maternal and wife identity | Change in priorities |
|---|---|---|
| Mary | 18.20-24 | 16.23, 17.12, 18.14-19 |
| Angela | 9.5-11, 9.19-31, 9.26-28 | 12.1-10, 10.21-23 |
| Nicole | 6.22-25, 7.24 | 5.26-29, 8.8-10 |
| Adriana | 8.15-23 | 5.10-11, 5.15-19, 8.6-10 |
| Paulina | | 4.9-10 |
| Rosie | 6.8-20 | 10.10-13, 14.3-5 |
| Jacqui | 6.16-21 | 5.13-15 |
| Laura | 15.6-8, 15.11-18 | 1.24-27, 2.1-2 |

**Theme 3: Withdrawing from others**

| Participants | Lack of understanding | Feeling judged | Affiliation with people that accept autism |
|---|---|---|---|
| Mary | 2.7-9, 20.9-17, 20.15-26 | 20.12-15, 21.8-10 | |
| Angela | | | |
| Nicole | 5.14-17, 9.7-9 | | 6.27-7.3, 8.13-20, 8.18-29, |
| Adriana | 6.16-25 | | 6.29-7.1 |
| Paulina | 5.3-5 | | 5.1-3, 5.20-22 |
| Rosie | 2.22-23, 3.17-21, 9.11-15 | 3.17-21, 3.5-7, 8.25-26 | 1.26-27, 2.1-2, 14.26, 10.14-20, 15.1-13 |
| Jacqui | 2.11-17 | | 4.11-13, 4.16-18, 8.25-27, 9.1-9 |
| Laura | 2.1-3, 2.17-21, 12.11, 12.16 | 5.2-7, 12.22-26 | 5.12-20, 4.18-19 |

## 4.2. Quality criteria in IPA

Morrow (2005) argues that quality criteria in qualitative research are very much related to the philosophical paradigm adopted by the researcher. In constructionist-interpretivist research, it is important to acknowledge that the nature of the data collected and the analytic strategies are influenced by the researcher's subjectivity. A way to manage the inherent subjectivity of IPA method is for the researcher to bracket or self-monitor her own assumptions (Morrow, 2005). The researcher throughout the research process actively tried to be aware of her own frame of reference, and efforts were made to limit and manage subjectivity by continually testing personal assumptions about the phenomenon under study and the findings in the data (Ajjawi & Higgs, 2007).

Yardley (2000) has suggested a number of broad principles for assessing the quality of qualitative research. The first, sensitivity, can be shown by awareness of related literature and analysis that is thoroughly grounded in the text. As far as the first principle is concerned, it is hoped that the researcher has demonstrated sensitivity through the thorough review of the literature on parenting children with special needs.

The second principle refers to commitment, rigour, transparency, and coherence. Commitment refers to engagement with the topic, rigour refers to completeness of data collection and analysis, transparency is the degree to which all aspects of the research process are disclosed, and coherence is shown by clarity in the description of the research process (Yardley, 2000). In order to assure the observance of this principle, a sample of coded transcripts were looked over by a counselling psychologist with experience in IPA research and by my research supervisor so as to consider the extent to which the emergent themes appeared to be grounded in the text and to facilitate a multi-layered understanding of participants' accounts. In order to ensure transparency the researcher kept a paper trail of all data concerned in the development of themes and super-ordinate themes so that all steps and reasoning are transparent and can be followed. This also includes the field diary where the researcher recorded her personal frame of reference, early ideas and conceptualisations in the continuing development of the research, and her impressions of the interviews. The goal was to path and build reflexivity (Willig, 2001).

Finally, in order to ensure authenticity and to ground interpretation in the data, the researcher constantly cross-checked her own interpretations with the text (Ajjawi & Higgs, 2007). Many verbatim quotes are included in the analysis to help readers evaluate whether the themes and

the arguments presented are consistent and grounded in the data (Smith, 1996). As for the clarity in the description of the research process, the completeness of data collection and analysis, and the researcher's commitment to the topic, it is hoped that these principles have been demonstrated in the current study.

**5. Ethical considerations**

The City University ethics forms were completed and submitted for authorization. All participants were given a Participant Information Sheet (Appendix 3) and asked to sign a Participant Consent Form (Appendix 5). In order to maintain confidentiality, no personal identifying information is included in the study. In particular, each participant was given a code which is attached on the transcripts of the tape recorded interviews. No names or any other information that would make it easy to identify the participant were attached to the transcripts. The digital tape recorded interviews were downloaded into a computer and were locked with a password that was known only to the researcher. The transcripts of the interviews were locked in a cabinet and it was only the researcher who had access to it. The digital tape recorded interviews and the transcripts were kept for 12 months and were used only for the purposes of the present study. The researcher presented participants' material to the research supervisor and examiners only for evaluation purposes. The third parties who had access to participants' data were required to treat the material as strictly confidential. All participants were informed that the content of the interviews is confidential, and will be used only for the purposes of the present study. In the case of publication of the study in a scientific journal or presentation of the study to scientific conferences, anonymity will be ensured as the names of the participants and any other personal identifying information will not be discussed.

Moreover participants were informed that their participation was voluntary and that they could withdraw at any time without having to provide an explanation. Participants were also informed that they could request the taping to cease at any time. If they became distressed they were encouraged to ask pause or stop. Only one participant requested to stop tape-recording, not because of high distress levels but rather because of issues of confidentiality. However, she did not withdraw despite being reminded of her right to do so by the researcher. She requested that certain parts of her account should not be included in the study; her request was respected by the researcher. A list of debriefing counselling agencies was

given to participants after the end of the interview (Appendix 7) as well as the researcher's contact details.

As far as ethical considerations regarding the email interviews are concerned, the ethical issues of informed consent, the avoidance to deceit, and the right to withdraw were applied in the current study (Hunt & McHale, 2008). In order to ensure that the person claiming to be the participant really is that person and really is the character suggested by her biographical information, the researcher asked participants to provide them with an address where the consent form was sent (Hunt & McHale, 2008). The consent form was obtained in both cases through a signature. Moreover, both participants were informed that participation was voluntary and that they could withdraw at any time without having to provide an explanation. In the case of the participant who withdrew from the study, the interview material was not analysed and not included in the study. A list of debriefing counselling agencies was provided to this participant. Appendices 4 and 6 provide details of the consent form, the information sheet, and the list of the debriefing agencies that were provided to the participants.

## 6. Reflections on the research process

According to Elliott, Fischer, and Rennie (1999, p.216), qualitative researchers accept that "it is impossible to set aside one's own perspective totally". Furthermore, according to Ponterotto (2005), the constructivist philosophical paradigm postulates that the researcher's values and experiences cannot be separated from the research process, and encourages the researcher to acknowledge and describe his/her values.

During my training as a counselling psychologist, I was given the chance to work with a child diagnosed with autism. In addition to the therapeutic work that I do with the child, I also have a close collaboration with the parents of the child, especially with his mother. My interaction with the child and his family stimulated me to consider how mothers of children with autism experience motherhood and motivated me to reflect on the way(s) they respond to the demands of parenting a child with autism. The aim of the present study is to give voice to the mothers of children diagnosed with autism to communicate and elaborate on their experience.

By reflecting on the initial stages of my research, I realize that in the beginning I held several assumptions and stereotypes about the mothers that parent children with special difficulties. It was personal as well as professional experiences that had influenced my attitude towards this

area. My training as a counselling psychologist as well as personal therapy helped me to become aware of my assumptions. Throughout the whole process of constructing the research design I tried to actively report them and bracket them. The process of the review of the literature for the purposes of the research proposal helped me bracket my assumptions. During the process of the literature review, I became more able to interact with and compare the data. This helped me to conceptualise and clarify the phenomenon under study.

The process of developing the interview questions was very challenging and demanding. I spent a lot of time brainstorming and considering possible interview questions. The help of colleagues and supervisors was valuable at this stage. This is my first attempt to carry out a qualitative study and I have to admit that the process of developing interview questions produced some levels of anxiety. The interview questions are the means through which you gather the data. Therefore, I was concerned whether my questions would stimulate the participants to elaborate on the issue that I am interested in exploring. At the same time I wanted the questions to be neutral and not directive in order to allow the participants to elaborate on their story. What I did at the first stage was to formulate a number of questions that were neutral and not value-laden or leading. At the same time I included in my interview schedule a number of prompt questions that I thought would help me not to miss anything.

What was quite challenging during the research process was the difficulty in recruiting participants. I approached as many different sources as possible and the initial very low response rate was frustrating. In particular some of the participants of the current study were recruited through my contacts with other professionals who work with children diagnosed with autism who kindly passed the information about my research to mothers they believed would meet the criteria. Some participants responded to the post I uploaded to the ASD Friendly web site, and one participant was informed by the Director of External Affairs of Disabilities Trust about the current study. Several people contacted me through the Autism File magazine, although most of them did not meet the sampling criteria. Interview arrangements were negotiated with a few respondents who did meet the sampling criteria, but no interviews took place as they lost interest during the process. None of the mothers who were informed about my research through Aylward First and Middle School expressed their interest for the present study. I had the same negative response from the mothers who received the newsletter of Peach: none agreed to participate in this study. The time restrictions to complete the components of my doctoral training programme added to my

frustration, but at the same time provided a strong motivation to explore and discover different routes to recruit participants for my study.

When I started interviewing participants, I realised that I was loosely following the interview schedule that I had formulated. After the first interviews, I realised that participants were willing to talk about their experience. Some of them elaborated on their experience in several areas without me actually having to ask explicit questions. Moreover, I actually used few of my initial prompt questions. The interview experience helped me realise that it is important to have a general outline of interview questions so to check whether all areas of participants' experience that are relevant and important for the interview questions have been explored. At the same time I gradually realised that it is equally important to be able to allow yourself to interact with your participant and listen carefully to their story. By doing so it allows the researcher to follow participants' track of thoughts. As a consequence, the researcher is more open to perceive participants' experience and gain some insight in the way participants are 'in the world'. I engaged with my participants by taking the stance of naive enquirer during the interview process: I never assumed that I understood what they implied with their statements and I always asked for clarifications so as to gain a better understanding about the meaning they ascribed to their experience and about the feelings they experienced. Every interview has been a learning process and changed me in meaningful ways as it challenged and changed my personal assumptions about how life is for a mother that parents a child diagnosed with autism.

As far as the analysis of data is concerned, this was a long term and challenging process. I found it helpful to discuss it with my research supervisor as it helped me to become aware of earlier conceptualisations and critically question whether the themes I had constructed captured the essence of my participants' experience. I was constantly aware during the process of the data analysis that although my interpretations were strongly grounded in the text, they were not merely descriptive; rather, they provided a greater understanding about participants' experience. I struggled with making the specific abstract, and with the process of creating abstract categories to include and reflect the meanings of the constituent sub-themes. I found myself working on this process for a long time in order to construct a final table of themes that would capture the essence of my participants' experience and at the same time would help others understand it.

# CHAPTER 3: Analysis of data

## 1. Chapter overview

In this chapter the three main super-ordinate themes which derived from the interpretative phenomenological analysis are presented together with the sub-themes that constitute them. The objective of these themes is to provide a rich portrayal of the breadth and complexity of the experience of parenting a child diagnosed with autism and to capture the essence of mothers' experiences. Each sub-theme will be presented and explained using verbatim quotations from the interviews. In the quotations, empty brackets indicate material that has been omitted. Participants and their children are referred by pseudonyms throughout. The source of quotation is indicated by page and line reference numbers.

Following the description of each theme and its sub-themes, the discussion section attempts to provide a more interpretative account in the context of existing literature and theories and to consider implications for the therapeutic practice.

## 2. Theme 1: Ambiguous loss

### 2.1 Introduction

The first theme that derived from the interpretative phenomenological analysis is concerned with the meaning mothers attach to their child's diagnosis of autism. It seems that the majority of the mothers that participated in this study (seven out of the eight participants) experience the diagnosis of autism as being a loss. In particular, it seems that they experience the loss of the child they thought they had. This theme is called ambiguous loss because the mothers of the present study also expressed ambiguity regarding the prognosis of their children, and all expressed the hope that their child will manage to live a productive life similar to that of typical people. The mothers that participated in this study described how this loss disrupted their assumptions about their child and their relationship with them. Furthermore, they described how they try to understand and make sense of the loss and how they have managed to find benefits in the stressful situation that they experience. In order to describe the 'Ambiguous loss' domain, four sub-themes have been identified: 'Loss of the child I thought I had', 'Ambiguity', 'Making sense of the loss', and 'Growth'.

**2.2 Sub-theme 1: Loss of the child I thought I had**

The first sub-theme is concerned with the meaning the diagnosis of autism has for the mothers who participated in this study. Seven out of the eight participants described that after they found out that their child was diagnosed with autism, they felt like they lost the child they thought they had. Therefore, it seems that for the mothers who participated in this study the diagnosis of autism meant a metaphoric death of their dreamed-for child.

Angela, Mary, Rosie, and Paulina mainly described this loss in terms of what they expected their child to achieve in their life. They described experiencing loss of their expectations for their child and a loss of the events that typically structure the family cycle (for example the child will become educated, find a job and get married). As Angela and Mary said:

*'Your expectations are completely broken, what you are expecting your child to be, obviously he is not going to be able to do that' (2.6-8). 'When you have a child you feel that your child will grow up and become an independent person and probably will be able to earn his own living, probably own a house or whatever, like a daily normal person would do, but with him, he probably won't be as independent as normal people will be because of his difficulties really' (3.18-26)*

*'I was very ambitious when I had Richard, I put him into private nursery, my vision was to educate him and he is going to become a professional, a lawyer, a doctor and he will earn good money, and he will make me proud' (11.14-20)*

Paulina also experienced this loss in terms of losing contact with her child due to the aloneness that characterises children with autism. Adriana and Jacqui also experienced the loss in a similar manner, in that the diagnosis disrupted these mothers' expectations of their relationship with their child. Adriana said:

*'When I first heard the term it meant a death sentence, it meant someone completely withdrawn, someone who couldn't be reached, someone who is lost to humanity, living in their own world' (1.1-2)*

Paulina and Jacqui also described the impact their child's aloneness had on them:

*'At that point I didn't think he knew what's going on around him, he didn't care, he would be like, I will just sit here, looking out the window the whole day, it was sad for me, not for him' (7.1-3). 'It makes me sad to see my son like that, being alone always, you know, not interacting, in his own little world around him, it wasn't nice. He wasn't interacting with us really, unless he was hungry or needed the toilet or he couldn't get the computer work' (7.10-12).*

*'When my older son was diagnosed it felt like somebody took my child away, he was not responding, he was not interacting'*

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Several years after her son's diagnosis, Nicole had difficulty in accepting her son's diagnosis of autism which suggests that she had a difficulty in coming to terms with the loss of her dreamed-for child:

*'Probably three or four years back I was like, why is George, why is George autistic?' (3.8-9). 'Why me, why do I have an autistic son?' (6.6).*
Rosie talked about a poem in order to describe her experience of the loss of her fantasised child:

*'When you have a baby you are expecting to go to Italy and it's kind of 'Oh no, I am in Holland', you know (...) I know that what the poem is saying is then you find the beautiful things in Holland, and things like that, yeah you do but still it's not Italy, you know' (8.5)*

It seems that for the majority of the participants of the present study, the diagnosis of autism signified a loss: loss of the child that they thought they had, and loss of the expectations and hopes they had for this child.

**2.3 Sub-theme 2: Ambiguity**

This theme aims to describe the uncertainty that mothers experience regarding their child's condition and prognosis. It seems that most of the mothers are unsure about the future, and at the same time they all hope that things will change for the better. Moreover, it seems that the experience of ambiguity contributes to feelings of maternal distress while the lack of ambiguity contributes to maternal well being. Therefore, although mothers experienced loss of their dreamed-for child, at the same time, due the ambiguity that characterises the prognosis related to autism , they all hope that the child will progress to the point where he will be able live an independent life. Some mothers also expressed the hope that the child might become able to sustain meaningful interpersonal relationships like having friends and getting married. Two mothers used the term 'recovery'. Their accounts suggest that what they mean is that the child should be able to live an independent life and experience stable, interpersonal relationships.

Nicole, for example, shared her concern about her son's future and his prognosis, and whether he would have a job or get married. At the same time she expressed her hopes for him:

*'I hope he has the potential, it's just he won't learn normally from the environment as other children do (...) I hope, obviously we need to help him reach that goal where he might not be*

*the super brightest, or the super intelligent, who knows, he might become a rocket scientist, he improves all the time, he surprises us, but I do hope' (9.19-29).*

Nicole's account appears to reflect her difficulty and ambivalence in adjusting her expectations to her child's abilities. Although she acknowledges the loss of the child she thought she has, she appears to be uncertain exactly what that loss mean for the child.

Angela, on the other hand, hoped that her son would live an independent life but she was ambiguous regarding his ability to 'recover' from autism and be able to live an independent life.

*'So we teach him lot's of things so he become an independent boy and earn a living, own a house, but at this moment I don't know if he will fully recover, probably he wont...they get better but they don't recover' (17.14-16).*

Mary was ambiguous about her son's ability to formulate appropriate social relationships, but hoped that her son would acquire social skills after experiencing difficult social interactions:

*'Hopefully as the years go on, he might learn himself, after having rejections from people, maybe that's the only way he will learn that he should behave in a different way' (9.8-13)*

Rosie was ambiguous about her sons' ability to live an independent life. Whilst she believed that her first son was less likely than her second son to be independent, she still retained the hope that her first son would show a very marked improvement:

*'It's kind like, I do believe that they will do something special in their life, their lives might be amazing, Like John might get married and have his own family unit, for that's amazing if that happens, that's the nice side of it' (13.3-6).*

Paulina's son had progressed a lot. She believed that he would be able to function in society independently, but, at the same time expressed her concern with the permanence of his progress. Consequently, she was afraid to terminate the behavioural intervention programme in case her son regressed to his former difficulties:

*'If we were to stop this programme now, I don't know what would happen, he has gone so far, would he regress, or would he stay at that point, you know, I would be too scared to stop this programme, I will have it keep going and going until I feel he gets where I want him to be. I thought he would never have friends, he didn't have friends, he couldn't speak...now he is completely different' (6.13-17).*

It appeared that she was concerned that she might lose her child again.

Jacqui, on the other hand, was not very confident that things would continue to progress, but expressed the hope that she would not have to face the difficult experiences of parents of older children with autism and that things would change for the better. Paulina was also ambiguous about her son's prognosis; although he has progressed she does not know what will happen in the future.

At the same time ambiguity seems to contribute to maternal distress. As Jacqui and Angela said:

*'Lots of uncertainty and worrying, lots of not knowing what the future holds, I wish I had a crystal ball to see that' (8.8-9).*

*'I worry a lot...is he going to be independent, because we are not always be there for him (...) how is he going survive in the world?' (16.24-29).*

On the other hand, lack of ambiguity seemed to facilitate maternal well being. Adriana's son and Jacqui's older son had both shown marked progress. Adriana's and Jacqui's accounts implied that their children's progress had helped them to relax:

*'This last year and a half I have relaxed because I can see he is going to be fine' (5.12-13).*

*'With him I'm thinking that he should be independent and in some ways it's not so painful, in some ways you sort of think, he is so able he has got to make it on his own, I think he will be OK' (8.1-2).*

**2.4 Sub-theme 3: Making sense of the loss**

The third sub-theme is concerned with the way mothers tried to make sense of the loss within their existing world views, and their conception of how the world worked. It appears that for some of the participants, the grief for the dream-for child they lost was an ongoing process. Some of the mothers attempted via spirituality to find meaning and understand the change that took place in their life. At the same time, these mothers grieved for what the child no longer was, or they tried to help their child overcome the atypical behaviours that characterise autism, again implying a focus on what the child was not.

Rosie, for example, tried and had managed to find a meaning for her sons' diagnosis through spirituality:

*'I am a bit of a spiritualist, not entirely, I believe in Buddhism and some other bits, it's kind of one of the things I do believe it's part of your journey on earth is that you have certain lessons to go through, and John and Bob decided to be different, and I decided that I want to*

*help people who are different, if that makes sense, and therefore, it's all for a reason (...) it was meant to be' (12.21-26)*

However, at the same time, she had difficulty accepting the impact autism had on her life, and grieved for the motherhood experiences she thought she would have when she had her sons:

*'You go through a massive grief cycle, when you see people with their children, sitting at a cafe, drinking a cup of coffee, I can't do that with my children (...) it's not going to happen, it's such a hard thing for a parent because it's not an obvious disability, it comes over time and you want to blame somebody or something' (1.7-10)*

It seems that Rosie's experience was fragmented, and that she had difficulty internalising the meaning she gave to the loss of her fantasised children. Therefore, it seemed as if her grief process was ongoing.

Similarly, Mary and Nicole relied on spirituality in order to understand the meaning of having a child with autism in their life. As Mary said:

*'When I had Richard, my mum said to me, you are lucky ummh everyone else around me were like Oh poor thing, you must be feeling awful, my mum said to me you are lucky, you are lucky you got a child, there is a reason you got that child, you didn't just get that child (...) she opened me a different world, the spiritual world' (23.5-15)*

At the same time, both Mary and Nicole seemed to have difficulty in accepting the permanence of the changed reality. Both found it difficult to believe in the long term aspect of autism, and as a consequence the loss of their dream-for child. In particular, Nicole was concerned with the limited time she had to make her son recover from autism. Mary, in contrast, appeared to try to accept that her son would not recover from autism:

*'Although we were told it's a life long condition, I didn't believe it. I thought there must be ways I can help him and I will help him, I'm not going to sit and say that's it he is not going to be able to develop' (3.8-13). 'At that time I was very much push, push, push and I can help him. At this present moment we have done a lot for him to help him, and now I'm starting thinking that I've got to accept it now that there are certain areas that he is not going to change' (3.26-31)*

On the other hand, she experienced disappointment every time she realised that he did not resemble typical children:

*'I am trying so hard to put him everywhere and he shows no interest (...) it is always on his terms, and I found it hard because I thought why am I making this effort? I actually thought that (laughs) maybe because I was running around that day (...) I was tired I think, I was*

*tired and I thought maybe I should just accept he is not going to join in with them' [group of typical children] (6.20-31).'I feel upset because maybe I thought that he really enjoys being around people, he hasn't got the skills, that's the problem, you know, that's the problem, but he enjoys it, and I thought I could get him to a level where he will be part of that group [typical children]' (7.5-11)*

Mary and Nicole's experience suggest that they too have difficulty in internalising the meaning of the loss of the child they thought they had as on one hand they try to accept it through spirituality while on the other hand they get emotionally upset when the child's behaviour differs to that of typical children.

Paulina and Adriana did not believe that autism is a life long disorder, and were convinced that there had to be ways to help their children progress:

*'And then I said that's it, I'll prove him wrong (the paediatrician), I did research on the internet and we decided to go on the ABA programme' (2.3-4).*

*'When we were there I said look, this child can learn, he may not be able to learn in a group environment at this stage, but he responds to one-to-one, there must be something that we can do' (2.16-17).*

It seems that the mothers who do not believe that autism is a life long condition or believe that it is a condition that can be addressed or indeed recovered from, have difficulty in accepting that they have (potentially) permanently lost the child they thought they had. It appears that they try to make sense of the loss by believing that it is reversible. This allows them to feel that they have some control over the change and the outcome. As a consequence, Mary, Nicole, Paulina, and Adriana invested in intense behavioural intervention programmes that they hoped would help their children progress and become part of the neuro-typical world.

Adriana's belief was indeed supported as she was lucky enough to see her son progressing to the point where she believes the gap between him and typical children has narrowed significantly. Her son's progress changed her perception and acceptance of autism. While she previously thought autism to be a death sentence, following her son's progress she believed that:

*'Before it was like grief, now it's just fears more mothers have' (4.8)*
*'It's a much more acceptable condition (...) a condition that can be addressed (...) there is rehabilitation in every single area' (1.8-13).*

Angela, on the other hand, described that five and a half years after her son's diagnosis, she still had difficulty coming to terms and finding meaning in her son's diagnosis. It seems that she was still grieving for the lost expectations she had for him:

*'It's very difficult to express it but all I can say it is very, very difficult as a parent to know that your own child has autism, it's very difficult to deal with, extremely depressing' (4.17-21).*

Jacqui had two sons diagnosed with autism. When she was referring to the loss she experienced, she was describing her reaction to her first son's diagnosis. For Jacqui, the fact that both her children were diagnosed with autism and that their prognoses differed considerably made autism an unpredictable disorder that presented itself in different ways:

*'In the spectrum there is a huge variety, for example my older son who...I wouldn't even describe it now as a disability, I think it's just a difference ummh to my younger son who, it is definitely a disability' (1.3).*

Similar to Adriana, when Jacqui's first son began to show signs of improvement, she felt as if she had found her son again. This experience allowed her to believe that she had some control over the situation. As a result, through the use of behavioural intervention programmes, she tried to help her younger son to progress as well. However, her younger son showed fewer signs of improvement, leaving Jacqui feeling overwhelmed by the ongoing responsibility of parenting a child with autism:

*'I think the responsibility feels quite overpowering at times, you do worry about the future, what happens when you are not there ummh I think it is the responsibility, the ongoing responsibility (becomes tearful)' (2.11).*

It appeared that Jacqui felt that she had little control over the situation, and that this affected her ability to adapt to the loss of the child she thought she had.

Mothers' accounts suggest that a child's improvement affects the mother's experience of the loss and the way she makes sense of it. Improvement to the point that the child is more similar to his typical peers allowed the mothers, Jacqui and Adriana in this case, to accept the diagnosis and not to experience it as a loss. As a consequence, they reported feeling less distressed about it. On the other hand, mothers whose children did not have this marked improvement appeared to be uncertain exactly what that loss meant for them and the child.

**2.5 Sub-theme 4: Growth**

The mothers who participated in this study were also able to find benefits in their experience of parenting not their dreamed-for child but their real child who had been diagnosed with autism.

