

**PARENTS' EXPERIENCES OF THEIR MARITAL
RELATIONSHIPS AFTER THEIR CHILDREN HAVE BEEN
DIAGNOSED AS HAVING AUTISTIC DISORDER**

By

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DECLARATION OF OWN WORK

“I herewith declare that **PARENTS’ EXPERIENCES OF THEIR MARITAL RELATIONSHIPS AFTER THEIR CHILDREN HAVE BEEN DIAGNOSED AS HAVING AUTISTIC DISORDER** is my own authentic work and that all the resources that I have used and quoted have been indicated and acknowledged by means of complete references.”

Carin Davel

Date

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ABSTRACT

The purpose of this study was to gain an understanding regarding parents' experiences of their marital relationships after their children have been diagnosed as having autistic disorder. The phenomenological approach was utilised as a means for collecting and interpreting material. Three couples from the Unica school, Pretoria, wrote accounts of their experiences and were interviewed. Both the written accounts and the interviews were analysed following Giorgi's method. The research findings that emerged were themes concerning diagnosis, coping, conflict, being different, the outside world, being a couple, partnership, family-life and autism.

Key terms: Autistic Disorder (Autism), parents, marital relationship, purposive sampling, qualitative research, phenomenology, descriptive phenomenological method and Giorgi's method of analysis.

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PRE-REFLECTION

This section will address my position before the commencement of this research. Taking a brief glance at where I come from, will facilitate a link with the post-reflection section at the end of the dissertation.

Except for knowledge gained from my training, I had a limited understanding of the research question, autism per se and the research position. This study was also my first exposure to the execution of such a project. Previously I have not really been involved much with couples and their relationships. Coming from this background, this research added a fresh dimension to my world of experience. With specific reference to the interviewing process, the main challenge was to distinguish the differences between an interview and a therapy session.

Experiencing an eagerness to learn, on the one hand, and not knowing what to expect, on the other hand, were some of the feelings I have encountered both at the beginning and at various stages throughout the research. The process of risking my comfort zone surfaced during several stages of the study.

Looking back, I may have been naïve about the impact of various steps undertaken in the research process: naïve with regards to its impact on others as well as on myself. Reading the participants' written accounts may serve as an example in this regard. The meaning I attach hereto will be discussed in the post-reflection section.

Following the phenomenological framework, this research repeatedly returned to its focus on the essence of experience. However, being the central theme, at a certain level it forced me to address the same theme in my own life experiences as well.

Last but not least, the process of documenting the study as well as my involvement with the role-players involved, left me with daunting experiences but with exciting insights into human nature that I would not have missed for the world.

CHAPTER 1

PREFACE

Introduction

The goal of this chapter is to provide an introduction to the study. This will be achieved by discussing the context, question, general and specific goals as well as the structure.

1.1 CONTEXT

The history of Unica School for Autistic Children dates back to the seventies of the previous century when a determined few individuals recognised the urgent need for specialised educational facilities for these children. Starting as a separate class at a school for mentally handicapped children in 1973, the facility grew and established a small private school in 1976. This school consisted of three staff members catering for the needs of eight pupils with autism. The school, known as the Pretoria School for Autistic Children, was housed in old buildings behind the hostels of the Pretoria Technical College. Two more class assistants were soon appointed as the number of children with autism increased rapidly (Owen & Greyling, 2004).

Enormous expenses, however, necessitated an application to the Government for the school to be declared a state-subsidised institution. On April 1976 the Government's support was obtained in the creation and subsidising of educational facilities for children with autism (Owen & Greyling, 2004).

On request of the previous Department of National Education, the principal of New Hope School for Cerebral Palsied and Learning Disabled Children agreed to accommodate the children with autism on their campus. A separate wing was on disposal for the facilities of the individuals with autism and in August 1978 the unit came into existence (Owen & Greyling, 2004).

Two noteworthy additions were made in 1979. Mrs. M. Goulding (former principal of the Vera School, their sister school in Cape Town) accepted a post as Head of Department at the unit for autism and the hostel opened its doors for the first time. In 1981 Mrs. C. Koudstaal succeeded Mrs. Goulding as Head of Department (Owen & Greyling, 2004).

Due to an increase in admissions it became crucial to convert the existing hostel facilities into extra classrooms. This resulted in the Department of Education and Culture supplying funds in order to renovate and restore an old building 15 kilometers from the school for the new hostel complex (Owen & Greyling, 2004).

In April 1983 the Minister of National Education declared the unit an independent school and the name was changed to Unica School for Autistic Children. The name Unica was derived from the word unique. The Northern Association for Autistic Children and Adults (NAACA), formed by parents and staff members and currently known as the Association for Autism, and the Northern Transvaal Cripple Care Association became the original sponsoring bodies of the unit (Owen & Greyling, 2004).

The Unica School for Autism is a public benefit organisation (Unica School for Autism, n.d.a.). The school's curriculum is outcome-based and the learning programmes, offered in a highly structured environment, are modified to the specific needs of each individual (Van Wyk, 2008). This dual-medium school (Van Wyk, 2008) is situated in Menlo Park, Pretoria. Unica school accommodates 107 pupils (between the ages of three and 18 years) per annum from across the African continent (Unica School for Autism, n.d.a.). Pupils from various cultural groups are accommodated in classes ranging from seven to nine individuals per class (Van Wyk, 2008). These individuals have varying degrees of remedial problems, learning difficulties and/or intellectual abilities (Unica School for Autism, n.d.a.).

The role-players in the school system follow a multi-disciplinary approach. Key staff members are the educators, psychologists, therapists, a nursing sister, educating support

staff, hostel parents, hostel support staff, as well as a visiting psychiatrist (RemSpecED: Remedial & Special Education, n.d.c.). The parents are very significant role-players in the context of Unica school. As these parents are often directly engaged with the children, attending to the parents' experiences of various facets of their lives is deemed important. This provides the background against which I explored these parents' experiences of their marital relationships.

1.2 QUESTION

The research question of this study is: What are parent's experiences their marital relationships after their children have been diagnosed as having autistic disorder?

1.3 GOAL

1.3.1 General Goal

The aim is to describe parents' experiences of their marital relationships after their children have been diagnosed as having autistic disorder.

1.3.2 Specific Goals

The objectives of this project are to explore the topic at hand by doing (a) a literature review, (b) to describe the research methodology, (c) to conduct the research project and (d) to write the research report.

1.4 STRUCTURE

Chapter 2 will provide an outline of the literature pertaining to autism. Specific reference will be made to relevant definitions, the manner in which the symptoms present themselves, etiology, treatment and the impact of autism on the family.

Chapter 3 will explore recent and relevant research on the subject of autism and parents' experiences of their marital relationships.

Chapter 4 will explain and discuss the research position used in this study. Approaches to research will be explored and the phenomenological approach will be addressed in detail.

Chapter 5 will outline the research method used in this study. The research method will be explained in detail with regards to the research context, research participants, research material, research quality, research ethics as well as the research relevance.

Chapter 6 will present the research findings. This chapter will present the themes that emerged during the analyses of the material. Direct quotations from participants are used to substantiate identified themes.

Chapter 7 is the concluding chapter and will provide summaries of autism, research on autism and research findings on autism. Previous and present research on autism will also be integrated. This chapter will also present the limitations of the study as well as recommendations for future research.

Conclusion

This study allows parents to share their experiences so that a better understanding of their position is generated. This chapter is the introductory chapter to the study outlining the context, question, general and specific goals as well as the structure. The following chapter will explore literature pertaining to autism.

CHAPTER 2

OVERVIEW OF AUTISM

Introduction

This chapter presents an outline of the literature concerning autism. I am going to look at the relevant definitions, how the symptoms present themselves, the etiology, treatment and the impact of autism on the family. The literature referred to here as well as in the following chapter will be written from the position of the DSM-IV-TR. I am using the DSM-IV-TR as a guideline to define and to set boundaries for my research.

2.1 DEFINITIONS

The definitions, as they pertain to pervasive developmental disorders and autism, will be discussed in this section.

2.1.1 Pervasive Developmental Disorders

The Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association [APA], 2000) lists autism among a continuum named Pervasive Developmental Disorders (PDD) and these are characterized by severe and pervasive impairment in several areas of development, namely, reciprocal social interaction skills, communication skills or the presence of stereotyped behaviour, interests and activities. This section consists of Autistic Disorder, Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (APA, 2000).

2.1.2 Autism

As autism is a central theme in this research, the following has already been ascertained about this disorder from a preliminary survey of the relevant literature. Autistic disorder, or autism, is a childhood disorder marked by the presence of symptomatology

in three areas: (i) qualitative impairment in social interaction, as manifested by such behaviours as abnormal or reduced eye contact with others, failure to develop peer relationships, lack of spontaneous sharing of interests with others (e.g. showing or pointing out objects of interest to the caregiver), (ii) qualitative impairment in communication, as manifested by delayed or deviant language development or use without attempts to compensate through nonverbal communication, poor conversational skills if speech is present, and repetitive and stereotyped language and play, and (iii) a restricted and repetitive repertoire of behaviours and interests, including preoccupation with rituals, or severe resistance to environmental changes (APA, 2000; Fein, Green & Waterhouse, 1998; Stone, 2006; Whitman, 2004). Zager (2005) observes that the defining feature of autism is the presence of a distinctive impairment in the nature and quality of social and communicative development.

The following section will address the symptomatology as it presents itself in autism.

2.2 SYMPTOMATOLOGY

The symptomatology of autism will be analysed to provide a clear picture of how it presents in individuals with autism. This will be discussed in terms of the social behaviour, communication as well as restrictive and repetitive repertoire of behaviours.

2.2.1 Social Behaviour

Social impairment is generally the most severe in the preschool years. Older children may initiate interaction to get their needs met, or may be responsive but non-initiating towards others. Older or higher-functioning individuals with autistic disorder may approach others in an idiosyncratic, intrusive and socially insensitive way (Fein et al., 1998).

Deficits in social interaction are varied. It may include marked impairment in the use of nonverbal behaviours such as eye-to-eye gaze and social interaction gestures (APA, 2000; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Stone, 2006; Whitman, 2004;

Zager, 2005), deficits in various joint attention skills including seeking out others for the purpose of sharing enjoyment, interests or achievements (APA, 2000; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Stone, 2006; Whitman, 2004; Zager, 2005), developmentally inappropriate peer relationships (APA, 2000; Stone, 2006; Whitman, 2004; Zager, 2005) and poor social or emotional reciprocity or spontaneous imitation of another's language and behaviour (APA, 2000; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Stone, 2006; Whitman, 2004; Zager, 2005; Zeanah, 2005).

