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An investigation into the coping resources of parents with autistic children

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CHAPTER ONE

INTRODUCTION

Autism is a pervasive developmental disorder that is characterised by a triad of deficits in social reciprocity, communication, and repetitive behaviours or interests. Numerous investigations have suggested that these deficits present the parent of an autistic child with unique challenges and that these deficits may adversely impact on the parents' well-being. Research has shown that mothers are most severely affected by their autistic child, and there is a characteristic stress profile in mothers of children with autism. There are many factors that may contribute to perceived parental stress such as child characteristics, parent characteristics and the environment. Furthermore, it is reported that families of children with autism report a greater number of stresses than those parents of children with other disabilities. This stress increases the vulnerability of the parents to physical and emotional distress.

Since the mid-1980's a general theory of stress and coping known as the *process model of stress and coping* has been used in research into families with disabled children. Here stress can be seen as a process that involves continuous interactions and adjustments between the person and the environment. The stress associated with raising an autistic child can be conceptualized as having a significant impact on parent's social and emotional functioning and is manifest in psychological and family difficulties. When

faced with stress the individual can influence the impact of the stressor through behavioural, cognitive, and emotional strategies. A central tenet of this model is that the process of coping mediates the effects of stress on an individual's well being. The process of coping may be physical, material, social, psychological or intellectual.

Autism presents some unique challenges to the family and in the present study the researcher sought to investigate the coping resources used by the parents of autistic children. Coping resources that mediate stress are personal variables such as personality variables, parenting skills, previous coping experiences, physical health and personal beliefs and ideologies. They can also be of a socio-ecological nature such as social support, spouse support, marital status, socio-economic status and support from formal agencies. The present study considers the following coping resources: cognitive, social, emotional, spiritual/ philosophical and physical.

The sample consisted of thirty-one volunteer respondents (n=31). Respondents were asked to fill out two self-report questionnaires. These were a self-developed biographical questionnaire and Hammer's Coping Resources Inventory (CRI). The methodological procedures are further discussed in chapter three. The data was then statistically analysed to yield descriptive statistics of the biographical data and the scales of the CRI. An independent t-test and chi squared test of association were used to analyse the remaining data. The descriptive statistics of the CRI scales indicated that the majority of the sample reflected high scores on all of the coping resource scales. These scales were cognitive, social, emotional, spiritual/ philosophical, and physical. Results indicated that males and

females do not differ in the coping resources that they use. No significant relationship was found for support group or marital status on stress. However, educational level and intervention were found to be significant. These results are presented in table form in chapter four and then discussed further in chapter five. Lastly, chapter six presents the limitations of the research, the implications of the research and suggestions for future research.

CHAPTER TWO

LITERATURE REVIEW

Autism: An overview

Kanner's infantile autism

The autistic syndrome was first identified by Leo Kanner in 1938, and again in 1944 by Austrian pediatrician Hans Asperger. In his paper 'Autistic disturbance of affective contact' (1943 in Cumine, Leach & Stevenson, 2000) child psychiatrist Leo Kanner described a group of children he had encountered over the years that seemed to have certain unusual characteristic in common.

Kanner was a pioneer in the field of autism. His study began in 1938 when a fascinating five year old, Donald, was brought to his clinic (Cumine *et al.*, 2000). From the age of two and a half Donald was able to list the names of all the United States Presidents, say the alphabet backwards and forwards, and recite the twenty third Psalm. However, he was unable to hold a normal conversation (Cumine *et al.*, 2000). Over the next few years, Kanner saw ten more children who displayed similar behaviour patterns. Kanner suspected the syndrome to be more frequent than it seemed and suggested that some children had been misdiagnosed as being mentally retarded or schizophrenic (Kaplan & Sadock, 1998). Kanner used the term 'autism' to describe what he saw and referred to the work of Bleuler (1911). Bleuler had used the term 'autism' to describe a withdrawal from previous participation whereas the children Kanner described had never engaged in social

interaction. (Cumine *et al.*, 2000). In Kanner's first papers on the syndrome that he called 'early infantile autism' he noted several points which he considered to be of basic importance in making a diagnosis. These were:

1. A profound lack of affective contact with other people.
2. An anxiously obsessive desire for the preservation of sameness.
3. A fascination for objects, which are handled with skill in fine motor movements.
4. Mutism, or a kind of language that does not seem to be intended to serve inter-personal communication.
5. The retention of an intelligent and pensive physiognomy and good cognitive potential, manifested, in those who can speak, by feats of memory and, in the mute children, by their skill on performance tests. (Kanner, 1943 in Wing, 1976).

Kanner also noted that the behaviour pattern that was observed was present from early childhood. At first he thought that the abnormalities were present from birth but later he described the same problems in children who had apparently developed normally for up to twenty months. Kanner emphasised the abnormality of the children's emotional responses to other people and considered this to be the fundamental impairment which then explained all the other characteristic features of the syndrome (Wing, 1976).

As the information provided by Kanner's observations on the nature of autism became more widely known, more children were referred for diagnosis. However, as more children were seen, it became clear that Kanner had only recognised one small group of children who fitted his particular criteria (Cumine *et al.*, 2000). It was felt that Kanner's

defining features were too limiting and that there were children for whom it was felt that the diagnosis of autism would be a useful descriptor yet who did not fit exactly into the criteria outlined by Kanner (Cumine *et al.*, 2000).

The autistic spectrum

Since the late 1970's the description of autism has been increasingly refined and the concept been extended to that of a spectrum disorder (Wing & Gould, 1979 in Aaron & Gittens, 1992). In a study by Lorna Wing and Judith Gould (1979) they identified a number of children with what they described as 'Kanner's syndrome' and a large number who showed similarities to this group, but didn't fit Kanner's exact criteria. Thus, in 1988 Wing went on to use the broader term 'autistic continuum' and later 'autistic spectrum' (Aaron & Gittens, 1992).

Today it is widely accepted that autism is not a clear-cut disorder but rather a "spectrum of difficulties with certain clusters of possible symptoms" (Aarons & Gittens, 1992, p.10). Autism is defined by a triad of deficits in social reciprocity, communication, and repetitive behaviours or interests, each of which can occur at different levels of severity (Lord & Risi, 2000). These difficulties have come to be described as the 'Triad of Impairments'.

The first aspect of the triad is the *impairment of social relationships*, which is marked by an aloofness and indifference to others. Autistic children may not try to share their

interests or emotions with other people in the same way that other children of their age might. While some autistic children may make social contact they often lack the subtle rules of social behaviour (Aarons & Gittens, 1992). Furthermore, they often fail to respond appropriately to social or emotional situations.

The second aspect to the triad is the *impairment of social communication.* A major deficit in autism is the development of language and communication skills and as such is an essential characteristic of the syndrome of autism (Mundy, Sigman, Ungerer & Sherman, 1987). Autism always involves some sort of delay in language acquisition with some individuals never developing functional language at all. The verbal abilities of children with autism range from the total absence of speech to communication that may be accurate in form (syntax and phonology) but reflect semantic and pragmatic abnormalities (Leahy, 1995). Individuals who do develop language may use language that is repetitive and imitative or idiosyncratic. Research has shown that autistic individuals primary use of language seems to be used for requesting objects, requesting actions and protesting. This problem of communication extends beyond verbal communication into the area of nonverbal communication as well. Autistic children have abnormal eye contact, their gestures (including pointing) are delayed, and facial expression and body postures are also affected (Whitaker, 2001).

The last aspect of the triad is an *impairment of social understanding and imagination*. The problems in this area of impairment extend beyond this, to a broader difficulty in thinking and behaving with flexibility and creativity (Whitaker, 2001). Problems in

inflexibility are apparent from the routines, rituals and resistance to change that are frequently seen in autistic individuals (Whitaker, 2001). Autistic individuals may demonstrate a restricted repertoire of activities and interests that are manifested in a preoccupation with restricted patterns of interest, inflexible adherence to routines, repetitive movements, and/ or preoccupation with parts of objects (Wetherby & Prizant, 2000). Furthermore, children with autism lack the spontaneous pretend play or social imitative play in which other children their age would engage.

Subgroups of autistic individuals

There is no adjective that can be used to describe every type of individual with autism because there are many forms of the disorder. However, Wing (1997) describes four subgroups of autism that is based on a description of the type of social impairment. These are the *aloof group,* the *passive group,* the *active but odd group,* and the *loners.* Although there is no specific way to sharply differentiate between the groups this subgrouping has proved helpful in clinical practice (Wing, 1997).

The aloof group

The aloof group has been the most easily recognised variant of the spectrum. These children appear aloof and indifferent to others, especially their age peers, though they may accept physical affection from familiar people (Wing, 1997). The aloof children fit most closely with the popular picture of autism and tend to have moderate or mild learning disabilities, with higher levels of skill in specific areas, especially visio spatial

tasks or rote memory (Wing, 1997). A few of these children have shown to have the cognitive ability in the normal or even superior range (Wing, 1997). This group of autistic children may have no speech, but typically, speech is delayed and shows abnormalities.

The passive group

The passive group shows a different picture to the aloof group. These children do not socially interact spontaneously but passively accept approaches from others (Wing, 1997). These children usually display the impairments of communication and imagination similar to the aloof group but in a less florid form (Wing, 1997). This group may have abilities in the average or high range and might manage to survive mainstream school, at least in the primary years (Wing, 1997).

The active but odd group

This group of children tend to make active social approaches that are naïve, odd, inappropriate, and one-sided (Wing, 1997). This group of active but odd autistic individuals tend to fit Asperger's clinical descriptions of his syndrome. Their speech is often fluent with good grammar and vocabulary, however, it is repetitive and not used for reciprocal conversation. The range of cognitive ability in this group is wide but levels tend to be higher than those of the aloof group (Wing, 1997).

The loners

The most subtle form of the triad is seen in the loner group. These individuals may exhibit average, high, or outstanding ability, including fluent speech. These individuals tend to prefer to be alone, lack empathy, and be concerned with their own interests regardless of peer-group pressures (Wing, 1997).

There has been considerable debate about what underlies the varied picture that autism presents, as each individual may present with different deficits and difficulties. In her book *Explaining the enigma* (1989), Uta Frith uses Premack's 'Theory of Mind' to explain the link between all autistic individuals. Theory of Mind is the ability that people possess to understand what is going on in other people's minds. It allows us to understand that others have thoughts, beliefs and feelings of their own, and that these might be different from our own. This theory has been used to explain some of the deficits seen in individuals with autism.

Normally developing children, from around the age of four years old, are able to understand (however implicitly) that other people have thoughts, beliefs, intentions and desires which impel their behaviour (Cumine *et al.*, 2000). They are also able to recognise that individuals vary in their thoughts, beliefs, intentions and desires, and that these differences will lead to differences in behaviour. The 'Theory of Mind' explanation of autism proposes that this ability is specifically impaired in autism. People with autism do not develop the ability to think about others' thoughts so that they are specifically impaired in certain social, communicative and imaginative skills (Happe, 1994).

Therefore, children with autism do not understand that other people are thinking and feeling (Jordan, 1999).

Baron-Cohen (1995) has proposed that the ability to engage in shared attention is the prerequisite for theory of mind to develop. Since this ability is impaired in autism, and the child is unable to engage in shared attention, theory of mind fails to develop. Baron-Cohen (1995) goes on to say that if children with autism are unaware that they and other people have thoughts about the world, then their world must be dominated by current perceptions and sensations unfiltered, as it were, by the lens of interpretation. The social world (that is usually guided, interpreted, and created as it is by our thinking about our own and other people's motives, beliefs, desires and intentions) must be a very frightening place for them.