Mary and Adriana described how the experience of parenting their sons had changed the way they interacted with other people. They both described having a better understanding of other people's behaviour. As Mary said:

*'He made me understanding of other people, I'm more understanding and more tolerant towards other people (...) accepting people's limitations' (12.31).*

Jacqui, Rosie, Paulina, and Mary experienced a change in their world view as a result of the experience of parenting their sons. Mary and Rosie mentioned that their human values are more heightened and that materialistic ambitions were not their first priority. As Rosie said:

*'When I was career orientated, it was very much about, you know, driving the Mercedes, and nice holidays, good restaurants in London...it's kind evaluating your life, it didn't mean anything, people are more meaning' (13.21).*
Jacqui mentioned that this experience helped her to understand better her priorities in life:
*'I think it has helped me put things in perspective, I think...you know, people worry about certain things and you think does it matter really? There are a lot of people that worry about superficial things (...) so I think it makes you focus on is it important or is it not' (6.24-27, 7.-1-2).*

On the other hand, the experience of parenting a child with autism helped Paulina acknowledge the possibility that unfortunate events could happen to her:

*'I think it just made me think life is a challenge, I don't know what is going to happen next so enjoy each day, take each day as it comes and enjoy it fully, you don't know what tomorrow will bring. I mean I never ever thought that I will have an autistic child... you don't think that this is going to happen to you, you think things like that happen to other people, you are the other people, you think nothing is going to happen to us, things happen to others but not to us, you know, I just thought that anything can happen'(4.20-23, 5.1-4).*

Some of the mothers also re-evaluated their goals in life and altered their priorities in a way that they considered helpful for them in their adjustment to the situation. For instance, Rosie aimed to increase public awareness regarding autism (11.12) while Nicole had decided to one day return to her country of origin so as to help other mothers deal with and potentially accept autism:

*'I want to do something that will help my son's condition, specifically other children that also have the same condition, like especially in India, if I go back to that country later on I definitely want my experience...to help other children and other families to overcome this condition (...) Help other mums to deal with it and accept it' (7.26-8.1).*

Rosie and Jacqui had planned to change career orientation as a result of their experience of parenting their sons. Rosie planned to set up a business to provide equipment for children's safety (13.17) while Jacqui was about to begin working as a learning assistant at a primary school:

*'Now I am sort of looking (...) working as a teacher, a primary school teacher for children with special needs but of course if I didn't have the children experience I wouldn't think to do that. I completed a postgraduate certificate in special education of autism ummh I guess I primarily did it for my children but then I thought it is something that I can use' (5.22-27, 6.1).*

Angela and Mary, who had both left their careers in order to devote their time to their children's care, had realised the negative impact that this had had on their emotional well-being. Consequently, both mothers had made the decision to reprioritise their personal needs. Mary had enrolled for a computer course, and had found that this experience had increased her self-confidence. Angela had gone back to work, an activity that she had found had helped reduce the time that she had spent worrying about her son's condition:

*'I'm very happy going back to work, it has changed my life quite a bit, I'm a lot lively now, I feel good when I come home cause I feel that I've been out, earn some money (...) have some adult interaction, so I feel quite good about it, I quite enjoy it' (12.1-10) 'I am a lot calmer now than I was (...) even the time that I wasn't with him, the mental worry was there' (12.12-16) 'Before I just couldn't stop thinking about it (...) I felt really depressed, but the last year my life has changed' (12.26-29).*

Adriana's growth was very much related to the fact that her efforts to help her son progress were successful. Once she perceived her son to be more similar to typical children, she could allow herself to focus on her own needs and priorities:

*'I have thoughts about fulfilling other aspects of my needs, my career, my aspirations, I have political aspirations ummh I have things that I would like to accomplish, I would like to fulfil (...) I want the bigger picture, a wider picture now (...) I want to open the world up for all of us' (9.17-22).*

Adriana reflected on the importance of having new experiences that would allow her to meet her personal needs. She did not resent the effort and the energy she devoted to her son's

progress and, as she said, if she had to, she would do it again. This experience also allowed Adriana to discover an inner strength that she was not aware she had:

*'It was a mission for him (...) I wasn't even aware of it at that time (...) I'll do it again I suppose, I don't know where I get the energy or the strength to do all that but it came (...) I have no resentment (...) just a real sense of gratitude' (7.1-6).*

**2.6 Laura's response to diagnosis**

Laura was the only mother who did not describe autism as a loss of the child she thought she would have. Laura mentioned that her son was diagnosed when he was six years old, while most children of the mothers who participated in this study were diagnosed when they were, on average, four years of age. Up until the time of her son's diagnosis, Laura was struggling to deal with his behavioural difficulties. When she asked for professional help and her son was diagnosed with autism, Laura was able to use this information in a way that enabled her to better understand her son and his behaviour. At the same time, the diagnosis helped her to stop perceiving herself as being an inadequate mother:

*'Finally when we got the diagnosis it was a huge relief, you know, finally it was not my fault, it was not his fault, he wasn't a bad boy and we started getting things in place to get help' (4.25-26).*

Laura, like the rest of the mothers who participated in this study, described the experience as being very demanding and stressful but at the same time she had managed to find positive and rewarding aspects. In particular:

*'I think it has given me a lot of confidence, in a way it is an extremely positive experience because I have learnt that I can have an almost endless amount of patience ummh that I can put myself in other people's shoes, which I have always been able to do but I can now do it in a much more meaningful way, it has given me a lot of tolerance and I am more resourceful than I used to be (...) generally it is a very positive experience and it made me grow up ummh it is different, I am better at understanding kids I think than I used to be' (14.24-27, 15.1-3).*

Laura, again like the rest of the mothers who participated in this study, hoped that her son would be able to progress to the extent that he would be able to function in society:

*'I have no idea how he is going to deal with puberty, that's the next big thing, he can turn all of the sudden be very, very mellow and be fine and we could manage to get him into college, and reinsert him into his peer group in society' (14.7-9).*

Laura's account suggests that she was going through a process that resembled that of the rest of the participants. Although she did not describe the diagnosis as the loss of the child she

thought she had, it is possible that she spent many years avoiding facing this reality by not contacting the professionals for an explanation of her son's behavioural difficulties. When Laura was ready to make this step, she managed to accept the diagnosis and use it to better understand her maternal experience.

## 2.7 Discussion

The analysis of the data revealed that the participants experienced a loss when their child was diagnosed with autism. The way they talked about this loss suggests that they experienced a loss of the expectations, a loss of the things they hoped their respective children would achieve in the future, and loss of the relationship they expected they would have with their child. This finding is consistent with existing theories and literature. Mercer (1995) and Rubin (1984) have suggested that having a child with a defect or chronic illness is a profound loss for the mother: it is the loss of her fantasised child. The mother experiences a painful withdrawal of attachment from her lost image of her child to be.

All the participants received their child's diagnosis of autism at least two years before their participation in the present study. The fact that they still talked about this loss and the way they described their response to this loss implies that finding meaning and coming to terms with the loss of their fantasised child was an ongoing process that continued for years after they had received their child's diagnosis. The literature on parenting a child with developmental disabilities is mixed. Up until the 1980s, the literature mainly described parents of disabled children going through a never ending bereavement process. Olhansky (1962) described the phenomenon of chronic sorrow, and Copley and Bodensteiner (1987) suggested that chronic sorrow is characterised by emotional highs and lows fuelled by the cycle of impact, hope, and denial that prevents parents from moving through the bereavement process. Schroeder (1974) and Carreto (1981) also reported the grief process as ongoing amongst mothers with handicapped children aged 1 month to 10 years.

More current research maintains that many families do not experience chronic sorrow but, on the contrary, have found that parenting a child with developmental disabilities has become the single most defining experience in their lives. For example, Turnbull et al. (1993) report that families are able to find meaning, power and value in their experience of parenting a child with disabilities. Interviewing mothers after the death of their child who had suffered developmental and physical disabilities, Milo (1997) found that after their child's diagnosis,

the mothers were able to let go of their original dream and originate a new dream to accommodate their disabled child. What can be concluded from these studies is that the birth of a child with disabilities may challenge the dreams, the fantasies, and the projections that parents hold as part of their role and identity of being parents. However, different researchers draw different conclusions as to how long parents grieve the loss of the child they thought they had, and whether or not they are able to find meaning in the loss of their dreamed-for child.

Social-cognitive theories of adjustment (Epstein, 1973; Janoff-Bulman, 1992) hypothesize that meaning making plays an important role in adjusting to a loss because it serves to maintain two aspects of our sense of self that are most threatened by loss: our sense of self worth, and our fundamental beliefs about how the world works. In their extensive research about loss, Davis and Nolen-Hoeksema (2001) report the salient role that meaning plays in how people cope with loss. The concern with finding meaning in loss represents two significant issues: the first is how individuals make sense of their loss, and the other is their search to find a positive aspect of the experience of the loss. Making sense of the loss involves the task of maintaining threatened worldviews, while finding benefit involves the task of rebuilding a threatened sense of self.

It seems that participants of this study reported a need to find meaning in the loss of their fantasised child, and it seems that the majority of the participants tried to do that within their existing worldviews, either through spirituality or by not believing in the permanence of the loss. In Western cultures, people tend to believe that the important events in their lives are controllable, comprehensible and non-random (Kelley, 1972). The sample of the present study is an ethnically diverse sample but most of the participants live their whole adult life in the United Kingdom. It appears therefore that Kelley's notion regarding western world views reflect the way mothers of the present study attempted to make sense of their child's diagnosis. In particular, it seems that the mothers who deemed that recovery from autism is possible, attempted to restore their beliefs that the world is relatively safe, predictable and benevolent. On the other hand, Angela who had difficulty in making sense of the loss of her fantasised child and believed that the future would bring more difficulties of a different nature, and Jacqui who felt that the situation was out of her control, seemed to go through a process where instead of making sense of the loss within their existing worldview, they revised it by acknowledging the fragility and unpredictability of life. According to Davis and

Nolen-Hoeksema (2001) when the event is perceived to be inconsistent with one's fundamental worldviews, the individual is faced with the difficult task of either making the interpretation of the event consistent with his/her worldviews or revising his/her worldviews to accommodate the event. Janoff-Bulman (1992), suggest that revising one's world views is a distressing task that seems to produce feelings of uncertainty and vulnerability and consequently distress. Indeed, Angela and Jacqui - more than any of the other mothers - talked about having difficulty controlling their worry about present and future difficulties. Davis, Nolen-Hoeksema, and Larson (1998) reported a similar finding in their longitudinal study investigating people who had lost a loved one. One mother included within Milo's study (1997) who also had a difficulty in finding benefit and meaning in her son's disability and death, continued to perceive the world as being unpredictable and full of danger.

At the same time, most of the participants of the present study were able to find benefits in their experience of parenting their child, either by discovering aspects of themselves that they were not aware they had, by considering new goals in their life, or by changing their outlook towards life. According to Joseph and Linley (2006) who reviewed the relevant literature in growth following adversity, the benefits that people report after a loss typically fall into one of the following three categories: growth in character, change in life perspective or strengthening in relationships with others. It seems that the benefits reported by the participants of the present study fall into the above mentioned categories. Concerning the impact of growth on mental health well being, the meta-analytic review of Joseph and Linley (2006) suggests that it is associated with better mental health outcomes when such outcomes were operationalised as depression and positive well being, but not related to anxiety. The authors hypothesised that the presence of anxiety could be a signal that people were working through the implications of the stressors, a process which is necessary for growth to take place. For the participants of the present study, it appears that the presence of anxiety was related to ambiguity, and the absence of ambiguity was related to low levels of maternal stress. A similar finding was reported by O' Brien (2007). Therefore, it can be hypothesised that the presence of ambiguity on a daily basis encouraged the mothers to reflect on the implications of the stressors; for some mothers, ambiguity propelled them to make changes to their priorities and attitudes towards life.

Milo (1997) mentioned that most of the mothers in her study were able to find a special meaning in their child's life once they had accepted the child as imperfect and given up the

dreamed-for child. Mothers in the present study described feeling ambiguous about their child's prognosis. Furthermore, they expressed the hope that their child would be able to become an independent person and do the things that typical people do. The mothers who participated in Milo's study and who were able to accept the reality of their child's diagnosis, had children with medical and developmental conditions including Cerebral Palsy, Down's Syndrome, and Trisomy 18. Therefore, it can be hypothesised that because these mothers were less ambiguous about their child's prognosis, they were able to let go of their fantasised child. Autism on the other hand, is a neuro-developmental disorder that bears ambiguity. According to O'Brien (2007), there are five areas of ambiguity related to autism: lack of clarity in diagnosis, difficulty in predicting outcomes, day-to-day variability in functioning, appearance of health in the early years, loss of the mother-child relationship. As far as difficulty in predicting outcomes is concerned, according to Howlin, Goode, Hutton, and Rutter (2004) the long term outcome for individuals with autism is highly variable and as a consequence, parents do not truly know what their child's prognosis is.

Therefore, it can be hypothesised that the ambiguity does not allow mothers to accept autism, and that they therefore hope for the best to come true. This is further supported by Adriana's and Jacqui's experience that they were able to accept autism and not feel distressed about it only after their sons progressed considerably. After their sons' progress, they reported not feeling ambiguous about their future prognosis. This finding is consistent with the findings presented by Milo (1997). Within this research it is suggested that the mothers of her study who were given a clear-cut, unambiguous prognosis were able to let go of their fantasised child and start accepting the actual child. On the other hand, the mothers of her study whose children were typical at birth and then developed problems were the ones who experienced a more prolonged, continually wrenching process, cycling in-between hope and despair. Many professionals who work with families of children with disabilities expect the parents to go through grief stages and eventually to achieve resolution following a child's diagnosis (O'Brien, 2007). This seems to be in accordance with the grief stage model suggested by Bowlby and Parkes (1970) according to which the bereaved individual goes through the stages of numbness, yearning, depression, and reorganisation so to recover from the loss and return to normal activities.

However, the experience of the participants implies that this is not a linear process. As Rosie said 'you are going through a massive grief cycle'. Mothers who parent children with autism

experience an inherently ambiguous situation. As found both in this study and in O'Brien's study (2007), such mothers experience ambivalence in adjusting their expectations and consequently accepting their changed reality. Mary struggled with the notion that her son would probably not change, while at the same time hoped that she would manage to get him to a level where he would be like his typical peers. This seems to highlight again the central role of ambiguity in adjusting to reality, and in accepting that the disruption to the family life will continue. This ambiguity is expressed in the variability of day-to-day functioning that characterises children with autism which could further contribute to mothers' reported difficulty to accept the finality of the loss of their dreamed-for child.

All mothers shared with the researcher their efforts to make sense of the loss they experienced and to find benefits in their situation, but at the same time they reported experiencing distress about the ambiguity inherent in their child's condition. Brady, Guy, Poelstra, and Brokaw (1999) describe the duality of stressors: they can be both destabilising and growth promoting at the same time. Further, as Davis and Nolen-Hoeksema (2001) argue, making sense and finding benefits in the adversity does not necessarily signify the end of the process. However, it is unclear whether the perceived growth and making sense of the loss can allow acceptance of their child's diagnosis in the presence of ambiguity. Boss (2006) has suggested that there is no closure in cases of ambiguous loss. Therefore, according to O'Brien (2007) the challenge for the parents is to accept that autism is a lifelong condition, and at the same time to be optimistic for some improvement although not full recovery of their child's symptoms.

This suggestion is consistent with the findings of Brice's (1991) study which found that acceptance of the paradoxes of one's experience can facilitate acceptance of the reality he/she experiences. It seems that this suggestion is consistent with the growth-oriented paradigms of bereavement. In this paradigm, the goal of the grief process is to achieve a transformed relationship with the deceased by acknowledging the end of the physical relationship instead of breaking all bonds after their death (Rothaupt & Becker, 2007). Thus, the goal of the parents could be to accept the presence of a child with autism in their lives and build a new relationship with their child by acknowledging their unique characteristics. This finding of the present study suggests the importance of communicating to the parents a clear picture of the child's diagnosis and prognosis so to allow the parents to go through a stage that could facilitate their acceptance of a new and different reality. The findings presented by Milo

(1997) are consistent with this suggestion as she reported that it was more harmful for the mothers of her study to hope for recovery only to have their hopes challenged, than to expect the worst and be happy with the child's progress. It would therefore be helpful to parents if professionals were to share their uncertainty with them so they do not develop unrealistic expectations regarding their child's prognosis and then have their hopes disconfirmed. At the same time professionals should facilitate optimism regarding some improvement in a child's symptoms as a number of researchers have reported that intervention programmes designed for children with autism can produce appreciable developmental gains in these children. (Loovas & Smith, 1989; Quinn, Carr, Carroll, & O'Sullivan, 2006). At this point, it is important to note that in the case of autism it is difficult even for the professionals to be clear about the child's prognosis.

An understanding of the ambiguous loss experienced by the mothers of children with autism can provide valuable information to clinicians working with this population, enhancing their understanding for deviations from the stages or the tasks that are suggested from bereavement models. Moreover, being aware of the way mothers of children with autism try to make sense of the loss of the child they thought they had before the diagnosis, can facilitate a deeper understanding of the phenomenon by considering both the positive and the negative changes that take place after the perceived loss. Moreover, positive changes can be used as foundations for further therapeutic work as suggested by Linley and Joseph (2004).

## 3. Theme 2: Identity shift

### 3.1 Introduction

The second theme that emerged from the interpretative phenomenological analysis is concerned with the way the experience of parenting a child diagnosed with autism affects mothers' own sense of identity. It appears from participants' accounts that parenting a child diagnosed with autism is the most central experience to their life, and affects their own sense of self. All participants in this study talked about their identity as mothers of children with autism - which for reasons of convenience will be referred to as maternal identity - and elaborated on how this identity had changed their priorities and choices in life, and their relationships with others. As a consequence, their perception of their other identities, for example as wife, professional, and their social identity had changed. It appears from mothers' accounts that the maternal identity and their other identities are not equal, for they devote the majority of their time and energy in parenting their child diagnosed with autism.

In light of the breadth of this theme and in order to provide a rich description of the identity shift of the participants of this study, this domain is further divided into 'Maternal identity' and 'Integrating maternal identity to the self system'. The latter sub-theme is further divided to 'Integrating maternal identity and wife identity' and 'Change in priorities'. Change in priorities refers to changes in personal, social, and career priorities so to accommodate the needs of children. It seems from the accounts of the participants that the maternal identity plays a central role in how they define their personal, social, and career needs, and as a consequence in how they experience themselves. Therefore, the first sub-theme the description and interpretation of which follows, aims to explore in depth how participants view themselves as mothers, and attempts to capture what is so central about this identity that defines the shift in the other identities.

## 3.2 Sub-theme 1: Maternal identity

Rubin (1984, p.243) defined maternal identity as "having a sense of being in the role, a sense of comfort about where you have been as a mother and where you are going". Rubin suggests that maternal identity is established by a process through which the mother establishes the identity of her child. She further argued that in knowing the child, there is a knowing of self in relation to the child and more active, more secure behaviour with or on behalf of the child. Therefore, the first sub-theme is concerned with how participants' perception of their child, the beliefs they have regarding motherhood, and their perceived competence about their role, affects the way they perceive their selves as mothers. Moreover, it aims to describe how their perception of their maternal identity affects their behaviour with their other children, their choices and behaviours, and their sense of affiliation with mothers of typical children.

### 3.2.1 Responsibility for the child

The first category of the first sub-theme is concerned with how mothers perceive themselves in relation to their child. It seems from the participants' accounts that all mothers perceived themselves as being primarily responsible for and the main caregiver of the child diagnosed with autism. Mary, Nicole, and Jacqui described how this was a central part of their identity as mothers. Nicole further elaborated on the amount of guilt she would experience in the case that she was not taking care of her child on her own, and involved social services:

*'I know his difficulties; I know I have to help him, otherwise if I don't help him, who else will help him' (4.15-16). 'I just mentally can't see myself doing that, you know dumping the child*

*to social services and saying that is your responsibility. I'm not made of that. How can that mum live with that amount of guilt? I don't know' (10.23-26)*

It appears that for Nicole, what distinguished a good mother was her devotion to her child's needs. Mary and Jacqui described their maternal identity in a similar way:

*'I have always been in charge of him' (7.25) 'What you do for your children (...) you do it because it's your responsibility, if you are a good mother...you brought them in this world, you should do it, otherwise why bring them in this world kind of thing' (19.17-30)*

*'That is your job that is why you are there for' (2.1)*

Adriana described how feeling primarily responsible for her child resulted in blurred boundaries between herself and her son:

*'I needed to be an extension of him, and it wasn't conscious at that time ummh but I did, I had to become an extension of him to help him, you know, wanted to facilitate everything for him, and that took it all on me as a person ummh I don't regret it, it just happened' (5.28-30)*

Angela and Rosie described how their love for their sons and practicalities due to their husbands' full time jobs made them the primary caretakers of their sons:

*'I love him to bits obviously and I'll do everything to give him all my teaching and all of my knowledge to get him ummh make him better' (6.26-29). 'My husband is very supportive but I have to understand that he works full time, I can't just rely on him (...) so obviously the main day is on me' (8.11-14)*

Laura described how her life goals were determined by perceiving herself as being primarily responsible for her son:

*'I cannot see anything before that, he is my responsibility and I cannot do anything before that' (16.23-24)*

It seems from the mothers' accounts that being primarily responsible for their child was central to their identity as mothers. However, at the same time five out of the eight mothers who participated in this study expressed their worries and concerns about the ongoing nature of this responsibility. Mothers' accounts suggested that there was a concern about how long they would carry out the demanding task of being primarily responsible for their child. It appears that what fuelled this uncertainty was the ambiguity regarding their son's prognosis and his future independence or dependence. As a consequence, they also anticipated ambiguity about the nature of their maternal role in the future. As Jacqui said:

*'It's like you have got a two years old child but it is going on for the foreseeable future, so there is no time when you can say that this is going to come to an end, it is ongoing'* (1.26-27, 2.1)

Jacqui became tearful while talking about the ongoing responsibility, describing it at times as overwhelming. For Jacqui, these feelings were coupled with the fact that she regularly, if not continually, worried about her son's future safety and happiness. So it seemed that for Jacqui, what contributed to her distress about her ongoing responsibility was not only the demanding situation she was in, but also her love and concern for her son.

Nicole, on the other hand, reasoned that if she prioritised her son at this point then it was more probable she would not to have to do it in the future. As she said:

*'If I put my career first and ignore my son what is going to happen to him 20 years from now? If he falls back in the problems, that means that 30 years from now we will have to deal with him anyway'* (10.15-17)

It would appear that Nicole was concerned both about her own and her son's future. She felt primarily responsible for him and could not envisage herself involving social services for his care. She hoped that by trying very hard to help him whilst he was young, she would not have to do it for the foreseeable future. Therefore, it can be further suggested that Nicole was trying to free herself from a role that was quite demanding and did not allow her to fulfil other needs, like her career needs. It was clear from her description of her experience that her maternal identity played an important role in the way she perceived herself, and she therefore strive to achieve fulfilment of her other needs in a way that would not threaten her perception of herself and her self worth.

Laura expressed her worries about the potential ambiguous nature of the future. There have been times that she was unable to see a way out and she was concerned about the length of the time that she would have to carry out the very demanding task of parenting her son:

*'I look for solutions but in those times I can't see the solution, it's very, very hard, you know, what is going to happen tomorrow, and how long am I going to keep doing that, what will happen when he is an adult, always the what, the how, and the whys, all just piling on the top of me'*(9.7-11)

It sounds that Laura, as Jacqui, also found herself in a situation that was ongoing and static, a state that at times felt overpowering as she was not in control of the outcome:

*'Nothing does change, at the end of the day I have got a child with autism and in so many ways it's the same as it was when he was 10 months old ummh there are things that have*

*improved but there is a lot that haven't and there are things that got worse (...) nothing changes and I still feel the same way and I cannot do anything about it' (10.23-27)*

Angela described the task of parenting her son as a 'burden' several times during the interview, but at the same time she described being determined to take care of her son as long as was necessary and for as long as she could. Angela was determined to continue living with her burden, but her determination contributed to feelings of continuous distress. Her distress seems to stem both from the ongoing demanding task of parenting a child with autism and from her ambiguity about his future well-being:

*'You have got that burden in your head, I've got to do this, I've got to do that, my life really revolves around him and it is very, very difficult' (7.13-16) 'I worry a lot (...) What is going to happen when we are not there (...) obviously I am going to support him as much as I can, I'll try to give him anything to support him ummh keep him with me as much as I can' (16.24-31, 17.1-2)*

It seems that mothers' accounts reflected their concerns and worries not only about their sons' future but also about their own future. They perceived parenting a child with autism as an ongoing responsibility with an ambiguous future reflecting the clinical uncertainty about their child's prognosis. Not knowing the length of time they will have to continue with the demanding tasks of parenting their child appears to have intensified the distress the mothers experienced.

Three out of the five mothers who expressed a worry about the ongoing responsibility also expressed a need to escape from the situation. This could be considered as an indicator of how stressful the situation is for these mothers.

As Laura and Angela said:

*'I suppose it's that feeling of wanting to be a little girl and just to go home (laughs)' (9.11)*

*'I feel I need to get out of the situation otherwise I'll go mad' (11.28-29)*

Jacqui talked about the time she had with her son outside the intense family environment:

*'I had a week away with my older son and that was good, you know, it felt I got away then, yeah' (2.27-28)*

It sounds from the participant accounts that they felt primarily responsible for their child, and that they all considered that this function played a central role in their understanding of motherhood. However, the possibility that this responsibility could go on for the foreseeable

future evoked feelings of distress, not only because of the considerable hard work that is involved in parenting a child with autism, but also because of the mothers' concerns about their sons' future well being and their own future as mothers. They did not know how things would evolve and the only thing they could do was try and hope for the best.

### 3.2.2 Devotion to child's progress

The second category of the first sub-theme aims to capture how mothers' perception of their child determined the major goal of their maternal role. Most of the mothers of the present study described their child as being vulnerable and expressed their concerns about their future happiness and safety. Moreover, as described, mothers also experienced ambiguity about their child's prognosis. Therefore, it seems that the maternal anxiety about their respective children's future well being and the hope that things might change for the better, motivated them to work as hard as they could to achieve their major goal: to help their children become independent. Mothers also talked about the hard work involved in parenting their child and in achieving this goal, and reflected on the way it affected the relationship with their other children.

All mothers expressed concerns about how their child's condition might situate the child in a vulnerable position in the future. For example, Mary and Jacqui expressed their concern that their child might not be able to protect himself in the future:

*'I fear that not everyone will do the right thing for him (...) I fear he might be abused and hurt, so I would like to be that link for him' (10.10-16)*

*'If he can do as much for himself then he will be less vulnerable ummh and if things are wrong maybe he might be able to alert people ummh and not having a big family, I mean if he had lots of brothers and sisters to look out for him that could be some reassurance' (8.11-14)*

At the same time, all the mothers who participated in this study expressed their determination to help their child become independent. For example, Rosie and Laura said:

*'I don't believe in disabling them more than they are disabled, so the fact they don't like going to supermarket, it's bad luck they get taken to the supermarket, because it's normalising them, they are going to have to cope with these things when they get older, I'm not going to be here for ever, nobody knows how long they got on this earth and I want them to be as independent as they can constantly be' (7.4-8)*

*'My one goal for Andrew in terms of education, is to teach him as much as possible to be independent, Maths and English are not my goal any more, we are doing that, he is very*

*intelligent, but I will like him to know how to keep himself clean and pay bills and if he can keep a job, any job, I will be thrilled for him'* (13.19-25)

Mothers acknowledged that working on that goal and dealing with their child's special needs on a daily basis involved a lot of hard work. It seems from most of the mothers' accounts that the hard work involved in parenting their child dominated their life in the sense that they had to devote most of their energy and time to parenting.