2.2.2 Communication

Impairments in communication affect both verbal and nonverbal skills (APA, 2000; Zager, 2005) and often go deeper than just language (Stone, 2006). There may be a delay in or absence of spoken language development as well as alternative modes of communication such as gestures (APA, 2000; Baron-Cohen & Bolton, 1994; Stone, 2006; Whitman, 2004; Zager, 2005), marked impairment initiating and/or maintaining a conversation with others (APA, 2000; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Stone, 2006; Whitman, 2004; Zager, 2005), idiosyncratic or stereotyped and repetitive language usage (APA, 2000; Stone, 2006; Whitman, 2004) and a lack of developmentally appropriate social-imitative or make-believe play (APA, 2000; Fein et al., 1998; Whitman, 2004; Zager, 2005).

The more severely affected individual with autistic disorder may remain nonverbal or minimally verbal and poorly intelligible. In those who develop more language, phonology, syntax and semantics are relatively spare, although still often at a lower level than nonverbal skills. Verbal memory, prosody and pragmatics are areas of particular difficulty for the average child with autistic disorder (Fein et al., 1998). The fashion in which these deficits are manifest is influenced by age, overall cognitive level, temperament and the presence of sensory or physical limitations (Zager, 2005).

2.2.3 Repetitive, Restricted and Stereotyped Repertoire of Behaviour

Impairments in repetitive, restricted and stereotyped patterns of behaviour may be seen in the preoccupation with one or several stereotyped and restricted interests which are abnormal either in their focus or intensity (APA, 2000; Stone, 2006; Whitman, 2004), inflexible adherence to non-functional routines or rituals (APA, 2000; Stone, 2006; Whitman, 2004; Zager, 2005), repetitive and stereotyped motor mannerisms like hand flapping, swaying and rocking (APA, 2000; Stone, 2006; Whitman, 2004; Zager, 2005) and persistent preoccupation with a specific part of an object (APA, 2000; Stone, 2006; Whitman, 2004; Zager, 2005).

The following section will attend to the etiology concerning autism.

2.3 ETIOLOGY

In order to provide a thorough background, this section will elaborate on the etiology of autism. It will achieve this outcome by looking at the relevant medical issues, neurobiology and environmental aspects.

Many different theories exist regarding the causes of autism. However, the only thing agreed upon is that it is likely to be a complex answer involving genetics, biology and neurology in combination with a number of environmental factors. One thing that is certain, is that parenting style does not cause autism (Barlow & Durand, 2005; Yapko, 2003).

2.3.1 Medical Causes

2.3.1.1 Genetic Issues

It has been increasingly recognized that autism is highly heritable (e.g., Whitman, 2004; Yapko, 2003). Twin studies indicate that concordance rates for autism in monozygotic twins vary significantly, but it is typically higher than 60% (Baron-Cohen & Bolton,

1994; Fein et al., 1998; Morgan & Okwumabua, 1990; Rutter, Bailey, Bolton & Le Couteur, 1994). Identical twins also show a much higher concordance rate for autism than do fraternal twins (Morgan & Okwumabua, 1990). Studies examining different-aged (non-twin) siblings indicate that approximately 3 percent of families with a child with autism will produce another child with autism – a prevalence rate that equals 50 to 100 times that of the general population (Barlow & Durand, 2005; Fein et al., 1998). Family studies also find higher rates of occurrences of autistic characteristics and characteristics of other psychiatric disorders, like depression and Obsessive-Compulsive Disorder, in the parents and other relatives of children with autism (Whitman, 2004). Baron-Cohen and Bolton (1994) also suggests that what is inherited may not simply be autism, but rather a range of psychological difficulties like learning problems. Siblings of children with autistic disorder may be more likely to show superiority in visuospatial over verbal abilities, cognitive difficulties and social disengagement (Fein et al., 1998).

Genetic analyses assist to locate genes involved with autism (Whitman, 2004). Possible genetic markers for autism are a marker for a gene that regulates neuron development as well as abnormalities on chromosomes two, seven, 15, 16 and 17 (Fein et al., 1998; Yapko, 2003). However, research has not identified a single gene that is the cause of autistic disorder, it is rather believed that there is a combination of genes and other factors (pre-existing conditions) which are likely to be involved (Yapko, 2003).

2.3.1.2 Medical Conditions

Several medical conditions have been identified in some children with autism. Fein et al. (1998) estimate that between one-eighth and one-fourth of children with autism have an associated medical condition, however, it is not known whether these conditions play a causal role in the development of autistic symptoms. These conditions will be briefly discussed and can be divided into genetic conditions, viral infections, metabolic conditions and congenital anomaly syndromes (Baron-Cohen & Bolton, 1994).

1. Genetic Conditions

There are a number of rare genetic conditions that can sometimes lead to autism. Phenylketonuria (PKU) is an inherited condition involving an inability of the body to break down the naturally occurring chemical phenylalanine. Fortunately, as a result of the discovery of treatment, autism due to PKU is now very rare (Baron-Cohen & Bolton, 1994; Fein et al., 1998; Yapko, 2003). Neurofibromatosis is a genetic condition that affects the nerves and skin and mental constraint due to brain damage may also occur. Occasionally, children with neurofibromatosis also develop autism (Baron-Cohen & Bolton, 1994).

Some studies indicate that autism is quite common in children who have the genetic condition tuberous sclerosis. However, because the disorder in itself is so rare it is thus not yet a proven cause of autism (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Yapko, 2003).

Fragile X syndrome refers to an abnormal gap on the X chromosome. This syndrome only occurs in a small portion of children with autism (under 10 percent), but this percentage nevertheless makes it the most common cause of autism yet identified (Baron-Cohen & Bolton, 1994; Fein et al., 1998; Yapko, 2003).

2. Viral infections

Infections that damage the brain during pregnancy or childhood may also contribute to the presence of autism (Baron-Cohen & Bolton, 1994). The rubella virus can damage the unborn baby's brain and result in mental handicap, deafness, blindness and autism. However, with the current vaccination programmes, this is no longer a common problem (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Yapko, 2003). Cytomegalovirus (CMV), together with other factors, may result in mental handicap and, more rarely, autism (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994). Occasionally, children with herpes encephalitis display an autistic-like condition. However, as many children who suffer a brain infection do not develop

autism, the cause of their problem still remains to be determined (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Yapko, 2003).

3. Metabolic Conditions

Metabolic conditions associated with autism are abnormalities of purine synthesis as well as abnormalities of carbohydrate metabolism (Baron-Cohen & Bolton, 1994). Although some children diagnosed with autism have been found to have an overproduction of purine compounds in their urine, no specific enzyme defect has thus far been identified to account for this (Yapko, 2003).

4. Congenital Anomaly Syndromes

Congenital anomaly syndromes (identifiable physical abnormalities from birth) associated with autism are Cornelia de Lange syndrome (Baron-Cohen & Bolton, 1994; Yapko, 2003), Noonan syndrome (Baron-Cohen & Bolton, 1994), Coffin Siris syndrome (Baron-Cohen & Bolton, 1994), William's syndrome (Baron-Cohen & Bolton, 1994; Yapko, 2003), Biedl-Bardet syndrome (Baron-Cohen & Bolton, 1994), Moebius' syndrome (Baron-Cohen & Bolton, 1994), Lieber's amaurosis (Baron-Cohen & Bolton, 1994), Angelman syndrome (Yapko, 2003), Pader-Willi syndrome (Yapko, 2003) and Landau-Kleffner syndrome (Yapko, 2003).

2.3.2 Neurobiological Causes

Neurobiology as a causal factor in autism will be discussed in terms of neuro-anatomical, neuro-chemical and neuro-physiological findings.

2.3.2.1 Neuro-Anatomical Findings

Studies of neuro-anatomical abnormalities in patients with autistic disorder have, although with great variability (Fein et al., 1998), revealed abnormalities in different regions of the brain (Baron-Cohen & Bolton, 1994). Gross cortical and ventricular

abnormalities have been found in some cases and not in others (Fein et al., 1998). Abnormalities in limbic areas of the brain (Baron-Cohen & Bolton, 1994; Fein et al., 1998), in the brain stem (Baron-Cohen & Bolton, 1994; Whitman, 2004) and fourth ventricle (Baron-Cohen & Bolton, 1994) have also been implicated. Studies have also found abnormalities in the cerebellum, although inconsistencies exist regarding the nature of these cerebellar abnormalities (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994; Fein et al., 1998; Matson, 1994; Whitman, 2004; Yapko, 2003). Brain structures such as the pons, amygdala, hippocampus have also been implicated (Yapko, 2003). Some studies have found a reduction in Purkinje cells, granule cell loss in the cerebellum and various size density issues of cells in the hippocampus, amygdala and anterior cingulate cortex (Yapko, 2003). Other studies have demonstrated the temporal lobes (Whitman, 2004; Yapko, 2003) and frontal lobes (Whitman, 2004) as playing a role in the development of autism. One must, however, note that no single abnormality has been found in all of these post-mortem brain studies and uncertainties thus still exist (Baron-Cohen & Bolton, 1994). While research continues, there are no firm conclusions that can be drawn yet regarding a specific brain structure or structures, either damaged or not developed, that consistently cause autism (Yapko, 2003).

2.3.2.2 Neuro-Chemical Findings

Investigations of neurotransmitter functions have produced inconsistent findings (Fein et al., 1998). The only brain chemical that has clearly been found in abnormal levels in individuals with autistic disorder is the neurotransmitter serotonin (Baron-Cohen & Bolton, 1994; Fein et al., 1998). It has been discovered that between 30 and 50 percent of children with autism have abnormally high levels of serotonin in the blood (Baron-Cohen & Bolton, 1994). Dopamine is another neurotransmitter implicated in autism (Whitman, 2004). However, despite reported improvements in many symptoms after treatment with drugs that block dopamine, research results in this regard are not in agreement (Fein et al., 1998). GABA, an inhibitory neurotransmitter that serves to modulate reactivity in the brain, may also play a role in autism (Whitman, 2004). With only limited empirical support, endorphins constitute much of the notion for considering them a possible causal agent in autism (Matson, 1994). Over-activity of the opiate

peptide beta-endorphin has been suggested by some studies and supported by findings that opiate blockade reduce negative effects of autism in some patients (Fein et al., 1998).