Diagnosis of autistic disorder

Although there are many reasons to believe that autism is a neurobiological disorder with a strong genetic component, a biological marker has not yet been found (Lord & Risi, 2000). Therefore the syndrome must be defined on the basis of observed and described behaviours. The behaviours are described in terms of a pattern of deficits in social behaviour and communication accompanied by restricted and repetitive behaviours or interests as well as an age of onset prior to 36 months (Lord & Risi, 2000). (Refer to Appendix A for DSM- IV criteria).

Although there is no data on the prevalence of autism in South Africa it is estimated that one in every 158 births, with four times as many boys as girls, are affected (Autism South Africa, 2004). Reports suggest that the number of children receiving a diagnosis of autism and other disorders on the spectrum are rising (Symon, 2001). This higher prevalence may be due to better detection and assessment procedures or better classification criteria. Much more is known about the diagnosis of young children with autism now than was known in the late 1980's. Methods are available that provide ways of acquiring structured information from parents and for observing children directly in diagnosis (Lord & Risi, 2000).

According to the diagnostic criteria laid out in the DSM-IV, individuals diagnosed with autism display global impairments in social skills and in verbal and nonverbal communication, and they exhibit stereotypical behaviours or restricted ranges of interests. The severity of the disorder can range substantially from mild to severe (Symon, 2001). As a result, individuals who display mild forms of the criterion behaviour are now being diagnosed, thus increasing the prevalence. Many children may also receive diagnosis at earlier ages if they present with behaviours that are suggestive of autism (Symon, 2001). In the 10th revision of the *International Statistical Classification of Diseases and Related Health problems* (ICD-10) the childhood autism category corresponds to autistic disorder in the DSM-IV (Kaplan & Saddock, 1998). The ICD-10 makes a distinction between atypical autism and childhood autism. This difference according to the ICD-10 is in age of onset or in failure to fulfill all three sets of diagnostic criteria for childhood autism.

Differential diagnosis for autism includes generalised learning disabilities and specific disorders that affect language, reading, number work, motor coordination, hearing or vision (Wing, 1997). These conditions can occur alone or with an autistic spectrum disorder. When any aspect of development is delayed or deviant, it is appropriate to consider whether the autistic triad of impairments is also present (Wing, 1997). Problems may occur when attempting to diagnose a child if attention is only given to one aspect of the child's development. For example, so-called semantic-pragmatic disorder, in which a child has fluent speech, that is used for repetitive talking about the child's own concerns and not for reciprocal conversation is a particular problem. A child presenting with these features might be incorrectly diagnosed as having autism, as workers may not know that semantic-pragmatic disorder may occur on its own. Attention deficit and hyperactivity, Tourette's syndrome and obsessive-compulsive disorder are examples of disorders that can also occur alone or together with the triad of impairments (Wing, 1997).

Causes of autistic disorder

As yet there is no known cause of autism and autistic spectrum disorders can be defined only on behavioural criteria. There has been much conflict and debate as to the cause of autism. Early theories as to the cause of autism were that it was psychogenic, that is, that psychological factors were responsible for its development. In the past parent's of autistic children have been described as 'rejecting', 'obsessive', 'overly intellectual' and 'emotionally cold' (Koegel, Schreibman, O'Neill & Burke, 1983). These characteristics were attributed to both mothers and fathers (Koegel *et al.*, 1983). The most elaborate

theory of direct parental causation was developed by Bettelheim (1967 in Koegel *et al.*, 1983). Bettelheim based his ideas heavily on subjective impressions and placed emphasis on a hypothesised abnormal mother-child bond (Koegel *et al.,* 1983). The mothers of autistic children were supposedly inadequate in displaying care and responsiveness, which in turn resulted in rage, hostility, and autistic withdrawal by the child. The child's abnormal behaviours (e.g. self-stimulation, echolalia) were seen as a defensive reaction to a hostile environment (Koegel *et al.,* 1983). This narrow and faulty perspective that blames parents has been replaced in recent years.

Current literature supports the biological basis for autism (Nissenbaum, Tollefson & Reese, 2002). There has been a growing body of evidence to suggest that autism has an organic cause as is supported by the fact that a high incidence of children with autism also experience epilepsy and learning difficulties. Although no precise site of lesion or disrupted neurochemical pathway can be identified, it is now confidently asserted that autism has a primary cause at the level of the brain (Cumine *et al.*, 2000).

The idea of a genetic component to autism has also been substantiated by recent research. Siblings of individuals with autism have an increased chance of having the disorder. Siblings and other family members are also more likely to demonstrate other developmental disorders, such as Asperger's Syndrome. Furthermore, the components of autism, rather than autism itself, tend to run in families (Nash, 2002). Even though profoundly autistic people rarely have children, researchers often find that a close relative is affected by the some aspect of the disorder (Nash, 2002). For example, a sister may

engage in odd repetitive behaviour, or a brother may have difficulty with language or be socially inept to a noticeable degree (Nash, 2002). In a similar fashion, if one identical twin has autism, there is a 60% chance that the other will as well and a better than 75% chance that the twin without autism will exhibit one or more autistic traits (Baron-Cohen, 1995). Baron-Cohen (1995) continues to state that as there are differing degrees of the disability this suggests that it is likely to involve multiple genes. Present estimates run from as few as three to more than twenty genes involved (Nash, 2002). Coming under intensifying scrutiny are genes that regulate the action of three powerful neurotransmitters: glutamate, seratonin and gammaaminobutiric (GABA) (Nash, 2002)

There are several methodological problems that make the search for the cause of autism more difficult. One problem in determining the cause of autism is the significant variation in the types of severity of problems exhibited by children with autism (Leahy, 1995). Another problem is that autism is not a discrete disorder but is the most severe form of a pervasive developmental disorder, therefore, the cause of autism must also account for the problems of children who have related disorders.

As Francesca Happe (1994) writes that although we are still a long way from pinpointing the area of damage in the autistic brain we are able to specify what function is lost in the autistic mind.

Education, management and treatment

There is, as yet, no curative treatment for autistic disorders. In recent years, alongside the expanding range of theories to explain autism, there has been a dramatic increase in the number and range of intervention approaches proposed. Some of these approaches have been specifically designed with autism in mind, while others are adaptations of approaches found to help children and adults with a variety of other difficulties. Each approach stems from a particular understanding of autism, its nature and causes, and aims to develop a way of compensating for the perceived deficit or enhancing the perceived strengths (Cumine *et al.* 2000).

The most effective way of helping children to maximise their abilities and minimise behaviour disturbances is through structured education intervention that takes into account their impairments and special skills (Wing, 1997). It is important that the intervention addresses the whole nature of autism and not focus on a single aspect of the condition. There are several intervention programmes that have been found to be extremely productive. These include *TEACCH* (Treatment and Education of Autistic and related Communication handicapped CHildren), *PECS* (Picture Exchange Communication System), *ABA* (Applied Behavioural Analysis), and *Musical interaction* (Cumine *et al.* 2000). However, it must be noted that no single approach has been found yet which is effective with all children with autism. It is best to combine elements from a number of different approaches that will make the intervention flexible enough to take into account individual differences.

Educational and behavioural methods are currently considered the treatments of choice (Kaplan & Sadock, 1998). Well-controlled studies have indicated that gains in the areas of language and cognition and a decrease in maladaptive behaviours are best achieved by consistent behavioural programmes. These programmes are, however, very intensive and require much of the parents' time. The autistic child requires as much structure as possible, and a daily programme for as many hours as feasible is desirable (Kaplan & Sadock, 1998). In addition to the large amount of time required for these intervention programmes there is also a huge financial burden that is placed on the parents. The programmes require specific training for the parents as well as many additional resources. These programmes are also usually run in conjunction with additional therapies that include occupational therapy, speech therapy and physio-therapy.

Although no drug has been found to be specific for autistic disorder, psychopharmacotherapy is valuable in that some drugs are used to target specific symptoms (Rapin, 1997). For example, the administration of haloperidol (Haldol) both reduces behavioural symptoms and accelerates learning, the drug risperidone (Risperdal) has also been used successfully to diminish aggressiveness, hyperactivity and self-injurious behaviour (Kaplan & Sadock, 1998).

Autism and the family

Autism is a severe, long-term developmental disorder that has potential to substantially influence different aspects of the family. As the focus of the cause of autism shifts from a psychosocial cause to an organic cause so the focus shifts on the perspective of the family. The family is no longer being studied for their presumed role in the cause of the disorder. Instead questions are being asked about the impact of an autistic individual on the functioning and interactions of family members, including parents, siblings and the family as a whole.

Child effects on the parents

There are many potential sources of stress for parents. At this time a definition of stress is necessary. Over the years the term 'stress' has been diluted by colloquial usage to come to denote a range of emotions from angst to fatigue (Everstine & Everstine, 1993). Lazarus and Folkman (1984, p354) define stress as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being". From this we see that the experience of stress is a subjective experience.

One of the major potential sources of stress for parents of autistic children is due to the characteristics of autism. Rodrigue, Morgan & Geffken (1992) have shown that parents of autistic children experience greater stress that parents of children with mental

retardation and Down Syndrome (Holroyd & McArthur, 1976). This may be a result of the distinct characteristics that are present in autistic individuals. A major deficit in autism is that in the area of communication. The autistic individual may not be able to express their basic wants or needs. This leads to the parents often having to play a guessing game. Is the child crying because he/she is thirsty, hungry, sick or tired? When the parent cannot determine the child's needs both are left feeling frustrated. The child's frustration can lead to aggressive behaviours towards others or self-injurious behaviours that threaten their safety and the safety of those around them.

The autistic child's social skills deficits, such as the lack of appropriate play, can also be stressful for families. Individuals lacking appropriate leisure skills often require constant structure of their time, a task that is nearly impossible in the home environment where the parents are just trying to deal with everyday living. Many parents of autistic children also struggle with the additional challenges of getting their child to sleep through the night. Meal times can also be a struggle as the autistic child may have a very strict diet and may be a fussy eater. These deficits and behaviours can be physically exhausting and emotionally draining on parents.

Additional sources of potential stress may come from the reactions of society to the autistic child. People in the general community may not understand the autistic child's behaviours and lack of ability to understand the social norms of society. People may stare or make comments. As a result parents often feel uncomfortable taking their autistic child

out and may become socially withdrawn. This has consequences for the amount and type of social support available to these families.

Social and emotional functioning of parents

Numerous empirical investigations have suggested that parenting developmentally handicapped children may have an adverse impact on parents' well-being (DeMyer, 1979). The stresses of parenting developmentally handicapped children include prolonged dependency and demands for special care, disappointments with delayed developmental milestones, and worry regarding future self-sufficiency (Wolf , Noh, Fisman & Speechley,1989). Delayed or forfeited parents' goals, isolation from family and friends, and the unpredictable, ambiguous nature of autism are important sources of life stress that impose physical and emotional strains on parents that exceed levels experienced by parents of normal children (Wolf *et al.*, 1989).