Most of the mothers talked about how mentally exhausting and demanding their experience was. As Angela and Laura said:

*'It's a lot of hard work' (4.22). 'At the end of the day you get extremely tired, it takes a lot out of you' (7.9-10). 'My life really revolves around him' (7.15)*

*'I think everything is hard, nothing is really easy' (7.21) 'On Monday he had a huge meltdown I can't remember what it was about it, it was trivial, and he threatened to throw a piece of Lego at me, I said if you throw that to me it will go to the bin (...) at which point he did throw it at me and it hit me in the face (...) I am not going to say well I know you didn't mean it but anyway, I think consciously he knows he has to learn but sometimes where he is not himself and he cannot control it and hopefully one day he will but I don't know when (laughs) but you cannot give up it's not an option' (2.2-10)*

Hard work also involved having to run for services, and find ways to support their child as not all mothers had the luxury to have private tutors. Some had to battle to involve national health services in their child's care, a process that absorbed much of their time and energy. As Laura said:

*'It has taken two years of knocking at the social services' door almost on a weekly basis and finally I got the social services contracted for that and I have managed to refer him to a speech therapist, to an occupational therapist, so instead of having all these services knocking at my door I have to go and knock on their door for him ummh we finally got him on to the learning disabilities team and we have a fantastic community nurse (...) so at the moment it feels that everything comes together and we finally get some help but it has been a battle'(3.13-20)*

It sounds from mothers' accounts that parenting a child diagnosed with autism dominated their life as it absorbed most of their time and was generally stressful. A child's special needs required the mother to be constantly present either physically or mentally.

Paulina was the only mother who did not make reference to the hard work of childrearing. She acknowledged that she tried hard to accommodate her child's needs, but she did not describe parenting as being mentally and physically demanding. As she said:

*'And how is it for you?  Much easier, it's nice, because I started working as well which is quite demanding. It sounds like you have more time to do other things now... yeah, now I have, in the beginning I didn't because I was very, very active in getting him to speak, in getting him to change the way he thinks about things'(4.7-10).*

It sounds from Paulina's account that it could be a mother's perception of their child's progress that determined both the amount of time and energy they needed to devote in order to parent their child and indeed, their perception of mothering. Paulina mentioned that, in the beginning her time was mainly devoted to her son to help him progress. Adriana's account further supported this interpretation:

*'I think it's more intense than it would be with a normal kid' (4.19).  'I think I couldn't have kept up that intensity, it was needed [hard work] in those early years, but I'm more relaxed now' (5.19-20).*

Adriana described how she devoted most of her time and energy to help her son progress. It was only when she perceived his progress as being satisfactory that Adriana stopped considering his condition as being an obstacle to his future happiness (9.13-17), and allowed herself to take a step back.

Feeling primarily responsible for their child with autism and devoting most of their time to parenting seems to have had an impact on the maternal relationship with their other child/children. Most mothers described their struggle to balance the needs of their child diagnosed with autism and the needs of their other children.

Angela, for example, described feeling split between her child diagnosed with autism and her typical child. In addition, Adriana expressed concern about dividing her time between her two children in a way that was fair for both of them:

*'I've got a second child to look after as well, I try to give him as much as possible, so I really have to balance my life because it's not fair for the other (...) it feels like I have to split my self into two, to juggle around, dealing with both of them' (7.17-27)*

Angela's account reflects a difficulty to smoothly integrate her role as a mother of a child with autism, her role as a mother of a typical child and her role as a wife and appears to experience these roles in a fragmented way.

Laura described a similar experience and elaborated on the amount of guilt they experienced about their other child:

*'The impact, the long term impact, is much more on the other two and on me, but as I said I try not to think, thinking is bad (laughs) I have more concern and far more guilt about my daughter, about the fact she cannot get friends over in the way she would do otherwise ummmh the fact she has to deal with this big brother (...) I try to spend time with her as much as I can but it is so easier if I am out at the shops to think, Oh she would like to have this'* (6.14-18)

Laura acknowledged the limited time she spent with her daughter due to the fact that she had to prioritise her son's needs, and the resultant guilt. She acknowledged the long term impact that this might have had on her and the other family members. However, it appeared that because she did not have a solution to this concern, she had tried to avoid thinking about it. It can be further suggested that her acceptance of the way she had prioritised her responsibilities as a mother protected Laura from worrying about a situation that she could not really change.

Jacqui's sons were both diagnosed with autism. Some years after her first son's diagnosis, her second son had been diagnosed as well. She described how she had had prioritised her first son when he was diagnosed:

*'Initially we thought this development delay was because the focus was on Antonio. Maybe he [Ron] wasn't attending the proper groups, so we sent him to the proper groups, and we did the music sessions but he wasn't interested in what other children were doing, he wasn't interested in toys, he wasn't really showing interest at all'* (4.1-4)

Jacqui described how she thought that the developmental delay of her second son was due to the fact her first son received most of her attention. Then she described how she had to put her first son into day care so as to focus on her second son:

*'It was hard work (...) it felt like it was impossible, you were trying to do some therapy with him and you were getting nothing back ummh and it was difficult, very stressful (...) you felt you should do more but there is a limit to what you can do, of course at that time I had another preschool child as well, so it was very difficult, I was working as well at the time, I think I did put one at the day nursery so I can work with Ron'* (3.19-26)

It appears from the mothers' stories that their perception of their role as mothers, the ambiguity regarding their child's progress, and the perception of the child as being vulnerable were the motives that had led them to devote most of their time and energy to their child with autism. According to their perception, a good mother would be primarily responsible for the child and would try her best to accommodate the child's needs with the ultimate goal of helping the child become independent and live a good life as an adult. As their sons' prognosis was ambiguous, they believed that the good mother should constantly try her best to help the child progress because there was a possibility that this might come to pass. The

mothers expressed the belief that if they stopped trying their best, this might affect the child's progress and as a consequence they would fail to achieve their maternal goal. This failure would threaten their perception of self and their self worth. The typical child has more skills to enable him/her to live an independent life even if the mother does not spend much time with her child. Therefore, the mother will not think that she did not succeed in helping her child develop and live an independent life. As a consequence, it would appear that mothers allocate their time and energy in a way that will help them think that they have done their best as mothers,  and have helped all their children to become independent adults in order to protect their maternal identity and as a consequence their self worth. As Mary said:

*'I have done the best for my children and that's the only satisfaction I can really have' (20.4)*

This interpretation seems to be further supported by the change in the participants' perception of mothering when they are not ambiguous about the child's future. In the absence of ambiguity, mothers report less distress and devote less of their time to accommodate the child's needs as they perceive them to be more able to develop into adults with the skills to live an independent life.

**4. Sub-theme 2: Integrating maternal identity to the self system**

The second sub-theme is concerned with the integration of maternal identity to the self system and it is further divided into two categories. The first category is concerned with the integration of the maternal and the wife identity and the second category is concerned with the integration of maternal identity with other identities as this is expressed through a change in priorities as a result of parenting a child diagnosed with autism.

**4.1 Integrating maternal and wife identity**

This category is concerned with the way mothers manage to integrate the maternal and the wife identity and the impact this has on them and the marital relationship. It seems that all mothers apart from one, had difficulty to integrate the two identities. It appears that what makes the integration of the maternal and the wife identity difficult is the priority mothers give to child's needs over marital needs. The reason they did that varied from participant to participant but it seems that the reasons fall into two categories, either to accommodate for their child's special needs or to devote their time to find ways to help the child progress.

Mary, Nicole and Angela's accounts suggest that the time spent or not spent with their husband was affected by their need to think of interventions they could use to help their sons' progress. As they said:

*'Things that I can go and buy him that might help him with his memory programme, there were more important priorities to me than looking good for my husband or go out for a meal just me and him'* (18.20-24)

*'Although you are with your husband, your mind is still with Nick, that you want to...you know, try things for him'* (9.26-28)

Adriana also talked about how the priority that was given to her son has deeply affected her relationship with her husband:

*'Both of us are devoted to Dennis, Dennis became the focus, and we still, as a team we are very good parents and we work great as a team, as a husband and wife that got put way back and we still suffering as a result of that. As a family we need each other, but as a husband and wife, big holes, big issues, because it was neglected and it was put at the back, so yes, there are some issues there'* (8.15-19)

Laura, Rosie and Jacqui, on the other hand, discussed how the priority of accommodating their children's needs affected the amount and the nature of time they spent with their husband. As Jacqui said:

*'I think we don't go out and do much together on our own, you know, sometimes it can be too much trouble, we have the baby sitter once per month but we do not actually use it once per month, it is easier to have the children with us rather than trying to get somebody in (...) It is difficult but somehow you take it for granted and actually when I spend time with him on my own we talk about the children, our life revolves around the children'* (6.16-21)

Laura and Rosie discussed how their sons' special needs and the way they needed to be parented affected the amount of time they spent with their husbands and their relationship with them.  As Laura said:

*'There are times when Andrew's behaviours and the way he needs to be parented conflicts with my husband's reaction and so I need to take an active role with both of them and this has an impact on us'* (15.6-8)

It sounds that, for the majority of the mothers of this particular study, accommodating their child's needs or devoting time to their child's progress, was a higher priority than accommodating their own and their husbands' needs as a couple.

The mothers who stated that they tended to prioritise their child over their marriage also reported having marital difficulties as a result.

Nicole and Laura talked about how their husbands' difficulty in adapting to the way they thought was the best way to parent their child and/or to the child's difficulties had a negative impact on their relationship:

*'Obviously there are issues with the husband and having an autistic child in the family. Now it's better, but previously when he wasn't talking, his father will have outbursts, so I knew it was basically because of his son, because of the amount of attention he has, because of his son's future' (6.22-25)*

*'There is a part of him that understands Andrew better but his reaction gets in the way and inevitably if he has a long day and he comes home and everybody is screaming their heads off, he wants to leave again, and he tells me I don't want to come home, I don't feel happy at home, that impacts a lot on me, I find it really, really difficult and it hurts' (...) I'm doing my best and I am not good enough... there is nothing I can do about it, I know that I do everything I can and it's not good enough, it's not good enough because life is not the way it should be, and that's hard, a feeling of hopelessness' (15.11-18)*

It sounds from Laura's story that her husband's difficulty in coping with Andrew's special needs had a negative impact on Laura's self esteem. As a consequence, the lack of emotional and practical support placed her in a position where she felt overpowered by her situation. Nicole acknowledged that the limited attention her husband had, compared to their son, contributed to their marital difficulties, but as she stated elsewhere, her son's progress remained her first priority.

Adriana also described how her husband's lack of support in parenting the child had contributed to their marital difficulties:

*'There is some resentment over there, but not towards the children but towards my husband (laughs) (...) because I had to be so strong, I had to make all the decisions (...) sometimes I wanted to be supported, I wanted someone else to make the decisions (...) I had to be self-sufficient, I had to be strong ummmh and that probably reflected my behaviour with my husband, maybe I pushed him away from me as a woman, you know, became this sort of dynamo, decision maker, facilitator, and the woman part of me... I don't know, there was some intimidation there, and then again you get to vicious circle because that made me more resentful' (8.20-30)*

Adriana also reflected here about her contribution to her difficulties with her husband. It sounds like Adriana found herself in a situation where she needed to be strong in order to facilitate her son's progress, and this was her major priority as she described elsewhere. According to Adriana's perception, her husband was not able to follow her pace and as a consequence, this affected her behaviour towards him she pushed him away. Adriana's story highlighted both partners' contribution to the marital difficulties.

Angela described how prioritising her son's needs led her to feel that she had to split herself between him and her husband:

*'It's very difficult to have time for ourselves (...) we try to do it because we feel we need to get away from the situation' (9.5-11). 'It affects me a lot (...) you feel you give your life...give all...sort of your time to Nick (...) I feel as if my relationship is divided in a sense among my husband and my children' (9.19-31)*

Mary, Jacqui, and Rosie described how parenting a child with autism had, in some way, contributed to them drifting apart from their husbands. As Rosie said:

*'We are emotionally and mentally drained most of the time, we argue, we have a lack of money because, obviously working circumstances, can't get child care ummmh because we had a nice life before the children, don't get me wrong I'm not blaming the kids, as I said it's much harder when you got a child with special needs (...) we live quite separate lives in lots of ways ummh we have set a time that we go out if we can afford to (...) it has drastically affect our relationship' (6.8-20)*

Rosie here compared how her marital life was before she had the children, and how it has changed due to their circumstances. Rosie's account appears to suggest that she experiences her family life in fragmented way as her marital relationship does not appear to be fully and smoothly integrated in her everyday life.

It appears from the mothers' stories that parenting a child with autism can affect mothers' ability to integrate the maternal and wife identity. This is reflected by their difficulty to find a balance between the time and the energy they devoted to their role as mothers and to their role as wives. As mentioned by most of the mothers, this had a negative impact on the quality of their relationship with their husband which, in turn affected the psychological well-being of the mothers: they were at risk of ending up feeling stressed, angry or, as Laura identifies, helpless.

## 4.2 Change in priorities

The second category of the second sub-theme aims to describe how the mothers changed their personal, social and professional priorities as a result of parenting their child with autism. It seems that they tended to prioritise their child's needs over their own needs, implying a shift in the way they identified their selves. Moreover, it suggested the centrality of the maternal identity and how this defined the other identities of the mothers.

All mothers talked about not having time for themselves, and as a consequence not having time to participate in activities that they enjoyed. Mary described how she stopped taking care of herself:

*'I let go off my self in terms of the way I look, for me a haircut for myself wasn't as important as sitting in front of the computer and researching another option of me to help Richard' (18.14-19)*

Laura talked about how she could not be herself any longer because of her need to accommodate her child's needs:

*'I do not use indirect speech any more, and every now and then an idiom speaks out and you can immediately see the reaction (...) those things that I do naturally as part of who I am, I have to check all the time and it is an effort to always being conscious of what you are saying, you can't let go and just be' (1.24-27, 2.1-2)*

Rosie talked about the self sacrifice in terms of personal time a mother needs in order to parent her child with autism:

*'You have to find a different meaning and direction in life, because if you look at the adoptions and there is a lot of children, a lot autistic kids, because people cannot cope, to be honest I can understand why, I really can, because you don't have any time about yourself' (14.3-5)*

Adriana described how her devotion to her son's progress became her only goal and priority:

*'In the early years I was absolutely driven, absolutely driven, I mean it took over everything and it exhausted me' (5.10-11)*

All mothers also talked about how the hard work involved in parenting a child with autism had affected their social life. As Nicole and Angela said:

*'My social life has gone completely down, because so much time is spent on George, following his progress at school and his home programme, I have limited time, probably go out on the weekend, go to the shop centre and then come back home' (8.8-10)*

*'I have friends that I go out with but again lately it has been very difficult because we are focusing a lot on him' (10.21-23)*

Jacqui described how it had restricted the range of her social contacts:

*'I suppose with the difficulties that I have the ones involving the children...because having children obviously changes your social life anyway, whether they have special needs or not, but I would expected to have more work social contacts than I have' (4.5-8)*

While Rosie described how it has restricted the places she can visit due to her sons' difficulties:

*'We don't go out that much because it's too hard, it's a place that we go and we feel comfortable or I feel comfortable because it's mainly me that take the kids out, where I don't get judged, it's OK to take them, you know, it's kind of, you get confined in to your own comfort zone in certain respects with what you can deal with' (10.10-13)*

Several mothers also elaborated on how it had affected their career life as they had had to give up their jobs or reduce the hours they worked, or changed careers in order to accommodate their child's needs.

As Nicole, Adriana, and Jacqui said:

*'I was a teacher working at a school, but when my son started having neuro-developmental problems, I gave up my job because I was unable to concentrate, in a sense I cannot help other children and ignore my own son, if I don't do it, who is going to give attention to him, so I had to prioritise George and I gave up my job' (5.26-29)*

*'I was working from home, so I will do therapy with him (...) we needed the income (...) I used to resent the fact that I had to work' (8.6-10)*

*'I was a dietician before having children and I worked full time up in London and then I had the children it was part time just locally, the idea was when the children go to school it would be something I can go back on and off on a permanent basis' (5.13-15)*

Nicole described having accepted the fact she had had to give up her job, and Adriana resented the fact she had had to work even if she was able to do this from home. It sounds that, for these two mothers, the identity of being a mother who had to devote herself to her child's progress was stronger and more important than their professional identities. This was not the case for Jacqui who described not feeling satisfied with her career change, nor for Mary who, after resigning, felt that she had lost her self-confidence:

*'I was getting a lot out of it [her career] and it raised my confidence as an individual' (16.23) 'I got a lot of self-confidence and a lot of my personal worth' (17.12)*

For this reason, Mary had decided to start a computer course. She had found it very helpful as she was able to see her self in other roles apart from parenting her child, and as she said, this had helped her increase her self confidence again (19.9-11). Angela, who had recently started working part-time, reported a similar experience:

*'I'm very happy going back to work, it has changed my life quite a bit, I'm a lot more lively now, I feel good when I come home cause I feel that I've been out, earn some money...have some adult interaction, so I feel quite good about it, I quite enjoy it' (12.1-10)*

Fulfillment of personal interests seems to have a positive impact on maternal well being, and a positive impact on the way the mothers perceive themselves. This could be because they allowed themselves to fulfill the needs of their other identities and as a consequence to satisfy other equally important needs apart from the maternal ones.

However, not all mothers like Mary and Angela allowed themselves to do that. Adriana and Paulina started exploring their other identities only when they judged their sons' progress to be satisfactory. Paulina described how she had started working and having time for herself only after her son had made substantial progress. She explained how fulfilling she found her work. As for Adriana, she reflected that her son's progress had allowed her to discover her own identity again:

*'For the first time in many years I'm beginning to remember I have my own identity as well (...)I relaxed a lot, whether that was because Dennis was so much further on, he has come so far, I think that has something to do as well' (5.15-19)*
*'I'm not just Dennis's mum, I'm me again, things that I want to do that are separate (...) there has been an extended umbilical cord that is now been cut, there is now this separation, he is his own individual and I am my own individual again and that is very liberating'(6.1-7)*

It sounds from the mothers' stories that the maternal identity was central to their lives, determining their priorities and how they experienced their self as a whole. All mothers described parenting a child with autism as a very demanding task, physically, mentally, and emotionally. At the same time, as described elsewhere in this chapter, autism is a very ambiguous condition, and as such parents cannot be sure how their child will be as an adult. It seems that for mothers of primary school children, this is a very demanding period, a period where they try to help their child become as independent as possible in order to increase the possibilities of a favourable prognosis. Therefore, mothers who feel primarily responsible for their child in a way devote their life to raising their child, a devotion that results in changing their choices and priorities in life, and consequently changing the way they identify themselves. It appears that being a mother of a child with autism is an identity that defines how mothers perceive themselves. It seems that for the participants of the present study, the fulfillment of the maternal identity need is more important than the fulfillment of other needs. However, almost all mothers described the negative impact this could potentially have on their psychological well-being. Therefore, it appears that there is an imbalance in the way mothers express themselves: maternal identity is so dominant that it leaves little or no space for the expression of other identities, including the self and the wife.

**4.3 Discussion**

**4.3.1 Mothering a child diagnosed with autism**

One major finding that the descriptive analysis of data revealed was that the mothers perceived themselves as being primarily responsible for their children and that they devoted most of their time and energy on a daily basis to accommodate their child's needs, and to help the child acquire the necessary skills for a future independent life. A similar finding regarding the time devoted to parenting a child with developmental disabilities has been reported by other studies (for example, Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murhy, 2004; Bernett & Boyce, 2005; Brewer, Eatough, Smith, Stanley, Glendinning, & Quarrell, 2008; Clark, Stedmon, & Margison, 2008; Donovan, VanLeit, Crow, & Keefe, 2005; Lam & Mackenzie, 2002; Kingston, 2007; Milo, 2007). Mothers described investing most of their energy and time monitoring their child's behaviour for safety reasons, handling the variability of their child's functioning and his behavioural problems, spending long hours in social skills training and behaviour, trying to find ways to secure a good education for their child and anticipating possible future problems. All these factors left the mothers feeling physically and mentally exhausted. Additionally, mothers described having to deal with the anxiety and the uncertainty of their child's future prognosis. Only mothers whose children had progressed substantially described not having these experiences, but they talked about feeling mentally and physically exhausted when the child's symptomatology was more severe. According to these mothers, what helped them relax was the lack of uncertainty about their child's future independence.

The demands of this type of parenting have been described by Ray (2002) (who studied parents of children with various medical conditions) as 'parenting plus', and by Rempel and Harrison (2007) (who studied parents of children with life-threatening heart disease) as 'extraordinary parenting'. Both concepts describe the extra effort parents make in a context of uncertain outcomes. Therefore, it can be concluded that parenting a child with mild or moderate symptoms of autism is an experience that differs from that of raising a typical child because it requires mothers to work much harder in order to carry out their maternal tasks over an indefinable amount of time. As a consequence, it can be concluded that parenting a child with mild or moderate symptoms of autism has many similarities with what has been described as 'parenting plus' or 'extraordinary parenting'.

Mothers described that as a result of the demanding mothering, they had limited time to fulfil other needs related to their personal interests, career aspirations, and socialisation. On an interpretative level, the analysis of data indicates an identity shift experienced by the mothers. After their child's diagnosis with autism, the participants acquired a new identity as 'the mother of a child with autism.' For reasons of convenience, this will be referred to as maternal identity. It appears that this identity is central to mothers' self system, and forces a shift in women's evaluation of their other identities. This is behaviourally expressed by the dramatic reduction of the time devoted to the expression of other identities (like the wife, the social identity, or the maternal identity in relation to the other children in the family) and/or by the abandonment of some already established identities (like the professional identity).

Mead (1934) introduced the notion of the relational self. His conception of self was symbiotic: the way we perceive ourselves is affected by the way we interact with others. Identity is intrinsically social and relational. The individual has a sense of identity as a result of symbiotic exchange. Identity does not remain static but is available for subsequent modification and transformation as a result of the social engagements the person encounters through their life. Consistent with Mead's conceptualisation of identity or self–concept, several theorists have conceptualised identity as being formed and maintained through actual or imagined interpersonal agreement about what the self is like (Schlenker, 1987) or as the process of constant negotiation with those around us (Jenkins, 1996). Therefore, identity is not static but it changes as we interact with other people around us and our life experiences (Erikson, 1980).

Rosenberg (1979) argues that the individual develops awareness and an acceptance of the social positions he/she occupies in the community and larger society. Therefore, the individual through interaction with others acquires a number of identities which are organised into a complex, semi-permanent, organised structure. Stryker and Serpe (1982) introduced the symbolic interactionsim identity theory according to which the identities incorporated into self are viewed as ordered in relation to one another in an hierarchical manner. The way identities relate to each other depends on their salience. Salience refers to the subjective importance that a person attaches to each identity (Stryker & Serpe, 1982). The salience of an identity is determined by the level of commitment an individual has to an identity. Commitment is 'the degree to which the person's relationships to a specified set of others depend upon his/her being a particular kind of person' (Stryker & Serpe, 1982). It refers to

relations to others formed as a function of acting on choices. It can be conceptualised in terms of costs of relationships foregone as a consequence of movement out of a social role (Stryker & Serpe, 1982). Commitment depends on the amount of time and energy invested in identity enactment (Thoits, 1983). Research has reasonably established the relevance of identity salience to behavioural outcomes, such as the amount of time devoted to activities related to a given role (Stryker & Serpe, 1994).

Serpe (1987) and Breakwell (1986) suggest that changes in the structure of self are related to the person's movement within the social structure, either by choice or by force of circumstances Therefore, it can be suggested that giving birth to a child with autism is a condition that forces the mother to negotiate with her environment and relocate herself within the social structure by identifying herself as being, among other things, a mother of a child with autism. This takes place through a process of assimilation and accommodation of new contents and values (Breakwell, 1986). The mother then evaluates the importance of this identity and reconstructs the way she has prioritised her other identities so far. If the salience of an identity depends on the importance one attaches to the identity and it is expressed by one's commitment in carrying out the activities related to the role then it can be concluded that the maternal identity related to the child with autism is the most salient for the participants. It affects the way they perceive themselves and guides their choices and behaviour. Moreover, mothers' choice to either restrict or eliminate the expression of previously established identities implies a change in their identity structure (Breakwell, 1986).

How one perceives one's self is situated within the social, cultural and historical context (Banister, 1999; Chesler & Parry, 2001; Duvdevany, Buchbinder & Yaacov, 2008). Social norms have established women's role in terms of caring for others (Gilligan, 1982) and emphasise motherhood as a valued role for women (Ingram & Hutchinson, 1999; Simon, 1992). According to Phoenix and Woollett (1991) mothers are seen to be responsible for ensuring that their children will turn out to be responsible and mature citizens. The perception of the mothers' role is to help the child's physical, cognitive, emotional and social development through nurturing, caring, teaching, guiding, protecting, and loving. In other words, the mother's role is to teach the child the art of living (Mercer, 1995). Therefore, it can be concluded that maternal identity is highly valued in the social structure as mothers are

seen to contribute to the smooth operation of the society by raising children who will turn out to be responsible citizens.

The social construction of motherhood appears to influence the way mothers construct their maternal identity in western societies judging from the large number of studies about mothers who raise either typical children or children with special needs which conclude that women consider themselves to be primarily responsible for their children's current and future psychological well-being (Bull & Whelan, 2006; Chesler & Parry, 2001; Gray, 1997; Kingston, 2007; Lam & Mackenzie, 2002; Mercer, 1995; Milo, 2007; Paris & Helson, 2002; Raphael-Leff, 1983). Mothers' accounts in the present study indicate that they had internalised the social construction of motherhood as they all considered themselves to be primarily responsible for their child. All described how they devoted most of their time to care for and about their child's progress, in an attempt to raise independent and responsible citizens of society.

Thoits (1995) argues that normative expectations attached to roles help guide and organise one's behaviour in specific contexts. As already mentioned, the normative expectations for the maternal role is to provide continuous sensitive mothering in order to ensure the child's development into an independent being. This is achieved through the maternal work. According to Ruddik (as cited in Kingston, 2007) the basis of maternal work is maternal thinking. This thinking is evoked by the child's need to be protected, nurtured and trained. Mothers in the present study seemed to identify their role and guide their behaviour in relation to their child through identifying the identity and the needs of the child. Rubin (1984) argues that maternal identity is established in relation to the child. The mother identifies her maternal identity through identifying the unique characteristics of her child. By acquiring their maternal identity in relation to their child, mothers then define the nature of maternal work. As Breakwell (1987) suggests, identity directs action.