2.3.2.3 Neuro-Physiological Findings

Neuro-physiological findings have suggested diminished temporal lobe activity and a possible delayed frontal lobe maturation in individuals with autistic disorder. Another finding, although not unique to autism, is a global glucose hyper-metabolism in individuals with autism. Research examining brain waves have suggested a developmental immaturity of brain mechanisms controlling sleep and an abnormally suppressed inhibition of sensory responding in individuals with autism. Other neuro-physiological research relying on cerebral electrical recording has indicated disruptions in normal lateralization in those with autism (Fein et al., 1998).

2.3.3 Environmental Causes

It has been suggested that environmental factors influence the expression of genes or even cause autism directly. Although specific environmental triggers for autism have not yet been isolated, it is known more generally that specific environmental factors can cause and/or place a person at increased risk for developmental disorders (Whitman, 2004). We will look at the difficulties concerning pregnancy, infections and toxins.

Environmental factors can include different kinds of events that can impact a fetus (before birth) or an infant or child (during or after birth) (Yapko, 2003). Various factors suggest that difficulties in pregnancy or delivery may cause brain damage in the infant. However, it is important to remember that these factors also occur in the histories of many children who subsequently develop perfectly normal. One can thus conclude that these factors alone are not sufficient to cause the condition. Rather, they may operate in combination with genetic or other factors, or merely indicate the presence of abnormalities already existing in the baby (Baron-Cohen & Bolton, 1994).

Infections, as a possible cause of autism, not only fall under the medical issues involved, but can also be seen as part of the environmental causes of autism. There is anecdotal evidence of several different infections in pregnant women who have subsequently given birth to children with autism. These infections include rubella (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994; Yapko, 2003), herpes (Baron-Cohen & Bolton, 1994; Yapko, 2003), HIV (Yapko, 2003), cytomegalovirus (Barlow & Durand, 2005; Baron-Cohen & Bolton, 1994; Yapko, 2003) and Epstein-barr (Yapko, 2003). Diseases of children associated with autism, include encephalitis (a swelling of the brain tissue which can be a complication of measles and mumps), otitis media (ear infections), yeast and streptococcus bacterial infection. However, these infections are not unique to autism (Yapko, 2003).

Pollutants and toxins in the environment and their effect on children's hearing, behaviour, sensory, motor and mental development are also being studied for a possible link to autism. Research in the area of lead poisoning has shown a relationship between environmental toxins and subsequent learning, behaviour and attention deficits. However, the link with autism is under investigation (Yapko, 2003).

The following section will address the treatment concerning autism.

2.4 TREATMENT

This section will look at the treatment of autism in order to gain an understanding of the treatment process involved. This will be achieved by discussing behavioural, educational, pharmacological and other treatments.

When considering treatment options for children with autism, it is of utmost importance to recognize that no single approach or programme is sufficient. It is often necessary to combine various approaches and to provide treatment on multiple levels, for example, behavioural intervention, education and speech therapy (Barlow & Durand, 2005; Yapko, 2003).

2.4.1 Behavioural Treatments

Behavioural approaches have been given most attention in the research and have been used the longest. They have shown to be highly effective in controlling or eliminating many symptoms as well as in developing new skills in individuals with autism (Yapko, 2003). Behavioural modification approaches are, however, most beneficial when they are incorporated into more functional treatment methodologies rather than being conducted in isolated drill sessions (Richard, 2000). Some effective behavioural approaches will be discussed next.

Applied Behavioural Analysis (ABA) was developed by Dr Lovaas. ABA uses psychological principles of behaviour to shape desired behavioural responses and decrease problematic behaviours. The common goal of this approach is to train a child to give a new behavioural response to a specific stimulus based on positive and negative consequences, simply referred to as either reward or punishment. The only “punishments” used in the programme are social rather than physical, such as saying “no” or giving “time outs” (Richard, 2000; Yapko, 2003). Scientific evidence has lent substantial support to the use of ABA in working with individuals with autism (Fein et al., 1998; Richard, 2000; Yapko, 2003).

Discrete Trail Training (DTT), also associated with the work of Dr Lovaas, consists of several basic components. It includes intensive home-based training for 30 to 40 hours a week in a one-on-one context. Behaviours are broken down into smaller parts. Tasks are repeated until achieved before moving on to more difficult tasks and a child is rewarded for each instance when a desired behaviour is demonstrated (Richard, 2000; Yapko, 2003). Empirical research supports the use of DTT in working with individuals with autism (Fein et al., 1998; Richard, 2000; Yapko, 2003).

Differential reinforcement typically involves providing reinforcement if an individual does not display deviant target behaviours for a specified time interval (Gardner & Cole in Matson, 1994). The procedure consists of furnishing praise and a favourite edible at the end of intervals in which the child did not display aggression. Available research

suggests that differential reinforcement is an effective treatment for aggression and noncompliance. However, reinforcement alone is not always effective and can, therefore, be used in conjunction with several forms of punishment like, restraint, response cost and overcorrection (Matson, 1994).

Pivotal Response Training (PRT) is considered a behavioural treatment based upon applied behavioural analysis principles and the natural language paradigm. The emphasis is on teaching individuals the pivotal skills associated with communication (eg. motivation) to facilitate their development in a variety of areas (play skills, social skills, language development). PRT works to increase motivation by including components such as allowing the child to make choices in the treatment such as what activity or task to engage in, turn-taking and positive reinforcement. This programme is based upon empirically supported research (Yapko, 2003).

2.4.2 Educational Treatments

A trend in special education has mainly been towards the child attending a class that is composed of a mixed group of special needs and typical peers, for part or all of the school day, sometimes with a one-on-one aside to facilitate participation (Fein et al., 1998). It does not, however, mean that integration into mainstream schooling is better than education in separate units or schools for autism, since such specialist units often have expertise and resources that are hard to find in mainstream settings (Baron-Cohen & Bolton, 1994). One must note that it is clinically obvious that at least some children with autism need more intensive one-on-one teaching than is available in a mainstream setting before they can benefit from the teaching and social opportunities in a regular class (Fein et al., 1998). Highly structured teaching programmes have claimed to produce the greatest gains. Even with as little as two years schooling, children with autism improve considerably in their educational development (Baron-Cohen & Bolton, 1994). Some educational interventions will be addressed next.

Treatment and Education of Autistic and Related Communication Handicapped Children, most commonly referred to as TEACCH, is a widely known educational

programme (Baron-Cohen & Bolton, 1994; Richard, 2000; Whitman, 2004; Yapko, 2003). The general focus of treatment is on improving adaptation by building on an individual's strengths and addressing limitations through the utilization of those strengths (Whitman, 2004). It aids the individual with autism to achieve his or her potential and to reach his or her own maximum competency as an adult (Richard, 2000). The programme includes a systemic way of organizing the environment, scheduling activities and teaching methods. One of the most common methods employed in the TEACCH programme is the use of visual materials. Organizing a child's world visually as well as the sequencing of behaviours helps to provide a structure for a child who might otherwise be stressed or highly agitated by not knowing what to expect or to do next (Richard, 2000; Whitman, 2004; Yapko, 2003). This programme also works with parents, either by encouraging parent training and counseling and/or facilitating parent support groups. Parents are considered to be the child's first and most important teachers (Baron-Cohen & Bolton, 1994; Matson, 1994; Whitman, 2004). This approach is based on sound research and programme efficiency is continually being evaluated (Matson, 1994; Richard, 2000; Yapko, 2003).

The SCERTS model prioritizes Social Communication, Emotional Regulation and Transactional Support. It incorporates these principles in an educational treatment approach for enhancing communication and socio-emotional abilities in individuals with autism spectrum disorders (Yapko, 2003; Zager, 2005). The SCERTS model is consistent with empirically supported interventions and it reflects current and emerging "recommended practices" (NRC in Zager, 2005, p. 354).

2.4.3 Pharmacological Treatments

There are no specific medications designed to either treat or cure autism spectrum disorders. However, the medication commonly used are for symptom management (Yapko, 2003), to control specific autistic and co-morbid symptoms as well as to manage problem behaviours (Whitman, 2004). One should bear in mind that drug treatment should only serve as adjuncts to more comprehensive behavioural and educational interventions (Morgan & Okwumabua, 1990). Neuroleptics, selective

serotonin re-uptake inhibitors, opioid antagonists, stimulants and anticonvulsants will be discussed as possible pharmacological treatments.

2.4.3.1 Neuroleptics

Neuroleptics are a class of drugs that are considered good early candidates for the treatment of autism, specifically because older children and adults with autism were found to have high levels of serotonin in their blood and cerebrospinal fluid (Whitman, 2004). Neuroleptics have been used in individuals with autism to reduce agitation, aggression and repetitive behaviour (Yapko, 2003). Haloperidol and chlorpromazine have also been found to reduce agitation, aggression and emotional lability, but most physicians are reluctant to use these agents in young children because they can produce movement disorders (Fein et al., 1998). Risperidone, an atypical neuroleptic, appears to produce less severe side effects than neuroleptics (Whitman, 2004; Yapko, 2003). It has shown to be successful for some individuals exhibiting self-injurious behaviour. Other drugs in this group include medication such as Clozapine, Olanzapine, Quetiapine and Ziprasidone. Some neuroleptics are strong and can produce possible permanent side-effects. Therefore, their use is typically for a temporary reduction in problem behaviour rather than long-term use (Yapko, 2003).

2.4.3.2 Selective Serotonin Re-uptake Inhibitors

Selective Serotonin Re-uptake Inhibitors (SSRIs) are used to treat anxiety and depression, reduce agitation and aggression and increase an overall tolerance for changes (Yapko, 2003). Clomipramine, a serotonin re-uptake inhibitor, has shown to reduce stereotypic behaviours, hyperactivity, anger and compulsive behaviours (Gordon, State, Nelson, Hamburger & Rapoport in Whitman, 2004). Fluoxetine (trade name Prozac) has been found to be useful in treating some symptoms of autism in both children and adults, especially in patients with co-morbid conditions of depression and anxiety (Fein et al., 1998; Whitman, 2004). Self-injury and aggression have also reported to be relieved by Fluoxetine (Fein et al., 1998).