Early research by DeMeyer (1979 in Shopler & Mesibov, 1984) found that families are intensely affected by the many failures of their autistic children, and that these failures affect each parent as an individual, the marital relationship, the parent-child relationship, and the other children in the family. DeMeyer found that mothers were most severely affected by the autistic child (1979 in Shopler & Mesibov, 1984) and results of various studies have showed that there is a characteristic stress profile in mothers of children with autism (Koegel, Schreibmen, Loos, Dirlich-Wilhelm, Dunlap, Robbins & Plienis, 1992). These results that show mothers to be seriously affected by their autistic child have been

noted in several studies (Moes, Koegel, Schreibman & Loos, 1992; Konstantareas, Homatidis & Plowright, 1992; Sanders & Morgan, 1997).

Holroyd and McArthur (1976) examined reports of stress from mothers of autistic children, children with Down syndrome, and children being seen at an outpatient psychiatric clinic. They found that the mothers of the autistic children reported more problems than the other two groups. Mothers of the autistic children were more upset and disappointed about their child, more concerned about their child's dependency, more concerned about the effect of their child on the integration of the rest of the family, more called upon to handle physical disability, more concerned about vocational handicaps and lack of available activities to keep their child busy, and more aware of personality problems in their child (Holroyd & McArthur, 1976).

Parents of autistic children often grieve over the loss of the 'typical' child that they expected to have. In addition these parents are grieving the loss of lifestyle that they expected for themselves and their family.

Personal difficulties reported by mothers of autistic children include increased stress, poor physical health, depression, excessive time demands, parental burnout, and concerns about their child's dependency, effect on family life and future psychosocial problems (e.g. Bristol & Shopler, 1983; DeMeyer, 1979; DeMeyer & Goldberg, 1983 in Rodrigue, Morgan & Geffken, 1990). Research has shown that there is a positive correlation between stress level and age of the child (Morgan, 1988). Bristol (1984) also reported a

developmental progression of family stresses similar to that reported by other investigators (DeMyer, 1979; DeMyer & Goldberg, 1983; Holroyd & McArthur, 1976). There are a number of explanations of why mothers may be more affected by their autistic child, for example, mothers may be the primary caretaker of the autistic child, and they may also be called upon to serve as crisis managers. In a study conducted by DeMyer (1979) it was found that mothers of very young autistic children focused on constant caretaking demands, lack of sleep, and concern for the physical survival of the child who might run into streets or get up and wander in the middle of the night. As children got older many of these problems abated, and management problems shifted from survival to self-help issues, difficulties with the children's behaviour in public, and attempts to maintain some semblance of normal family functioning or family survival (DeMyer, 1979). Management problems with older children, although less frequent, took on greater importance because of the increasing physical size and strength of the children and decreasing strength and energy of the mothers (DeMyer, 1979).

Research has shown that the influence of developmentally handicapped children on the psychosocial well-being of parents is substantially greater for mothers than for fathers (Wolf *et al.*, 1989). While some research has indicated that mothers and fathers of children with disabilities do not differ in their overall perception of stress they may differ on the types of stress that they experience (Hadadian, 1994). For example, research has commonly reported that women are more likely than men to blame themselves for the child's problems and have their identities threatened by illness and disability in their children (Gray, 2003). In a study by Moes, Koegel, Screibman, and Loos, (1992) the

researchers found that mothers perceived greater stress for themselves, other family members and the family as a whole in caring for the child with autism. Furthermore, mothers were also at a greater risk for experiencing depression (Moes *et al.*, 1992). Research has consistently repeated these findings and generally shows that stressful life events cause more psychological distress and depression in women than they do in men (Gray, 2003).

Fathers have largely been neglected in previous research of families of autistic children and we know more about the effects of autism on mothers than we do about fathers (Rodrigue *et al,* 1992). However, it is important to also study the effects of autism on the father as they too form part of the family system. In addition, recent changes in the family structure, with a lot of mothers employed and the emergence of a growing number of households headed by fathers, it is important to also study the effects of autism on fathers (Hadadian, 1994). In a study by Rodrigue, Morgan and Geffen (1992) fathers reported significant concerns about financial costs incurred and whether family income was sufficient to cover the child's current and future expenses. Like mothers, the fathers in this study also reported disruption in family activities due to the child with developmental delays. The results of the Rodrigue, Morgan and Geffen (1992) study suggest that fathers adapt relatively well to the demands associated with raising a developmentally delayed child. These results may be due to the fact that fathers are more removed from day-to-day child management activities relative to their spouses. Furthermore, since mothers often assume the primary caregiver role fathers may harbour the perception (accurate or not) that their personal and family lives have not been significantly disrupted. Fathers may

also believe that their primary role with respect to their developmentally delayed child is to attend to the present and future financial concerns (Rodrigue *et al.*, 1992).

There are many factors that contribute to perceived parental stress such as child characteristics, parent characteristics, and the environment. Research has shown that three of the most stressful factors associated with parenting an autistic child are the concern over the permanency of the condition, poor acceptance of autistic behaviours by society, and, often by other family members, and the very low levels of social support received by parents (Sharpley, Bitsika & Efremidis, 1997). Further factors that contribute to parental stress include the difficulties in acceptance of the child's diagnosis, marital conflicts associated with rearing a handicapped child, additional financial burdens, fatigue and loss of leisure time due to care-taking responsibilities, disappointments with delayed developmental milestones, isolation from friends and family, and the ambiguous nature of autism (Sanders & Morgan, 1997, Wolf *et al.*, 1989). The above situations are important sources of life stress that may impose physical and emotional strains on parents that exceed the levels of stress experienced by parents of normally developing children.

Several studies indicate that families of children with disabilities experience more stress than do similar families of typically developing children or young adults (Pargament, 2001). Furthermore it appears that families of children with autism report a greater number of stressors than those parents with children with other disabilities as a result of the distinct characteristics that individuals with autism display. Bouma and Schweitzer (1990) compared stress levels of parents of children with autism and stress levels of

parents of children with cystic fibrosis and with those of parents of children without disabilities. Stress levels were higher for both parents of children with disabilities. However, stress levels were highest for parents with children with autism. Similarly, Sanders and Morgan (1997) showed that parents of autistic children generally reported more family stress and adjustment problems than parents of children with Downs Syndrome. However, Rogrigue *et al.*, (1992) showed that whereas mothers of children with autism tend to report more stress than mothers of children with other types of anomalies (e.g., Bouma & Schweitzer, 1990; Rodrigue *et al.*, 1990), fathers seem to report similar concerns and equally low levels of stress, regardless of their child's type of developmental disability.

According to some reports, the persistent stress associated with raising an autistic child may lead to parental 'burnout' (Bristol & Shopler, 1983). Marcus (1984 in Morgan, 1988) proposed that the foremost stressor leading to burnout is the unrelieved care of rearing a chronologically handicapped youngster. "Other stressors contributing to burnout include problems associated with getting a proper diagnosis and suitable services, loneliness and isolation resulting from having a child whose idiosyncratic behaviour and constant demands set the family apart, inadequate supportive services, and neglect by parents of their own personal, social and medical needs" (Morgan, 1988, p. 268).

In summary, the stress of caring for an autistic child is real and acute. Research has shown that parents of children with autism experience greater stress that parents of children with other types of handicaps. There are many factors that contribute to perceived parental stress. These include child characteristics, parent characteristics, and

the environment. These characteristics include those mentioned above such as the behaviours and deficits present in autism, reactions from society and feelings of isolation, concerns over future caregiving, finances, and feelings of grief. Furthermore, mothers appear to be more affected by their autistic children. However, it must be noted that fathers have largely been neglected in previous research of families of autistic children. Research that has included looking at fathers has shown that fathers are able to adapt relatively well to the demands associated with an autistic child (e.g. Rodrigue *et al.*, 1992).

Marital relationship of parents

There has been little systematic research conducted with a focus on the impact of the autistic child on the parents' marital relationship. There has been evidence to suggest that a child with autism in the family can stress the marital relationship and decrease marital satisfaction (Rodrigue *et al.*, 1990). This may be because the family is divided while one parent looks after the autistic child while the other parent looks after the other children. It may also be due to the fact that one parent is not able to 'accept' their autistic child. Duties may also be divided and as such there is little 'family' time. However, some parents have reported that their marriage was strengthened (Wood Rivers & Stoneman, 2003). The divorce rate among parents with autistic children has been found to be in fact lower than the average divorce rate (Morgan, 1988).. This may be because parents come together in times of a crisis and form a closer bond. The evidence therefore doesn't indicate that the child necessarily impairs the marital relationship or strengthens it.

Perhaps there are certain mediating variables, such as the age of the child, severity of the autistic behaviour, and availability of appropriate services, that affect marital adjustment (Morgan, 1988).

Child effects on siblings

The autistic child appears to influence both directly and indirectly the functioning of siblings within the family. “Siblings have to learn to adapt to, and cope with, the severe problems presented by an autistic brother or sister. They have to deal with the often extreme demands that the autistic sibling places on their daily lives and the alterations in the family relationships that result from his presence” (Morgan, 1988, p.271).

It is generally believed that children of impaired siblings are at risk of suffering a variety of problems themselves, however, research studies indicate that living with impairment is not necessarily a harmful experience. It is important to note that families of normal children have their own considerable problems to contend with and unless this fact is taken into account there is the danger of exaggerating the impaired child’s role in ‘causing’ problems (Howlin, 1988).

There are several studies that point out the problematic effects on siblings of having an autistic child in the family. Some of these problems include a higher incidence of learning problems in siblings (Howlin, 1988) and a higher incidence of language-related problems (Howlin, 1988). Amongst other types of difficulties reported in normal siblings

are feelings of guilt and fears that they might, in some way, be responsible for the condition (Howlin, 1988). Many children may also feel that they have not received the same amount of attention from their parents and may express feelings of jealousy and feelings of unfair treatment. There are also difficulties associated with being expected to do more household tasks, having to care physically for their sibling (Howlin, 1988). There are several sources of potential stress for siblings of an autistic child. These may include embarrassment about their autistic sibling around their peers, frustration over not being able to engage or get a response from their sibling, concern and feelings of resentment over different treatment of their sibling, concern over their parents stress and grief and concern over their role in future caregiving.

There are however many studies that report that far from being harmed by their experiences, siblings of autistic children are often remarkably well-adjusted. There are a number of ways in which the effects on siblings can be minimised such as increasing other family interactions, meeting the social and educational needs of other children, avoiding undue physical and emotional pressures on siblings, explaining and discussing the nature of autism and involving the other children in treatment (Howlin, 1988). Unfortunately the effects of the autistic child on his or her siblings is beyond the scope of this research study and as such will not be expanded on.

Stress

Stress can be defined as "a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being" (Lazarus & Folkman, 1984, p.354). From this definition we see that the experience of stress is a subjective experience. The term stress has also become a common term in modern society and as such many people have knowledge of what is meant by the term stress.

Most research on stress and health has focused on the variety and quality of individual reactions to stressors (Rice, 1999). However, stress is seldom an isolated event that affects only one person in one remote situation. Stress often affects the family in many ways. One point of view supports the notion that stress in the family increases vulnerability of individual members to physical and emotional distress (Rice, 1999). While on the other hand factors unique to the family may in fact increase resistance to distress (Rice, 1999). Recent research has included the positive contributions that a child with a disability can bring to a family (Symon, 2001). Positive adaptations can serve as a resiliency factor for children with a disability and their family.