Mothers described their child as being vulnerable, and expressed intense worries about their future happiness. In addition, they expressed ambiguity about their child's condition as his prognosis was unclear. It appears that the perception of the child is an important motivational factor for maternal role identity. Maternal aspirations about their child were underpinned by a desire for their child to be happy. Although mothers also recognised that their child's condition could prevent the realisation of this goal, at the same time they spent most of their time working on that goal, and searching for appropriate therapeutic interventions for the

child with autism. This aspiration for their child's future happiness and the ambiguity that characterises autism seemed to be a considerable source of motivation for the mothers to sustain their maternal work and devote most of their time and energy to that. A similar finding has been reported by a qualitative study conducted by Bull and Whelan (2006) for parents with children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), and by Larson (1998) who conducted a qualitative study for the experience of mothers parenting children with various physical disabilities like cerebral palsy-spastic and blindness. Larson described how her participants made sense of their child's disability by embracing the paradox of their situation. The features of this phenomenon include holding two oppositional thoughts about the child: loving the child, yet wanting to erase the disability. According to Larson, it was this attitude towards the disability that motivated the mothers to sustain their maternal work and energized them with optimism for the future.

The results of the qualitative studies about parents with children diagnosed with autism regarding this issue are mixed. Woodgate, Ateah, and Secco (2008) conducted a study for parents of children diagnosed with autistic symptoms of varying severity, and described that the participants were able to acknowledge that their child would not be able to change in certain ways and for this reason they were able to step back and not assume responsibility for everything. A similar finding was reported by King, Zwaigenbaum, King, Baxter, Rosenbaum, and Bates (2005) who conducted a study about parents with children diagnosed either with autism or with Down's syndrome. At this study, it was found that some of the parents had given up the priority of trying to 'fix' the child. The authors do not provide any information about the rest of the parents in their sample regarding this issue. The findings of these two Canadian studies are different to the findings of the present study. In Gray's study (1997) about parents of children with high functioning autism, the results were mixed as he found that some of the participants in his sample were able not to dwell excessively on the child diagnosed with autism while others were not. Kingston (2007) conducted a qualitative study about mothers in Ireland who raise children diagnosed either with autism, Down's Syndrome, or ADHD, and described how some of her participants tried to normalise their child so that s/he became a typical member of the society. Kingston notices how this commitment to maternal work motivated these mothers to make huge personal sacrifices to achieve the goal of developing their child into an independent human being.

Nicholas (1999) conducted a qualitative study about mothers who parent children with End Stage Renal Disease, and described the different meanings his participants attributed to care giving. Nicholas identified three clusters of maternal meaning about care giving: the trapped caregiver, the adaptive caregiver, and the embedded caregiver. The trapped caregivers usually provide the majority of their ill child's day-to-day care but they resent doing so as they perceive that they are sacrificing their independence. They experience anger about their personal losses. This anger is directed either towards family members or care professionals, or towards the child and/or his illness. The adaptive caregivers perceived care giving as a series of problems to overcome. For this reason, they adapt care giving to fit within their other responsibilities and priorities. The adaptive caregivers spend less time thinking whether their child will attain typical developmental milestones and have fewer expectations about what their child should become, or what the caregiver should do. The embedded caregivers are primarily - and in some cases solely - involved in care giving activities, and they view their identity and role in life to be providing care for their ill child. They view the provision of care giving as normal, and they quietly accept any difficulties they encounter.

Most of the participants in this study seem to have had similar experiences as the trapped caregiver. They all were the primary providers of care to their child, but at the same time they expressed their discomfort about the things they have had to sacrifice and the stress involved. The majority of the mothers expressed anger towards health care or educational professionals, people in society who could not understand the child's disability, or family members, and especially the husband who did not provide adequate support. None of the mothers expressed anger towards her child. This could be either because mothers in the present study did not feel angry with their child or because they did not feel comfortable to openly share with the researcher their maternal ambivalences. In Kingston's study (2007), some mothers were able to share with the researcher their maternal ambivalences, and the author highlighted the courage of this act since these women were at risk of being judged by others as unfit mothers.

The mothers of the present study who seemed to share similar experiences with the adaptive caregivers were Adriana and Paulina who both had sons who had progressed adequately; these mothers were far less uncertain about their child's ability to manage effectively in the society. A similar experience was expressed by Jacqui in regards to her older son who, according to her, was also quite able to live an independent life. Therefore, what can be

concluded is that a child's progress together with minimal ambiguity about the child's future prognosis allows the mothers to adopt an adaptive care giving approach where they fit the care giving tasks in with their other responsibilities and priorities. So, a change in the perception of the child's needs and condition is what allows the mother to achieve a balance between care giving and her other responsibilities and interests.

Knafl and Deatrick (2002) have carried out research on normalisation in families of children with chronic conditions like diabetes and rheumatoid arthritis. Normalcy is defined as the process through which mothers achieve a family life style that is not centered on the child's vulnerability, care giving and caregiver burden. The identified attributes of normalisation include: acknowledging the condition and its potential to threaten life style, adopting 'normalcy lens' for defining the child and family, engaging in parenting behaviours and family routines that are consistent with 'normalcy lens', developing a treatment regime that is consistent with 'normalcy lens', and interacting with others based on a view of child and family as normal. 'Normalcy lens' refer to recognising the seriousness of the illness while continuing to view the child and family as unchangeable in important ways. Families who focus on the normalcy of their situation typically adopt a flexible approach to the care giving tasks, and incorporate the illness into the usual routines of the family. This reminds us of the adaptive caregivers described in Nicholas' study (1999) where the adaptive caregiver fits the care giving into her/his other priorities and responsibilities.

Knafl and Deatrick (2002) based their study on families who seemed unable to introduce normalisation in their everyday life as (according to the researchers) less attention has been focused on this type of families. Knafl and Deatrick (2002) identified the following characteristics in the families who seemed unable either to introduce or sustain normalisation: parents emphasised how the child was different from peers and how their parenting style has changed to accommodate the view of their child, they described the illness as the major focus in their life and a source of conflict in the family life, and they described their family as different to other families because of the demands of the care giving.

Knafl and Deatrick's (2002) description of the features of lack of normalisation in family life resembles the findings of the present study where mothers talked about how their child was different to his typical peers, how their life revolved around the child diagnosed with autism, and expressed the hope that he would develop into an independent individual. In order to achieve that, as earlier mentioned, mothers prioritised their child's needs over their personal

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needs or the needs of other members of the family. Knafl and Deatrick (2002) found in their study that parents who perceived the child's illness as improving experienced a shift in normalisation in their family life. This is again consistent with the findings of the present study in which Adriana and Paulina described a similar experience after perceiving their sons' improvement substantial. They consequently perceived autism to be a manageable condition.

What can be concluded is that normalisation of a chronic condition is a challenging process for parents of children with autism. The participants in Woodgate et al. (2008) and King et al. (2005) described being able to introduce normalisation in their everyday life, and this was further supported by their expressed willingness to protect their own sense of self by not allowing autism to 'get the better of them' and their family. The way these parents managed to normalise the situation was by working towards a balance so that their life was not solely focused on the child with autism. They focused on the child's needs and strengths, rather than focusing on what the child was not. A similar finding was reported by Rempel and Harrison (2007) in a study they conducted about parenting a child with life threatening heart disease. Parents in this study reported that they managed to reduce their worry by trying not to think constantly about the child's health problem, and by acknowledging that some aspects of the child's condition were out of their hands.

However, this was not the case for most of the participants of the present study, for whom autism appears to be a dominant motif in their everyday life. The factors that seem not to have allowed the participant mothers to normalise their child's condition was the perception of their child's condition and their perceptions of effective mothering. The factors that appear to be strong motivations for intensive care giving include both ambiguity about the child's prognosis and the child's abilities and the perception of the child as being currently vulnerable. The majority of the mothers of the present study described their child as having high functioning autism, and most of them talked about the high IQ of the child. These factors, combined with the variability in day to day functioning appear to contribute to ambiguity regarding the child's potentials. As a consequence, mothers hoped that the child had the prospective to manage his difficulties. Verhaeghe et al. (2007) argue that uncertainty about the outcome is a precondition for hope. Ray (2002) reported a similar finding as parents in her study invested great effort in helping their child close the gap between them and their typical peers in those cases where there was hope that the child would be able to do that.

Paulina and Adriana were two participants that were able to normalise their child's condition due to his substantial progress. Their child's progress allowed mothers to perceive them as having the ability to live an independent life. Therefore, a change in the perception of the child's condition facilitated normalisation of the condition. Two other mothers, Mary and Angela, also tried to normalise their child's condition. What motivated these mothers to change their attitude towards the time commitment required to fulfil the maternal role was the realisation that they were losing aspects of themselves in their mothering endeavours. According to their accounts, their awareness of this process caused them significant distress, and they actively tried to do something by investing again in those identities they had abandoned, in particular in their career identity. Although both Mary and Angela reported that this shift had a positive impact on their psychological well-being and on their relationship with their child, they continued to feel stressed about their child's future and devoted most of their time to his progress. Therefore, it can be concluded that for the mothers in the present study, the factor that seems to be most strongly related to normalisation is the lack of ambiguity about the child's prognosis and the perception of the child as able to manage in society.

**4.3.2 Integrating maternal identity with other identities**

As discussed, lack of normalisation of the child's condition results in parents' life revolving around the child, and having limited energy and time to devote to other roles. Thoits (1983; 1992) suggests that multiple identities can produce ego gratification, and the sense of being appreciated or needed by diverse role partners. In her study, she found that the greater the number of identities an individual possesses, the less the psychological distress. Gray (1997) found in his study of parents of children with high functioning autism that mothers tend to view their family as less 'normal' than fathers did. According to the author, one possible reason for that was the fact almost half of the mothers had quit their jobs, or were working part-time. Consequently, their domestic role was their only role and they had no other social role on which to draw. Mercer (1995) found that mothers with careers report higher life satisfaction scores, and in order to manage role conflict they reconstruct their cognitions about mothering and priorities, and delegate responsibilities to spouses. This is similar to the process suggested by Knafl and Deatrick (2002) regarding the process of normalisation of a chronic illness in the family life, and the cognitions described by Nicholas (1999) about the adaptive caregiver.

Most of the mothers of the present study talked about the negative impact of abandoning multiple roles, in terms of either feeling restricted, feeling stressed or losing sources from which they derived self worth. A similar finding was reported by Nelson (2002) after reviewing a number of qualitative studies about mothers who raise children with special needs, and by Cashin (2004) who found that the dominance of autism in parents life left little time and energy for other roles apart from that of the parent. According to Cashin (2004, p.167), "the self shrank to the role of the parent". Mothers of the present study who were able to take on identities they had previously abandoned talked about experiencing a sense of fulfilment; on one occasion, a mother said that it was like rediscovering her self again. The findings of the present study also support the positive and protective impact of multiple roles on maternal well-being. Moreover, the findings of the present study suggest that in the case where other identities do not co-exist in balance with the maternal identity, the impact on maternal well-being is negative.

Identities related to other members of the family also seemed to be influenced by the centrality of the maternal identity in relation to the child with autism. There was a strong tendency among the mothers in the sample to believe that they were more responsible than their husbands for the child's upbringing, and as a consequence they prioritised the child's needs over marital and personal needs. This priority was also expressed by the perception of the husband's support which was mainly associated with the husband's care of children in general, and of the child diagnosed with autism in particular. A similar finding was reported by Chelser and Parry (2001). As far as the satisfaction with the perceived support from the husband is concerned, results are mixed. Some respondents stated that they had no support; others mentioned having practical, but not emotional support, while a few mothers reported having both. A major observation is that almost all mothers talked about the difficulty in nurturing their marriage due the demands of care giving. Almost all the mothers talked about the limited time they spend with their husband whilst their focus was on the child's needs. The perception of support in combination with the difficulty to set time aside for the couple was a source of distress for the mothers.

Strain on the marital relationship due to these factors has been reported by a number of qualitative studies (Gray, 1997; Kingston, 2007; Knafl & Deatrick, 2002; Lam & Mackenzie; 2002; Nelson, 2002; Ray, 2002; Seideman & Kleine, 1995Waters, Avatori, & Charles, 1999). On the other hand, what seems to contribute to marital satisfaction, as reported by other

qualitative studies, is where both parents' involvement in the child's care is combined with refocusing on the needs of the couple (King et al., 2005; Rempel & Harrison, 2007;). According to Mercer (1995), one of the major tasks of achieving a successful maternal identity is to integrate the maternal role harmoniously with the wife identity. Role integration has been defined as a process of organising multiple roles into a meaningful larger whole. Women who did not identify their partners as being supportive had more difficulty in the transition of maternal role. Research findings regarding the achievement of the maternal identity after the birth of a child seem to be relevant in understanding participants' difficulty in integrating the maternal and wife identity. It appears that this process is prohibited to some extent by the perceived lack of either the practical or emotional availability of the husband. The result is that the mother carries out most of the care giving tasks, and has limited time for herself and her marital needs. However, this should not be considered as the only factor, as mothers who had adequate support from their husbands still considered their child's diagnosis to be a dominant motif in their life in a way that absorbed most of their time and energy.

As already discussed, maternal identity is salient in the mothers' self system, and consequently guides mothers' behaviour and choices in their life. Their commitment to this role is reflected by the amount of energy and time they spend carrying out the normative tasks related to this role. Thoits (1995) argues that the most salient identities are more potent sources of meaning and guidance than those that are perceived by the person as less salient. Rogers and White (1998) found that mothers view maternal identity to be central to their lives, and the results of the present study appear to support this finding. All mothers wanted their children to achieve their maximum potential, and therefore, to effectively fulfil their maternal role. However, the child's condition has the potential to obstruct maternal goals. Schlenker (1987) defined threat to an identity as a blocking or interruption that has potential implications for people's goals and identity. Therefore, the child's condition seems to threaten the maternal identity as it can prevent the child from fulfilling maternal hopes and attaining societal standards. Research has shown that people sometimes respond to adversity in a role with increased, rather than decreased commitment (Lyndon & Zanna, 1990; Thoits, 1995) and this seems to be the case in the participants' experience in this study. Schlenker (1987) argues that when impediments threaten a desirable identity, individuals' cognitive and behavioural activities become focused and mobilised in order to deal with the problem. This resistance aims to eliminate or control the problem, and as a consequence to preserve the desired identity. Therefore, it can be argued that mothers have mobilised all their energy to

eliminate or control the child's condition that threatens not only the maternal identity but the whole self-system, as it prohibits the expression of other desired identities and threatens the source of meaning and goals these women had for their life before their child was diagnosed with autism.

Ryan and Deci's (2000) self determination theory conceptualises self from the perspective of the organismic paradigm according to which organisms are systems in which the functioning of the parts must be understood in terms of the whole. This system is characterised by a significant orderliness. As an aspect of this orderly regulation, organisms appear to have aims, purposes, or needs that their behaviour and component parts function to serve. Similarly cognitive developmentalists argue that there is an internal consistency and equilibration among varied functions and structures. In accordance with the organismic paradigm, Schelenker (1987) conceptualises stress as a pressure on a person to change shape versus the person's capacity to resist change. Schelenker defines 'shape' as the identity of a person, and 'pressure' is an event of environmental origin that has the potential to change the identity of an individual in a way that is not desirable (Schelenker, 1987). In this case we can suggest that the 'pressure'-event is the child's diagnosis. Mothers have to change fundamental cognitions, character and nature of their maternal role. This change goes beyond their original role expectations (Seideman & Kleine, 1995). The new role forces them to make many sacrifices in order to respond to its demands adequately, and as a consequence to restrict or eliminate expressions of other roles. Therefore, their identity changes in a way that was not expected or desired.

Therefore, mothers are faced with the challenging task of integrating the maternal identity into the self system in a way that will promote harmony and consistency with their other identities. According to Ryan and Deci (2003), this process is crucial as it promotes mental well-being. Baumgartner (2007) conducted a study for the incorporation of the HIV/AIDS identity into the self over time and identified two processes involved in the integration of a new identity: (1) Time- and health dependent decentralising and (2) Balancing. The first process refers to the internal process of realising that an individual is more than a given identity. This process is facilitated by time. Balancing refers to the external manifestation of this realisation. Participants of this 2007 study allowed themselves to get involved with other activities apart from the ones related to the HIV/AIDS identity. The mothers of the present study did not communicate a similar experience. On the contrary, they elaborated at length the dominance of their child's condition over their life. It was only a child's substantial

progress that allowed them to open up to the world. As Adriana said, 'I am not just Dennis's mum, I am me again'. This suggests that the process of integrating the maternal identity with the self system is long-term and ongoing.

According to Breakwell (1986), the extent and speed of identity modifications depends upon the degree of personal relevance of the change, the immediacy of involvement, how much revision of identity content and value is demanded, and how negative the change required is deemed to be. As far as the first two factors are concerned, having a child diagnosed with autism has a high degree of personal relevance for the mother as she is involved more than anybody else with the child. Breakwell (1986) suggests that high personal relevance and immediacy result in great identity change. Having a child diagnosed with autism is a condition that greatly affects the perceived identity of the mothers as their accounts reflect the great effort and attempt to accommodate the change in their life. As far as the revision of identity content that is demanded and the perceived negativity of the change are concerned, Breakwell (1986) suggests that these two factors result in slower integration of the new identity. These two factors seem to explain why mothers in this study have not fully integrated their new maternal identity and they remain resistant to this change. Having a child diagnosed with autism does not only require changing the maternal identity, but also the way you perceive yourself as a whole. This requires changing other identities as well. It can, therefore, be suggested that the significant revision that is required contributes to the resistance of change.

According to Breakwell (1986), only if resistance strategies fail can integration of the new identity occur. In the case of mothers of primary school children with autism, this is a process that can be prolonged for years as childhood is considered being the period during which children learn to build the skills and abilities necessary to achieve goals (Erikson, 1964). Therefore, during this period, mothers will employ and devote all their energy to help their children acquire such skills. As far as the perceived negativity of the change is concerned, having a child diagnosed with autism was not something that the mothers wished for. Moreover, this was very upsetting for the mothers as their children were in danger of being vulnerable and not able to support themselves in the future. Therefore, the diagnosis bears negativity not only because of the impact that it had on the mothers' lifestyle, but most importantly because of the negative impact that it had on child's well-being. This is another

factor that contributes to resisting integrating the identity of being a mother of a child diagnosed with autism.

Ambiguity about the child's future potential also seems to play an important role in this process; the child might manage to learn the necessary social skills and as a consequence he might manage to live an independent life. If this is the case, the mother's role and identity will change. She will not have to provide active parenting for her whole life, and she will be able to experience the life events that characterise the life cycle of a typical family (the child will receive an education, get a job, and then get married). At the time of the interviews with the participants, this was not the case, but the mothers expressed the hope that this situation might come to pass. Therefore, ambiguity about child's prognosis delayed the process of integrating the new identity: being a mother of a child with autism.  In the present study, it is clear that maternal identity does not exist in balance with the other identities, but rather appears so dominant and central to the self system that it leaves no or little space for other identities to be expressed. This lack of harmony and consistency with other identities implies that mothers' identity shift resulted in an internal disequilibrium. Therefore, it can be concluded that this identity has not been fully integrated into the self system as it dominates the self system. Behaviourally, this is expressed by the amount of time these women devote to their child's care; emotionally, it is expressed by the levels and amount of anxiety they experience, and cognitively, it is expressed with the preoccupation with the child's condition.

Yalom (1980) argues that humans appear to be meaning-seeking creatures who live in a world devoid of intrinsic meaning. Humans have a central role in constituting the world by the meaning they ascribe to it. Life choices, plans, and goals are ways of doing that. This further suggests humans' need for control and structure. According to Cohen (1995), uncertainty is ever-present in life but usually lies outside the purview of everyday consciousness. It appears that autism heightens awareness of uncertainty, and as a result mothers experience a loss of control and structure in their lives. The purpose, the predictability and the structure they thought they had with the birth of their child is lost, and they find themselves on uncertain and unpredictable ground. The majority of the mothers stated that they avoided thinking about the future as a way of coping with the anxiety inherent in the uncertainty about their child's prognosis. According to Schelenker (1987), individuals respond to stressful events by focusing on information that is relevant to the problem and the means of dealing with the difficulty. This contributes to a process of generating explanations

about the causes of the difficulty. Most of the mothers had constructed the diagnosis in a way that assumed that through intense provision of care giving and training the child had a strong possibility that he would be able to manage his difficulties. These explanations have implications for the self (Schelenker, 1987).

In situations of uncertainty, people have to construct their own meaning and interpret the situation in a way that will allow them to regain some control over their life. What seems to be happening is that these mothers try to make the unpredictable, predictable by investing in their child's development and progress. It is the behavioural tasks involved in the maternal role that need to be modified in order to bring about this change, this desired predictability and structure in their life, in other words to gain more control over their lives. By gaining more control over their lives, mothers will also be able to refocus on themselves and to explore their potentials through other routes. Therefore, the anxiety that mothers experience could represent their struggle to maintain themselves and actualise their potential (Kierkergaard, as cited in Cashin, 2004). This seems to be in accordance with Ryan and Deci's (2000) self-determination theory which suggests that the contexts where the basic psychological needs for competence, autonomy, and relatedness are neglected or frustrated and consequently promote fragmentation and alienation rather than integration and congruence. The perception of autism as a threat to preserving potentiality can be considered as a threat to one's autonomy and can further explain the difficulty in integrating this experience in a harmonious way. Moreover, it can explain the reason why most of the participants seemed to share characteristics with the trapped caregiver, as described by Nicholas (1999).

A large number of studies have concluded that parenting a child diagnosed with autism is a quite stressful experience. On the other hand, several studies have shown that parents are able to cope in a way that does not to allow autism to overwhelm themselves and their families. According to Schelenker (1987) coping has a ground rule: people must keep in touch with reality as it is perceived by the members of their social group. The mothers who participated in the present study managed to do that: they were not depressed and anxious to a degree that they were not able to care for their child, their family, and themselves. However, most mothers talked about the anxiety that they experienced as a result of the demanding care giving, the restrictions in their social and career life, the concerns about the time they devoted to their other child, the limited time they spent with their husband and the unpredictability

about their child's prognosis. They talked about how thinking about the future made them feel anxious, and how they avoided doing so. They talked about their concerns regarding their child's safety in the future, their concerns about the ongoing responsibility, and the likelihood that they would have to provide active parenting for the rest of their life. Therefore, what can be concluded is that the mothers were able to manage emotional distress so it did not negatively impact upon their maternal responsibilities, but they nevertheless experienced emotional distress as a result of parenting a child diagnosed with autism, and they spent most of the interview time discussing these issues.

### 4.3.3 Conclusion and implications for therapeutic practice

The aim of the discussion of the second theme is to gain a better understanding about the factors that contribute to maternal distress. It appears that the perception of the child's diagnosis plays a significant role. Mothers had made their child the centre of their lives, and had made personal sacrifices in order to accommodate this new role. As a consequence it appears that mothers seemed to perceive the diagnosis as a threat to their self system, and the way they had structured the meaning and the goals in their life. Diagnosis appears to be a threat because it forced mothers to change their maternal identity in a way that was not desirable. Additionally, it obliged them to change the equilibrium of their other identities in a way that again is not desirable. As Menaghan (1989) argues, psychological distress is more likely when one's role repertoire departs from the normal expectable situation. As earlier discussed, maternal perception of the child's diagnosis and care giving seemed to play an important role in their psychological well-being. Therefore, psychological input may facilitate self awareness through helping the mother explore the meaning they attributed to caregiving and the significance of changing their attitude towards it. The goal would be to help mothers negotiate child's care in a way that was consistent with their own priorities and needs. This might help the mothers balance their child's needs with their needs. In this way, the mother's perception of the autism-threat could be minimised as they would allow themselves to engage in activities and roles they used to enjoy before their child's diagnosis, and therefore increase their subjective well-being.

It is also important to consider practical reasons that can prevent mothers from having more time to devote to roles and activities that they find beneficial. For example, in cases where mothers do not perceive the support from the family members as being sufficient, empowerment strategies could be considered to help them renegotiate care arrangements in

the family. Moreover, the National Health Service should provide information to mothers about available support. To mitigate the psychological distress that results from uncertainty, clinicians could help mothers understand this phenomenon and explain that uncertainty inheres in the situation; it is not a consequence of their actions or abilities. Uncertainty is assumed to be linked with psychological constructs such as control and mastery (Parry, 2003). As discussed above, it seems that mothers attempted to gain control over their child's condition, and consequently over their life, by devoting most of their time and energy to help the child master his difficulties. Addressing these issues therapeutically could help mothers to embrace this uncertainty in a way that would allow them to grow by appreciating the certainties that provide positive meaning and well being in their life (Parry, 2003). Sensitive communication of the facts related to autism and treatment plans for the child that would involve small and achievable goals could also assist the process of embracing uncertainty. This could allow mothers to experience the reward and satisfaction of helping their child achieve goals, and, at the same time, preserve her hope and her motivation to help her child gradually progress to his potential.

After their child's diagnosis, mothers went through a process where they had to reconstruct their maternal role in order to meet the demands of the situation. However, it seems that the challenge of their current situation was to reconstruct this role in a way that would allow the maternal identity to exist in equilibrium with the rest of the identities of the self system in order to promote maternal well-being and growth. Psychological counselling could be beneficial in this process in order to explore with mothers cognitions and feelings that might make this reconstruction difficult.

## 5. Theme 3: Withdrawing from others

### 5.1 Introduction

The third theme that derived from the interpretative phenomenological analysis is concerned with the way that participants described their experience of others' reaction to their child's condition and to them. The interpersonal context included both professionals and people in their family and social environment. This domain seemed to capture the way that participants spoke of the sense of criticism and disapproval they received when their child misbehaved in public places. In addition, it seemed to capture the way that participants spoke about the lack of understanding both from their social environment and from professionals that often resulted in their child being labelled or discriminated against. Moreover, it seemed to capture mothers' response to the perceived lack of understanding and criticism.

This theme is divided into three sub-themes, the first two sub-themes, 'lack of understanding' and 'feeling judged' are concerned with the way participants described negative reactions towards them or their child as a result of lack of understanding and awareness regarding autism. The last sub-theme, 'affiliation with people related to autism' is concerned with mothers' response to the perceived lack of understanding.

### 5.2 Sub-theme 1: Lack of understanding

This sub-theme aims to capture the way mothers feel misunderstood by others. Lack of understanding can come from different sources, but what was common to all the mothers' experience was that they feel that other people could not understand what autism was and what it meant to be a mother who parents a child diagnosed with autism. This left mothers feeling isolated and alienated from their environment.