2.4.3.3 Opioid Antagonists

High levels of opioids have been found in the cerebrospinal fluid of some children with autism. It appears that opioids inhibit the feeling of pain associated with self-injurious behaviours (Whitman, 2004) and reduce social withdrawal and stereotypes (Fein et al., 1998). Kolmen, Feldman, Handen and Janosky (1995) have found that Naltrexone, an opioid antagonist, reduces hyperactivity and restlessness in about one-half of their participants.

2.4.3.4 Stimulants

Stimulant drugs, such as Ritalin, have been prescribed for children with autism. Although greater improvements have been shown for higher functioning children, results have been inconsistent regarding the efficacy of these drugs. Stimulants are not widely prescribed for autism per se, but rather to control problem behaviour such as hyperactivity (Fein et al., 1998; Quintana et al., 1995).

2.4.3.5 Anticonvulsants

Several anticonvulsant medications are used to control seizures which occur in almost one-third of individuals with autism spectrum disorders. These drugs include valproic acid, divalproex sodium, lamotrigine, topiramate, carbamazepine and vigabatrine (Whitman, 2004).

2.4.4 Other Treatments

Some of the other treatments that will be addressed here are speech and language therapy, occupational therapy, adapted physical education and music, dance and art therapy.

2.4.4.1 Speech and Language Therapy

Individuals with autism spectrum disorders can necessitate Speech-Language Therapy for many different types of reasons (Baron-Cohen & Bolton, 1994; Fein et al., 1998; Whitman, 2004; Yapko, 2003). Difficulties with communication can range from being nonverbal and unable to use speech at all to the other end of the continuum in which an individual is highly verbal yet unable to grasp certain concepts or engage appropriately in social skills. Some common communication problems experienced by individuals with autism spectrum disorders include, among others, a lack of speech, regression of speech, echolalia, incomplete sentences or limited and poor language comprehension (Yapko, 2003). There is a substantial base of empirically supported data that Speech-Language Therapy is effective in helping to reduce communication problems in individuals with autism (Baron-Cohen & Bolton, 1994; Yapko, 2003).

2.4.4.2 Occupational Therapy

Occupational Therapy is a form of treatment that usually includes self-care, sensory motor and fine motor skills (Yapko, 2003). There is considerable scientific research that supports Occupational Therapy services for some motor impairments in individuals with autism (Fein et al., 1998; Yapko, 2003).

2.4.4.3 Adapted Physical Education

Physical Therapy is a form of treatment that specializes in developing strength, coordination and movement in the large muscle groups and thereby improving the gross motor skills (Yapko, 2003). Physical therapy is an empirically supported treatment for specific motor deficits (Fein et al., 1998; Yapko, 2003).

2.4.4.4 Music, Dance and Art Therapy

There is testimonial evidence suggesting the potential utility of music, dance and art therapies. However, the efficacy thereof has not been subjected to empirical

examination. These therapies can be designed to build on the special abilities and interests of individuals with autism as well as to help them develop in areas in which they are deficient (Baron-Cohen & Bolton, 1994; Whitman, 2004). Music therapy is used in most special schools for autism, with good results (Baron-Cohen & Bolton, 1994).

The next section will deal with the impact of autism on the family as this is the primary focus of this study.

2.5 IMPACT ON THE FAMILY

This section will attend to the impact of autism on the family. I acknowledge that, in this case, autism not only has an influence on the family but also on various other relationships and role-players. However, I would like to limit this literature review to the family in order to set a boundary for my research. I will thus from now on only attend to the parents' experience in general, the experience of siblings, the experience of the extended family and the experience of the parents' marital relationship. In the following chapter the research will focus on the experience of the parents' marital relationship.

2.5.1 Experiences of Parents

According to DeMyer (1979), parents of children with autism face enormous difficulties and pressures in rearing them. Kingston (2007) analysed narratives from parents with children with autism. She concluded that normal family life ceased to exist in the case where the child with special needs also had behavioural problems. The resulting stress of living with a child with autism seems to have weakened some marriages. However, it should be noted that it has also strengthened some other marriages (DeMyer, 1979).

Parents of children with autism are intensely affected by the developmental failure of their child (DeMyer, 1979). Many parents of children with autism experience depression, anxiety and hopelessness and experience a lack of support from the other

spouse, friends and family. Parents may even feel anger and withdrawal and marital strain may occur (Ross & Jolly, 2006). DeMyer (1979) also found in her research many experiences of parental guilt, frustration, anger, feelings of sadness and failure and a general reduction of joy in life. Several mothers expressed anger at some symptom or feature of the condition, but rarely directly towards the child. One or both parents also described increased physical and psychological tension (DeMyer, 1979). According to Kingston (2007), family members experience having a child with autism as isolating and in effect disabling the whole family. Eventually, acceptance and adaptation, both positive and negative consequences may occur (Ross & Jolly, 2006).

Receiving the diagnosis of autism can cause significant stress on the parents. Aspects like the reality of the child's limited life, the loss of expectations for the child the parents hoped to have and the burden of care for the child are only some of the aspects that can have an effect on the parents. However, early diagnosis and assessment is widely considered to be the first step in helping parents develop awareness of the challenges they have to face (Ross & Jolly, 2006).

DeMyer (1979) found in her study that several fathers experienced that the mothers' preoccupation with their child and the need to be home with the child cut down on their pleasure in life, because they are not able to go about as much as a couple. About a third of the mothers in the group responded that they were satisfied with the way their husbands helped, however, about 27 percent were at the other end of the continuum.

2.5.2 Experiences of Siblings

Autism affects everyone in the family. Perhaps no one feels this effect more than the siblings of the child with autism (Tilton, 2004). Previous research has demonstrated that the consequences of having a sibling with a learning disability are not unequivocally positive or negative (Randall & Parker, 1999).

DeMyer (1979) states that increased parental tension and worry inevitably affect the siblings of children with autism. The child with autism usually requires a great deal of

parental time, energy, attention and resources (Randall & Parker, 1999). In her study DeMyer (1979) determined that the most prominent negative effect in 30 percent of families was that one or more children in the family felt neglected or the parents reported relative neglect because so much time was spent and attention was paid to the child with autism. About 15 percent reported regression in habit training that seemed related to the effect of their sibling with autism. On the other hand, she mentions that the most common effect in 54 percent of the cases was that the special problems brought out the helpful side of one or more of the siblings. Kingston (2007) remarked that siblings of children with special needs get on with their own lives and they also become aware of and open-minded about disabilities. However, when confronted with ignorance and prejudices, they might react angrily and defensively. Nevertheless, being a sibling of a child with autism undoubtedly is a deep affecting experience (DeMyer, 1979).

Kingston (2007) found that mothers of children with autism expressed feeling guilty for neglecting their non-disabled children and sacrificing their needs because of the demands of the child with a disability. Paradoxically, mothers also found great comfort and support from their non-disabled children who had quickly adjusted and accepted the family life with a difference.

2.5.3 Experiences of Extended Family

Autism and its related conditions are often not understood by the extended family (Tilton, 2004). DeMyer (1979) remarks that while many members of the extended family try to be helpful in the childrearing, parents sometimes feel more stress than being assisted by the family. Remarks made generally in the spirit of helpfulness can nevertheless be critical and contribute to the stress. Events like outings, shopping and holidays can be stressful for the entire family when a child with autism has behavioural issues (Tilton, 2004).

A positive experience is most common for parents of children with autism and their extended family. Such a support system can do wonders for the immediate family of a

child with autism. When a situation with the extended family is not ideal, it is often because of lack of involvement (Tilton, 2004).

2.5.4 Experience of the Parents' Marital Relationship

Tilton (2004) remarks that it is estimated that 50 to 75 percent of marriages fail if a disabled child is part of the family. Exact statistics vary widely depending on the source, but the numbers are always high (Tilton, 2004). Research regarding marital happiness and unhappiness, divorce and sex for parents with children with autism will be briefly discussed next.

DeMyer (1979) studied parents of normal children in comparison with parents of children diagnosed with autism. She concluded that general ratings of marital happiness and unhappiness were not significantly different between couples who had a child with autism and those who did not; however, there were obviously more strain in marriages where there was a child with autism. There also tended to be more extremely happy or happy marriages among couples with normal children (autistic 30%; normal 42%) and more extremely unhappy marriages among couples with a child with autism (autistic 30%; normal 18%). DeMyer (1979) concluded that the effects of the stress of the child with autism seriously affected parents as individuals and spilled over into the marriage itself.

The child with autism figured more prominently in thoughts about divorce than did a normal child (autistic 27%; normal 0%). DeMyer (1979) states that if the parents do not learn early in the life of their child with autism to be supportive of each other, divorce may be one of the negative results. However, knowing that couples with a special-needs child have a higher divorce rate is the first defence to protect a marriage (Tilton, 2004).

One of the most difficult things in a marriage, not even to mention a marriage with a disabled child, is maintaining the intimacy that is unique to marriage (Tilton, 2004). When it comes to sexual adjustment, DeMyer (1979) states that parents of normal

children tend to have a better sexual relationship than parents of children with autism. While groups were equal as to minor or moderate sex difficulties in the mentioned study, there tend to be fewer parents with children with autism reporting an excellent sexual relationship and more reporting severe problems. Mothers of children with autism reported more often than mothers of normal children that worries about the child with autism interfered with their interest in sex (DeMyer, 1979).

Conclusion

The goal of this chapter was to give the reader an overview of the literature concerning autism. This goal was achieved by addressing the relevant definitions, how the symptoms present itself, the etiology, treatment and impact of autism on the family. In the following chapter I will focus on the relevant research pertaining to the parents' experiences of their marital relationship after their children have been diagnosed as having autistic disorder. The next chapter will explore research more specific to the topic.

CHAPTER 3

RESEARCH ON AUTISM

Introduction

The goal of this chapter will be to look at the recent and relevant research pertaining to parents' experiences of their marital relationship after a child of theirs has been diagnosed as having an autistic disorder. This will be achieved by addressing related research and exploring the various issues surrounding it. The process of gathering information for inclusion in this research consisted of searching the PsycInfo, Sabinet, JStor, InfoTrac, EbscoHost, Eric and Social Work Abstract databases. I will now briefly look at the broad areas I have come across during the search.