Several authors use stress definitions that recognize differences between personal and family-stress. Reuben Hill's (1949 in Rice, 1999) ABCX model provided one of the most comprehensive family-stress theories. The basic premise is that: some event (A) interacts with the family's resources for meeting crisis (B) and with the family's definition of the

event (C), to produce a crisis (X). Later this model became the Double ABCX model when it was extended to include the family's perception of other stressors and family resources (Rice, 1999). These family resources as outlined in the Double ABCX model play an important role in the family adaptation to stressor events. Such stressor resources include the personal resources of individual family members, the internal or systemic characteristics of the family that contribute to its structure and organisation, and the social support received from extended family, friends, professionals and outside agencies (Minnes, 1988).

The stressor event is an occurrence that is of significant magnitude to provoke change in the family system. While the event has the potential to raise the family's level of stress it does not do so every time. The degree of stress caused by the event depends not only on the actual magnitude of the event but, also, on the family's perception of that event (Boss, 1988). Individual members in the family often see the same event differently. Furthermore, parenting developmentally handicapped children has been reported to produce stress from varied sources- child, family, developmental stage, and environment (Wolf *et al.*, 1989).

Although there seem to be consistencies in patterns of responses for families of children with autism, one must also recognize the possible wide range of responses and feelings that family members experience when they learn of their child's diagnosis (Symon, 2001). After learning that their child has a disability some families may experience feelings of sadness, guilt or depression associated with uncertainty about the child's

future. On the other hand, a parent who previously questioned the child's developmental progress may experience a sense of relief at learning that his/her child does have a diagnosis and now an intervention of some sort can be implemented.

The characteristics of autism make raising an autistic child challenging and place great stress on the family. These characteristics include child characteristics, parent characteristics, and the environment. These characteristics are mentioned above such as the behaviours and deficits present in autism, reactions from society and feelings of isolation, concerns over future caregiving, finances, and feelings of grief. This stress can be conceptualised as a significant impact on the parent's social and emotional functioning and is manifest in psychological and family difficulties (Morgan, 1988; Sanders and Morgan, 1997). Literature on life stress indicates that among many potential threatening events and life circumstances, those characterised by their magnitude, intensity, duration and unpredictability tend to constitute the most stressful situations (Wolf *et al.*, 1989). There is increasing evidence that parenting an autistic child appears to provide the characteristics to produce life stress and affect many aspects of family life. Among the diverse parental problems reported are depression, fear and anxiety, difficulties in daily management of the child, burnout, financial worries, and concern over inadequate educational and professional resources for the child and the family (Morgan, 1988).

The ABCX model has offered important insight into the dynamics of family life and the ways in which families react in times of stress. However it is limited in a number of ways (Beresford, 1994). First, little attention is given to the role of factors external to the

family and intrapersonal factors in mediating the effects of stress (Beresford, 1994). Second, approaches such as the ABCX model have been slow to incorporate the notion of coping (Beresford, 1994). Third, if coping is considered, it has only been in terms of strategies which seek to maintain family stability. Thus, the outcome of coping is defined in terms of family, as opposed to individual, well-being (Beresford, 1994).

Since the mid-1980's a general theory of stress and coping known as the process model of stress and coping (Lazarus & Folkman, 1984) has been used in research into families with disabled children. Here stress is seen as a process which involves continuous interactions and adjustments, called transactions, between the person and the environment (Quine & Pahl, 1991). The individual is seen as an active agent who can influence the impact of a stressor through behavioural, cognitive and emotional strategies (Quine & Pahl, 1991).The central tenet of this model is that the process of coping mediates the effects of stress on an individual's well-being. Lazarus and Folkman (1984) define coping as "the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person" (p. 283).

Coping resources

A central feature of the transactional approach to stress is the process of cognitive appraisal (Quine & Pahl, 1991). "Cognitive appraisal is a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being, and if so, in what ways" (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986, p. 992). This is when the individual assesses whether a demand threatens their well-being and appraises their resources for meeting the demand. There are two processes involved: primary and secondary appraisal. In primary appraisal the individual yields a judgment of the event as irrelevant, benign-positive or stressful (Quine & Pahl, 1991; Folkman *et al.*, 1986). Events appraised as stressful are further appraised for three implications: harm-loss, threat or challenge (Quine & Pahl, 1991). Following from this process secondary appraisal takes place in which the individual does an assessment of the resources available for coping.

Coping is defined as the person's constantly changing cognitive and behavioural efforts to manage specific external and/ or internal demands that are appraised as taxing or exceeding the person's resources (Lazarus & Folkman, 1984). Thus coping is a process by which people try to manage the perceived discrepancy between the demands made on them and their resources in a stressful situation (Quine & Pahl, 1991).

Coping resources are aspects of the individual's external or internal environment which are not completely under the individual's control, they exist in a inactive state ready to

mediate in a positive or negative direction the individual's response to the advent of a stressor (Quine & Pahl, 1991). They may be physical, material, social, psychological or intellectual (Quine & Pahl, 1991). The nature and type of coping then generated by the individual will then be determined by the coping resources in the individual's environment. Research has reported that women are more vulnerable than men to stressful life events and use different coping resources and strategies to cope with them (Gray, 2003). A sense of mastery and control are useful resources as buffers to stressful life events, however women report a lesser sense of control over their circumstances than men do. Studies have also shown that while men use a more stoical and inexpressive style of coping women use a more emotional and expressive style. Women are also more likely than men to seek social support from family members and friends.

Understanding stress and its relationship to health has increasingly become a focus of both researchers and clinicians (Hammer, 1988). Recent research on stress has been directed towards the identification of variables that are believed to mediate between stressors and the psychological and physical outcomes produced by stressors. These variables include psychodynamic defences, specific coping strategies, social indicators such as income and education, cognitive appraisal, and coping resources (Hammer, 1988). The Coping Resources Inventory (CRI) was therefore developed to provide a standardised measure of coping resources that may prove important in mediating the stress response. The CRI is a 60- item questionnaire with the items on a four-point Likert scale, with answers being never or rarely, sometimes, often, always or almost always.

Respondents are expected to mark the answer for each of the sixty statements that describes them best in the last six months.

One of the goals of the CRI was to provide a tool for identifying resources currently available to individuals for managing stress and therefore places an emphasis on resources rather than deficits (Hammer, 1988). The CRI has been used for a number of purposes in both clinical and educational settings. The CRI's potential uses are in the treatment planning for stress-related problems of individuals in counselling; as a tool for designing stress workshops tailored for specific groups; and as a research instrument to investigate coping resources in various populations and to provide a standardised measure in coping research.

Coping resources and successful adaptation

Despite the various stresses placed on families with an autistic child some families appear to adapt better than others. This observation has led to research that aimed at trying to identify why some families cope better than others (Wolf *et al.*, 1989).

Research has shown that successful family adaptation to autistic children can be best understood in the context of successful family coping with any kind of stressful event (Bristol, 1984). However, as noted above, recent research has also noted the importance of individual coping resources as a means to buffer the effects of a stressful event. Although every disability brings with it problems, autism presents some unique

challenges to the family. Coping is necessary for the maintenance of the family and for the quality of life to remain intact for the individual family members (Norton & Drew, 1994). There are two widely recognized functions of coping: regulating stressful emotions (emotion-focused coping) and altering the troubled person-environment relation causing the distress (problem-focused coping). Demographic variables such as age, social class, level of education and cultural variables may all influence an individual's ability to cope.

McCubbin and Patterson (1982) define resources for adaptation as:

> "The psychological, social, interpersonal, and material characteristics of individual members, the family unit, and the community that may be brought into play in reducing tension, managing conflicts, and in general, meeting demands and needs. Individual resources include education, psychological stability, the capacity to be nurturing, the ability to manage the home, the ability to function independently, and the ability to manipulate various resources to one's advantage. Family resources could include integration, cohesion, flexibility, organisation, moral religious values, and expressiveness. Finally, environmental resources might include social support networks, medical and psychosocial counselling services, and social policies that enhance family functioning and protect families from financial disaster."
>
> (Bristol, 1984, p. 293-294)

Personal coping resources

Personal coping refers to efforts made by an individual acting as his or her own resource, rather than seeking support, assistance or validation from a social environment (Schilling, Gilchrist & Schinke, 1984). These can be both physical and psychological variables.

They include physical health, morale, ideological beliefs, previous coping experiences, parenting skills, intelligence and personality characteristics (Beresford, 1994).

Physical health

Physical health is an important coping resource for parents of disabled children (Beresford, 1994) and caring can be physically demanding. Caring for a disabled child may create vulnerabilities as the physical and health resources of parents are worn down as they care for their child.

Beliefs and ideologies

Parents' approach to life and their religious or ideological beliefs have been shown to be an important coping resource (Pargament, 2001). Research has pointed to a variety of religious coping methods that serve various ends. For example Pargament *et al.* (1988 in Pargament, 2001) have distinguished three different approaches to responsibility and coping in a stressful situation: the self-directing approach in which the individual relies on self rather than God; the deferring approach, where the individual places the responsibility for coping on God; and the collaborative approach, where the individual and God are both active partners in coping. Religious beliefs may also offer a way for parents to interpret or redefine their child's disability (Beresford, 1994).

Personality variables

Personality variables are important to coping resources in themselves and also affect the availability of other personal and socio-ecological coping resources (Beresford, 1994).

Some of the personality variables that have been shown to have a positive association with coping are optimism, extraversion, and humour. Further more beliefs about locus of control are also important stress mediators, with those who have an internal locus of control being less vulnerable to the effects of stress.

Previous coping experiences

All individuals bring a history of experiences of coping to any new situation. This may affect the initial appraisal of an event as well as the choice of coping strategy (Beresford, 1994).

Parenting skills

Parenting skills embrace those competencies or behaviours that enable parents to manage or deal with their children (Beresford, 1994). These skills include discipline, supervision, communication and negotiation with the child.

Socio-ecological coping resources

The second group of coping resources are those found in an individual's environment and social context (Beresford, 1994). They include the marital relationship, social networks, practical and functional resources and economic circumstances.

Social support

One important parental resource is social support (Bristol, 1984; Boyd, 2002). Cobb (1976 in Bristol, 1983, p.267) describes social support as "information leading to the person to believe that he is cared for and loved, esteemed and valued, and part of a network of mutual communication and obligation". Cobb notes that the actual exchange of goods and services in such a relationship is less important than having the persons know that they are loved and valued and that they can count on help from others and are expected to provide assistance in return.

Schilling, Gilchrist and Schinke (1984) define three levels of social support. The first level is derived from close family members and friends. The second level extends to include neighbours and more distant friends. And the third level offers a less intimate, less frequent support in the form of formal and institutional support. Social support has a number of functions including emotional support, information, practical help or encouraging feelings of normality (Beresford, 1994).

Social support affects the way that parents are able to cope in a number of ways. Among mothers of children with autism it has been found that there is an association between the degree of available social support and parental and family stress (Boyd, 2002). However, the ability of social support to serve as a stress mediator has been found to be related to the parent's gender. For example, it has been found that social support contributed to lower maternal stress, yet for fathers social support was not a significant contributor to lower stress levels. The efficacy of social support as a coping resource is not only a

function of the quality or availability of support as individuals also differ in their ability to seek out social support (Beresford, 1994). Socially skilled parents are more likely to extend their social support networks more effectively than parents with poor social skills.

Spouse support

Relative to other forms of social support spouse support is the most significant (Beresford, 1994). Furthermore, perceived spouse support is as important as its objective existence. Knowing that support, if needed, would be forthcoming is an important resource for mothers. Single parents of handicapped children experience more stress than parents with spouses (Bristol & Shopler, 1983). Mothers alone with an adult-size autistic child may be physically unable to cope with them as they reach adolescence. The lack of an adult male in the home may precipitate residential placement of a child who might otherwise be able to continue living at home.