Mothers whose children had behavioural difficulties talked about the lack of public understanding and awareness regarding autism. Mothers seemed to be angry when they talked about it. Nicole said:

*'At times I wish the genuine awareness of his condition increases because it's something all over the UK, also anywhere in the world, and people to try to understand that it is a severe mental disability, and with George... if they can only understand what autism is' (5.14-17)*

Laura, who had one son with physical disabilities, compared public responses and reactions to her sons' disabilities:

*'His brother has physical difficulties and medical problems and it is much easier for people to understand, the wheelchair is a symbol, yes he has disabilities but he is neurologically typical and people are concerned about how you are coping and that's easy, autism is just this brick wall that nobody can get pass' (12.11)*

Rosie also believed that the lack of understanding and awareness about autism resulted from the public fear regarding mental health issues:

*'It's not worth describing to people that they have autism because the understanding isn't there, if you say my son is disabled because he is paralysed, they are like Oh God, that must be awful, you know, if you say my child has schizophrenia, or depression, or anything mentally... it has very much to do with mental health, people are scared' (9.11-15)*

Paulina's son did not have behavioural difficulties, and as she said, he was able to behave appropriately in public places. However, she was also concerned about her son being labelled or discriminated due to the lack of public awareness about autism:

*'People who haven't come across autism before, would think Oh what's that, you know, he must be like this, he must be like that, and you know, or pity, I don't want that'(5.3-5).*

Mothers whose sons had behavioural difficulties also talked about the lack of awareness regarding autism among professionals. As Nicole and Laura said:

*'So there is so much luck of awareness about this condition even among professionals (...) So how can I expect other people who don't know anything about autism to empathise when the so called professionals discriminate on a child because of his condition, the minute they hear autism, they think it's an alien condition. That's the feeling that I got, the minute they hear autism it's like, Oh my God, what kind of thing is this, are you from Mars?' (9.7-9)*

*'And to be honest I have found very few doctors that can understand it, with his paediatrician I had a couple of occasions that I thought Oh my God she does not get it' (12.16)*

Moreover, mothers felt that parents of typical children could not fully understand what it meant to parent a child diagnosed with autism. As Jacqui and Laura said:

*'How do I feel? Resentful is the wrong word, it is actually much harder for you than for other people' (2.1-3) 'What you are going through, you know, other friends, I don't think they have an idea, they can try be sympathetic but I think that they can't fully acknowledge or understand' (2.17-21)*

*'They just don't get it, there is no common ground' (12.11)*

A similar experience was described by Mary who felt that other people could not understand the amount of time and energy she devoted to caring for her child.

*'What you do for your child it's never...nobody can see it really ummh and sometimes you can't see it yourself' (19.17-19) 'I've done the best, I can't do any more than that but other people can't see (...)Sometimes very angry, very upset, disappointed (...) people can't understand and of course this makes me feel down' (20.7-17)*

Adriana, on the other hand, felt that other people could not understand her maternal goals and as a consequence, she felt alone and unsupported in her parenting journey as they could not follow her pace:

*'Oh Gosh, I feel so alone because, you know, either the people who love Dennis, they couldn't keep up that momentum ummh not my husband, not his godmother, they would say...ummmh yeah I felt so alone ummh (pause) it was Dennis really, it was Dennis that kept me going, the potential that I could see in him, that's what kept me going, I didn't get...any...no one could give me that support because (...) they would say give it a rest, you know, let him go away this time (...) people were like don't push him, and they didn't understand, they didn't understand that we have to do this, we have to do this' (6.16-25)*

In many examples the perceived negativity about autism was evident. The mothers were also recipients of this negativity as the lack of understanding about autism undermined the effort they invested in parenting their child. It seems that the lack of understanding and awareness about autism left these mothers feeling isolated and different to the rest of the community, and it was evident by the way they described their experience that this made them feel angry or disappointed.

## 5.3 Sub-theme 2: Feeling judged

It seems that the physical invisibility of autism contributed to the lack of awareness about this condition. In some cases, it resulted in negatively labelling the mother for poor mothering abilities. As a consequence, this lack of understanding about autism left mothers feeling not only misunderstood, but judged as well.  As Rosie said:

*'I'm educated enough to understand parenting models and behaviour models and that type of things, which I do use with my children, I'm educating them as well (...) it's hard when you are that way inclined yet the way your children react or act in public because of the difficulties and the frustration appears for them to be mini yobs' (3.17-21)*

The lack of understanding also had a negative impact on the way mothers perceived themselves and evaluated their maternal abilities. Laura, Rosie, and Nicole's sons had behavioural difficulties and misbehaved when they were in public. All the mothers whose

sons experienced behavioural difficulties described sometimes feeling inadequate as parents due to the negative public responses to their sons' difficulties. As Rosie and Laura said:

*'People think you are bad parent, I often say to my husband I'm going to get one of them neon signs you know, bad mother, cause that's how people make you feel' (3.5-7)*

*'My child is not typical and again this was lack of understanding, and again it is hard to explain and justify what I am doing, and she said, Oh you do not have to justify yourself to me, well actually I do because what you are saying has a lack of understanding and you are judging me, my response based on that lack of understanding, at least allow me to defend myself, I am allowed doing that. And friends have been like that a lot' (12.22-26)*

It appears that how they perceived their competence as mothers was very much affected by the way other people perceived their maternal abilities. It sounds from their stories that negative public response contributed to feelings of low self worth.

Laura further described how support could also have a negative impact on maternal confidence:

*'And for her to say that, it punched me right back to four, five years ago when all I was hearing was all you need to do is this and if only you did that, and he is manipulating you and he is very naughty' (5.2-7)*

It appears that the way some people suggested parenting interventions left the mother feeling unsupported and misunderstood, and as a consequence affected her confidence. Rosie described her experience of people whose suggestions implied that she did not know how to parent her child:

*'And on the top of that you have family that... for example my father believes that they just need a wallop there is nothing wrong with them' (8.25-26)*

It was mainly mothers whose children had behavioural difficulties who reported feeling judged. However, Mary whose son did not have these difficulties also felt judged by the people in her close environment. Her feelings stemmed from their lack of understanding about her priorities:

*'People have a perception of me that I probably sit all day having cups of tea, not having a worry in the world, people cannot see where my time goes' (20.12-15) 'I think they must think she is lazy, why she can't do that ummmh kind of judging me' (21.8-10)*

It appears that the lack of knowledge regarding the child's condition and the way in which this was sometimes communicated could have a negative impact on maternal confidence and well-being. These two experiences forced mothers to withdraw from others, or to feel

affiliated only with people who had a relation with autism. It was only in this latter group that mothers could find the understanding and the acceptance that they did not receive either in the family or the community. The following two themes aim to describe mothers' responses to perceived judgement and lack of understanding.

**5.4 Sub-theme 3: Affiliation with people that accept autism**

This sub-theme was developed to capture the way that participants felt and behaved as a result of negative reactions and criticism from others. It appears that such negativity led mothers to lose all sense of affiliation with people who did not relate in any way to autism. It is apparent that the mothers in the study were in need for support and understanding. According to their accounts, it was usually their relationship with people who accepted and understood autism which provided support. These people usually belonged to the following groups: family members, people in the community who are open to differences, other parents of children with autism, support groups, and professionals who offer substantial and sensitive support to mothers.

Rosie described how she avoided other people in order to avoid criticism:

*'Withdraw into yourself, I'm not as outgoing, I'm hiding from other people to some respect, I know that's a strange thing to say (...) you are judged as a parent, people say nasty things, people treat you differently, it's not just the circumstances your in' (1.26-27, 2.1-2)*

It seems that Rosie did not only withdraw from others but also felt alienated from others as she felt she was treated differently to mothers of typical children. Rosie also described having difficulty in  fully and meaningfully engaging with mothers of typical children:

*'When they are babies, it's things like being sick all over you, and then all the nice things, Oh he said the first word, but then the differences start happen and you start thinking I can't really talk about that (...) and then the other side of it which is hard, they talk about their kids' achievements which is way above my kids (...)* **How does this make you feel?** *There is something that I do, this is a very big confession ummh you know about Homer Simpson, there is one thing he does, I call it Homer mode, other people talk to him and he sings songs in his head ummh I find myself doing that a lot, it's like I switch off, it's a funny thing to say but it stops you have any emotions, it's those things you learn to cope with your own emotions as well (14.26, 15.1-13)*

The emotions that Rosie talked about might have to do with shame as well, an emotion that is often evoked when people feel inferior to others. It appears that Rosie was ashamed to share with other mothers her sons' achievements as they appeared insignificant to mothers of typical children. Therefore, it appears Rosie was 'switching off' when relating to mothers of

typical children in order to avoid any unfavourable comparisons in her mind, or possible disapproval about her abilities to help her sons achieve typical milestones.

A similar feeling of alienation was expressed by Nicole who could empathise and connect only with people related to autism. She expressed her anger for the vast majority of society who could not understand her and her son:

*'I'm not blaming anybody probably if I did not have an autistic child, probably I wouldn't understood, unless you really put yourself, unless you really facing it from scratch, can only understand, empathise. Very few people, out of one hundred, five probably would be really able to empathise with the children, without having the experience of that (...) and these people who are the minority, these are the good people left in the world, and I call them George's angels, they are the angels that have been the right time, to the right place to help him (...) I don't blame them [people that cannot empathise and understand autism], they haven't gone through that experience. I'll definitely try to show them my point of view, to make them understand, but I have no sympathy for people' (8.18-29)*

It sounds like Nicole felt unsupported and alienated from most people, and had rejected them in the way they had rejected her and her child. Nicole appeared to feel angry when she talked about this experience.

Laura also described how she avoided interacting with those whom she believed criticised her and judged her son and her. She described an incident where a friend told her that her son was manipulating her:

*'It is a question of me having to take it on board and me having to deal with it when really what I wanted and needed to do was to say you have to stop doing this, Andrew is not a typical child, he has got a disability, and his disability comes out like this, he cannot control his emotions, he reacts very badly, we are working on it but he is disabled and I have a real concrete problem' (5.12-20). 'She meant in the best way possible but it is so hard and I haven't been able to see her since' (4.18-19)*

Laura's need to explain her son's condition and how much she tried to deal with it implied that she felt misunderstood and criticised, and as a result, she withdrew from her friend to avoid facing this difficult experience.

Paulina did not describe withdrawing from others in terms of avoiding interacting with people who did not relate to autism. However, she did not tell most of the people in her social environment that her son was diagnosed with autism:

*'We didn't really feel the need to tell everyone because we didn't want him labelled by other people and treat him differently, we only tell to people that are close to us and we trust them' (5.1-3).*

It sounds like the fears of discrimination prevented Paulina from being honest and open with the people in her close environment regarding her son's diagnosis. So in a way she did not allow herself to fully interact with the people in her family and social environment.

Adriana also described withdrawing from the people in her close environment, not because she was feeling that she and her child were judged and discriminated against, but rather because she was feeling unsupported in her maternal aspirations:

*'Maybe that's why I locked everybody out in a way I think, because I had to focus so much on him, so he gave me the strength, it was a mission, it was a mission for him. Just seeing him blossom and seeing the results kept me going' (6.29-30, 7.1)*

All mothers of sons with behavioural difficulties reported being subject to negative reactions due to others' lack of understanding and awareness regarding autism. It seems from their accounts that this left them feeling judged and isolated. Their response to that was to further withdraw from others. Adriana also withdrew from the people in her close environment as a result of feeling unsupported.

Some mothers mentioned that they mainly related to other parents who had children with autism as they felt understood by them, and and not criticised. As Nicole, Rosie, and Jacqui said:

*'Social network is reduced, and even if I have it, it's with mums who have kids of similar issues. In a way I empathise with them and I find it constructive to do that (...) Probably because they know, I'm not blaming anybody but probably if I did not have an autistic child, probably I wouldn't understood, unless you really put yourself, unless you really facing it from scratch, can only understand, empathise' (8.13-20)*

*'There is a lot of support that I get actually from other families, there is a support group, we meet every fortnight, it is for parents that have children with special needs, and I talk to other parents' (4.11-13) 'I think it is about to share the experience, they know where you are coming from ummh you don't have to explain things in great detail, you sort of have a common ground (...)I think just to know that you are not the only one, I think that is definitely the case' (4.16-18)*

*'I met some lovely mums there that are on the same boat, and the great thing about it is that we can seat round and talk about the fact that your kid is driving you mad, you know the kind of conversations that you couldn't have with the other friends because their kids don't do things like that, it's a safe environment to talk about staff, and they are not socked. You need*

*to talk because you are in such extraordinary circumstances, it's so different because of the emotional factor' (12.6-10)*

It is apparent that a non-judgemental environment facilitates maternal coping and well being. Support can have a positive impact on mothers' ability to carry out the demanding task of parenting a child diagnosed with autism. The support can also come either from within the family, the extended family, the professionals that help the child therapeutically. The common element in the positive perception of support, irrespective of its source, is a perceived acceptance about the child's diagnosis and a perceived acceptance of the mother and her efforts.

All the mothers reported finding therapeutic interventions for their child helpful, both for the child and for themselves. Jacqui talked about receiving emotional and practical support from professionals:

*'I think that intensive therapy of whatever form should be available to everybody (…) they mention about the early interventions but hey, who is going to do it, especially when you have other children in the house and they never explain how you are supposed to do it. We had a wonderful consultant who came every three weeks and gave you a real pat on the back for what you were doing, and you think as a mother no one knows whether you are doing a really good job but he did it was an excellent experience. At that time what we had from the authorities was someone coming for an hour every fortnight to show what to do, it was not enough, when you are talking about early intervention this is the appropriate early intervention [ABA]. You need extra hands of people that know what they are doing' (8.25-27, 9.1-9)*

Mothers also commented on the support they received from the family. Angela, Paulina, and Nicole talked about the importance of having support and acceptance from their husbands as this helped them cope with the situation. As Nicole said:

*'I think, he is an excellent father (…) if I think about it I could have been married to another man, who probably would have given up our autistic child (…) he could have been a less supportive man, but he is not, he takes good care of his son and spends time with him (…) It's critically important because if my husband was not supportive, I don't know what I could have done with it' (6.27-7.3)*

Support from friends was viewed as providing mothers with both practical and emotional support, and a sense of being accepted and valued for their efforts. As Paulina said:

*'Our close friends are great (…) they are telling me how much he has progressed, they are telling me you have done so much, so they can see the progress' (5.20-22)*

Two mothers also expressed their need to have individual counselling so they could talk to somebody who would be able to understand, accept, and offer emotional support. Laura had received counselling in the past. At the time of the study, she was taking an antidepressant medication, and her GP had suggested that she should have some counselling sessions. She commented on the positive aspects of her past counselling experience:

*'Having some place, some person that I can just go and be myself and do the crying thing without it being in the realm of I've come to ask for help for my children (...) I have the support for the kids which helps hugely, emotional support I don't have, I did see a counsellor some time ago and that was good because I know that the counsellor at the end of the day it's their job and they go home and in one way or another they can put that load down which is what family can't do and friends can't do, so when the GP suggested that it was quite welcomed' (10.14-20)*

The characteristics of the people who mothers described as being a source of support for them highlighted that what mothers were seeking was acceptance for their child and acceptance for themselves. They were looking for people who were able not to judge them and criticise them based on their child's diagnosis; they were looking for people who would attempt to understand what they were going through, and not undermine their efforts.

## 5.5 Discussion

A number of studies have reported the lack of relatedness that parents of children with autism experience with the rest of the community. This phenomenon has been described in different ways by several researchers. Woodgate et al. (2008, p.1078) described it as "living in a world of our own", whilst Cashin (2004, p.167) described it as "less of social contact", and Gray (2002) talked about the stigma that parents of children with autism experience as a result of their social interaction with others. The researcher of the current study describes the lack of relatedness expressed in mothers' accounts as 'withdrawing from others' to highlight mothers' emotional and behavioural isolation from the people who cannot accept and understand autism. It was apparent from the mothers' accounts that this was particularly salient for mothers whose children encountered behavioural difficulties. It may be argued that these mothers are subject to stigmatism when they interact with others in a social context.

Stigma is a sociological concept introduced by Goffman (1963) who defined it as the discrepancy between virtual social identity (i.e. expected attitudes) and actual social identity (i.e. attributes in fact). Research has shown that the parents of children with disability experience 'courtesy stigma' as defined by Goffman. This is a stigma of affiliation that

applies when one associates with stigmatised groups rather than through any quality of their own. A courtesy stigma is attributed to parents because they are members of the same family, rather than because of any sharing of the disability itself (Gray, 2002). Mother's perception of others as being critical, not accepting either their child with behavioural difficulties or their maternal child-raising abilities implies that these parents are subject to stigmatisation in certain social interactions.

According to Ryan and Deci (2000) satisfaction of the basic psychological needs of relatedness, competence and autonomy facilitate optimal functioning of the natural propensities for growth and integration, and constructive social development and personal well-being. Social contexts that conduce feelings of competence are those that offer optimal challenges, competence promoting feedback, and freedom from demanding evaluations. It appears from mothers accounts that some of their social environments do not have these characteristics. On the contrary, mothers often face criticism and mistrust about their parenting abilities. Moreover, the support that they sometimes receive can be unhelpful, as it implies mistrust in mothers' knowledge of their child and a focus on those areas where the mothers appear not to be doing well. Therefore, it may be concluded that some social contexts do not promote satisfaction of some mothers' basic psychological need for competence.

In these contexts, therefore, the mothers' reaction was to withdraw into themselves and avoid social interaction with people whom they perceive as being unsupportive and judgemental. Ryan and Deci (2000) argue that the basic need for relatedness can be met in environments that are characterised by a sense of security. This can explain why mothers tended to restrict their social interactions to environments where they felt understood and supported. These environments usually are the family, support groups and/or a small number of friends who can accept autism due to their direct experience with this condition. Ryan (1995) argues that environments that offer a secure relational base allow the people who are embedded into them to experience greater integration and psychological well-being as the higher the perceived quality of relatedness, the greater one's feelings for relatedness and autonomy. On the contrary, environments that do not satisfy these basic psychological needs promote alienation. It is very important that mothers have access to environments where they can satisfy their basic psychological needs, but at the same it is important to notice that attitudes from people in public, friends, family and extended family environment restrict mothers' expression in different contexts and restrict their options in the world. This highlights the

importance of increasing public recognition about autism in order to protect both the mothers and their children from stigmatising attitudes.

It is equally important for mothers to become aware of their own reactions in these circumstances and help them feel empowered and confident to represent themselves and their children in several social contexts. Mothers talked about their way of coping with the perceived judgement and lack of understanding through withdrawing from the situation, either mentally or physically. It can be argued that these behaviours further reinforce this disconnection between the mother and the social environment. The feelings that seem to reinforce these behaviours is embarrassment and, in some cases, shame. According to Gray (2002), there is a distinction between enacted and felt stigma. Enacted stigma refers to instances of overt rejection or discrimination experienced by stigmatised individuals. Felt stigma refers to feeling shame or the fear of rejection. It can be suggested that some mothers perceive themselves as being subjects to enacted stigma, but it can also be argued that they experience felt stigma. This assessment is endorsed by the mothers' avoidance of interaction with certain social groups or particular people in order to avoid judgement and the painful feeling of shame.

Naso (2007) describes shame as an inescapable sense of exposure about a personal flaw. According to Lewis (1992), shame requires the internalisation of standards, rules, and goals against which one's behaviour is evaluated and it requires that judgements are global and pertain to one's identity. Moreover, it requires a failure to live up to an ideal and the perceived failures are attributed to internal rather than external factors. According to Smith, Webster, Parrott, and Eyre (2002) shame is directed to the self which is the focus of evaluation and for this reason shame is different to guilt where the focus of negative evaluation is on the individual's actions. Moreover, Smith et al. (2002) argue that shame is different than embarrassment which entails feeling foolish, self-conscious, and awkward. When a person feels embarrassed, there is little sense of being inferior. Therefore, it can be argued that in the contexts where mothers feel judged, they experience shame as a result of failing to present themselves as competent mothers. As one participant said, people make her feel she is a bad parent. This implies a general negative self evaluation. Moreover, some mothers said that at times they doubt their maternal abilities, a self-assessment that implies that they tend to blame themselves and not the challenges presented by their child's difficulties.

According to Smith et al. (2002) there are two types of shame. One results from the public exposure of defects, and is characterised by the cluster of emotional appraisals that concern the loss of one's reputation, the decrease of one's status, disapproval in the eyes of others and consequent future constraints. The second type of shame experience results from a more private evaluation of the self. It may be characterised by emotional appraisals of self-contempt and helplessness. Based on the data available, it can be concluded that mothers of the current study experience the first type of shame, as no data is available to comment about the second type. According to Van Vliet (2008) shame is elicited in response to social rejection and other events that threaten the individual's self-esteem, social status, and a sense of belonging. This reminds us what has been suggested by Ryan and Deci (2000) regarding the importance of satisfying the basic psychological needs so to experience psychological well-being. In particular, research has shown that satisfaction of the basic psychological needs decrease the experience of feeling ashamed, depressed and lonely (Wei, Shaffer, Young, & Zakalik, 2005). Moreover, research has shown that children's compliance in social settings relates to mothers self-esteem since the maternal ability to manage children's behaviour is characterised as an essential characteristic of effective mothering (Woolett & Phoenix, 1991). Therefore, it can be concluded that in these circumstances mothers lose their status as competent mothers, and as a result they avoid this painful 'exposure' by withdrawing from these social settings. A similar mechanism seems to take place when mothers avoid talking about their children's achievements, difficulties or avoid disclosing their child's diagnosis. As Van Vliet (2008) has suggested, shame is associated with an overwhelming impulse to hide or withdraw from social contexts, and this can result in isolation and psychological distress (Van Vliet, 2008).

The research highlights the importance of clinical interventions that will help mothers to satisfy their desire for self-direction, relatedness, and competence in as many social settings as possible. Van Vliet (2008) argues that socialising with others helps people restore a sense of connection to the outside world. Therefore, it could be beneficial for mothers to talk to others who do not relate to autism about what this condition is, and how their child's behaviour occasionally evokes shame. The goal would be to help mothers normalise the shame experience and bring greater understanding of contributing factors.

Another important intervention would be to help mothers work towards their goals, take on activities and formulate relationships that will strengthen their self-concept, sense of power and control and help them redirect their attention from their shortcomings to their strengths

in order to develop a sense of pride (Van Vliet, 2008). One of the participants talked about her need to run away with her children to a 'fluffy world where others do not exist'. Therefore, it appears that it is important to help mothers realise that despite one's wishes for the contrary, the situation has not disappeared. One way to facilitate this acceptance would be helping mothers to interact in a more assertive way with their environment. Assertiveness training could help mothers resist criticism, reject negative judgements, and challenge others (Van Vliet, 2008). Cognitive interventions would be very helpful in this process. According to Lazarus' cognitive theory of emotion (as quoted in Power & Dalgleish, 1997), appraisal of a situation in terms of goal relevance, goal congruency, and ego involvement, as well as appraisal of coping resources determines the type and the intensity of the emotions experienced. Therefore, emotional and behavioural aspects of one's experience can be modulated through altering cognitions and evaluations of one's self.

Morris (as cited in Duvdevany, Buchbinder, & Yaacov, 2008) argues that portrayals of the disability experience should depict the person's difficulties, the discrimination and prejudice against them, their struggle against social oppression, and the fight for self-esteem and self-determination. The analysis of the interviews illustrates how society's dominant attitudes and responses shape the parenting experience of mothers of the current study, and highlights the importance of increasing public awareness regarding autism. On the other hand, it is also very important to highlight that it is one's own interpretations that matter most (Naso, 2007). Therefore, it is crucial to examine the way in which mothers respond in these situations in order to understand their difficulties, and provide them with interventions that will empower them and help them confidently determine themselves and satisfy their psychological needs in order to experience greater psychological well-being and integration within society. As Ryan (1995) argues, psychological processes through which basic psychological needs are satisfied facilitate individual totality and integration of people within their cultures and groups.

**CHAPTER 4: Overview and Conclusions**

## 1. Chapter overview

This chapter offers an overview of the main findings by describing the essence of mothers' experience as emerged from the super-ordinate themes and sub-themes of the interpretative analysis of data. The chapter then considers the relevance and implications of the findings for counselling psychology. The overview concludes with an evaluation of the current study and makes suggestions for further research.

## 2. The essence of mothers' experience: disequilibrium

According to Yalom (1980), humans appear to be meaning-seeking creatures who live in a world devoid of intrinsic meaning. One of humans' major tasks is to invent a meaning robust enough to support a life. Humans have a central role in constituting the world by the meaning they ascribe to it. As a consequence, humans have a need for structure and control over their life, and they achieve that by ascribing meaning and constituting the world they live in. Life choices, plans, and goals are ways of doing that. According to Yalom (1980), an individual who possesses a sense of meaning experiences life as having some purpose or function to be fulfilled, some principal goal or goals to which to apply oneself.

Having a child, taking care of a child, and ensuring a child's development to adulthood is an activity that provides human beings with a sense of life purpose. Several studies have demonstrated the centrality of this experience in a woman's life as parenting appears to be one of the woman's key developmental tasks, one of current and expected future identities, and a task that is generally more central to women's self conception as it determines her personal goals (Cowan, Cowan, Heming, & Miller, 1991; Salmela-Aro, Nurmi, Saisto, & Halmesrnaki, 2000). The presence of a child in a woman's life implies that she will have several experiences that are associated with the child's development. As a consequence, this creates some structure and predictability regarding one's life, and also provides a sense of purpose and direction about fulfilling the goal of raising a child.

The diagnosis of a mother's child with autism appears to be a threat of one's meaning in life. The mother experiences a loss: loss of the child she thought she had, loss of the maternal identity she thought she had, and as a consequence loss of her own direction in life since identities provide a purpose, existential meaning and guidance (Thoits, 1982). The mother now faces the task of acquiring a new identity: the mother of a child diagnosed with autism.

The child's diagnosis, affects the mother's identity. Mead (1934) argues that identity is developed and maintained in relation to others, and Rubin (1984) argues specifically for the maternal identity that is developed in relation to the child. It is through identifying the child that the mother identifies herself.

However, in the case of mild or moderate autism, mothers appear to experience challenges in the integrating their new identity. Ambiguity about the child's future potential imposes a great challenge for these mothers. The child might manage to learn the necessary social skills to live an independent life, therefore, this makes it harder for the mother to identify the child. In this case, the mother's role and identity will change. She will not have to provide active parenting for her whole life and she will be able to experience the life events that characterises the life cycle of a typical family (the child might be able to acquire education, secure a job, and in time, get married). Therefore, the ambiguity about a child's prognosis seems to freeze the grieving process of the lost identity, and as a consequence freeze the process of integrating the new identity of being a mother of a child with autism.

It seems that mothers at this stage experience a loss of control and structure in their lives. The purpose, the predictability and the structure they thought they had with the birth of their child is lost, and now they find themselves on ambiguous and unpredictable ground. Humans have a need for control and structure as the loss of it results in anxiety (Yalom, 1980). What seems to be happening is that these mothers try to make the unpredictable, predictable by investing in their child's development and progress. It is the behavioural tasks involved in the maternal role that need to be employed in order to bring this change, this desired predictability and structure in their life. It appears that the participants rearranged their internal equilibrium of identities in a way that would help them achieve predictability and structure. This rearrangement seems to result in an internal disequilibrium as the identity of the mother who parents a child diagnosed with autism seems to be so dominant and central that it leaves no or little space for other identities to be expressed. It seems that the maternal identity does not exist in balance with the other identities as it occupies the largest part of the self and overshadows other identities. Baumgartner (2007) argues that an identity is integrated harmoniously with the self system when an individual stops being absorbed and involved with activities that are related to one identity only. The mothers of the present study talked about their life revolving around the child diagnosed with autism. It was only when they

perceived the diagnosis as being manageable and not restrictive for the child, that they were able to open themselves up to the world.