3.1 RESEARCH OVERVIEW

There were a few available research resource areas that came up during the search when viewing the recent and applicable literature. Parental stress when there is a child with a disability in the family, whether it be a pervasive developmental disorder (e.g., Donenberg & Baker, 1993; Fisman & Wolf, 1991; Lecavalier, Leone & Wiltz, 2006; Yamada et al., 2007), or another handicap (e.g., Kazak & Marvin, 1984), features in the literature. Research pertaining to the support for and/or coping of parents with a child with autism (e.g., Twoy, Connolly & Novak, 2007) and other disabilities (e.g., Pain, 1999; Taanila, Syrjala, Kokkonen & Jarvelin, 2002) is also prominent. Research focuses on the parental marriages where there are children with developmental disabilities (e.g., Kersh, Hedvat, Hauser-Cram & Warfield, 2006; Rimmerman, Turkel & Crossman, 2003), physical and intellectual disabilities (e.g., Withers & Bennett, 2003), behavioural problems (e.g., Mahoney, Jouriles & Scavone, 1997), mentally retarded children (e.g., Floyd & Zmich, 1991) and disabilities in general (e.g., Risdal & Singer, 2004; Stoneman & Gavidia-Payne, 2006). Literature containing information concerning the marital relationship when there is a child with autism in the family are covered by Blair et al. (1996), Fisman, Wolf and Noh (1989), Hutton and Caron (2005),

Rodrigue, Morgan and Geffken (1990), Shelly (2004) and Woodgate, Ateah and Secco (2008). I will now turn to the specific research question at hand.

The focus of this research project calls for literature concerning the marital relationship between parents when a child of theirs has been diagnosed with an autistic disorder. As is evident in the previous paragraph, I could not find much information specifically linking the marital relationship and children with autism. Worthy of mention is the fact that these studies at times only state that there is an effect of a child with autism on the marriage. The literature does not describe this phenomenon in much detail. For me, this realization indicates a gap in the field and constitutes the motivation for my research topic. I will now turn to the relevant literature that I managed to locate.

I intend exploring the studies pertaining to the marriage and children with an autistic disorder (Blair, et al., 1996; Fisman et al., 1989; Hutton & Caron, 2005; Rodrigue et al., 1990; Shelly, 2004; Woodgate et al., 2008). Using these studies as a frame of reference, I will now further elaborate on my motivation for my research. I will achieve this by looking in detail at the specific information pertaining to the research.

3.2 SPECIFIC RESEARCH ON AUTISM

In this section I will address the relevant literature sources from the following positions, namely, time, place, researchers, theoretical position, method and findings.

3.2.1 Time

The five studies under discussion (as specified in paragraph 3.2.6 below) were undertaken from 1989 to 2008. One can therefore argue that there is relative little recent research in this area. The time period in which I did my research can thus be seen as a motivation for doing this project. I will now address the location of the studies under discussion.

3.2.2 Place

Four of the five studies mentioned have been researched and implemented abroad. Only the dissertation by Shelly (2004) has been done in South-Africa. I regard the research already done in this field of utmost importance. However, with the limited relevant and available literature, I am of the opinion that we have a need in South-Africa to explore local parents' experiences and perceptions on this point in more detail. In doing so, I want to give voice to the individual experiences in my vicinity as well. Next, I will elaborate on the researchers of these studies.

3.2.3 Researchers

Not all the researchers' orientations, when looking at the literature under discussion, is available. However, taking the available information into account, I could identify the orientation of some of them. Fisman (Fisman et al., 1989) is a professor at the Department of Psychiatry at the University of Western Ontario, Wolf (Fisman et al., 1989) is a research epidemiologist and Noh (Fisman et al., 1989) works at the Department of Occupational Therapy at the University of Western Ontario. Hutton (Hutton & Caron, 2005) is involved in an autism programme in Bangor, Maine, whereas Caron (Hutton & Caron, 2005) is a professor of family relations and human sexuality at the University of Maine. Roderigue (Roderigue et. al., 1990) works at the Department of Clinical and Health Psychology at the University of Florida. Shelly (2004) did her research from a speech therapy and audiology frame of reference.

Taking the above information into account, it is evident that there are a variety of occupations involved in research in this area. However, not much research has been done by psychologists per se. My approach to this project is from a psychological and academic point of view. I will now attend to the theoretical position of the studies under discussion.

3.2.4 Position

Only the study by Woodgate et al. (2008) confirms that hermeneutic phenomenology is being used in their research. The theoretical positions of the other contributors under discussion are not stated. One could critique the fact that the researchers do not clearly state the position they are working from. Not explicitly stating a position leaves the reader without a frame of reference as well as the lack of important background information. My project is done from a descriptive phenomenological frame of reference. The position of my study can thus add to the knowledge already gained in the study by Woodgate et al. (2008). I will elaborate on the methods used in these studies.

3.2.5 Method

Looking more intently at the work of Blair, et al. (1996), Fisman et al. (1989), Hutton and Caron (2005), Rodrigue et al. (1990), Shelly (2004) and Woodgate et al. (2008), one can recognize a pattern in the research method used. The majority of the studies used questionnaires as their method of gathering information. Only the studies by Hutton and Caron (2005) and Woodgate et al. (2008) utilized interviews. Questionnaires for such research can be very valuable – it is less expensive and offers greater anonymity (Kumar, 2005). However, from a phenomenological point of view, questionnaires can be limiting in the sense that spontaneity is not allowed, responses cannot be enhanced with other information and answers to one question may be influenced by the responses to other questions (Kumar, 2005). One could argue that the understanding of the phenomenon is thus limited. Interviews, on the other hand, broaden the scope of the topic at hand. Interviews have the advantage of being more appropriate for complex situations, it is useful for gathering in-depth information and the answers of questions can be explained and elaborated on (Kumar, 2005).

Phenomenological interviews as a research method lends itself more to the exploration of the individual's lived-experiences (Osborne, 1994). This links with and enhances my motivation for the research methodology I have chosen. In my research, I will collect

material by, firstly, requesting the participants to write about their experience of their marital relationship after their child has been diagnosed with autism. The written experiences of the participants will enable me to form a picture of their worlds. It will also assist me in preparing for the interviews. After this information has been analyzed, interviews will be conducted with the research participants. Next, I will elaborate on the results of the studies under discussion.

3.2.6 Findings

Turning to the relevant literature, I am interested in the main findings applicable to my research. Blair et al. (1996) assessed parents' perceptions of their lifestyles associated with having children with autism. More than half of the participants in the study felt that having a child with autism has added more stress to their marriages. Nearly a third of the couples interviewed reported an adverse impact on their marriages. In the latter cases, the constant demands made by their child with autism seemed to be the most problematic. However, many participants also reported that they felt that their marriage had been strengthened by their experience. In these instances, partners seem to have learned to work together to overcome the challenges. There were also couples who stated that having a child with autism had not affected their marriages at all. Blair et al. (1996) mention that it is worthwhile to note that this sample was drawn from members of a local support organization and that may have contributed to their effectiveness in managing stress.

Fisman et al. (1989) examined the role of perceived parenting stress and parental depression on marital intimacy between parents of handicapped (autism and Down syndrome) children versus developmentally normal children and investigated possible discrepancies between husbands' and wives' reports of marital intimacy. Results indicated lower levels of marital intimacy for mothers as well as fathers of children with autism than for mothers with normal children.

In the study by Hutton and Caron (2005), parents were asked in what ways their child with autism has affected the family. Most parents offered several answers to the

question. Among these responses was the fact that such a child added stress to the marriage.

Rodrigue et al. (1990) compared mothers of children with autism, Down syndrome and developmentally normal children on several significant demographic variables. Mothers of children with autism reported less marital satisfaction than did mothers of children with Down syndrome or developmentally normal children. Furthermore, mothers of girls with autism reported less marital satisfaction than did mothers of developmentally normal girls. Noteworthy is the fact that this study only portrays the mothers' perspectives of their marriages.

Shelly (2004) examined the effect that children diagnosed with autism spectrum disorder had on their parents' social interactions. One of the questions asked determined whether the child with autism spectrum disorder placed strain on their parent's marital relationship. The majority of the parents answered "yes" to this question. This is an indication that they agree that their child placed strain on their marriage.

Woodgate et al. (2008) described the experiences of parents who have a child with autism. The findings indicated that parents at times felt detached from their spouses when both experienced different feelings that led to them not "always being on the same wavelength" or stage concerning the autism path. Noteworthy is the fact that 16 participants were mothers and five were fathers with a total of five couples participating in the study.

The aim with this research is to explore parents' experiences of their marital relationships after a child of theirs has been diagnosed with an autistic disorder. The literature discussed describes a picture of positive as well as negative experiences. However, this literature overview illustrates a more negative picture with regard to these parents' experiences. Having this in mind, I am interested in exploring this phenomenon in detail from a psychological and academic point of view. This topic will be investigated in the year 2009 in a South-African context by making use of the

descriptive phenomenological research method. One can conclude by stating that I cannot substantially answer my research question now.

Conclusion

The goal of this chapter was to look at the recent and relevant reported research pertaining to parents' experiences of their marital relationship after a child of theirs has been diagnosed with an autistic disorder. This was achieved by looking at related research and exploring the various issues surrounding it. The next chapter presents the research position that underpins the study.

CHAPTER 4

RESEARCH POSITION

Introduction

The goal of this chapter is to address the research position used in this research project and this will be achieved by exploring the approaches to research and then focusing on the phenomenological approach in detail.

4.1 APPROACHES TO RESEARCH

The approaches to research will be addressed by discussing both quantitative and qualitative research.

4.1.1 Quantitative Research

Beck (1993) points out that quantitative research is needed to control phenomena and to predict results. “Quantitative methods (usually using deductive logic) seek regularities in human lives, by separating the social world into empirical components called variables which can be represented numerically as frequencies or rate, whose associations with each other can be explored by statistical techniques and accessed through researcher-introduced stimuli and systematic measurement” (Payne & Payne, 2005, p. 180). It focuses on causal associations described in terms of observation statements, verification and prediction (Maggs-Rapport, 2001) and is based on the notion that social processes exist outside one’s comprehension, restricting individual actions and is accessible to researchers by their prior theoretical and empirical knowledge (Payne & Payne, 2005).