Support from the extended family and friends

Family members provide not only the emotional support of an understanding confidant, but also actual physical care for the child, transportation and, in a few cases, financial support (Bristol & Shopler, 1983). Practical support, especially child-minding, provided by extended family is important (Brown & Hepple, 1989), and support gained outside the marital relationship can also relieve burdens on the spouse.

Support from formal agencies

"Formal support is defined as assistance that is either social, psychological, physical, or financial, and is provided through an organised group or agency or for which a fee is paid" (Bristol & Shopler, 1983, p. 271). These formal support services have the potential for relieving the burdens of informal support networks and also for offering specialised support (Beresford, 1994). This level of support is usually the least intimate level of support. Research has shown that parents usually use formal support differently from informal support, in that parents often use formal support in times of crisis, and only after other forms of support have been tried (Unger & Powell, 1980).

Parents needs for support resources may vary across their own and their child's life-cycle. For example, informal support may dwindle over the years after initially high levels of support (Brown & Hepple, 1989). The need for professional support may then increase as the child grows and as parents make decisions about the child's future after schooling has finished, and when the parents become infirm and unable to continue care (Beresford, 1994).

Respite care

Respite care has been consistently specified as one of the support services families need to help them cope (Bristol & Shopler, 1983; Factor, Perry & Freeman, 1990). Respite care tends to be used in families that have limited support networks, and is generally evaluated by parents as positive. Satisfaction with the level of perceived support has also been found to be related to lower stress levels (Factor *et al.*, 1990).

The family environment

There are certain family characteristics that seem to make families more able to adapt to crises. For example, cohesion, integration, organisation, and adaptability (Bristol, 1984; Beresford, 1994). However, the family environment can either be a resource for coping or an additional source of stress. Bristol (1984) has found the family environment to be related to the degree of adaptation of parents of autistic children.

Marital status

Marital status has been said to be an important coping resource (Beresford, 1994). However, there are many different interpretations as to why marital status appears to be an important coping resource. Single parenthood has a number of ramifications. There may be increased financial strain, and housing problems. Such parents may also have to bear the stresses of care by themselves.

Socio-economic circumstances

Socio-economic circumstances are believed to be a fundamental source of stress in families with a disabled child (Beresford, 1994). There are a number of stresses associated with socio-economic circumstances, ranging from worries about money to the strain of living in poor housing conditions. Quine and Pahl (1991) describe ways in which money can buffer the effects of stressful behaviour for mothers of handicapped children as money can buy practical resources such as child-minding, laundry equipment and cleaning services, thus relieving parents of certain care and household tasks.

There have been a number of studies on parents' views of which coping strategies are most helpful. (McCubbin, McCubbin, Patterson, Cauble, Wison & Warwick, 1983) present some of the coping strategies found to be helpful by the majority of mothers were in their studies:

a. believing that the intervention programme from which they were seeking help for their child and their family's best interests at heart;
b. learning how to help their children improve;
c. believing in God;
d. talking over personal feelings and concerns with their spouses;
e. building closer relationships with spouses;
f. trying to maintain a stable family life;
g. developing themselves as persons;
h. telling themselves that they had many things to be thankful for;
i. doing things with their children;
j. believing that their children will get better.

Implications for intervention

It cannot be disputed that parents of autistic children face a great deal of stress. However, research should focus on exploring the ways in which families cope. Such work has far greater implications for understanding and improving the ways that these families can be helped (Beresford, 1994). The information gathered from the process model of stress and coping can inform, in an innovative way, practice and intervention with families who

have a disabled child. One main implication of adopting this model is that there should be two prongs to an intervention programme. These are: firstly, intervention at the level of the personal and socio-ecological coping resources; and secondly interventions to enhance parents' coping skills. The process model of stress and coping has shown that coping resources are inter-related and that coping resources affect the choice of coping strategy. Social support is a clear example here. Personal coping resources and coping skills affect the availability of social support as a resource, and hence the use of social support as a coping strategy. "…interventions with families under stress need to address the factors which mediate social support and influence parents' access to and use of social support" (Sloper *et al.*, 1991, p. 673). It is therefore important that intervention programmes identify people in the child's environment who can support the parents.

In addition the process model emphasises the active role that parents play in dealing with the stresses associated with caring for their child (Beresford, 1994). They are seen to be actively coping with their circumstances and seeking out ways to alleviate their situation further. As such, early intervention services are beginning to be driven not by system needs or child needs, but by family needs, as families perceive and articulate those needs (McGonigel & Garland, 1988).

There have been a few intervention programmes recently reported in literature that have utilised the process model of stress and coping. One such programme used the process model of stress and coping to develop a support programme for families with young disabled children (Zeitlin, Rosenblatt & Williamson, 1986). After assessing the stresses,

perceived needs, coping resources and coping strategies of the parents, the project staff used this information to feed back to the family about their 'coping status'. Weaknesses in the family's coping process were then dealt with through a range of intervention activities. These interventions included parent support groups, fathers' groups, informational workshops and lectures, sibling groups, respite care, problem-focused counselling and referral to other agencies.

Other groups have also used the process model of stress and coping to inform their interventions (e.g. Schilling *et al.*, 1984 in Beresford, 1994). These interventions have however focused exclusively on the parents' coping strategies. Parents' have been trained in the use of personal coping strategies, such as positive self-statements, self-praise, relaxation, developing social skills in order that social support can be accessed and cultivated, and problem solving skills (Beresford, 1994).

Conclusion

A child with autism presents with many unique difficulties that require a vast amount of parental time and energy. Past research has been devoted to exploring the stressors associated with caring for such a child and the deleterious effects these stressors have on the parents' well-being. Early research found that families are intensely affected by their autistic children, parents are affected as individuals, in their the marital relationship, the parent-child relationship, and the other children in the family are also affected. Research has shown that mothers were most severely affected by the autistic child and results of

various studies have showed that there is a characteristic stress profile in mothers of children with autism. Research into the effect of the autistic child on the father have largely been neglected, however, it is important to also study the effects of autism on the father as they too form part of the family system.

The characteristics of autism make raising an autistic child challenging and places great stress on the family. This stress can be conceptualised as a significant impact on the parent's social and emotional functioning and is manifested in psychological and family difficulties. There is increasing evidence that parenting an autistic child appears to provide the characteristics to produce life stress and affect many aspects of family life. Among the diverse parental problems reported are depression, fear and anxiety, difficulties in daily management of the child, burnout, financial worries, and concern over inadequate educational and professional resources for the child and the family

It cannot be disputed that parents of autistic children face a great deal of stress. However, it is now important that research begin to focus on the ways that such families cope, with varying degrees of success, with the care of an autistic child. Such work has far greater implications for understanding and improving the ways in which these families can be helped.

How well family members adjust to having a child with autism in their home may depend on the ways that they cope with the stress of raising such a child. Research has shown that the effectiveness of coping depends on the particular coping strategies used

by the parents, the resources available within the family, and the availability of social support (Paragament, 2001; Bristol, 1984). By using the process model of stress and coping many different types of coping resources are drawn upon. These include both personal and socio-ecological resources.

Rationale

The literature reviewed above highlights the issues concerning the diagnosis of autism and the sources of stress resulting from living with an autistic child in the family. Coping resources have received little attention in South African literature. South African literature instead tends to focus on the various intervention strategies available in the treatment of autism e.g. Home based programmes, speech and communication therapy and specialized education. The existing South African literature pays little attention to the parents of autistic children. The South African literature does not explore sources of stress resulting from living with an autistic child in the family, nor does it address the issue of coping resources used by parents of autistic children to deal with their various stresses. The above literature review highlights the many sources of stress faced by parents of autistic children. This research aimed at exploring the resources used to cope with the stresses arising from living with an autistic child.

Research questions

In this study the coping resources used by parents of autistic children were investigated. In order to achieve this the researcher sought to answer questions that came out of the literature review. The literature points to several coping resources that act as a mediator for perceived stress. These include the education level of the parents, if the parents belong to a support group or not, if the parents are married or not and whether the autistic child is receiving some form of intervention or not. From this the question arose: What is the relationship between perceived stress and specific coping resources? Furthermore, do mothers and fathers use the same coping resources or not?

Hypotheses

The research questions have been formulated into the following hypotheses:

1. Are there significant differences in the coping resources used by males and females?
2. Perceived stress levels will be lower if the parent has a support group
3. Parents with a high education level will perceive lower stress levels than those parents with a lower education level.
4. Perceived stress levels will be lower if parents are married.
5. Parents whose autistic child is receiving some form of intervention will perceive lower stress levels than those parents whose autistic child is not receiving some form of intervention.

CHAPTER THREE

METHODS

The methods of the current study are discussed in the following section. The sample, the procedure undertaken, the instruments utilised to assess the hypotheses, the ethical issues presented in the research, the nature of the research design adopted, as well as, the statistical procedures used to analyse the data, are examined.

Research design

In light of the fact that the present research aims to ascertain the existence of a relationship between variables and measures certain characteristic at a particular point in time, the current research can be classified as quantitative, non-experimental, descriptive design with elements of cross-sectional research (Bailey, 1982).

This research is classified as non-experimental owing to the fact that there is no control group and no manipulation of the independent variable (Kerlinger, 1986, p.348). That is in the present study the researcher measured existing variables in the sample and did not manipulate the levels of the variables at all. This approach does not allow for causal inferences to be made about the areas for concern, but does allow for associations to be made (Neale & Liebert, 1986). No randomisation procedures were used as this is not a necessary prerequisite in a non-experimental design (Neuman, 1997). Further benefits of

non-experimental research design include: flexibility, cost-effectiveness as well as ease of this design.

Descriptive research tends to have as its goal the careful mapping out of a situation or set of events in order to describe what is happening behaviourally (Rosenthal & Rosnow, 1991). This focus does not then concern itself with causal explanations. The present research study is therefore of a descriptive nature as the researcher sought to describe the coping styles of mothers and fathers of autistic children

Since the data is recorded and analysed numerically the present study is classified as quantitative. Self-report type survey questionnaires were utilised to collect the data. Advantages of using this method are that it allows for the anonymity required for this particular type of research, it is convenient for distribution purposes. Furthermore, self-report questionnaires are more economical, and they can be administered to a large group of people (Rosenthal & Rosnow, 1991). Despite these advantages, Kerlinger (1986) cautions that the voluntary nature of survey questionnaires can be biased. For instance, in the current study those who volunteered to respond may have different characteristics to those that didn't respond. A further problem involved in this type of research design is the presence of social desirability (Rosenthal & Rosnow, 1991), which is defined as "a bias or set to respond to self-evaluative questions in a socially approved manner as to appear more socially desirable either to oneself or others" (Reber, 1985, p.705). The present research assured confidentiality in an attempt to encourage respondents to respond truthfully.