The study reveals that the mothers' lives had changed. The participants seem to have felt alienated from familiar life, from the meaning and purpose they had ascribed to their lives. As a consequence it seems that the meaning of their life in this stage of their life was to restore the lost balance, structure, and purpose they had before the diagnosis. This seems to be reflected both in their difficulty making sense of the loss in a way that would facilitate its acceptance, and by their preoccupation with their child's future independence. It appears that preoccupation with one identity only alienates the mothers from herself as she loses touch with her potential to express herself in ways other than parenting her child with autism. Moreover, focusing on a single identity alienates mothers from the rest of the world. Career opportunities are restricted and socialisation is mainly limited to people that share similar experiences, as the mothers in this study felt misunderstood by others. Negative reactions from others seem to further intensify this imbalance as some mothers reported not feeling embedded in other contexts. Josselson (1994) has identified embeddedness as one of the dimensions that define the relational space in which people live and as a consequence where their sense of identity is shaped. She further argues that the individual who wishes to belong, but does not belong, may have an intense sense of yearning and feel excluded from the ongoing process of life (Josselson, 1994). This view endorses the present study's finding that the mothers' internal disequilibrium, which resulted from the need to reconstruct their sense of self after the loss of their dreamed-for child, is further intensified by public responses to the child and the mother. Moreover, it can be argued that by placing their main focus on their maternal identity in order to achieve the maternal goals of helping the child progress will further facilitate and support these mothers' embeddedness within more social contexts, and will consequently preserve their potentiality in the world (Heidegger, as cited in Cashin, 2004).

It may be concluded that the loss experienced by the mothers in this study following the child's diagnosis resulted in disequilibrium in the way they experienced themselves. Loss threatens our sense of self worth and our fundamental beliefs about how the world works (Epstein, 1973; Jannof-Bulman, 1992). Davis and Nolen-Hoeksema (2001) argue that making sense of the loss involves the task of maintaining threatened worldviews, while finding benefit involves the task of rebuilding a threatened sense of self. It appears that, for the participants in this study, the process of making sense of the loss resulted in an effort to

reconstruct their sense of identity and their fundamental beliefs about how the world works. This reconstruction process appeared to result in disequilibrium as the maternal identity that is mostly threatened by this loss appears to dominate the self system after the loss of their dream-for child. It appeared that intense commitment to maternal tasks reflects the participants' efforts to maintain their threatened world views and their own self worth as they focused on helping their children live a happy, independent, and meaningful life. It should be noted though, that this experience is quite challenging for the mothers as they appear to struggle with their sense of responsibility and loss of world views, priorities, and relationships they hold prior to their child's diagnosis.

## 3. Critical evaluation of the research
### 3.1 Strengths

This study has drawn attention to an area where qualitative research has been sparse, and mainly undertaken by researchers from other disciplines such as sociology and nursing. Research that focuses specifically on mothers' experience has been even more limited as the majority of the studies conducted in this area have mainly focused on the family unit. This study gives voice to mothers to express their personal experience, and provides an opportunity to gain a deeper understanding of the unique challenges they face because of their identity as women and mothers. The qualitative methodology has enabled mothers to reveal, in their own words, a rich portrayal of their experiences. Therefore, the study has shed some light on how mothers see themselves, what they think and how they feel in their interactions with others, and how they compare themselves and their experience to mothers who do not parent a child diagnosed with autism.

Moreover, the cultural diversity of the sample allowed a deeper understanding of themes that are common to all mothers' experience, irrespective of their ethnic and/or cultural background. However, this could be due to the fact that all the mothers had spent most of their adult life in the United Kingdom. In addition, the homogeneity of the sample in terms of child's age, intensity of autism symptoms and marital status allows conclusions to be drawn about the effect of these variables on the mothers' experience. For example, the mild or moderate severity of autism symptoms that do not severely affect a child's everyday functioning, together with the child's age, suggest that these variables affect (to some extent) maternal ambiguity regarding a child's future prognosis and, consequently,  the way in which

mothers respond and experience this situation. For example, mothers of adults with autism might not have similar concerns.

As far as the credibility of the interpretation is concerned, it was facilitated by having two colleagues not involved in the study check the plausibility of the analysis of data, and ensure that the explanation fits the description. Moreover, attention was paid to discrepant data as the analysis maintained a balance between what was distinct to individuals and what was common to the group as a whole. The thematic analysis has highlighted the sources of maternal challenges, behavioural and emotional difficulties - reasons for which counselling might be required - and these themes have been explained and conceptualised through the framework of psychological theories in order to inform the work of professionals working with this population.

## 3.2 Limitations

In considering generalizability of these findings, it is important to take into consideration the intrinsic limitations of qualitative methods, including IPA. While qualitative methods offer depth, generalizability of the findings is not possible. The analysis is context-specific, and as such, other interpretations of the same material are possible. The researcher acknowledges that her experience as a researcher and her current professional and personal experiences could have also affected the analysis of the data.

The sample itself also prohibits the generalizability of findings as a different sample of mothers might reveal different preoccupations and concerns. For example, mothers of the present study had primary school children with mild or moderate symptoms of autism. Further, all the mothers lived with their partners. Mothers in different life circumstances might have different concerns. For example, mothers of adolescent children might have different experiences because their child goes through a transition period when individuals become more independent. Similarly, single mothers might have different concerns as a result of not having the support of a partner. Therefore, the findings of the current study might not be applicable to mothers of children with autism who are in different life situations.

Furthermore, the sample of the present study is a sample of convenience as some of the participants were recruited by a mixture of professional and personal relationships which may have introduced a systematic bias of some kind. Although other methods of recruiting

participants were also employed, the researcher heavily relied on this way due to time restrictions imposed by the requirements for completion of this research.

## 3.3 Reflections on the process of doing research

In anticipating the interviews with the mothers, I was wondering whether they would regard me as an outsider who might find it difficult to understand their situation as I am not a mother and I do not have the experience of parenting a child diagnosed with autism. I believe that this motivated me to show my participants my commitment to this area by presenting my professional background as an applied behaviour analysis (ABA) therapist. I wanted them to know that I had an understanding of what it means to interact with a child diagnosed with autism, and to express my commitment to help people with autism therapeutically. My aim was to encourage a relaxed co-operative stance for the interview, and to put participants at their ease. For this reason, I avoid the use of psychological concepts and language. I believe that the mothers engaged fully in the interview process and had the courage to share with me their difficult and painful experiences. I allowed myself to engage in the interview process not as an expert, but as a person with a genuine interest to explore with my participants the meaning of parenting a child diagnosed with autism. I felt compassion as the mothers in my study described the difficulties they encountered in day-to-day living, and their struggle to help their child in every way they could. Of course, I had some assumptions as I worked as an ABA therapist privately, but I did not have a full understanding of how difficult it is for mothers to find appropriate help and support for their children through the National Health Service. I was particularly struck by accounts of negative experiences with service providers and the lack of understanding about a child's condition.

What I can honestly say is that before conducting this research I did not really know what it means to parent a child diagnosed with autism. Although I had some thoughts about it, at the end I realised that I could not really grasp the depth of this experience, and I could not really grasp how transforming this experience was for my participants. I feel grateful for the trust these mothers showed in my research project, and in me, as this experience has truly changed my understanding of the difficulties and the benefits of parenting a child with special needs. I believe that what facilitated this understanding were both my engagement with the participants as someone who wanted to learn from them, and my engagement with the analysis of the interviews. As far as the former is concerned, my work as a counselling

psychologist helped me engage with the mothers in order to understand from them the quality of their experience and what they believe to be the sources of their difficulties.

As far as my engagement with the data is concerned, I believe that it was appropriate to select IPA as the method of analysis because it provided interesting insights about the transforming power of this experience in the way that the participants experienced themselves. Moreover, it provided understanding about the transformation of the individual's sense of self as a result of symbiotic exchange. At the same time, I am aware that by selecting this specific research question, these specific interview questions, and this specific method of analysis of data, I have actively contributed to the construction of my participants' experience. My own personal and professional experiences have shaped my epistemological assumptions, and consequently the way I have attempted to present my participants' experience. However, throughout the whole research process my commitment was to ensure the credibility of this presentation by grounding my interpretations in the data and by using techniques that will promote this.

## 4. Implications for counselling psychology

Although the current emphasis in much of the literature is on coping and resilience, it is important to acknowledge the overwhelming burden that parents are under (Brewer, Eatough, Smith, Stanley, Glendinning, & Quarrell, 2008). Throughout the present study, the mothers stressed the negative impact autism had on them, rather than the positive outcomes of their situation. This highlights the need of interventions that will empower mothers of children with autism to face the challenges of the situation. Many of the therapeutic approaches employed by counselling psychologists, like cognitive behaviour therapy, psychodynamic and humanistic approaches aim to help clients develop confidence and reach their potential.

As discussed above, not satisfying basic psychological needs results in internal disequilibrium and consequently, psychological distress. Psychological processes function to maintain an individual totality and integration of the individual into groups and cultures (Ryan, 1995). Therefore, psychologists can facilitate awareness about the sources of distress by helping clients examine in what way psychological needs are not met, and consider the ways that will empower them to develop the circumstances that will help them satisfy these needs. This objective appears to be consistent with the CBT approach which aims to help individuals, through a collaborative relationship, to acknowledge and modify maladaptive

beliefs which prevent the individual from satisfying his/her basic psychological needs and live a fulfilling life (Corey, 2001). Moreover, it appears to be consistent with person centred therapy which emphasises individuals' ability to move forward in a constructive manner if the appropriate conditions for fostering growth are present (Corey, 2001). Empowering mothers to develop the appropriate conditions to satisfy their basic psychological needs will help them resolve the disequilibrium experience as a result of revolving their life around their child's needs, and will expand their possibilities in the world.

The importance of the normalisation of the experience of parenting a child with autism has earlier been noted. Normalisation allows parents to preserve and sustain their own sense of self so their life does not revolve around autism. An insight into the meanings mothers assign to their experience can help professionals inform their practice and treatment plans. Theoretically, parents who are so preoccupied with their child's autism are unable to view their own lives as independent from their child's difficulties, and as a consequence, unable to maintain clear boundaries between themselves and their child, and preserve their own sense of self. Psychological therapy can help mothers understand the beliefs that prohibit the normalisation process, and help them adjust in a way that will enable them to reprioritise their needs. Reprioritisation of their needs will help mothers preserve their own sense of self so they do not feel restricted in the situation they experience.

Moreover, the child with autism although physically present, is psychologically different from the child mothers expected. Consequently, mothers are required to adapt to those differences on a day-to-day basis as most of the children present variability in daily functioning. Thus, as the current study has revealed, mothers can be expected to experience ambiguity and loss over many years (O'Brien, 2007). Psychological support can assist mothers in their effort to live with the emotions that often emerge at each new phase of the child's development (O'Brien, 2007). The goal of support could be to help mothers find a fit between normative development and what autism will permit at each phase of both the illness life-cycle and the child's stage of development (Brewer, Eatough, Smith, Stanley, Glendinning, & Quarrell, 2008). This will enable mothers to maintain hope and have a sense of forward momentum.

The findings of the present study highlight the importance of considering psychological interventions that will focus on mothers' needs. Clear therapeutic interventions for the child have a positive impact on mothers: all of the participants stated that having professional

support for the child facilitates coping. All the participants in the present study had support structures for their children in place, and some described the difficulties they encountered in order to get this support. However, even with support, mothers still face difficulties and find the experience of parenting a child with autism challenging. Psychological counselling can help mothers address these issues and as a consequently enhance their subjective well-being.

## 5. Suggestions for further research

Taking into consideration the fact that there are few qualitative studies on mothers who parent children with autism, it may be argued that confidence in the findings of the present study would be enhanced by additional qualitative work in this area. It would be interesting to carry out research with homogeneous groups in terms of the child's age and severity of autism symptoms in order to explore the issues that arise in different developmental phases of the child, and explore how this affects maternal well being and the meaning mothers attach to their experience. Specifically, it would be interesting to explore whether mothers of older children (adolescents or even adults) experience a loss of the child they had imagined having, as has been suggested by a number of researchers. Moreover, it would be helpful to explore whether the child's age affects the process of normalisation, and whether mothers of older children feel less ambiguous about their child's prognosis and, consequently, allow themselves to take a step back from devoting most of their time and energy to help the child progress. Furthermore, it would be interesting to carry out a study with single mothers parenting children with autism, and explore how the absence of the father in a child's care giving affects both the mothers' experiences and the issues that arise. Finally, it would be informative future studies to focus on the paternal experience of parenting a child diagnosed with autism. The researcher did not come across any studies that explore the fathers' experience of children with autism. Therefore, future studies could focus on filling that gap in the literature.

It would be interesting to research further the influence of culture in maternal experience. The sample of the present study was culturally diverse, but the findings did not suggest important differences in the mothers' experience: there was an underlying common essence in their experience. The findings of the present study appear to be different to the findings of a study conducted by Magana and Smith (2006) where it was found that Latina mothers were less likely to report negative aspects of co-residence with their adolescent or adult child diagnosed with autism than non-Latina White mothers. The authors suggested that this could be due to

cultural differences. This was not the case in the present study as all mothers, irrespective of their ethnic background, focused on the strains of parenting a child diagnosed with autism. This could be due to the fact that all the mothers were integrated in UK society as they had spent most of their adult life in this country. Nevertheless, it would be interesting if future qualitative studies were to include in-depth investigations examining cultural issues such as gender roles, religion, and cultural meanings of caring and disability.

Most of the mothers who participated in this study appeared to have linked their well-being with the child's well being. This focus affected their definition of support which was construed solely in terms of what their child needed. Only two mothers talked about the importance of having counselling for them outside the realm of seeking help for their children. Therefore, it would be interesting to survey psychologists working with mothers who parent children diagnosed with autism about the factors that motivated them to seek therapy, and the type of issues they bring to therapy. This information could help build a profile of their stressors and salient issues, and facilitate the implementation of intervention programmes that are congruent to mothers' world views and values.

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# Appendices

**Appendix 1: Interview schedule**

1. *What does the term autism means to you? How do you define it?*

2. *Can you tell me a little bit about your child's condition?*
   <u>Prompt areas:</u>
   (i)   How do they perceive child's disability: *severity-predictability-level of understanding-prospects of the child*
   (ii)  Acceptance of diagnosis.
   (iii) Feelings and thoughts about the child's special needs.

3. *On a day-to-day basis how do you experience raising your child?*
   <u>Prompt areas:</u>
   (i)   How do they receive the relationship they have with the child :*How do they engage with the child-affection toward the child-perception of closeness-how responsible they feel about the child's life-thoughts and feelings about the child's behaviour and the way they interact with the child*
   *(ii)*  Perception of parenting skills: *thoughts and feelings about the way they deal with parenting demands*
   *(iii)* Type of support they receive: *reasons they have chosen this type of support-perception of support*

4. *Has the experience of raising your child made a difference to how you see yourself?*
   <u>Prompt areas:</u>
   (i)   How do they say they have changed?
   (ii)  The role of motherhood in the definition of self
   (iii) Career
   (iv)  Leisure activities

5. *How do you see your relationship with others?*
   <u>Prompt areas:</u>
   (i)   With the other children-husband-extended family-friends-social network (thoughts-feelings)

6. *Do you think about the future much?*
   <u>Prompt areas:</u>
   (i)   Thoughts and feelings regarding future.

**Appendix 2: Demographic questionnaire**

<u>**Personal characteristics**</u>

Please answer the following questions or tick the appropriate box. The information that you give is confidential, no personal identifying information will be included in the study.

*What is your age?_____*

*What is the highest educational qualification you have completed?*

None                                            _____

GCSE(s)/O-level(s)/CSE(s)        _____

A-level(s)                                     _____

Diploma (HND, SRN, etc)          _____

Degree                                          _____

Postgraduate degree/diploma      _____

*Are you employed?*

Yes, full-time        _____

Yes, part-time       _____

No                          _____

*Number of children in the family?_____*

*Ethnic origin?_____*

<div align="center">**Appendix 3: Information sheet**</div>

**<u>Information Sheet</u>**

My name is Kalliopi Vounisea and I am conducting a research for my Doctorate in Counselling Psychology at City University. The research has been approved by City University and is supervised by Dr. Paul Holland.
This leaflet explains why the research is being done and what it will involve. This will assist you in deciding whether or not you wish to take part. Please take time to read the following information carefully.

*What is the purpose of the study?*
The aim of the research is to explore the maternal experience of raising a child diagnosed with autism. We hope that the findings will be used to improve and develop effective interventions and support systems for mothers raising a child diagnosed with autism. If you would like to be sent a summary of the findings, please write your e-mail or name and address on the consent form.

*Do I have to take part?*
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason.

*What will I have to do?*
If you would like to be involved in the research, you will need to participate in an interview lasting approximately one hour. That will be tape recorded on a voice recorder. During the interview the researcher will also keep brief notes as part of the process. Moreover, you will be asked to complete a brief form on personal characteristics.

*Will my taking part in this study be kept confidential?*
Yes, anonymity will be ensured since the interviews will be recorded and later on transcribed for the purposes of the research project. All your information will be stored in a locked location. Moreover, no personal characteristics will be attached to the transcripts of the interviews or on the notes. The tape recorded interviews, the transcripts, the notes, the form on personal characteristics, and the consent form will be kept in a locked location for 12 months and will be used only for the purposes of the present study. After that they will be destroyed.

*What will happen to the results of the research study?*
Our aim is that the results of this study are included as part of a thesis and/or published in a scientific journal. Your name or any other identifying information will not be mentioned in any of these documents.

**If you would like further information about the study please contact:**
Kalliopi Vounisea- Counselling Psychologist in Training– City University
Tel: 07910314730
E-mail: calliopev@gmail.com

Supervisor's contact details: Dr. Paul Holland, School of Social Sciences, City University, Northampton Square, EC1V 0HB or on 020 7040 0173, or at <u>Paul.Holland.1@city.ac.uk</u>.

**Information Sheet**

My name is Kalliopi Vounisea and I am conducting a research for my Doctorate in Counselling Psychology at City University. The research has been approved by City University and is supervised by Dr. Paul Holland.
This leaflet explains why the research is being done and what it will involve. This will assist you in deciding whether or not you wish to take part. Please take time to read the following information carefully.

*What is the purpose of the study?*
The aim of the research is to explore the maternal experience of raising a child diagnosed with autism. My aspiration is to conduct a valuable piece of research that would explore the experiences of mothers that raise a child diagnosed with autism. The aim of my study is to explore the thoughts and feelings of mothers parenting a child diagnosed with autism, thereby getting a better understanding of the mothers' needs in order to improve and develop effective interventions and support systems for them. If you would like to be sent a summary of the findings, please write your e-mail or name and address on the consent form.

*Do I have to take part?*
No. It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. If during the course of the interview, you feel uncomfortable about any questions that are asked of you, you can refuse to answer at any time during the interview or ask the interview to stop. You can withdraw at any time and without giving a reason.

*What will I have to do?*
If you would like to be involved in the research, you will need to participate in an e-mail interview. Before participating in the e-mail interview the researcher will post you a consent form. You will need to sign and send back to the researcher the consent form before starting the e-mail interview itself. After agreeing to participate in the study the researcher will e-mail you the interview questions and it would be helpful your answers to be as detailed as possible. The researcher will then get back to you for further clarifications. Moreover, you will be asked to complete a brief form on personal characteristics.

*Will my taking part in this study be kept confidential?*
Yes, anonymity will be ensured since the e-mail interviews will be transferred to a word document where no personal characteristics will be attached. The e-mail will be deleted as soon as the researcher receives it and she will transfer the data to the word document and no personal characteristics will be attached to the document. All your information will be stored in a locked location and only the researcher will have access to them. The transcripts of the interviews, the form on personal characteristics, and the consent form will be kept in a locked location for 12 months and will be used only for the purposes of the present study. After that they will be destroyed.

*What will happen to the results of the research study?*
Our aim is that the results of this study are included as part of a thesis and/or published in a scientific journal. Your name or any other identifying information will not be mentioned in any of these documents.

**If you would like further information about the study please contact:**
Kalliopi Vounisea- Counselling Psychologist in Training– City University
Tel: 07910314730
E-mail: calliopev@gmail.com

Supervisor's contact details: Dr. Paul Holland, School of Social Sciences, City University,
Northampton Square, EC1V 0HB or on 020 7040 0173, or at Paul.Holland.1@city.ac.uk.

***Thank you for taking the time to read this leaflet.***

**Appendix 5: Consent form**

<u>**Consent Form**</u>

Dear Participant,

Thank you for agreeing to contribute to this research project that aims to explore the experience of being a mother raising a child diagnosed with autism.

By signing this consent form you agree on the following:
- I confirm that I have read and understood the information sheet for the above study.
- I understand that my participation is voluntary and that I am free to withdraw at any time without needing to give any reason.
- I understand that the interview would be approximately one hour long.
- I consent to the fact that the interviews will be recorded on a voice recorder for the research purposes and that I can request the taping to cease at any time.
- I consent to the fact that the researcher will keep notes during the interview and that I can request her to stop doing so at any time.
- I understand that my name will not be attached to the transcripts of the digital tape recorded interviews, on the sheet of personal characteristics or the notes kept by the researcher during the interview.

Thank you again for agreeing to participate. Please don't hesitate to contact me or my research supervisor should you have any further enquiries.

-------------------------------------------      -----------------      ------------------
Name of participant                                   Date                        Signature

-------------------------------------------      -----------------      ------------------
Name of researcher                                   Date                        Signature

**Request for summary of the findings (optional)**

**Please tick box**

I would like to receive a copy of a summary of the research findings          ☐

at either my e-mail address: _____

or my postal address: _____

_____

*Thank you very much for agreeing to take part to this study*

**Appendix 6: Consent form for email interview**

Dear Participant,

Thank you for agreeing to contribute to this research project that aims to explore the experience of being a mother raising a child diagnosed with autism.

By signing this consent form you agree on the following:

- I confirm that I have read and understood the information sheet for the above study.

- I understand that my participation is voluntary and that I am free to withdraw at any time without needing to give any reason.

- I understand that the e-mail interview will start after the researcher has received the present consent form signed by me.

- I understand that my answers should be as detailed as possible.

- I consent to the fact that the researcher will e-mail me back for further clarifications and questions based on my answers.

- I understand that anonymity will be ensured as the researcher will delete my e-mail as soon as she receives it and she will transfer the interview transcript to a word document where no personal characteristics will be attached. I understand that the transcripts of the interviews, the form on personal characteristics, and the consent form will be kept in a locked location for 12 months and will be used only for the purposes of the present study. After that they will be destroyed.

Thank you again for agreeing to participate. Please don't hesitate to contact me or my research supervisor should you have any further enquiries.

---------------------------------------------        ----------------        ------------------
Name of participant                              Date                  Signature

---------------------------------------------        ----------------        ------------------
Name of researcher                              Date                  Signature

**Request for summary of the findings (optional)**

**Please tick box**

I would like to receive a copy of a summary of the research findings       ☐
at either my e-mail address: _____

or my postal address:  _____

_____

*Thank you very much for agreeing to take part to this study*

**Appendix 7: Debriefing External Agencies**

- **Hoffmann, Foundation for Autism**
  4th floor Cumberland House
  80 Scrubs Lane, London, NW10 6RF
  Tel: 020 89646650


- **The National Autistic Society**
  393 City Road
  London, EC1V 1NG
  Tel: 020 78332299


- **The National Autistic Society**
  Diamonds Business Centre,
  Attley Way, Nene Park, Irthlingborough,
  Northants, NN9 5GF.


- **Autism.West Midlands**
  18 Highfield Road
  Edgbaston
  Birmingham, B15 3DU
  Tel: 0121 450 7582


- **National Autistic Society Scotland**
  Fairways House
  Fairways Business Park
  Castle Heather
  Inverness IV2 6AA
  Scotland
  Tel: 01463 258 802

**Appendix 8: Summary of demographic information**

**Age**

35-40  5

40-45  3

**Number of children in the family**

Two children   7

Three children 1

**Number of children with autism in the family**

One child        6

Two children   2

**Ethnic background**

2        British white

4        Indian

1        French

1        Mixed race: Half White British, half Iraqi

**Educational background**

GCSE(s)/O-level(s)/CSE(s)   1

A-level(s)                    1

Diploma (HND, SRN, etc)    1

Degree                        1

Postgraduate degree/diploma 4

**Occupational background**

Full-time              1

Part-time              4

No employment

**Helping Anna to deal with the loss of her mother: Considering the role of working alliance on therapeutic outcome**

## 1. Introduction and selection of case

This client study aims to examine the impact of working alliance on the therapeutic outcome. I applied Cognitive Behaviour Therapy (CBT) in the work I did with a client who, after the death of her mother acquired a new role, that of being the primary caregiver of her younger brother. My client had difficulty to adjust to her new identity as she was not feeling confident and supported in her new role. This contributed to behavioural and emotional difficulties and activated dysfunctional beliefs related to self worth. At the assessment session it was apparent that Anna[1] found the cognitive rationale to be compatible with her way of thinking; she was able to identify negative automatic thoughts, she was aware of her emotions and she could differentiate them. Moreover, she expressed a general optimism about therapy. Her problems were of acute nature and she had the ability to remain focused on a particular problem. According to Curven, Palmer & Ruddell (2005) these factors need to be present, in order for brief CBT to be suitable for a client. According to Curven, Palmer & Ruddell (2005) other essential factors include: acceptance of personal responsibility for change, alliance potential (in-session and out-of-session evidence), and being free from behaviours (i.e. avoidances or excesses) that preserve a sense of security but which are counterproductive to the client's well being and to the therapy itself.

On subsequent sessions I realised that there was a difficulty to formulate a good working alliance with Anna. This was a very challenging case for me, as it triggered me to consider how client's dysfunctional thinking and my own therapeutic style can affect the development of the working alliance and how this can affect the therapeutic outcome. I learned a lot about myself as a therapist; I understood the importance of lexibly reconsidering the content and the process of the therapeutic encounter so to adjust it to clients' needs. Although in the beginning it was difficult to formulate a good therapeutic relationship, gradually we managed to work through this issue and to achieve a good therapeutic outcome.

---

[1] For the purpose of confidentiality, the client's name has been changed.

## 2. Theoretical orientation

According to Cognitive Theory, the way people interpret the events they encounter determines the way they feel and behave. Emotional and behavioural disturbances are due to faulty processing and interpretation of information. Information processing is based on fundamental beliefs stored in schemata. The content of a schema is reflected on automatic thoughts (Nelson-Jones, 1995). Self-Schemata contain information about the way one evaluates him/herself as well as feelings of satisfaction or dissatisfaction. An individual evaluates him/herself (self-esteem) by comparing his/her success and his/her pretensions (Papakostas, 1994).