4.1.2 Qualitative Research

Beck (1993) states that qualitative research is needed to recognize the characteristics of phenomena. “Qualitative methods produce detailed and non-quantitative accounts of

small groups, seeking to interpret the meanings people make of their lives in natural settings, on the assumption that social interactions form an integrated set of relationships best understood by inductive procedures” (Payne & Payne, 2005, p. 175). This design treats actions as part of a holistic social process and context and focuses on the detail of human life (Payne & Payne, 2005). Qualitative methods are used to address research questions that require explanation or understanding of social phenomena and their contexts. I decided on a qualitative approach for my research project as it aims at providing an in-depth and interpreted understanding of the social world of people by learning about their social and material circumstances, their experiences, perspectives and histories. The outputs focus on the interpretation of social meaning through mapping and ‘re-interpreting’ the social world of research participants (Ritchie & Lewis, 2003). Next, I will explore the qualitative research approaches.

4.1.2.1 Narrative Approach

Narrative research is concerned with the story of individuals unfolding in a chronology of their experiences, set within their personal, social and historical context and includes the significant themes in those lived experiences (Creswell, 2007).

4.1.2.2 Grounded Theory Approach

In grounded theory research, the inquirer generates a general explanation (a theory) of a process, action or interaction shaped by the outlook of a large number of individuals (Strauss & Corbin in Creswell, 2007). Such a study uses a prescribed set of procedures for analyzing data and constructing a theoretical model from them (Leedy & Ormrod, 2005).

4.1.2.3 Ethnographic Approach

Ethnographic research allows the researcher to describe and interpret the shared and learned patterns of values, behaviours, beliefs, patterns and language of a culture-sharing group in depth (e.g., Harris, 1968; Leedy & Ormrod, 2005). It emphasizes the

natural environment of the research participants and the relationship between research participants and the cultural world (Spradley in Maggs-Rapport, 2001).

4.1.2.4 Case-study Approach

Case-study research is the study of an issue explored through one or more cases within a bounded system over time, through detailed, in-depth data collection involving multiple sources of information (Creswell, 2007; Leedy & Ormrod, 2005). It is also particularly appropriate for learning more about a little-known or poorly-understood situation (Leedy & Ormrod, 2005).

4.1.2.5 Phenomenological Approach

Phenomenological research is the study of lived experiences of individuals with the view that these experiences are conscious ones (Van Manen, 1990). It attempts to understand people's perceptions, perspectives and understandings of a particular situation and how these individuals give meaning to the event(s) (Leedy & Ormrod, 2005). Phenomenology attempts to describe the essences of these experiences (e.g., Moustakas, 1994; Patton, 2002). I now turn to the phenomenological approach of this project.

4.2 PHENOMENOLOGICAL APPROACH

In this research project, I am interested in parents' experiences of their marital relationship after a child of theirs has been diagnosed with an autistic disorder. Having this aim in mind, I chose the phenomenological method since it focuses on understanding the essence of human experience (Creswell, 2007). I will discuss the phenomenological approach in terms of its definition, history and schools of thought.

4.2.1 Definition

The etymology of the term *phenomenology* shows that it is derived from the Greek words *phenomenon* (plural, *phenomena*) and *logos*. *Phenomenon* literally means appearance, that is, that which shows itself. In psychology, phenomena are commonly defined as experiences which can be observed and described by the experiencing subject at a given time (Misiak & Sexton, 1973). *Logos* means to explain or to describe (Pivcevic in Van der Nest, 2007). Therefore, phenomenology means to describe that which appears.

Phenomenology aims at remaining as faithful as possible to the phenomenon under study and to the context in which it appears in the world. The intention is to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place (Smith, 2004). The purpose of phenomenological research is to develop a description that leads to an understanding of the meaning of the experience(s) (Osborne, 1994). I want to achieve these aims in my research.

Phenomenological research can be identified as descriptive and qualitative and is unique in the sense that its focus is on the subject's experienced meaning (Polkinghorne, 1989). Phenomenology is neither a science of objects nor a science of the subject, it is a science of experience. It does not concentrate in the first place on either the objects of experience or on the subject of experience, but rather on the point of contact where being and consciousness meet. Phenomenology is a radical empiricism and is concerned with the fullness of experience in its total, concrete, existential destiny (Thevenaz, 1962).

4.2.2 History

The term phenomenology was used as early as 1765 in philosophy and occasionally in Kant's writings, but it was Hegel who constructed its well-defined technical meaning. It was not Hegel, however, but Descartes who influenced Husserl in a dominant sense (Moustakas, 1994). Phenomenology is the name given to the philosophical movement

beginning mainly with Edmund Husserl (1859 – 1938) and thereafter developed by Martin Heidegger and his followers. With phenomenology Husserl meant the study of how individuals describe things and how they experience them through their senses. His most basic postulation was that individuals can only know what they experience by attending to perceptions and meanings that awaken their conscious awareness (Husserl in Patton, 2002). It was intended to be a science of consciousness (Osborne, 1994). With Heidegger, the movement took an existential turn, with the essential focus on understanding existence. More recently, work by Hans-Georg Gadamer and Paul Ricoeur have lead to the (re-)emergence of a hermeneutic turn in phenomenology with the focus on interpretation (Langdridge, 2007).

4.2.3 Schools of Thought

The position I chose for this project is that of the descriptive phenomenological method. My rationale for this choice is twofold in nature. First, I focus on the experience by parents of their marital relationships after their children have been diagnosed with autism. Second, seeing that it is the first time I do a master's study, I chose a descriptive project and not an interpretative one. However, I am open to incorporate aspects from the other phenomenological schools of thought where it would mean that my research findings will be enhanced by doing so.

I will discuss the phenomenological schools of thought firstly in terms of descriptive phenomenology, secondly existentialism and lastly by looking at hermeneutic phenomenology.

4.2.3.1 Descriptive Phenomenology

Giorgi (1983, p.146) defines phenomenology as “the study of the phenomena of the world as experienced by conscious beings” – as it is presented with evidence to the world as it is lived (Richards & Morse, 2007). Phenomenological methods attempt to explore how human beings make sense of experience and transform experience into consciousness [consciousness refers to the presentation of objects to human experience

through the process of intuition. Intuition here refers to the way in which individuals respond to objects (Giorgi in Maggs-Rapport, 2001)], through a specialized form of introspection (Osborne, 1994; Patton 2002). Phenomenology is committed to descriptions of experiences and not analyses or explanations (Moustakas, 1994). This methodology assumes that there is an essence or essences to shared experience. These essences are the core meanings mutually understood through a phenomenon frequently experienced (Patton, 2002). One can thus conclude that phenomenology is concerned with one's understanding of human experience as it is presented to conscious awareness. This process allows the role-player(s) to attach meaning to a given phenomenon.

Descriptive phenomenology is the most classically Husserlian method (Langdridge, 2007). The Husserlian phenomenology always asks about the meaning of human experiences (Koch, 1995). Husserlian research does not exclude or stop short of the structures of the *Umwelt* (experiencing the environment) (Misiak & Sexton, (1973), *Mitwelt* (experiencing the interpersonal realm) and the *Eigenwelt* (the world of private experience) (Thevenaz, 1962). The ultimate aim is to grasp the essences of things appearing in the consciousness (Misiak & Sexton, 1973). It focuses on identifying the essence of the phenomenon through epoche and the psychological phenomenological reduction, but also builds on existential philosophy. This approach has emerged in the 1970s at Duquesne University in the United States, with the work of Amedeo Giorgi (Langdridge, 2007). I will now briefly discuss three dominant notions that are essential to Husserlian phenomenology, namely, intentionality, essence and phenomenological reduction ("bracketing").

1. Intentionality

A distinctive feature of descriptive phenomenology is that it aims at describing phenomena exactly as they are presented to the conscious (Maggs-Rapport, 2001). For Husserl, intentionality is the key feature of the conscious. It refers to the fact that there is always an object of consciousness – we are always aware of something (Langdridge, 2007; Misiak & Sexton, 1973). One can thus say that the intentional correlation leads to

a focus on the experience of things in their appearing form and the way in which they appear to us as we focus our attention on them in consciousness (Langdridge, 2007).

The essential role of intentionality can be described by making use of the terms *noema* and *noesis*. Husserl was of the opinion that all experience is an experience of something and, with this, seeks to transform the division between subjects and objects into a correlation between what is experienced (the *noema*) and the way it is experienced (the *noesis*). This correlation is termed intentionality. The position just discussed was very much the one Husserl had at the beginning of his work. However, he later took a transcendental turn. Here the subject (or experience) was no longer part of the correlation between *noema* and *noesis* and was instead able to make a reflexive move (Ihde, 1986) outside this relationship to observe the process from the outside (or above) (Langdridge, 2007). I will now address intentionality in terms of my study.

When looking at the term intentionality in relation to my research study, the focus of this project is on describing exactly how parents experience their marital relationships after a child of theirs has been diagnosed with autism. Linking this detailed description to the terms *noema* and *noesis*, one can say that *noema* is that what parents experience in their marital relationships after the diagnosis of autism where *noesis* is the way parents experience their marital relationships after a child of theirs has been diagnosed with autism.

2. Essence

Descriptive phenomenology is the search for essences (Maggs-Rapport, 2001). According to Husserl, essences constitute the consciousness and perception of the human world (Koch, 1995). The identification of essences in phenomenology represents a move from the description of individual experience to exploring the structure underlying such experience. Husserl believed that it is possible to discern the essence(s) of an experience from any individual experience. However, phenomenological psychologists have tended to attempt to determine essences through

multiple descriptions from a number of participants (Langdridge, 2007). I will now look at essence in terms of my study.

When addressing the term ‘essence’ in relation to my research, the focus is on exploring the structure underlying the experiences of parents’ marital relationships after a child of theirs has been diagnosed with autism. It is a search for exploring the essence(s) of such an experience.

3. Reduction

The *epoche*, a Greek word used by Husserl, entails the process of continually identifying one’s presuppositions about the nature of the phenomenon and attempting to set them aside in order to finally see the phenomenon as it is (e.g., Langdridge, 2007; Misiak & Sexton, 1973; Moustakas, 1994; Osborne, 1994). This process is sometimes referred to as bracketing (Langdridge, 2007). This is a challenging task and requires that we allow a phenomenon or experience to be just what it is and to come to know it as it presents itself (Moustakas, 1994). In phenomenology there are two broad camps that are split over this issue. The transcendental phenomenologists, who follow Husserl, argue that the *epoche* is achievable. However, the existential phenomenologists, who follow Heidegger, believe that one should strive to achieve *epoche* but that one can never truly bracket off one’s presuppositions. Whichever position is taken, the aim remains to attempt to set aside (or bracket off) one’s natural attitude, or all those assumptions and preconceptions we have about the phenomenon being investigated and to be open to the participant’s experience by returning to the things themselves in their appearance to the conscious world around us (Langdridge, 2007). I will now look at ‘reduction’ in terms of my study.