Sample

The sample for the present study consisted of 31 volunteer parents of an autistic child (*n*=31). Due to the low incidence of the target population non-random purposive sampling was used. This meant that questionnaires were only handed out to individuals whom the researcher had already identified as having an autistic child. All potential participants were informed about the study through an information letter. This letter explained that participation was voluntary and that should they wish to, participants could withdraw at any stage without any negative consequences to either themselves or their children. Families were mainly recruited through the Key School in Johannesburg and Unica School in Pretoria. A few additional families were recruited through Autism South Africa (ASA). The Key School and Unica were chosen as they both provide for the special needs of children between the ages of 3 and 18 with the condition of autism. The researcher sent out 100 questionnaires. Two questionnaires went home with each child so that the mother and father could each answer individually. All parents were given questionnaires and no parents in the target sample were excluded. The criteria for family eligibility was that the child has received a diagnosis of autism using the criteria laid out in the Diagnostic and Statistical Manual of mental disorders (DSM-IV) and that the autistic child is living at home, not in an institution. The researcher received 31 completed questionnaires, yielding a return of 31%. The 31 responses were from 23 female and 8 male subjects.

Materials

There are two instruments used in this study, a self developed biographical questionnaire and the Coping Resources Inventory (Hammer, 1988).

Biographical questionnaire

This questionnaire requested answers concerning both information about the parents as well as their autistic child. With regard to the information about the parents, questions included: their relationship to the child; age and gender of all family members; their marital status; their highest grade completed at school; whether or not they were involved in any support groups (formal or informal); and lastly what their stress level was when completing the questionnaire. This question asked the respondent to state whether they felt that their level of stress was very low, low, high or very high. Over the years the term 'stress' has been diluted by colloquial usage to come to denote a range of emotions from anger to extreme tiredness. Most people have an understanding of stress due to its common usage, the question therefore is asking the respondent to measure the level stress that they perceive themselves to be experiencing.

For the child's biographical information, questions included: the current age of the autistic child; the age of the child when diagnosis was made; the child's most recent diagnosis; at what age the autistic symptoms first appeared; and whether or not the child was attending any type of intervention programme.

The Coping Resources Inventory

An introduction to the Coping Resources Inventory has been given in the literature review. In the literature review an explanation of what the test is, how it is structured, what is being measured and how it is administered is expanded on and as such will not be expanded on in the current chapter. The CRI can be administered to individuals or to a group and is appropriate for a wide range of ages (Hammer, 1988). The inventory can normally be completed in ten minutes.

For each of the sixty items, respondents use a 4-point scale to indicate how often they have engaged in the behaviour described in the item over the past six months (Hammer, 1988). Scale scores are then simply the sum of the item responses for each scale.
The total resource score is obtained by summing the five scale scores. The higher the scale score, the greater the resource. There are six items that must be reverse scored.

The CRI measures coping resources in five domains: cognitive, social, emotional, spiritual/ philosophical and physical (refer to Appendix C). The cognitive scale (COG) measures the degree to which a person maintains a positive sense of self-worth, a positive outlook toward other people, and general optimism about life. Representative item: “I feel as worthwhile as anyone else”. Items for this scale include statements number 3, 6, 11, 12, 14, 18, 23, 55, and 48. The minimum score for this scale is 9 and the maximum score is 36.

The social scale (SOC) measures the extent to which a person is involved in social networks that are capable of giving support during stressful times. Representative item: “I am part of a group, other than my family, that cares about me”. Items for this scale include statements number 4, 8, 9, 15, 25, 27, 28, 30, 35, 50, 53, and 59. The minimum score for this scale is 13 and the maximum score is 52.

The emotional scale (EMO) measures the extent to which a person is able to express and accept a range of affect. Representative item: “I can cry when sad”. Items for this scale include statements number 2, 7, 16, 17, 19, 24, 29, 31, 34, 37, 39, 40, 45, 47, 54, and 57. The minimum score for this scale is 16 and the maximum score is 64.

The spiritual-philosophical scale (S/P) measures the extent to which an individual's behaviours are guided by consistent values from personal philosophy or familial, religious, or cultural tradition. Such values might serve to define the meaning of potentially stressful events and to prescribe strategies for responding effectively. Representative item: “I know what is important in life”. Items for this scale include statements number 10, 20, 22, 32, 33, 38, 41, 44, 46, 48, and 52. The minimum score for this scale is 11 and the maximum score is 44.

The physical scale (PHY) measures the extent to which an individual engages in health-promoting behaviours thought to contribute to enhanced physical well-being. Physical well-being is thought to decrease the level of negative responses to stress and to enable

faster recovery (Hammer, 1988). Representative item: “I exercise vigorously 3-4 times a week”. Items for this scale include statements number 1, 5, 13, 21, 26, 36, 42, 43, 51, 56, and 60. The minimum score for this scale is 11 and the maximum score is 44.

A CRI profile can yield two kinds of interpretation. The first is ipsative, whereby an individual’s high and low resources are identified. Professionals can then suggest to individuals that high resources may help lessen some of the negative psychological and physical impact of stressors. Sometimes just identifying the fact that they have some relatively high resources can be a useful intervention in itself (Hammer, 1988). This may increase self-esteem, and provide a starting point for selecting coping strategies in specific situations. Professionals can also identify the low resources and explore with individuals the ways in which they can improve these areas.

A normative interpretation of the scores is also possible by referring to the standard scores on each side of the profile (Hammer, 1988). Separate profiles are provided for men and women. Normative interpretations may be most useful for identifying individuals who are especially vulnerable to stressors and who may be at-risk for a stress-related disorder. However, at present there are no reported norms for South Africa and as the CRI is normed in the USA any one using it in South Africa must interpret the scores with extreme caution.

Reliability and validity measures have been reported for the CRI (Hammer, 1988) Cronbach's alpha ranged from .77 to .91 for the six dimensions and test-retest correlation

coefficients from .60 to .73. Predictive, concurrent, and discriminant validity have been established. As mentioned above these norms have not been collected in SA and as such reliability and validity have not been established on a South African population.

Procedure

Once consent was achieved from the schools and Autism South Africa, the researcher placed two envelopes in each child's suitcase, one addressed to the mother and the other to the father. Each envelope contained a covering letter explaining the research, a letter of informed consent (refer to Appendix B), Hammer's (1988) Coping Resource Inventory and a section requesting biographical information (refer to Appendix D). In addition to this, a letter was attached from the Principal of the Key School for the parents of children at the Key School that endorsed the research being carried out (refer to Appendix E). Potential participants were thus informed about the nature of the research, their confidentiality rights, and their rights to end participation in the research at any time.

Parents who were willing to participate in the study were asked to complete the letter of informed consent and the questionnaires and return them to the school in the envelope provided and place the envelope in the sealed box provided. Most parents simply handed their completed questionnaires to the class teacher who then passed the sealed envelopes on to the researcher.

The data was then statistically analysed to yield descriptive statistics of the biographical data and the scales of the CRI. An independent t-test, and chi squared test of association was used to analyse the remaining data.

Ethical issues

The researcher was aware of the ethical difficulties that might have arisen due to the nature of the research. As the research was dealing with questions around stress and coping it was acknowledged that some people would not like to participate. In order to protect people who responded the researcher undertook many ethical precautions.

All potential participants were informed about the study through an information letter. This letter explained that participation was voluntary and that participants could withdraw at any stage should they feel the need to with no negative consequences to either themselves or their children.

Anonymity was ensured as no names were used in the reporting of the study. The information received from the parents was coded and treated statistically. At the conclusion of the study all raw data, such as the questionnaires, was destroyed. Furthermore, as no identifying information was asked from the participants (for example names, id numbers) anonymity was also ensured.

The researcher gained ethics approval through an internal process through the Psychology Department at the University of the Witwatersrand.

CHAPTER FOUR

RESULTS

The aim of this chapter is presenting the results of the statistical analyses outlined in the previous chapter. The statistical analysis of the raw data was carried out on the SAS computer programme. In this chapter the descriptive statistical analyses of the biographical data and of the scales of the CRI are presented. Each of the hypotheses laid out in chapter two will be addressed and the results of the analyses employed to answer them provided.

1. Descriptive statistics

Descriptive statistics to summarise the data were computed. Shown in Table 1.1 are the means, frequencies and standard deviations for the biographical variables of both the parents and the autistic children as well as for the subscales of the CRI.

Table 1.1

Descriptive statistics for the sample of the present study (N=31)

Variable	Frequency	Percentage
Gender		
Male	8	26
Female	23	74
Marital status		
Single	2	6.5
Married	24	77.5
Widowed	0	0
Divorced	5	16.1
Highest educational level		
Less than matric	3	10
Matric	5	16.7
Undergraduate Degree	5	16.7
Postgraduate Degree	12	40
Diploma	5	16.7
Support Group		
Yes	7	22.6
No	24	77.4
Intervention Programme		
Yes	20	66.7
No	10	33.3
Stress		
Very low	3	10
Low	15	50
High	11	36.67
Very high	1	3.33

Before commenting on the biographical nature of the sample, the reader is alerted to the table representation of these characteristics above. It is evident from Table 1.1 that 23 (74%) of individuals from the sample were female and 8 (26%) were male. The predominance of women can be explained by the fact that mothers continue to be the primary caregiver of children with special needs (DeMyer, 1979; Rodrigue *et al.*, 1992), as well as the fact that females are more likely than males to volunteer for research in general (Rosenthal & Rosnow, 1991).

With respect to the sample group, 6.5% (*n*=2) of the respondents were single, 77.5% (*n*=26) were married, and 16.1% (*n*=5) were divorced or separated. None of the respondents were widowed. The table reflects that 10% (*n*=3) had an educational level of less than matric, 16. 7% (*n*=5) had a matric, 16.7% (*n*=5) had an undergraduate degree, a large portion of the sample 40% (*n*=12) had a postgraduate degree, and 16.7% (*n*=5) had a diploma.

With regard to involvement in a support group, a large portion of the sample 77.4% (*n*=24) reported that they were not involved in a support group, either formal or informal. Only 22.6% (*n*=7) reported that they were involved in a support group. These support groups were largely formal and included ASA (Autism South Africa), PACK (Parents of Autistic Children, Kwazulu Natal), and Autism Western Cape. Only two respondents identified themselves as belonging to an informal support group that included family, friends, other parents and the teachers at their child's school.

The majority of respondents *n*=15 (50%) reported that they were experiencing low levels of stress when answering the questionnaire. Following closely behind this *n*=11 (36.67%) of the sample reported experiencing high levels of stress. 10% (*n*=3) of the sample reported experiencing very low levels of stress, and one individual reported experiencing very high levels of stress.

Lastly, 66.7% (*n*=20) of respondents reported that their child was attending some type of intervention programme. All of these parents named their child's schooling as the intervention programme. 33.3% (*n*=10) of the respondents reported that their child was not attending any type of intervention programme.

Data for the autistic children focuses on their current age, their age when they were diagnosed and their age at which the symptoms first appeared. The mean current age of the autistic children in the study is $\underline{M}$=4.73 years old, with a minimum of 4 years old and a maximum of 20 years old. The mean age when the child's autistic symptoms first appeared is $\underline{M}$=1.96 years old with a minimum of 0 years old and a maximum of 5 years old. The mean age of the child when they received their first diagnosis is $\underline{M}$=3.66 with a minimum of 1.11 years old and a maximum of 6 years old. This is represented in Table 1.2 below.

Table 1.2

Descriptive statistics of the autistic children in the present study

Variable	Frequency	Mean	Std Dev.	Minimum	Maximum
Current age	31	11.21	4.73	4.00	20.00
Symptom age	30	1.96	1.18	0.00	5.00
Diagnosis age	31	3.66	1.15	1.11	6.00

- *Current age* is the age of the autistic child at the time of completing the questionnaires.
- *Symptom age* is the age of the autistic child at the time the autistic symptoms first appeared.
- *Diagnosis age* is the age of the autistic child at the time a diagnosis of autism was made.