When it comes to problems that originate from negative self-concept, CBT acknowledges that it is central to emotional disorders. Fennel (1997) has proposed a CBT model that synthesises cognitive therapy for anxiety and depression, and schema-focused cognitive therapy. According to this model, emphasis should be placed on helping the client understand these beliefs in a historical context. Moreover, the therapist should help the client identify, re-evaluate and challenge negative predictions and interpretations so to decrease anxiety and depression symptoms. Depending on the case, elements of schema-focused cognitive therapy can be applied when it is needed to place more emphasis on the past, the therapeutic relationship, or non-verbal methods of working.

## 3. Context and referral

Anna was referred by her GP to an in-house counselling psychology service in an NHS Primary Care Setting. The practice offers free, confidential, brief CBT (limited to 12 sessions) to adults. On the referral it was stated that she is feeling stressed after the death of her mother because she has to raise her young brother on her own. Anna was in a waiting list for individual treatment for 1 month.

## 4. Profile of client

### 4.1 Appearance and behaviour

Anna was on time for her first appointment. She was casually dressed. In the beginning of the session Anna appeared feeling uncomfortable, she seated herself in a rather closed body position, with her arms closed and she was looking at the floor. However, she became more relaxed throughout the session and the conversation flowed increasingly freely. Anna was

able to clearly describe her thoughts and to set clear goals about what she wanted to change in her life.

## 4.2 Biographical details

Anna is a 20-year-old woman. She originates from a Caribbean island but she was born and raised in the United Kingdom. Her mother died from cancer about nine months ago. Anna mentioned that they had a very good relationship and that she was the only person she could trust. Her father died when Anna was 6 years old. Anna did not grieve over her father's death as her mother asked her to be strong and move on. Her mother got married again when Anna was 9 years old and had a son with her new husband. Following her mother's death, Anna raises her 7-year-old brother mostly on her own but with some help from some friends of her mother and her extended family. Anna does not have a good relationship with her step-father and she does not want him to have any contact with her brother. Anna's step-father is threatening to take legal action. Her extended family lives at the outskirts of London. She communicates with them on a regular basis and they visit each other occasionally. Anna is studying law, she receives state benefits for raising her young brother on her own and at the same time she has a part-time job. She is in a relationship over the past year and she has one close friend.

## 4.3 Presenting problem

Anna stated that she decided to seek counselling because the experience of bringing up her brother is overwhelming; she has many responsibilities and she has to change her life style in order to meet her brother's needs. Friends and her extended family provide some practical support and advice yet Anna often feels that she is criticised for the way she is raising her brother. Moreover, she perceives this support as being inadequate and she feels that they can not understand her needs. Anna's mood is low, she is often tearful, she does not have the motivation to attend university lessons, she does not socialise with her friends regularly, and she has sleep problems. Anna stated that she has not grieved over her mother's death and that she does not plan to do so because emotions are pointless and would prohibit her from moving on.

**5. Case Formulation**

**5.1 Cognitive behavioural profile**

**5.1.1 Core beliefs, intermediate beliefs, negative automatic thoughts**

It seemed that in order to manage this situation Anna activated the rule: "I should be strong and independent at all times". Failure to live her life according to this rule activates a core belief of self worth and Anna thinks of herself as being a failure. This interaction between the core belief related to self worth and the rule that she must be strong at all times led to the development of the following assumptions: "If I am not strong and independent, then I am a failure" and "If something goes wrong, then it is my fault". Anna's Negative Automatic Thoughts (NATs) demonstrated the content of these underlying and intermediate beliefs in the form of the cognitive distortions of "all or nothing thinking" ("I am not raising my brother as good as my mother did. I am not a good mother. I have failed") and "personalisation and blame" ("My brother didn't want to get dressed this morning and he was late for school and it is my fault").

As far as her relationship with others is concerned, Anna seemed to have a core belief that other people are critical and rejecting. As a consequence, it seemed that Anna had developed the assumptions that "If I ask people to help me, then they will criticise me" and "if I ask for help, then they will see me as a burden". It seemed that the interaction between the rule of "I should be strong and independent" and her attitude towards other people led to the development of another rule: "I should not need other people". Anna's NATs demonstrated the content of these underlying and intermediate beliefs in the form of cognitive distortion of "jumping to conclusions" ("my boyfriend cancelled the excursion we had arranged so he doesn't care about me", "my friends didn't call me to go out on Friday night because I'm a burden to them", "my brother hates me because I'm not doing things right").

**5.1.2 Behavioural factors**

Anna engaged in frequent arguments with her brother as well as the people in her close environment and was socially withdrawn.

### 5.1.3 Emotional factors

Anna experienced intense feelings of anxiety and sadness in response to her perception of being inadequate. Anna experienced feelings of anger and guilt when she perceived her close environment being judgmental and rejecting.

### 5.1.4 Motivational factors

Anna exhibited loss of interest in her studies; she did not attend university lectures and procrastinated carrying out her educational tasks.

### 5.1.5 Cognitive factors

Anna kept ruminating about the things she believed she did not do right. Her concentration was poor and as a consequence she could not study.

### 5.1.6 Somatic symptoms

Anna had sleep disturbances as she could not sleep at nights and she tended to wake up in the middle of the night.

### 5.2 Problem Formulation

The death of her mother forced Anna to face a challenging situation: she now had parental responsibilities and at the same time she had to meet her professional and educational responsibilities. It seemed that Anna was highly critical with herself. She kept blaming herself for things that went wrong and labelling herself in a negative way. She kept forgetting of all the things she achieved to carry out on a daily basis. Research on clinical practice has shown that these are behaviours and attitudes found in people that are self-critical. According to McKay & Fanning (1992) people high in self-criticism tend to view themselves as failures and fear of being disapproved, criticised or rejected. According to Lundh (2004) self criticism is associated with low unconditional self acceptance which has been found to be associated with depression, anxiety, high reactivity to negative feedback, low self-esteem and low objective personal performance evaluation.

Moreover, this challenging situation seemed to have activated Anna's core belief that other people are critical and rejecting. As a consequence, she was angry with her close environment and often engaged in arguments. Research has shown that people high in rejection sensitivity perceive rejection in ambiguous cues and react automatically and strongly to threat related

cues at the expense of more cognitive and contemplative responses (Ayduk et al., 2000). Anna was also feeling guilty because she believed that she is restricting other people's lives. As a consequence, she isolated herself socially. It seemed that Anna had difficulty to assertively communicate her needs and wants. Gilbert and Irons (2005) argue that people who have fear of rejection or criticism may adopt perfectionistic attitudes so to have control and defend themselves against fears of inferiority. Therefore, it can be hypothesised that Anna's need to appear strong and competent prohibited her from revealing her doubts and concerns about her ability to cope with the demands of her new reality.

Anna had to face several losses, actual and symbolic; the loss of her mother, the loss of her previous life style, the loss of her identity, the loss of safety. According to Sanders (1989) the death of a parent in early adulthood leaves the survivor with the realization that she now must fend for herself. Social-cognitive theories of adjustment (Epstein, 1973 & Jannof-Bulman, 1992) suggest that in order to adjust to a loss it is important the individual to make meaning of the loss because this helps to maintain two aspects of our sense of self that are most threatened by loss: our sense of self worth and our fundamental beliefs about how the world works. It appeared that Anna had a difficulty to adjust to the loss as she did not allow her self to think about it, because this would make her feel emotional and as a consequence she would not be strong to support both herself and her brother. Therefore, in order to bring some predictability and structure in her life she activated the rule that she should be strong at all times and able to move on with her life. Anna's perception of feelings as a form of weakness suggests that she repressed the painful loss feelings in order to adapt to the new reality. Anna tried to block her feelings by avoiding thinking about her mothers' death. According to Raphael (1984) the bereaved may feel that survival is impossible without the deceased and that the pain is too great to be tolerated. As a consequence, the bereaved might rely on behaviours that aim to shut out the pain of loss.

## 5.3 Contract and therapeutic aims

It was agreed to meet on a weekly basis, for the twelve hour-long sessions that are allowed within the counselling service. In the first session, information was provided and confidentiality was explained in terms of self-harm, the risk of harming others, supervision, and correspondence with Anna's GP. Anna requested to receive some help that would help her deal with sleep problems and to overcome her difficulty to attend university lectures.

Therefore, it was agreed to work on sleep disturbances and motivation issues within the CBT framework description of which was provided.

## 6. Development of therapy

### 6.1 The therapeutic plan

Sleep disturbances have been found to be a symptom of anxiety (Morin, Belanger, & Fortier-Brochu, 2006) and low mood (Tower, Casey, & Dryden, 1988). Moreover, sleep disturbances have been found to lead to lower levels of performance, memory, and cognitive ability as well as increased levels of anxiety and decreased levels of well-being (Word, 2007). Therefore, it was reasoned that the goal of counselling would be to help Anna understand how anxiety and low mood affect her sleeping patterns and vice versa and to help her manage these difficult emotions. As far as motivational issues are concerned, Clark (1992) argues that avoiding the stressful situation decreases the emotional disturbances in the short term but does not solve the problem in the long-term. Therefore, the aim of the treatment plan was to help Anna understand how stress and sadness affect her motivation to attend university lectures. By taking under consideration Anna's emotional and behavioural difficulties, the treatment goals she set, and the literature suggestion regarding the therapeutic approaches that can successfully address these difficulties, it was decided to work through the CBT framework which has been found to be suitable for the treatment of mood disturbances (Clark, 1992; Tower, Casey, & Dryden, 1988).

### 6.2 Key content issues-Main techniques used

Anna was asked to keep an anxiety diary where she would record and rate her anxiety on an hourly basis. Moreover she was asked to record the event that was associated with anxiety and what she was thinking at that time. The goal was first to assess whether and how much Anna was worrying before going to bed and if this was the case to help her see the connection. The second aim was to identify the thoughts that cause anxiety and low mood and to help Anna challenge them. One of the behavioural interventions that were discussed was that of the "worrying time". Additionally, distraction techniques and breathing exercises were introduced in order to help Anna prevent from worrying. Anna was very collaborative and actively tried to apply this behavioural intervention.

During the discussions we had, it seemed that Anna believed she has little control over her life; she believed that nothing will ever change. It seemed that this belief contributed to

feelings of low mood and anxiety. According to Seligman (1975) perceiving a situation as uncontrollable can affect an individual's motivation to attempt change. It is the expectation and not the objective conditions of controllability that determine the emotional difficulties (Seligman, 1975). As a consequence, focus was placed on encouraging Anna to increase her awareness about the level of control she had over the situation by getting her to consider alternative options (i.e. to let her step-father raise her brother or to ask her grandparents form her father's side to help her).

Great focus of our work was also placed on self-criticism, which seemed to be a factor that greatly contributed to Anna's difficulties. Whenever the downward arrow technique was employed, the belief that Anna perceived herself as a failure was always revealed. The goal was to make Anna aware of the occasions she was talking to herself in a negative way and to try to challenge it. This was achieved by encouraging Anna to keep thought records of NATs. Moreover, she was encouraged to make a list of her achievements so to test the validity of her self-critical thoughts. Finally, assertiveness training was employed in order to help Anna communicate in an assertive way with the people in her close environment and not to engage in arguments.

At the 10<sup>th</sup> session, Anna had to attend a ceremony for the first anniversary of her mother's death. This was a very difficult experience and she was overwhelmed with painful feelings of loss. It was agreed to extend the therapy for four more sessions (Anna attended 16 sessions in total) in order to help Anna manage this stressful experience. During these sessions enough space was provided to Anna in order for her to come in touch with thoughts and feelings she was trying to block for about a year. Anna was sad of losing her mother and at the same time angry with her for leaving her alone to carry out the difficult task of caring for her brother and for having to change her sense of identity in a way that was not desired. Furthermore, it was revealed that much of the self criticism was triggered from unfavourable comparisons between her and her mother in regards to care-giving abilities. We used this new material to further address the self-criticism issues. Moreover, in order to help Anna adjust to the new reality, it was suggested to introduce in her daily schedule meaningful activities she used to enjoy before the death of her mother.

**6.3. Pattern of therapy-The therapeutic process and changes over time**

Anna was always on time for her counselling appointments and never missed or cancelled an appointment. Anna was quite responsive to the behavioural interventions that were

introduced to her in the beginning sessions; however, it seemed that her attitude was not the same to cognitive interventions related to issues around controllability. During the first three sessions after the initial assessment, Anna seemed to have an argumentative attitude; she would talk to me in a quite annoyed way, she would made facial expressions to show her disapproval to my attempts to challenge dysfunctional beliefs, and she would counter my suggestions with a yes-but response. Hovarth & Greenberg (1989) argue that agreement and willingness to collaborate and work on a common goal are essential components for the establishment of a therapeutic relationship. However, in the beginning our therapeutic relationship was not characterised by these factors.

Yalom (2001) suggests that referring to the immediate events of the therapeutic hour (Here-and-Now) can facilitate the therapeutic process and the therapeutic relationship and can help the client understand the way she interacts with others. Comments on Here-and-Now issues should describe how the therapist feels and not what the client is doing. I tried to deal with the difficulty to establish a therapeutic relationship by reflecting back to Anna my thoughts about the therapeutic process and how I felt in that situation. I tried to explore her thoughts regarding my cognitive interventions and it was revealed that Anna felt that she was not understood. I explained to Anna the rationale behind my interventions and my intentions. Then we tried to consider other settings where she did not feel understood and we tried to compare them to the current situation. This discussion revealed that thoughts related to low self-worth greatly affected her interaction with other people and her perceived sense of control over the situation. Therefore, we both agreed the focus of our work to be on low self-esteem issues. Fennell (1997) argues that self criticism is considered to be a major factor in the development of emotional difficulties. This session with Anna helped me realised that I undermined the importance and contribution of self-criticism to her behavioural difficulties.

This intervention helped us develop a strong therapeutic relationship. It helped me consider the way I expressed my empathic reaction to Anna's difficulties and consider re-prioritising the focus of my cognitive interventions. Furthermore, it helped Anna to fully engage in the therapeutic process and to work well within the CBT framework. She was keeping thought records where she reported the occasions she was self-critical or the occasions she felt rejected and criticized. Moreover, she actively tried, in the session and out of the session, to challenge these difficult thoughts.

I hypothesised that Anna's engagement in the therapeutic work was a sign of a well-functioning working relationship between us. It showed me that the tasks were relevant and efficacious for achieving the goals of therapy. When Anna shared with me the difficult emotions related to her mother's death, I felt that we had managed to create a strong therapeutic relationship. According to Roth & Fonagy (1996) the therapist should offer to the client emotional availability, a comforting presence, affect regulation, and a secure base from which to explore inner and outer world. It appeared that our therapeutic relationship allowed Anna to explore the difficult issues related to her mother's death as she was able to share with me and later on with her close friends the painful emotions of loss.

## 6.4 Difficulties in the work and use of supervision

One of my major difficulties with my work with Anna was in the beginning of the therapy sessions and when I had to deal with her argumentative attitude. I felt that I had to fight in order to make my point across. Gradually, I felt losing my confidence in the sessions. Walen, DiGiuseppe and Dryden (1992) suggest that in similar occasions, the therapist can either not try for an entire session to convince the client of anything or agree with the client in order to work on client's resistance. However, I felt that if I relied on a set of techniques to work on the difficulties I experienced in my interaction with Anna, this would not address the process of therapy as it has been defined by Yalom (2001), meaning the nature of relationship between the individuals who express the words and concepts. I considered that by referring to the Here-and-Now would help us explore both my and client's contribution in the development of this relationship. I discussed these difficulties with my supervisor and considered with him the appropriateness of addressing the therapeutic process and he greatly encouraged me to do so. He emphasised that this would facilitate the development of a therapeutic relationship and that this would make the process more transparent to the client. This would help the client understand my efforts to be helpful to her and consider what could change so counselling to be a positive and effective experience.

Anna mentioned that she felt that she was not understood so this triggered me to consider my empathic response towards her. Thorne & Lambers (1998) define empathic relationship as one in which the client feels understood and accepted. The role of empathy in CBT is somehow controversial, Beck and his collaborators (1979) have argued that although a therapeutic relationship is desirable, at the same time it is not necessary for therapeutic change. However, it was clear to me that in this case the absence of an empathetic

relationship prohibited Anna's engagement. Therefore, I considered that by exploring together the nature of our interaction would help us understand what could change so Anna to get the most of the counselling experience and work on her difficulties.

My supervisor greatly emphasised the importance of acknowledging the very difficult situation Anna was facing and explicitly communicating that to her. In addition he suggested that it was important to acknowledge and communicate to Anna how things can become more difficult when she is harsh to herself. This could contribute in helping the client feeling understood and accepted. Moreover, it was considered how I could formulate the treatment plan in a way that I would empower my client. Therefore, it was suggested to focus on helping the client build a stronger sense of self by addressing self criticism issues and by enabling her to engage in supportive relationships.

## 7. The therapeutic ending and evaluation of the work

CBT made perfect sense to Anna and after some sessions she very accurately assessed the occasions she was self-critical and challenged these thoughts. Gradually, Anna managed to control anxiety and anger and to consider practical solutions in a difficult situation.

I believe that another demonstration of the positive impact of CBT was when Anna felt safe to acknowledge and emotionally express in the session the impact her mother's death had on her. After that Anna shared these difficult thoughts and feelings with a few very close friends without worrying whether she would be judged. Anna described this experience as liberating. It seemed that Anna had managed to challenge to some extend the perception that other people are critical and rejecting. We had built a strong working alliance which had a positive impact on the CBT work and on the therapeutic outcome. I believe that the success of the CBT interventions further enhanced Anna's trust on therapy and the outcome was to relate with me and with other people in her close environment without the fear of rejection.

### 7.1 Learning about psychotherapeutic practice and theory

The role of therapeutic empathy in CBT is somewhat controversial. Carl Rogers (1957) suggested that an empathetic relationship is a necessary and sufficient condition for therapeutic change. However, Beck and his collaborators (1979) have argued that a good therapeutic relationship is necessary but is not a sufficient condition for change. Recently, several researchers have attempted to examine the relationship between therapeutic alliance and CBT outcome. Rector, Zuroff and Segal (1999) found that agreement on goals and tasks

predicted change in dysfunctional beliefs. This finding implies that therapeutic alliance can be necessary for therapeutic change.

My experience in this case led me to hypothesise that working alliance is a necessary factor for therapeutic change. A therapist should be aware both of the content and the process of the therapeutic encounter as any obstacles in these domains can threaten the development of therapeutic alliance. Therefore, a therapist should critically consider what needs to change in these areas and communicate that to the client with honesty and empathy. In this particular case it appeared that Anna's negative models of herself and others affected negatively her response to my cognitive interventions. Brennan and Bosson (1998) argue that the client's difficulty to be open to feedback seem to have implications with the therapeutic process. Therefore, in order to establish a strong working alliance, it was crucial for me to reconsider and adjust therapeutic interventions in a way that would not make the client feel threatened and misunderstood by the therapist.

## 7.2 Learning about myself as a therapist

While working with Anna I realised the importance of listening and acting upon client feedback. Anna was trying to communicate with her attitude some information both about me and about herself. I tried to use supervision in order to increase my awareness about what was the therapeutic content and reconsider what needed to be changed. Moreover, and again with the help of supervision, I went back to my client and tried to explore with her what was going on in the process. This collaborative interaction helped me understand better my client and to develop with her a good therapeutic alliance. Moreover, it helped my client understand better how she interacts with other people.

This case helped me realise that it is important to change the therapeutic style in order to suit client's needs when difficulties arise. In the Primary Care context the number of sessions is limited, so there is a need to try to achieve some change within a short amount of time. I experienced an urge to try to be actively helpful for Anna. I could see that she was going through a very demanding phase and I wanted to help her to manage this situation as soon as possible. The core work of CBT is cognitive restructuring and it is considered to be a necessary factor for therapeutic change (Papakostas, 1994). So, I believe that I probably rushed into cognitive challenging without placing enough emphasis on empathetic responses. Finally, I realised that when working with a client that goes through a big life change that forces her to change her sense of self in a way that is not desirable, it is beneficial to give to

the client the space to explore and understand how her beliefs about this change contribute to emotional and behavioural difficulties. This can be facilitated by using Socratic questioning in order to help the client develop a better awareness and acceptance of the new reality she experiences.

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**A counselling psychology perspective on working alliance: Considering the challenges that therapists face in developing strong working alliances with their clients through the framework of Bowlby's attachment theory**

## 1. Overview

Research has shown that working alliance is an important component of the therapeutic process as it appears to be an intermediate criterion of positive therapeutic outcomes (Kivlighan, Patton, & Foote, 1998; Satterfield & Lyddon, 1998). Several studies have shown that the interpersonal characteristics of both the therapist and the client appear to play an important role in the development of the therapeutic alliance (Black, Hardy, Turpin, & Parry, 2005; Fitzpatrick, Janzen, Chamodraka, & Park, 2006). A number of researchers have considered Bowlby's attachment theory to be a useful framework for understanding the role of clients' and therapists' interpersonal characteristics in the development of the working alliance. These studies have mainly focused on examining whether and how the clients' and therapists' attachments style affect the development of the working alliance.

The purpose of the present critical literature review is to focus on the challenges that therapists face in developing strong working alliances with their clients and examines them through the framework of Bowlby's attachment theory. The aim of the present critical literature review is to answer the following questions: What is the impact of clients' and therapists' attachment style on the development of the working alliance and consequently on the treatment outcomes? Is there a preferable combination of therapists' and clients' attachment style that will foster better therapeutic outcomes? This review is selective and makes no claim of being exhaustive. It will be presented in several different sections. Initially the concept of working alliance will be discussed and a number of studies that have examined working alliance will be presented. Then Bowlby's attachment theory will be presented and research that has examined attachment style across life span will be discussed. The review will close with the discussion of a number of studies that have examined how clients' and therapists' attachment style affect the development of working alliance and therapeutic outcomes.

## 2. Working alliance

According to Roth and Fonagy (1996) it was Freud who first highlighted the importance of the agreement between the analyst and the patient, which creates an alliance with a common goal, based on the demands of the external reality. The term therapeutic alliance was invented by Zetzel, who argued that, in order therapy to be successful, the therapist and the client need to make a conscious collaborative and rational agreement (Roth & Fonagy, 1996). Hovarth (1993) distinguishes three aspects of therapeutic alliance from a pantheoretical point of view: (1) client's perception of the relevance and the potency of the interventions offered, (2) client's agreement with the therapist on reasonable and important expectations of the therapy in the short and medium term, and (3) a cognitive and affective component, which is based on the client's ability to form a personal bond with the therapist and the therapist's ability to present himself or herself as a caring, sensitive, and sympathetic helping figure.

The development of working alliance between the therapist and the client is considered to be an important component of the counseling process (Satterfield & Lyddon, 1998). Working alliance has been viewed as a kind of intermediate criterion of counselling effectiveness (Kivlighan, Patton, & Foote, 1998). Several studies have reported quite strong associations, with the working alliance counting for up to 30%-45% of the variance in therapeutic outcome (Mallinckrodt, 1991). A meta-analysis of 24 studies contacted by Horvath and Symonds (1991) reported a more modest but nevertheless significant effect size.

The majority of the research on working alliance has been focused on the therapist's responses to clients based on the therapist's competence and her/his reliance on the therapeutic orientation that she/he employs.

Mallinckrodt and Nelson (1991) examined three groups of therapists (novices, advanced trainees, and experienced therapists) and their ability to form therapeutic alliance. The results indicated that there were great differences in the goal component of the working alliance, somewhat smaller but still great differences in the task component and no differences in the bond component of the working alliance. A possible explanation for this outcome could be the emphasis that is given during the training of novice therapists on rapport building, empathy skills and reflective listening. Although a strong emotional bond is the prerequisite for successful completion of tasks and goals, the last two components of working alliance are necessary for a successful therapy outcome. Therefore, it can be hypothesised that novice therapists are able to meet the prerequisites but are less able to set treatment goals or perform

in session tasks to achieve these goals. In a similar vein, Mohr, Gelso, and Hill (2005) have suggested that perhaps experienced therapists are more able to identify internal and external triggers to countertherapeutic behaviour and therefore may have a better ability to form strong working alliances.

Dunkle and Friedlander (1996) have also examined the relationship between therapist's experience and his/her ability to form strong working alliances. The results of this study were in agreement with the results of the Mallinckrodt and Nelson (1991) study as far as the relationship between the bond component of working alliance and therapist's experience is concerned. Specifically, it was found that experience does not relate with the therapist's ability to form warm and affectionate relationships with their clients. However, the results of this study indicated that the therapist's ability to negotiate goals and tasks was also irrelevant to his/her experience. Authors interpret this discrepancy of the results to the differences of the samples of the two studies. The sample of Dunkle and Friedlander study was less homogeneous compared to the sample of Mallinckrodt and Nelson study (1991) and therefore more representative.

The discrepancy in the results of these studies suggest that future study could focus on examining whether or not experienced therapists have this ability and whether this ability is present to novice therapists.

A problem that is important with studies that attempt to examine the relationship between therapists' experience and their ability to form productive working alliances is the difficulty to define the term experience. Beutler (1997) argued that the passage of time is an acceptable measure of experience, only if what happens within any period of time is the same for all the participants that belong to the same group and the nature of the events during the passage of time is relevant to the type of activities designed to be reflected in the index by the research objectives. The concentration of relevant activities within the time frame is necessary to assume that experience has occurred. For example, national survey that took place in the United States of America revealed very widely dispersed concentrations of time spent in activities as wide ranging as teaching, consultation, individual psychotherapy, and the like.

According to Beutler (1997) another measure of experience is the nature of the patient population with whom the practitioner works. She further suggested that there is evidence to indicate that improvement is associated with the level of therapist experience when this experience is defined in terms of specific exposures to and compliance with structured

training methods. Finally, she emphasised that experience and training are of little consequence, without knowing for which patients experience-based skill is necessary. Thus, it is critical to assess and understand the role of patient variables in determining the effects of specific and different types and amounts of therapist experience. The majority of the studies that have been conducted so far mainly measure experience according to the number of years a therapist has graduated from a training institution and fail to take under consideration Beutler's suggestion about the operationalisation of experience. Therefore, it is not possible to conclude whether experience has indeed an effect or not in a therapist's ability to form strong working alliances.

As far the type of treatment a therapist is employing and its relationship with alliance is concerned, research suggests that alliance is significantly predictive in the majority of the therapies (Hoverth & Greenberg, 1994). In a study by Black, Hardy, Turpin, and Glenys (2005), the relationship between the therapeutic orientation, the evaluation of the therapeutic alliance and the frequency of reported problems in therapy was examined. It was found that psychodynamic therapists had the lowest self-reported alliance score and Cognitive Behaviour therapists had the highest. The authors proposed a number of possible explanations for that result including the way the theoretical model informs the therapist for his evaluation of the therapeutic alliance. It was also suggested that the quality of the working alliance might be different within the therapeutic groups.