When addressing the term ‘reduction’ in relation to my research, the focus is on addressing my presuppositions. From a Husserlian point of view, this would require me to set aside my beliefs about parents’ experiences of their marital relationships after their children have been diagnosed with autism. Although striving to achieve this, I also realize the need to identify, acknowledge and explore my own assumptions on marriage,

relationships per se as well as autism. At the end of the day, my aim is to set aside my natural attitude and to be open to the participants' experiences as these present themselves. Such a position would allow me to be actively present in the moment.

Phenomenological reduction maintains the process initiated with the epoche (Langdrige, 2007). Moustakas (1994, p. 90) states that the task of phenomenological reduction is "that of describing in textual language just what one sees, not only in terms of the external object but also the internal act of consciousness, the experience as such, the rhythm and relationship between phenomenon and self". Description, horizontalization and verification are three of the key fundamentals in this process. The goal with description is to capture and describe the total experience of consciousness in as much detail as possible. You must describe what is seen in terms of your perception as well as your consciousness. Verticalization (thinking one thing is more important than the other) is resisted as much as possible in phenomenological psychology. The key to the reduction is repeated, looking at uncovering the layers of meaning inherent to the phenomenon being perceived. Once this process has been carried out, one might begin to formulate tentative hypotheses about hierarchies of meaning and engage in the process of verification. Verification entails taking the analysis back to the text to check that it makes sense in this context (Langdrige, 2007). I will now further explore reduction and the epoche in terms of my study.

When looking at phenomenological reduction and the epoche in terms of this project, my aim is to capture and describe the total experience in as much detail as possible. By revealing the layers of meaning, I will make certain that one aspect is not seen as more important than the other. I will also always go back to the text in order to clarify it in terms of the context.

4.2.3.2 Existentialism

Although the roots of existentialism can be traced back to the philosophy of Soren Kierkegaard (1813 – 1855) and Friedrich Nietzsche (1814 – 1900), Martin Heidegger (1859 - 1938) was undoubtedly the most important philosopher to follow Husserl, and

the first real existentialist. The existentialists built on the phenomenological foundations provided by Husserl. However, instead of developing a new philosophical method, they sought to address fundamental questions about our very existence and the forms it takes (Langdridge, 2007; Misiak & Sexton, 1973). The existentialists who immediately followed Heidegger, namely, Sartre, Merleau-Ponty and de Beauvoir, were more concerned with the understanding of the human condition. Their thoughts have directly impacted on some contemporary forms of phenomenological psychology (Langdridge, 2007).

Husserl foreshadowed the existential turn in phenomenological philosophy through the concept of the life-world (*lebenswelt*) or lived experience. The life-world is the world as concretely lived, which should be the foundation for all phenomenological psychological investigation (Langdridge, 2007). Misiak and Sexton (1973) define the life-world as the world of experience of everyday life. Husserl states that this life-world is not readily accessible because it represents what is taken for granted or those things which are common sense. The task is to revisit the taken-for-granted experiences and re-examine it (Koch, 1995).

Existential phenomenology gives more explicit attention to ontological issues. There is an interest in understanding the certainty of Being. The whole person's existence, not just consciousness, is the centre of attention. Heidegger believes that pure description is limited in its ability to reveal meaning. This has led him to formulate the hermeneutic method in order to interpret the meanings which lie beyond descriptive phenomenology (Osborne, 1994).

Heidegger is of the belief that everyone is inseparable from the world they inhabit – this world is always contextualized by existence and not without presuppositions. It is therefore not possible to bracket off one's way of seeing and identifying the essence of the phenomenon as Husserl had proposed (Langdridge, 2007; Osborne, 1994). Heidegger argues that our way of existence must be seen in its historical and cultural context and understood with regard to the role of language. This phenomenological method is thus concerned more with interpreting the meanings of the things in their

appearance from a standpoint that is always grounded in the things themselves. Philosophers must now be content with a position in relation to whatever it is they want to understand (Langdridge, 2007).

One of the most important concepts developed by Heidegger is *Dasein* (often translated as being-in-the-world), a German word that in every day use means “existence” (Langdridge, 2007; Misiak & Sexton, 1973). Heidegger uses the term *Dasein* instead of man (person or subject) to allow us to enhance a new approach to what it means to exist. *Dasein* is used to emphasize a number of features of existence that may be vague when using the term ‘man’, ‘person’ or ‘subject’. Some of these features are temporality, facticity, mood, being-towards-death, care, authenticity, being-with (or *Mitsein*) and discourse (Langdridge, 2007). To be a person thus refers to *Dasein* – being already in the world. One can therefore conclude that the researcher brings his or her pre-understanding to the text (Koch, 1995).

4.2.3.3 Hermeneutic Phenomenology

Following Heidegger and his move to a hermeneutic phenomenology, two philosophers, namely Hans-Georg Gadamer (1900 - 2002) and Paul Ricoeur (1913 - 2005) stand out as being particularly important (Langdridge, 2007). The term hermeneutics is derived from the Greek word *hermeneia*. This Greek root suggests that it is “bringing to understanding particulars where the process involves language” (Annells, 1996, p. 706). Hermeneutic phenomenology is concerned with interpretation designed to grasp the understanding of a phenomenon or research participant (Langdridge, 2007). I will now introduce some of the ideas of Gadamer and Ricoeur. I will start by attending in brief to the notions of Gadamer.

Gadamer stressed that understanding is situated in a particular space, historically and culturally contingent. Like Heidegger, Gadamer argued that understanding is at the core of human existence. They also reasoned that we gain understanding of the world that we inhabit through language. For Gadamer the focus must always be on language and the way in which it can be used through conversation to reveal something that was

previously concealed (Langdridge, 2007). Building on the notion that all understanding is hermeneutic, Gadamer acknowledged that language, understanding and interpretation are indissolubly bound (Gadamer in Maggs-Rapport, 2001).

Gadamer also argued that our understanding is both enabled and limited by our pre-understanding as well as our horizons. All understanding occurs within a certain horizon, a history (Langdridge, 2007). The notion of history refers to our ability to be aware of our own past and incorporate that awareness into our present (Giddens in Maggs-Rapport, 2001). However, Gadamer believed that we can and do gain understanding [or produce meaning (Allen, 1995)] through the fusion of horizons where we acknowledge agreement in our particular worldviews (Langdridge, 2007; Maggs-Rapport, 2001). The process of fusing horizons is circular and is thus described by Gadamer as the hermeneutic circle (Annells, 1996; Gadamer in Maggs-Rapport, 2001). I will now address some of the notions of Ricoeur.

Ricoeur's work is primarily concerned with the interpretation of text. His position, like that of Gadamer, recognizes the embodied being-in-the-world of human beings that is beyond and pre-exists language and an interpretative understanding of human nature through language. Ricoeur makes an important distinction between discourse and language. This distinction between language, which is the focus of classical structuralist analyses, and discourse, which represents the creative action of human agents, is a critical one for hermeneutic phenomenology. He also makes a further distinction between spoken and written discourse. Ricoeur argues that reconceptualizing human action as text enables better understanding and interpretation, as one becomes able to employ techniques from hermeneutic phenomenology (Langdridge, 2007).

Approximation is the act of capturing the meaning being expressed by a text through a fusion of horizons (a term from Gadamer), where we expand knowledge of ourselves through engagement with the other. However, unlike Gadamer, Ricoeur does not simply believe that this entails capturing meaning at face-value. Ricoeur believes that empathy and suspicion (two essential approaches for understanding meaning according

to Ricoeur) are both necessary means for the appropriation of meaning. We need to understand the text both at face-value and through the use of hermeneutic interpretation, which enables us to see beyond this surface meaning of hidden meanings beyond (Langdridge, 2007).

When looking at Gadamer's and Ricoeur's views regarding bracketing, one can state that both are of the opinion that even attempting to bracket our preconceptions, we speak from somewhere – we always occupy an ideological stance even if we are unaware of it. This needs to be recognized in research and must itself be subjected to critique that allows us to work better with the text and our analysis of it (Langdridge, 2007). Consequently, the Husserlian techniques of phenomenological reduction and bracketing have no place here, just as they are also rejected by hermeneutics (Annells, 1996).

Conclusion

The goal of this chapter was to address the research position used in this research project. This was achieved by exploring the approaches to research and then by focusing on the phenomenological approach in detail. In the following chapter the research method for the study will be explained.

CHAPTER 5

RESEARCH METHOD

Introduction

The goal of this chapter is to address the research method used in this project. This will be achieved by exploring the research context, research participants, research material, research quality, research ethics as well as the research relevance.

5.1 RESEARCH CONTEXT

The context of this research project is situated in the academic field as well as in the community context.

5.1.1 Academic

This study represents the academic field of a psychology student at the University of Pretoria (UP).

UP offers more than 2800 academic programmes in two of the official languages of the Republic of South Africa. The academic programmes are offered in the faculties of Economic and Management Sciences, Education, Engineering, Built Environment and Information Technology, Health Sciences, Humanities, Law, Natural and Agricultural Sciences, Theology and Veterinary Sciences. In 1996, UP became the university with the highest research output in South Africa and is proud to be the leading research university (Nel, 2008).

The Department of Psychology falls under the Faculty of Humanities. The discipline of psychology not only focuses on helping people in their different life situations, but, as a science, also seeks to understand human behaviour in different contexts. However, understanding in itself is not enough and it is therefore essential to apply this knowledge to daily life. The Department of Psychology offers three directed MA programmes,

namely clinical, counselling and research psychology (Haug, 2008). This study falls under the MA counselling psychology programme.

5.1.2 Community

The community context of this project is twofold in nature. It consists of the Gauteng Department of Education as well as the Unica School, Pretoria. The researcher has obtained permission from both these role-players in order to conduct the research project.