Descriptive statistics of the CRI Scales

The following Table 2.1 highlights the statistics for each of the subscales of the Coping Resources Inventory that was used to measure coping resources in the study. The table contains means, standard deviations, minimum and maximum scores for the sample as a whole.

Table 2.1

Descriptive statistics of the CRI scales

Variable	n	Mean	Std Dev	Minimum	Maximum
Cognitive	31	46.81	9.14	9.00	36.00
Social	31	42.97	11.76	13.00	52.00
Emotional	31	47.10	10.06	16.00	64.00
Spiritual/ Philosophical	31	50.29	9.77	11.00	44.00
Physical	31	48.52	10.22	11.00	44.00
Total	31	46.52	10.33	29.00	64.00

As is indicated in Table 2.1, which contains minimum and maximum scores, mean values and standard deviations, it is apparent that for all of the scales of the Coping Resources Inventory, namely cognitive, social, emotional, spiritual/ philosophical, and physical, the mean score is closer to the maximum value than the minimum value, indicating that all of the coping resources represented by the CRI are employed by the sample. The mean value for the cognitive scale being *M*=46.81, social *M*=42.97, emotional *M*=47.10, spiritual/ philosophical *M*=50.29, physical *M*=48.52. These scores, one may infer, indicate that although some variances of the scores are evident, the majority of the sample reflected high scores on all of the coping resource scales.

Males and females use different coping resources

Hypotheses one states that males and females use different coping resources.

Table 3.1 is a representation of the mean and standard deviation for men and women for the subscales of the Coping Resources Inventory.

Table 3.1

Mean scores for Coping Resources Inventory

Subscale	Mean Male	Std Dev. Male	Mean Female	Std Dev. Female	Df	t Value	Pr>|t|
Cognitive	44.00	10.53	47.78	8.65	29	-1.01	.322
Social	45.13	8.87	42.22	12.70	29	.60	.557
Emotional	45.13	11.12	47.78	9.84	29	-0.64	.529
Spiritual/ Philos.	46.75	5.65	51.52	10.68	29	-1.20	.241
Physical	45.00	9.77	49.74	10.29	29	-1.14	.266
Total	44.63	7.50	47.17	11.22	29	-0.59	.557

By looking at these means we see that for the cognitive scale the mean for women is $\underline{M}$=44 and $\underline{M}$=47.78 for men. This is a difference of 3.78. For the social scale women achieved a mean score of $\underline{M}$=45.13 and men $\underline{M}$=42.22, with a difference of 2.91. The emotional scale yielded a mean score of $\underline{M}$=45.13 for women and $\underline{M}$=47.78 for men. This

yields a difference of 2.66. On the spiritual/ philosophical scale the mean score for women is *M*= 46.75 and *M*=51.52 for men. This yields a difference of 4.77. On the physical scale women had a mean of *M*=45 and men *M*=49.74, with a difference of 4.74. Lastly the mean scores on the total of the subscales for women yielded a result of *M*=44.63 and *M*=47.17 for men. This yields a difference of 2.55.

Cronbach's alpha ranged from .77 to .91 for the six dimensions and test-retest correlation coefficients from .60 to .73.

An independent sample t-test was then conducted in order to ascertain whether there were any statistical differences between the means of women and men in the coping resources used. The results are presented in Table 3.1. At a five percent level of significance no significant main effects were found between women and men (Table 3.1). Thus we find that coping resources for men and women do not differ significantly.

What are the mediating variables of perceived stress?

Hypotheses two to five were all investigated using the chi-squared test of association as they all had nominal data. “The chi-squared statistic is an estimate of the degree to which the observed frequencies in all the cells differ from the expected frequencies if the two variables were in fact independent” (Terre Blanche & Durrheim, 1999, p.116). The variables that were examined here were support group, education level, marital status and intervention.

Hypothesis two states that perceived stress will be lower if the parent has a support group. The results for hypothesis two are represented in Table 4.1. As indicated in the table p= 0.29 so we conclude that there is no significant relationship between being in a support group and stress.

Hypothesis three states that parents with a high education level will perceive lower stress than those parents with a lower education level. The results presented in Table 4.2 indicate a significant association between educational level and stress.

Hypothesis four states that perceived stress will be lower if parents are married. As indicated in Table 4.3 there is a /p/ value of 0.60 that indicates that there is no significant relationship between marital status and stress.

Hypothesis five states that parents whose autistic child is receiving some form of intervention will perceive lower stress than those parents whose autistic child is not receiving some form of intervention.

As indicated in Table 4.4 intervention is significantly related to stress.

Table 4.1

Chi-squared statistic for support group by perceived stress

Statistic	DF	Value	Prob
Chi-Square	1	1.12	0.29

Table 4.2

Chi-squared statistic for educational level by perceived stress

Statistic	DF	Value	Prob
Chi-Square	1	5.15	0.02*

*.05 level of significance

Table 4.3

Chi-squared statistic for marital status by perceived stress

Statistic	DF	Value	Prob
Chi-Square	2	1.03	0.60

Table 4.4

Chi-squared statistic for intervention by perceived stress

Statistic	DF	Value	Prob
Chi-Square	1	6.20	0.01*

*.05 level of significance

Conclusion

In summary, for the tests conducted using the chi-squared test of association, no significant effects on stress levels were found for support group or marital status on stress. However, a significant effect was found to exist for intervention and educational level. Due to the low sample size (N=31) more than 25% of the cells had expected frequency counts of less than 5. As such all of the tests with a chi-squared statistic must be interpreted with extreme caution as this low expected frequency count can lead to false non-significant or false significant results.

CHAPTER FIVE

DISCUSSION

Autism is a pervasive developmental disorder that appears to have a high degree of stressful impact on family members. Research efforts during the past few decades have expanded the body of knowledge about children with developmental disabilities and the psychosocial adaptation of their parents. Despite this we do not know what the impact is of autism on the autistic child's parents.

In this study the researcher was interested in the coping resources used by parents of autistic children in an attempt to understand the resources used by parents in order to cope with the stressful situation of living with an autistic child. This type of research has implications for understanding and improving the ways in which families with an autistic child can be assisted. The major standpoint of this study is that there are various variables that mediate the perceived stress of parents caused by having an autistic child in the home. Research has shown that perceived stress is usually multifactorial in nature. In the present study perceived stress is considered to be the consequence of numerous variables. These variables include both personal and socio-ecological coping resources. Personal coping resources included in the present study were physical health, beliefs and ideologies, cognitive appraisal and emotional capabilities of the individual. Socio-ecological variables included were social support, child intervention, marital status and

level of parent education. Results of this study indicate that intervention and parent education level are associated with the level of stress experienced by parents of autistic children.

In the following paragraphs, each hypothesis is discussed in relation to the findings from the study and the literature. At the same time, the possible reasons why variables may or may not be significant are discussed.

Research has reported that women are more vulnerable than men to stressful events and that they use different coping resources and strategies to cope with these events (Gray, 2003). It is often also asserted that these gender differences in coping may also partially explain the differential impact that stressful events have on men and women. Given the results shown that men and women differ both in their vulnerability to stressful events and their coping behaviours it has frequently been assumed that the two are linked. However this may not necessarily be the case. Several points regarding gender, stress and coping need additional development. Most research has treated gender roles as equal and has failed to take into account the different roles that men and women play and their differential access to power and resources. In other words, it is inaccurate to assume that men and women experience the same problems when exposed to the same stressful life event and that they react in the same way.

Despite the difference in what mothers and fathers find stressful and that they often have access to different resources both parents completed the same questionnaire on coping resources in the present study. These measures have often been tailored to focus on stress

that the mothers have encountered and how they cope with this stress. Thus data obtained from the fathers responses to the questionnaire designed for mothers may well be invalid. Furthermore, the scales are highly subjective and often force extreme responses, either positive or negative. Future researchers may include a qualitative section in order to obtain an objective response from mothers and fathers as to what aspects of parenting an autistic child they find produces the most stress and what they do in order to cope with this stress. Unfortunately the present study did not allow for the pairing of spouses and as such a comparison between the responses from spouses could not take place. Future research might endeavor to pair spouses.

From Table 1.1 it can be seen that fathers experience the same amount of perceived stress as mothers. This knowledge creates a need for professionals to be more aware of the needs of fathers as well as mothers. However, fathers may be experiencing stress from a different source to mothers and professionals would have to take this into account and actively plan interventions for this.

Hypotheses two to five sought to investigate whether certain variables were mediators of perceived stress in the parents of autistic children. These variables included being in a support group, parent educational level, marital status and intervention. Education level and intervention were found to have a significant relationship with the level of perceived stress.

Results presented in Table 4.1 indicate that social support was not a mediating variable of stress. However, research contradicts these findings and points to social support as an important mediator of stress. Research has shown that social support has a number of functions that includes emotional support, information, practical help or encouraging feelings of normality (Beresford, 1994). Social support therefore affects the way in which parents cope in a number of ways. Social support may come from an informal structure of networks, such as family, friends or marital status, or social support may come from more formal structures such as specific support groups.

There are problems that arise when measuring social support. First, it is important to measure perceived social support resources. There may be a discrepancy that exists between parents' perception of the availability of social support, and an objective assessment of support. The parents that participated in the study were recruited from two schools that do in fact fulfill a role of social support. Schools that cater to the child's specific needs are seen to fall under the third level of social support. This level provides support at a formal level. Furthermore, schools offer practical help, provide parents with information and often have trained professionals such as psychologists and social workers on site to help parents deal with their individual needs. Despite this the majority of parents did not recognise their child's school as a form of social support. Only two respondents identified other parents and teachers at their child's school as a form of social support.

A second problem with social support as a coping resource is the fact that individuals differ in their ability to seek out or utilise social support. Research shows that the availability of social support is affected by personality variables and that socially skilled parents are more likely to extend their social support networks more effectively than parents with poor social skills. Parents who are not coping well are likely to have poor social support, and because they are under stress they are less able to negotiate and hence utilise social support.

The results in Table 4.2 indicate a value of 5.15 with a probability of 0.02, using a .05 level of significance we find a significant effect of education on perceived stress levels. The construct of education in the present study was used to measure the highest level of education obtained by the parent. The risk of family crisis may be increased in families of autistic children because of the ambiguity of the child's handicap. It is reasonable to expect that the risk of family crisis could be substantially reduced if the ambiguity surrounding the child's handicap were dispelled through early diagnosis and parental education regarding the nature of autism. Individuals who have some degree of tertiary education are more likely to have access to this type of information. Information that is accessible and easily understandable to all individuals with varying education levels should be made available. This would include those individuals who only have access to primary health care. There should be an effort to increase awareness and hence understanding of the disorder by the general public in the forms of education programmes or the distribution of informative pamphlets.

The present study found that marital status was not a mediating variable of stress as shown in Table 4.3. This is in contrast with the literature that suggests that marital status is an important coping resource. It is important, however, to be aware of a range of implications arising from marital status. Each implication is based on a different interpretation as to why marital status appears to be an important coping resource. For example, marital status may be seen to have a mediating effect on stress where there is perceived spouse support. Spouse support is seen to be an important form of social support. The same problems may then arise that were noted above under social support. There may be a discrepancy that exists between parents' perception of the availability of spouse support, and an objective assessment of support.