Agnew-Davis, Stiles, Hardy, Barkham, and Shapiro (1998) found that psychodynamic orientation predicted a less positive alliance compared to other groups of therapeutic orientations. As far as the presenting amount of problems is concerned, psychodynamic therapists tended to report more problems compared to other orientation groups. The authors suggested that this might be the consequence of the underlying theoretical model that informs responses about problems in therapy. The psychodynamic model emphasises the focus on interpersonal and relationship issues, which make psychodynamic therapists to be more conscious and focused upon problems when they exist. It has been found that the techniques psychodynamic therapists use in order to deal with problems related to poor alliances included dealing with the patient's defenses, guilt, and feelings in relation to the therapist. Cognitive behavioural therapists also attempted to resolve problems related to alliances by addressing problematic relationships and not the solution of problematic situations (Hover & Greenberg, 1994). These findings imply that no matter the therapeutic orientation of the therapist, when he/she has to deal with problems related to alliance, he/she focus on issues

related to interpersonal relationships. These findings can imply that therapeutic alliance is affected in a way by the nature of past and present relationships of the clients as it has been suggested by Kokotovic and Tracey (1990) and Mallinckrodt (1991).

Research has shown that the development of working alliance over time is not always a linear process (De Roten, Fischer, Drapeau, Beretta, Kramer, & Favre, 2004; Kivlighan & Shaughnessy, 2000). These researchers tried to explore how working alliance develops by sampling behaviours randomly across therapy. However, according to Stiles (2002) this approach does not highlight key moments or critical events that may play an important role in the development of therapeutic relationships and therefore provide limited information regarding the development of working alliance. For this reason, several researcher have attempted to explore how working alliance develops by considering the impact of an important or meaningful event during therapy has on it. Fitzpatrick, Janzen, Chamodraka, & Park (2006) used this methodology and identified that working alliance is facilitated when the clients identified positive meanings to the interventions the therapist made regardless of intervention type. Clients identified these incidents as being critical and they responded by increasing their openness to exploration. According to the authors critical moments in early therapy, positive feelings (liking or bond) and exploration (task-goal) may interact in a way that allows clients to engage in an exploratory process that will support productive therapeutic work.

It appears therefore, that therapist's capacity to form warm and supportive relationships is equally important in alliance formation (Black, Hardy, Turpin, & Parry, 2005). According to Wheeler (2000) the personal characteristics a therapist needs to hold include empathy, acceptance, genuineness, sensitivity, flexibility, open-mindedness, emotional stability, confidence, fairness, and interest in people. Moreover, the above mentioned characteristics, along with resourcefulness and sympathy are the less responsive to be trained.

Tryon (1990) conducted a study with the intention to examine whether clients who turn up for the second session are doing so because they are engaged in the counselling process. The results of this study revealed that clients that return for a second session have rated their counselors as deep, valuable, powerful, and full. It was also found that therapists who were rated having these characteristics appeared to feel more comfortable in interpreting and confronting their clients, while therapists that have a high rate of drop out tended to either encourage or guide too much their clients.

The research on the development of working alliance highlights the importance of exploring the interpersonal characteristics of both the client and the therapist as their interpersonal interactions appears to play an important role in the development of working alliance. One useful framework for understanding interpersonal characteristics is Bowlby's attachment theory.

## 3. Bowlby's attachment theory

According to Bowlby (1977), attachment conceptualises "the propensity of human beings to make strong affectional bonds to particular others". Attachment behaviour is characterized by: specificity -is directed towards one or a few specific individuals; duration -endures usually for a large part of the life cycle; engagement of emotion; ontogeny; learning -the learning process is involved in order to distinguish the familiar from a strange; and organisation of sophisticated systems that are activated by conditions like hunger, strangeness, fatigue, and anything frightening, and survival function (Bowlby, 1979).

According to Bowlby (1973), children over time internalise experiences with caretakers in such a way that early attachment relations form a prototype for later relationships outside the family. These internal representations are also called working models and share two key features: a) whether or not the attachment figure is viewed as the sort of person that will respond positively to calls for support and protection and b) whether or not the self is perceived as the sort of person towards whom other people, and especially the attachment figure, will respond in a helpful way (Bowlby, 1973).

Mary Ainsworth by conducting a laboratory experiment where infants were separated and then reunited with their caregivers managed to translate the basic components of the attachment theory into empirical findings. Ainsworth identified three distinct patterns of infant attachment, one secure and two insecure. A) The secure type of attachment: Infants classified into this category welcome their caregiver after a separation and, in the cases they are distressed, they approach them for comfort. B) Anxious-resistant type of attachment: Infants classified in this category show ambivalent behaviour towards caregivers and inability to be comforted after reunion. C) Avoidant type of attachment: Infants classified as avoidant avoid interaction with the caregiver after reunion. It is hypothesised that when the quality of primary attachment relationships persists over time, there is continuity in infant attachment patterns (Bartholomew & Horowitz, 1991).

## 4. Attachment style across life span

"Attachment behaviour is held to characterise human beings from the cradle to the grave" (Bowlby, 1979). Bowlby suggested that attachment style in adulthood is the product of both early attachment history and ongoing contextual factors. Working models both accommodate and assimilate information (1973). Bowlby (1973, 1988) suggested that adult cognitive, affective, and relational functioning are derived form distinct developmental experiences. The internalisation of these experiences forms working models of attachment that guide interaction, perception, and behaviour in future relationships including the relationship with the therapist. According to Bowlby (1973) adult attachment styles reflect relative stable and enduring relationship orientations. However, in the case of disconfirming life events and experiences there is a possibility of modification (Bowlby, 1988).

The outcomes of several studies on the stability of adult attachment styles are mixed. Some researchers have concluded that the stability of the attachment style depends on the stability of the family environment. The results of few longitudinal studies that have taken place suggest that attachment style is moderately stable across the first 19 years of life (Mallinckrodt, Porter, & Kivligham, 2005). An outcome, which has been found to be consistent across studies, is that several individuals are more prone compared to others to change attachment style (Davila, Burge, & Hammen, 1997; Lopez & Gormley, 2002; Kirkpatrick & Hazan, 1994; Baldwin & Fehr, 1995). Research suggests that attachment style changes is a process characteristic of attachment insecurity and is experienced by individuals with stable vulnerability factors (Davila, Burge, & Hammen, 1997; Lopez & Gormley, 2002). Such factors include personal history of psychopathology, stable personality disturbance, and family history of psychopathology (Davila, Burge, & Hammen, 1997).

Bartholomew and Horowitz (1991) hypothesised that adult attachment varies as a function of the valence of individuals' representations of self and others. She identified four categories of adult attachment, which are similar to those suggested by Ainsworth for infant attachment. Individuals with secure attachment perceive themselves as lovable and others as emotionally responsive to them. Individuals with insecure anxiety attachment style hold a negative model of themselves and a positive of others. Individuals with insecure fearful attachment style have negative representations both of themselves and of others. Adults with insecure dismissing attachment style have a negative working model of others but a positive working model of

self. In order to protect their self-esteem, they deny that attachment relationships are important (Bartholomew & Horowitz, 1991).

According to Bowlby (1973), mental health is determined, in large part, by individual differences in the quality of attachment relationship between the individual, when she/he was a child, and the primary caregiver. The mental representations of self and others are stored in the working models of individuals and affect the quality of mental health. According to Dozier (1990) individuals with secure attachment expect that others will be available in case they need them, therefore they engage in behaviours that allow them to maintain rewarding interpersonal relationships. On the other hand, insecure individuals have internalised the idea that they are not lovable; therefore, it is less likely for them to experience others as being available or caring. Furthermore, in order to deal with the insecurity, they employ strategies that enable them to interact with others in distancing or demanding ways. As a consequence, individuals with insecure attachment lack of supportive system, which in turn is associated with psychological and physical breakdown (Dozier, 1990).

## 5. Working alliance and attachment

According to Bowlby (1988), alliance may promote a positive treatment outcome by providing the client with a new, "healthier", positive relationship than the ones he/she had experienced in the past. According to Mallinckrodt, Gantt, and Coble (1995), the attachment system established in childhood continues to have a major influence in adult social relationships. It may be activated by any close relationship that evokes any potential of love, security, and comfort, including friendship, romantic partnership, and therapeutic relationship. Psychotherapy relationship shares some common elements with the child-parent relationship. Similar to a caregiver, the therapist offers emotional availability, a comforting presence, affect regulation, and a secure base from which to explore inner and outer world. Therefore, psychotherapy relationship can activate an adult's attachment system, which consists of expectations and behaviours. Expectations about the therapeutic relationship are influenced by the working models of self and others that the adult applies to all close personal relationships (Mallinckrodt, Gantt, & Coble, 1995).

 A recent review of the studies that have focused on attachment and working alliance, suggests that client attachment style plays an important role in the therapy process (Daniel, 2006).

## 6. Working alliance and client's attachment style

Mikulincer and Shaver (2007) suggest that when the primary attachment strategy is working well, the individual organises knowledge about distress management around a secure base script according which includes the following proposition: 'If I encounter an obstacle and become distress, can I approach a significant other for help? Is this person likely to be available and supportive? Will I experience relief and comfort as a result of proximity to this person? If so I will be able to return to other activities'. According to Mikulincer and Shaver (2007) individuals who are securely attached are likely to give positive answers to these questions and they experience a sense of security. Individuals who are insecurely attached are likely to give negative answers to these questions and as a consequence they weaken proximity in response to relationships were vulnerability has been disapproved and punished. Therefore, it can be suggested that interpersonal relationships and one's ability to seek support from significant others is related to individual's attachment style.

Taking under consideration that clients' attachment style affects the nature of their interpersonal relationships and the interpersonal nature of counselling process, several researchers have attempted to study the relationship between clients' attachment style and how these clients perceive the working alliance they have with their therapists (Eames & Roth, 2000; Kanninen & Salo, 2000; Mallinckrodt, Gantt, & Coble 1995; Mallinckrodt, Porter, & Kivlighan, 2005; Satterfield & Lyddon, 1998). The outcome of these studies indicates that clients' attachment styles are related with the strength of the working alliance that is created between the client and the therapist.

A finding common in these studies is that individuals with secure attachment perceived their therapists as being emotionally responsive and accepting, and tended to report positive working alliances. Individuals with preoccupied attachment seemed to desire dissolution of boundaries, by wishing a more frequent and intensely personal contact with their therapists. These clients seemed to form a working alliance with their therapists much more readily than the one they originally agreed upon or understood concerning the primary goals of therapy. Individuals with fearful attachment tended to distrust their therapists and fear rejection. They tended to report the poorest working alliances. Participants with dismissing attachment style exhibited an unwillingness to reveal themselves. However, they seemed to have the ability to engage with their therapist and report fairly strong working alliances. (Eames & Roth, 2000;

Kanninen & Salo, 2000; Mallinckrodt, Gantt, & Coble 1995; Mallinckrodt, Porter, & Kivlighan, 2005; Satterfield & Lyddon, 1998).

A number of studies have shown that therapists' ability to form strong working alliances with their clients is affected by therapists' experience (Dunkle & Friedlander, 1996; Mallinckrodt, 1991). Kivlighan, Dennis, Patton, and Foote (1998) attempted to offer a theoretical and empirical explanation of the contradictory results found at Mallinckrodt and Nelson and Dunkle and Friedlander studies by suggesting that the client's attachment style moderates the relationship between therapist's experience and working alliance. The results of this study indicated that when the clients were uncomfortable with intimacy, the counselor's experience was positively related to working alliance strength. When clients had moderate or high levels of comfort with intimacy, the therapist's experience was unrelated to the strength of working alliance. These results can offer some explanation about experienced therapists' ability to engage difficult clients in an alliance more quickly than their less experienced colleagues. Hardy, Stiles, Barkham, and Startup (1998) and Kivlighan (1990) also explored the impact of therapist's experience on the development of the working alliance. More specifically, it was found that skillful therapists were able to respond appropriately and in different ways and were able to employ different therapeutic interventions with clients with fearful and preoccupied attachment. Moreover, it was found that the strength of the working alliance was affected in a negative way when therapists were employing techniques that put the clients in a passive role. The results of this study suggest that effective therapeutic interventions that seemed to be meaningful for the clients do not imply that the therapeutic process will be a comfortable one. Therapists that were willing to engage in such a process seemed to have the best results.

Nevertheless, the outcomes of these studies should be generalised with caution, given the small sample size and the fact that all measures were self-report, which introduces the possibility that correlations are inflated and results biased because of common method variance and response set.

Several other researchers have attempted to examine the relationship between a client's attachment style and hers/his ability to from working alliance with the therapist, by examining patient's nature of social relationships. The rationale behind this approach is that the client's ability to establish a good working alliance is related with her/his capacity to form productive attachments to others and the capacity to trust others. For example, Kokotovic and

Tracey (1990) found that hostile and negative clients are unable to enter a positive alliance with therapists, while a history of good interpersonal relationships is related to a client's ability to form an alliance. In a study conducted by Mallinckrodt (1991), it was found that social support was a significant predictor of client rated working alliance. Kokotovic and Tracey (1990) conducted a study in order to examine whether past and present interpersonal relationships of clients affect their ability to form a positive working relationship. Data analysis revealed that both client and therapist assessments of the alliance were related to the quality of past and present relationships. Therapists rated the rate of adjustment as related to working alliance but clients did not.

Several researchers have stressed that the ability to understand and predict the relationship between clients' attachment style and their approach to counselling relationship can be valuable for a therapist. Such knowledge may give the therapist the ability to observe client's interpersonal difficulties in action and ultimately disconfirm dysfunctional working models and interpersonal patterns (Satterfield & Lyddon, 1998). For example, Lopez (1995) has suggested that, when distressing themes arise in psychotherapy, clients with fearful attachment style, in order to avoid feelings of rejection, might exhibit both "approach" behaviours (seeking reassurance and proximity) and "avoidant" behaviours (withdrawal from interpersonal interactions). This occurrence could affect therapists' perception of the client and therefore react in a disengaged or aloof manner, confirming the expectations of the client. Furthermore, Reis and Grenyer, (2004) suggest that mastery of the perceptions of others as rejecting and unavailable might be beneficial for fearfully attached clients, especially in the early stages of therapy, as it may help them to overcome their reluctance to form a working alliance.

A study conducted by Dozier (1990) with adults who suffer from serious psychopathological disorders yielded results similar to the Reis and Grenyer study. Specifically, it was found that severely disturbed individuals excessively employ avoidant strategies, in order to reject treatment. It was hypothesised that the motive behind these behaviours was a need of the individuals to prove that they do not need anything from the attachment figure, in this case the clinician, in order to avoid possible rejection. Similar results were found by a study conducted by Satterfield and Lyddon, (1995) where participants were clients that seek counselling for the first time in a counselling clinic at a small university. More particularly, it was found that clients who perceive others as being rejecting and unavailable have a difficulty to form working alliance, especially in the early phases of the counselling process.

According to Satterfield and Lyddon (1995) this fact is related with poor counselling outcomes.

Mallinckrodt, Porter, and Kivlighan (2005) found that secure attachment to therapists is associated with deeper and smoother sessions. Although they did not assess the therapeutic outcome, they hypothesized, based on previous studies, that this result implies positive therapeutic outcomes. Furthermore, it was also found that secure attachment was related with ratings of positive working alliance. Additionally, it was found that clients who had negative working models about self and the others influenced in a way their perceptions of therapists' intentions. This finding is in accordance with the findings of a study conducted by Brennan and Bosson (1998), where it was found that those with negative models of themselves and others appear to be more distressed in response to feedback. This finding seems to have implications with the therapeutic process. Specifically, openness to feedback, valuing that feedback, and incorporating the feedback are thought to be processes necessary for a productive therapeutic outcome.

In a recent study conducted by Janzen, Fitzpatrick, and Drapeau (2008) it was found that individuals with avoidance attachment style carry their attachment patterns over into the therapeutic relationship. However, the researchers found that this pattern changed after clients were able to identify an incident that had a positive impact on the development of therapeutic relationship. The type of incidents described by the clients varied including therapist's ability to help the client understand motivation behind his/her action and a perception of the therapist as being accepting. The researchers found that after that incidence clients were able to securely attach to the therapist, to experience support and relief, and to increase exploration regarding other issues. This study offers a support to Bowlby's hypothesis that as the client develops an attachment to the therapist, the therapist may function as a secure base form which the client can explore distressing experiences. The finding's of a study conducted by Romano, Fitzpatrick, and Janzen (2007) further support Bowlby's hypothesis regarding the impact of attachment on therapeutic relationship. In particular it was found that session depth is related to the client's experience of attachment security with the therapist. The results of both studies should be interpreted having in mind that participants were volunteer clients. In particular, client participants were students enrolled in a counselling course in an applied human sciences program at a Canadian university who chose a counselling experience as an optional, experiential component of their course. Participant's distress levels were relatively mild and this could affect the activation of

the attachment system. Therefore, it can be suggested that the findings could be different if the distress levels of the participants were similar to those seen in clinical populations (Janzen, Fitzpatrick, & Drapeau, 2008); Romano, Fitzpatrick, & Janzen, 2007).

The review of the above mentioned studies indicate that clients' attachment styles are, in a way, correlated with their ability to form working alliances. Taking under consideration that working alliance has been related to the therapeutic outcome, it can further be hypothesised that clients' attachment styles can contribute to the therapeutic outcome. This creates a number of challenges for the therapists that work with individuals with insecure attachment style as they need to take under consideration the unique needs of the clients that are related to their attachment style and adopt their interpersonal and clinician skills accordingly, so that they can manage to develop a strong working alliance with them. However, it should be taken under consideration that the data in the above mentioned studies was analysed by using correlation statistical procedures and therefore cannot securely imply any cause and effect relationship. This fact implies that there could be other variables that might mediate between clients' attachment styles and therapeutic outcome. Given that counselling is an interpersonal procedure, it is generally considered that it would be valuable to examine therapists' attachment styles and their ability to form working alliances with their clients. Finally, it should also be taken under consideration that, in several studies, therapists and clients had a different perception of the variables which seemed to affect the development of strong working alliances. These results can also inform the therapists about what seems to be important for a client and, therefore, inform their therapeutic practice accordingly.

 Although research has been focused mainly on determining clients' characteristics that affect the formulation of the working alliance, little is known about therapist's attachment style and its relation to the formulation of the working alliance.

## 7. Working alliance and therapist's attachment style

In a recent study conducted by Romano, Fitzpatrick, and Janzen (2007) it was found that session depth is related to the client's experience of attachment security with the therapist and that therapist global attachment moderates the relationship between client global attachment and session exploration. In particular, it was found that a negative association was observed between client's attachment anxiety and session depth when the therapist reported high levels of attachment avoidance. A similar finding was reported in a study conducted by Mohr,

Gelso, and Hill (2005). In particular, it was found that the relationship of clients high in attachment anxiety and therapists high in attachment avoidance is characterised by high levels of distancing and hostile countertransference behaviours.

Black, Hardy, Turpin and Parry (2005) carried out a study in order to examine the way the therapist's attachment style affects the working alliance and the development of problems in the therapeutic process. It was found that therapists with secure attachment reported having better therapeutic alliances with their clients. In contrast, therapists who found to have higher levels of insecure attachment significantly predicted poorer general therapeutic alliances. However, it was not concluded that insecure attachment was related with more problems in therapy. What was found to be related with more problems in therapy was the need for approval. It was hypothesised that the need for approval was associated with perfectionist targets and less ability to manage difficulties when arise. The fact that the data consisted of therapist's own perceptions about the quality of the working alliance is considered to be one of the limitations of this study. Furthermore, because the data was correlational, the study does not allow any cause and effect relationship to be made. The sample was consisted of experienced psychotherapists, therefore, the results cannot be generalised to inexperienced or less experienced psychotherapists and therapists. In addition, the response rate was quite low. What seemed the most important limitation however, is the fact that therapists were asked to reduce all the relationships they have with all their clients down to the average client. However, it should be taken under consideration that relationships with clients can vary within a therapist.

Rubino, Barker, Roth, & Fearon (2000) examined how therapist's attachment style can affect their ability to respond empathetically to clients' statements. It was found that more anxious therapists responded overall less sympathetically compared to less anxious ones, suggesting that their attachment style prevented them from empathising with their clients' concerns. Taking under consideration that empathy is related with the strength of therapeutic alliance, it can be further hypothesised that insecure attachment of the therapist can affect his ability to form a strong working alliance with the client and therefore, since working alliance predicts outcome, these therapists may result to be less effective. One of the limitations of this study was that therapists' ability to respond empathetically, was measured by their response to an actor that was role playing the client, therefore there is dangerous of generalising the nature of this response to the ability of the therapist to form close and warm relationships.

Henry, Schacht, and Strupp (1990) found that therapists' representation of past relationships had an impact on the session process and the quality of the working alliance with at least some of their clients. Specifically, it was found that therapists with problematic past relationships tended to be subtly hostile and controlling towards their clients. These therapists tended to have poor outcome cases and their clients tended to be self-critical. The major conclusion of this study was that although the absence of a negative interpersonal process may not be sufficient for therapeutic change, the presence of even relatively low levels of negative therapist behaviour may be sufficient to prevent change.

Despite the limitations, the outcomes of these studies suggest that therapist's attachment style has an impact on the formulation of the working relationship. However, what these studies fail to take under consideration is how the therapist's attachment style interacts with the client's attachment, and how this interaction affects the formulation of the therapeutic relationship.

Dozier, Cue, and Barnett (1994) conducted a study in order to determine how case managers attachment strategies affect their ability to respond therapeutically to clients. The results of this study revealed that secure attachment of the clinicians was highly related with their ability to respond therapeutically to clients' needs. Secure case managers were able to respond to clients' underlying needs, where insecure case managers were responding to the most obvious presentation of needs. It was hypothesised that secure case managers were more willing to intervene with ways that may be uncomfortable for themselves. The authors of this study also attempted to relate how case managers' attachment style was related to clients' attachment style. It was found that secure case managers tended to respond more to the dependency needs of the clients who were dismissing, than did with the clients who were preoccupied. As a consequence they were able to provide interpersonal experiences that challenged the content of clients' working models. On the other hand, insecure case managers tended to act accordingly to clients' attachment strategies and therefore, verifying clients' existing models about themselves and others.

Although this study provides valuable information on how case managers' attachment styles interact with clients' attachment style and how this interaction affects the therapeutic benefits a client can gain, the results should be generalised with caution because the participants were case managers and not clinicians. The authors suggested that a possible application of the results to clinicians could imply that clinicians who rely heavily on preoccupied strategies

would tend to intervene intensively with their clients, while clinicians who rely heavily on dismissing strategies would tend to intervene non-intensively regardless of clients characteristics (Dozier, Cue, & Barnett, 1994). Nevertheless, further research needs to be done on that area; research that would also take under consideration the therapeutic outcome of interventions of clinicians with either secure or insecure attachment style.

Tyrrell, Dozier, Teague, and Fallot (1999) also attempted to examine how case managers' attachment styles interacts with clients' attachment style in the formulation of the working relationship and the how this affects the therapeutic outcome. It was found that case managers with secure and anxious attachment style tended to have better therapy outcomes and stronger working alliances with clients that had fearful or dismissing attachment style. On the other hand, case managers with secure and less anxious attachment style tended to have better therapeutic outcomes and stronger working alliances with clients with preoccupied attachment style. It was again hypothesised that when case managers and clients have opposite attachment styles, the outcome is a disconfirmation of clients' working models about self and others.

The results of those two studies imply that therapists with secure attachment style would feel more confident to act in ways that although may make them feel uncomfortable, they will be beneficial for the client style. Although the results of these studies are valuable, they should be generalised with caution to the clinician's populations since the participants of this study were case managers. Therefore, it would be helpful future research to focus on examining whether opposite matching of clients' and therapists' attachment can facilitate positive therapeutic outcome.

The results of a recent study conducted by Mohr, Gelso, and Hill (2005) contradict the results of the above mentioned studies. In particular, it was found that when therapists and clients differ in their patterns of attachment insecurity, then therapists had more chances to engage in inappropriately hostile, critical, and rejecting statements. A difference of this study to the previous studies is that the participants were trainee counselors which were probably not so experienced in order to be able to recognize internal and external triggers to countertherapeutic behaviour. Therefore, it was suggested by the authors that experience might prevent therapists to rely on counterproductive attachment strategies.

## 8. Conclusion

The review of the studies that have examined how clients' and therapists' attachment styles affect the formation of the working alliance implies that working alliance should be seen as an interpersonal process and that it could act as a guide about the therapeutic interventions of the therapists. This interpersonal process can be affected by both the attachment styles of the therapist and the client. The results of these studies offer a range of multiple correlations, sometimes making it hard to conceptualise and narrow down to a consistent conclusion. Although the results of these studies do not provide any cause and effect relationship between adult attachment style and working alliance, their results however imply that there are some consistent patterns on how client's and therapist's attachment styles can affect the formulation of the therapeutic relationship. In particular, it appears that attachment theory can offer a consistent framework to understand clients' reactions in the therapeutic relationship and their ability to form working alliances with their therapists. There is also data to suggest that therapists' attachment style can also affect the formulation of working alliance but there is contradiction as to whether there is a preferable combination of therapist and client that will be better for treatment outcomes. Therapist's experience has been considered as a variable that might mediate this relationship. In particular, the results of some studies suggest that therapist's experience could facilitate both a better understanding of internal and external triggers to counterproductive behaviour and a more flexible attitude in adopting interpersonal and clinical skills so to disconfirm client's dysfunctional working patterns and form strong working alliances.

Based on these consistent patterns, therapists can inform their practice in order to promote better therapeutic interventions and to carry out assessments that will help them to better conceptualise the nature of their clients' conditions, as well as the nature of the relationship they have with them. Consequently, to act in a way that will be able to match a particular client's needs.

The American Psychological Association Division on Psychotherapy Relations has however, concluded that the evidence that exists so far about the influence of client's attachment to therapeutic relationship is insufficient to make a clear judgment about whether customizing the therapy relationship to account for client attachment style could make a positive contribution to treatment outcomes. This finding implies the methodological limitations of the studies that have been reviewed above. The difficulty in operationalising the concept of

working alliance can be one of them. For example, it has been found that there is no agreement across the instruments that are supposed to measure working alliance as to the underlying structure of the alliance. Each instrument has different subscales that render any comparisons difficult to be made (Horvath & Luborsky). Furthermore, the majority of the studies rely on self-report data collected at one time of the therapeutic relationship, increasing the possibility of common method bias and inflated correlations as a result of halo effect (Mallinckrodt, Porter, & Kivlighan, 2005). Therefore, further studies need to be carried out in order to clarify the contradictory results and identify the therapeutic conditions that will be able to address client's negative working models about themselves and the others and as a consequence to enable the client explore and address distressing issues.

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