The literature also points out that there are several ramifications of single parenthood (Beresford, 1994). These include an increased financial burden and housing problems. Single mothers alone with an adult-size autistic child may be physically unable to cope with them. However, there are several factors that might mitigate the stress risk factors associated with lone parenthood. These may include increased support from extended family and friends. As the number of single parent families increases it is important to learn more about alternative sources of support and resources for these families.

Intervention can occur at two levels. First at the level of personal and socio-ecological coping resources and second to enhance parents' coping skills. Intervention can include parent support groups or formal education for the autistic child that includes the service of a range of professionals such as psychologists, speech therapists, and occupational

therapists. It is important that intervention strategies be driven by family needs, as the family perceives and articulates those needs.

As shown in Table 4.4 intervention had a significant effect on perceived levels of stress. This may be due to several factors. First, intervention strategies that have a focus on increasing the child's use of language and communication may improve parent-child interaction and make this interaction more pleasurable. Second, intervention that makes use of the parents as therapists may help increase the parents' knowledge and confidence in dealing and coping with their child. Furthermore, intervention that involves groups of parents working together has the potential to lead to parents developing continuing support networks. Parents may find out for the first time that they are not alone in the world. In parent groups families can share coping strategies with one another, and can offer suggestions. In the present studies parents indicated the type of intervention, if any, that their child was receiving. As indicated in Table 1.1 the majority of parents (66.7%) indicated that their child was receiving some form of intervention. All of these parents named their child's schooling as the form of intervention.

Although intervention is a mediator of stress it is not readily available to all parents. Unfortunately at present all types of intervention that are available for autistic children are extremely expensive to implement and as such is only available to the minority. Without adequate services, it is unlikely that any amount of psychosocial support can prevent family stress. It is therefore of utmost importance that intervention programmes and education about the nature of autism become readily available to individuals in the

lower socio-economic bracket. Providers that support and enhance family coping skills are challenged to address the multiple and varied needs of the specific family and tailor each intervention to the family's needs and resources.

In conclusion, one must remember that successful adaptation or coping is a process. The 'best' way to cope with having an autistic child depends on the individual child, the particular family, and the particular situation the family is dealing with.

Autism is a pervasive developmental disorder that is characterised by a triad of deficits in social reciprocity, communication and repetitive behaviours or interests. Research has suggested that these deficits present the parent of an autistic child with unique challenges and that these deficits may adversely impact on the parents' well-being. Characteristics of autism such as the child's deficits and behaviours, reactions from society and feelings of isolation, concerns over future caregiving and finances all contribute to perceived parental stress. Furthermore research has shown that mothers are most severely affected by their autistic child.

Since the mid-1980's a general theory of stress and coping known as the *process model of stress and coping* has been used in research with disabled children. A central tenet of this model is that the individual can interact with the environment and influence the impact of the stressor through behavioural, cognitive and emotional strategies. In the present study intervention and parent education level were found to mediate the stress experienced by parents of autistic children. This was done by sending out questionnaires to parents of autistic children. The questionnaires looked at both stress levels as well as

resources that mediate these stress levels. The results of the present study highlight the need for family-based intervention programmes that are specifically tailored to suit the needs of the family being helped.

In the following paragraphs implications of findings for theory are proposed and the limitation of the present study are outlined. Finally, areas for future research are suggested.

Limitations of the research

The present study has a number of limitations that the reader should be made aware of. These limitations may temper the results of the research, influence the outcomes and thus prompt improvements that future researchers may want to consider.

The sample may be limited in terms of low external validity. This is due to the fact that the sample was drawn from parents whose autistic child was attending a special needs school. This may be seen in itself as a form of intervention. There are many other parents with autistic children that are in home programmes who were not contacted to be part of this research. Thus, the research may not be able to be repeated in other contexts. Furthermore the researcher could not generalise the results to the general population, i.e. the results are only valid for parents whose autistic child is attending a special needs school.

In addition, as the sample was only selected from special needs schools this may not control for possible confounding variables particular to special needs schools. For example, the parent has access to a dedicated team of therapists, teachers, and fellow parents with whom they can share their load. Therefore, there is no assurance that extraneous variables have not systematically biased the results of the study and reduced the generalisability of the study.

Since the study used self-selection of participants (i.e. volunteer), the sample used may have confounded the study. Research has shown that individuals who volunteer may have certain characteristics that are lacking or fewer in individuals who do not volunteer (Rosenthal & Rosnow, 1991). Rosenthal and Rosnow's (1991) research has shown that volunteers tend to be better educated, have higher social class status, be more intelligent, be higher in need for social approval and tend to be more sociable than non-volunteers. As a result, those individuals missing from the sample may have provided profound insights and extra information that could have added to the study. Thus, the sample may be biased and non-representative of the general population. In addition only one third of the questionnaires sent out were returned and this is likely to skew the results. Those that did not answer could have possibly added important information had they responded.

Self-report measures, in the form of questionnaires, were used. This may mean that feedback from the respondents is very susceptible to bias and is often answered in a socially desirable way (Rosenthal and Rosnow, 1991), which is defined as "a bias or set to respond to self-evaluative questions in a socially approved manner so as to appear

more socially desirable either to oneself or to others" (Reber, 1985, p.706). Self-report questionnaires were therefore the method used as these not only uphold the ethical standards required for research but also may give respondents a sense of anonymity thus allowing them additional honesty in their responses.

Scales themselves are highly subjective. The current study relied solely on the scales presented and thus limited the responses. To account for this limitation a qualitative aspect to the research should have been included. This would have resulted in a more in depth understanding as to the reasons behind why individuals responded in the way they did.

As a result of the small number of individuals to participate in the study, the small sample size (n=31) may have reduced the statistical power of the study. This can be observed in the fact that more than 25% of the cells in the Chi-squared test had expected counts of less than 5, thus lowering the validity of the test. This may also cause false non-significant results.

In the present study a cross-sectional design is used. This is used in order to assess the relationship between variables. The research observes these variables at one point in time. Cross-sectional designs are often limited by the small amount of information available and the limited accuracy with which respondents report their perceptions and attitudes (Singleton, Straits & Straits, 1993). There are a number of problems that are inherent in cross-sectional research that may limit the conclusions drawn. One of the most prominent

threats pertains to the issue of causality, which cannot be inferred from such a design. Thus, a major limitation in the present study concerns causality issues. Such a linear outlook on the variables may not have reflected the true relationship between the variables. Furthermore, as stress is dynamic and continuous a suggestion for longitudinal research is a necessity and will be expanded on in the 'suggestions for further research' section.

A further limitation of the present research stems from the ages of the autistic children. In the present research study the ages of the autistic children ranged from 4 years old to 20 years old. This is a range of 16 years. As with normally developing children this age range presents different challenges for the different ages. Challenges at infancy, early childhood, adolescence and early adulthood would all be different. As such the variable of age in the present study cannot be said to be a uniform variable. Future studies in this area would have to attempt to look at a specific age group and examine the challenges present for that age group.

Future researchers might endeavor to undertake research with a carefully defined control or comparison group. We cannot assess the affects of an autistic child on family members unless we know how families without an autistic child function. In order to assess the effects of the disability the autistic children should be matched for adaptive behviour and other pertinent demographic variables. More consideration needs to be given to the developmental variables of the autistic child to determine how these interact with measures of family and individual functioning.

There are numerous limitations to the questionnaire that the researcher used. The literature made reference to Holroyd's (1974, 1987) Questionnaire on Resources and Stress in the majority of the studies. This questionnaire was created in an attempt to measure both the positive and negative impact of a dysfunctional child on the family (Konstantareas, Homatidis & Plowright, 1992). Its 15 a priori and clinically determined scales aim to address a variety of factors related to perceived sources of stress and support (Konstantareas, Homatidis & Plowright, 1992). Despite efforts the researcher of the present study was unable to get this questionnaire or any form of this questionnaire. The researcher then decided to use Hammer's (1988) Coping Resources Inventory. This inventory was not created for the purposes of testing the impact of a dysfunctional child on the family and thus may have limited the results. Furthermore, although there are norms for the CRI these are the norms from the USA. The CRI has not yet been normed on a South African population and the results should therefore be interpreted with caution.

Implications of the research

The results of this study serve to support and extend the research in the areas of coping resources that parents of autistic children use to cope with the many challenges they face. A traditional emphasis has been placed on treatment of the autistic child, especially through behaviour management and special education programmes. However, recently more attention has been devoted to providing supportive and counselling services to the

families of autistic children. Results of the current study serve to reinforce the importance of intervention. Furthermore the present study reinforces the need for intervention at a primary health care level for the majority of South Africans who are unable to afford the expensive intervention programmes currently available.

Focusing on the areas of stress in parents of children with autism has some important implications. First, a clearer understanding of the situations leading to stress should allow for treatment providers to assist families in changing the environment in which the family operates in order to eliminate some of these stresses. Second, given an understanding of specific child characteristics associated with elevated stress in the parents, it should be possible to focus intervention more efficiently and in a manner that will reduce these specific areas of stress.

The current study showed that intervention acts as a mediating variable for parental stress and as such highlights the need for family-based intervention programmes that are specifically tailored to suit the needs of the family being helped. Providers that support and enhance family coping skills are challenged to address the multiple and varied needs of the specific family and tailor each intervention to the family's needs and resources. Parent counselling should focus on the needs of the entire family, specifically at critical periods. It should also increase parents' understanding of their child's development, and enhance parenting confidence and self-esteem. Intervention programmes for the families of autistic children should not only focus on the needs of the child but should also deal with the despair, shame, and isolation that may be experienced by the other family

members. Furthermore intervention programmes could also lobby for an increased understanding of the disorder by the general public in the forms of educational programmes or the distribution of informative pamphlets.

The current research also shows that fathers are experiencing the same amount of stress as mothers. This knowledge creates a need for professionals to be more aware of the needs of fathers as well as mothers. The stress being experienced by fathers may be of a different nature and as such professionals would have to take this into account and actively plan interventions for this.

Suggestions for further research

Informal reports provide information that suggest that autistic children have a special impact on the family, this information is only a starting point for controlled research that may allow for a clearer interpretation of the effects of child, family and environment variables on family and individual functioning. The following suggestions are offered for future research in the area.

Although a longitudinal study would be ideal for this type study, they are costly and time consuming, therefore a cross-sectional design was used. Future researchers might endeavor to examine longitudinally those specific individual and family variables that lead to more successful psychosocial adaptation among family members of autistic children. There is a need for research with a carefully defined control or comparison

group. We cannot assess the affects of an autistic child on family members unless we know how families without an autistic child function. Furthermore, in order to assess the effects of the disability the autistic children should be matched for adaptive behaviour and other pertinent demographic variables. More consideration needs to be given to the developmental variables of the autistic child to determine how these interact with measures of family and individual functioning.

Future researchers might use more objective, behavioural measures of individual and family adaptation to enhance the validity of their findings. Researchers might also use measures to assess the impact of the autistic child on overall family interaction patterns, for example, sibling-parent interactions, sibling-sibling interactions and spousal interactions.

In addition to objective, behavioural measures further research should also include qualitative aspects as this might reveal a range of coping resources and strategies used by parents. By using a strictly quantitative method a limited list of coping strategies is presented. This practice of clustering a number of discrete resources into a single category may actually mask the impact of particular strategies on parents adjustment.

In sum, research on families with an autistic child would benefit from becoming more theoretically driven. It will be important for future research to examine exactly what are areas of parental stress and what resources both inside and outside the family are best to buffer the impact of various forms of parental stress.

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