The Gauteng Department of Education has five priorities in its envisaged education programme. These include the increasing investment in young citizens through improved early childhood development centres, the consolidation and reinforcement of the public school education system, the building of skills of young individuals, ensuring life-long learning as well as to link industry, higher-education institutions and government departments to match the demands of the growing economy (Department of Education, 2004). The Department of Education's vision is the delivery of public education which promotes socio-economic growth and development in Gauteng and South Africa (Department of Education, n.d.).

The Unica School for Autism provides specialised education for learners with PDD between the ages of three and 18 years (Unica School for Autism, n.d.a.). Unica provides a highly-structured learning environment that focuses on the development of academic abilities; communication and behaviour management programmes; movement and visual perceptual skills; social skills; computer training, vocational training and leisure skills; and life orientation and thinking skills (Unica School for Autism, n.d.b.). The school also offers, among others, residential facilities, diagnostic services and family counselling, training programmes, therapeutic intervention and acknowledgement of parents as partners (Unica School for Autism, 2008).

5.2 RESEARCH PARTICIPANTS

The research participants will be discussed in terms of the participants (the parents) as well as the researcher.

5.2.1 Participants

1. Criteria

In order to have participated in this study the following criteria had to be met:

- (a) the participants had to be parents of a child with autism and the child is a learner at the Unica School, Pretoria. The reason being that this limits the extent of the study;
- (b) the participants had to be able to supply first-hand information how they experience their marital relationships after their children have been diagnosed as having autistic disorder. Direct experience of this phenomenon leads to a focus on first-person accounts of experience as the focus of descriptive phenomenology (Langdridge, 2007);
- (c) both parents had to be willing to participate because the experience of both partners in the marital relationship are valued;
- (e) the child had to have a medical and / or clinical diagnosis of autism to ensure that the medical limitation of this study is adhered to; and
- (e) the participants had to be able to express themselves fluently in either Afrikaans or English. The reason being that this is a study of limited extent and that the use of translators could slow the process or the translator may not accurately translate the meaning conveyed by the participant (De Vos, Strydom, Fouché & Delport, 2005).

2. Sampling

This research project made use of purposive sampling (Henning, Van Rensburg & Smit, 2004; Langdridge, 2007). Purposive sampling looks who fit the criteria for desirable

participants. These criteria are dependent on the researcher's knowledge of the topic and how the theorising on the ground develops during the research (Henning, Van Rensburg & Smit, 2004). As Osborne (1994, p. 180) states, "the phenomenological researcher seeks out those who have experienced the phenomenon in question and can communicate their experiences". The aim is to develop detailed descriptions of the experience of a small number of individuals who all share the experience at the heart of the investigation (Langdridge, 2007).

Phenomenological methods are likely to use a small number of participants due to the time-consuming nature of the analytical process (Langdridge, 2007). This research study thus explored the experiences of three couples of whom a child was diagnosed with autism and who is at the Unica School, Pretoria.

Sampling was done according to the following phases:

- Phase 1: The researcher approached the school psychologist at Unica School. The school psychologist assisted in selecting suitable participants for the project. The rationale behind this was that she is familiar with the school population.
- Phase 2: The school psychologist contacted possible parents to obtain their permission for the researcher to get in touch with them. The researcher went about in this manner because, as parents of Unica School, their personal information couldn't be made public without their consent.
- Phase 3: The researcher then made contact with the participants and arranged suitable dates to meet with them.

3. Information

Based on the criteria and sampling method, the following individuals participated in this study:

Table 1

Couple A

Father	
Present occupation	Business consultant
Mother	
Present occupation	Skills development facilitator / assessor
Child with autism	
Age currently	4.5 years
Age when autism was diagnosed	3.5 years
Family	
Date of marriage	22/04/2000
Home language	Afrikaans
Other siblings	8.5 years

Table 2

Couple B

Father	
Present occupation	Attorney
Mother	
Present occupation	Bookkeeper
Child with autism	
Age currently	7 years
Age when autism was diagnosed	2.5 years
Family	
Date of marriage	26/08/1995
Home language	Afrikaans
Other siblings	9 years

Table 3
Couple C

Father Present occupation	Sports co-ordinator
Mother Present occupation	Correctional officer
Child with autism Age currently Age when autism was diagnosed	6 years 3.5 years
Family Date of marriage Home language Other siblings	14/02/2003 Setswana 3 years (sibling); family member residing in the same dwelling

5.2.2 Researcher

When looking at the researcher's previous research background, there are two specific experiences worth mentioning. Firstly, during my honours degree, I attended a module in which I formulated the proposal for this research project. This aided as the foundation from which this project was launched. Secondly, in my Master's degree, I attended a community psychology module in which, together with my colleagues, we developed an emotional enrichment programme for Early Childhood Development (ECD) practitioners. This programme was presented to the staff members of Head Start, a non-profit organisation, which provides the practitioners with training to stimulate the cognitive and emotional development of the children under their care. We also presented this programme at the Psychological Society of South Africa (PsySSA) conference in 2008.

Although the researcher has previous research experience, this project is the first of its nature for the researcher. Exposure during the previous experiences, however, assisted the researcher in doing research and writing psychological accounts.

5.3 RESEARCH MATERIAL

The research material was approached in terms of the following phases:

- Phase 1: Producing a written account
- Phase 2: Analysis of the written account
- Phase 3: The interview based on the written accounts
- Phase 4: Transcription of the interview
- Phase 5: Analysis of the interview

The research material will be discussed with reference to collecting, transcribing and analysing the material.

5.3.1 Collecting Material

Descriptions were gathered from the participants through written statements as well as interviews. The combination of these methods encourages active reflection on the topic under investigation (Langdridge, 2007). I utilized written accounts and interviews since it is a demonstration of the research-practitioner model. My rationale being that the manner in which I did this research will subsequently enhance my practitioner training. Written accounts and interviews will be discussed as methods for collecting material.

1. Written Account

Self-descriptive accounts have a considerable role in descriptive phenomenology. Written descriptions are time-saving, there is no need for transcription and it may be used as a basis upon which to formulate further exploration (Fischer in Moustakas, 1994). As Langdridge (2007) puts it, “it involves the researcher providing the

participants with some instructions asking them to produce a written document describing in as much detail as possible an experience of interest to the researcher”.

Material for this study was collected by, first requesting the participants to write a detailed account of how they experience their marital relationship after their child has been diagnosed with autism. The writing of an account provided participants with the opportunity to tell their story and describe their experience. This material enabled the researcher to form a picture of the participants’ lived-worlds. It also assisted the researcher in preparing for the interviews.

2. Interview

In phenomenological investigation, the interview is a method through which material is collected on the topic in question (Moustakas, 1994; Patton, 1990). The interview allows the interviewer to probe and explore within the predetermined inquiry areas and allows for individual variations (Patton, 1990). The rationale of interviewing is to permit ourselves to enter the other person’s perspective (Patton, 2002). The purpose of phenomenological interviewing is to develop from the set of protocols, with their naïve descriptions to specific illustrations of the experience under consideration, a description of the essential features of that experience. The aim is thus to get as close to the experience of the individual as possible by making the interview process minimally intrusive and allowing the individual’s experience to present itself as spontaneously as possible. The interview seeks to describe and understand the meaning of the central themes of the experience being explored (Polkinghorne, 1989). The structure of such an interview requires an invitation to the participant to talk about the experience of the phenomenon at hand (Osborne, 1994).

Material for this study was, in addition to the written accounts, also collected through the interviews with the participants. After the information of the written accounts had been analysed, interviews were conducted with the research participants. The researcher interviewed three couples. The mother and father of the child were

interviewed jointly. Talking together and listening to each other's experience could have enabled the parents to see the experience from each other's point of view.

The research participants were aware that the duration of the interview would be one and a half to two hours. The interviews took place at the UP. The school psychologist suggested this setting as it is an environment where the parents are not as involved and thus less distracted as when it would have been at the school premises or their homes.

The interviews were designed to encourage participants to elaborate on and clarify the written material they had provided. The researcher utilized semi-structured interviews to explore the individuals' experiences. The interview procedures followed will now be elaborated in more detail.

Firstly, the interview began with social conversation aimed at creating a relaxed atmosphere (Moustakas, 1994). The conversational style of the interview leads to rapport with probably more open and honest responses (Langdridge, 2007).

Secondly, the researcher focused the participants' attention on the fact that no identifying information about them or their children will be disclosed. She explained that any such information will be codified during the transcription of the interview. The style of the interview thus allows the participants to talk freely whilst knowing that their confidentiality is protected.

Thirdly, before the commencement of the interviews, the researcher briefly discussed the process of the interview with the participants. The researcher explained that she as well as the couple will first read, for example, the husband's written account. Thereafter, the wife and the researcher will have the opportunity to request an exploration and/or clarification regarding various aspects contained in the written account. The same procedure will then be followed with the wife's written account. The researcher highlighted the fact that the purpose of the interview is only to explore and/or clarify aspects that were already raised in the written accounts.

5.3.2 Transcription

Transcription is a vital part of phenomenological study and its focus is nearly always on producing a transcript that offers a verbatim account of the interview (Langdridge, 2007). This provides the researcher with a valuable opportunity to actively engage with the research material right from the beginning of the collection of the material (Leavy & Hesse-Biber, 2006). After the taped interviews have been transcribed, the phase of formal explication begins.

5.3.3 Analysis

Material will be analysed according to the method proposed by Giorgi (Giorgi, 1975; Human, 2006; Langdridge, 2007; Polkinghorne, 1989). This method was chosen as it is in line with the phenomenological research design of the project. This method involves the following five phases:

- Phase 1: Read the material as a whole.
- Phase 2: Identify meaning units in the material.
- Phase 3: Connect meaning units with one another and with the whole.
- Phase 4: Transform the descriptions of the concrete experiences into scientific language.
- Phase 5: Integrate the results of the project and present them to the scientific community.

After the transcription phase, the analysis of the material is a major part of the research. Responses were analysed for underlying themes. The material was studied to determine meaningful patterns and themes that are connected (Henning, Van Rensburg & Smit 2004). The last step in the analysis of the material was the writing up of the research results as a complete text.

5.4 RESEARCH QUALITY

Research quality is vital to establish trust in the outcomes of the project. Guba and Lincoln (1981) refer to the terms within the scientific paradigm of internal validity, reliability and objectivity as credibility, auditability and confirmability. They propose that the latter terms are more appropriate to the naturalistic paradigm. These terminologies are explained in more detail in, for example, Beck (1993), Krefting (1991) and Sandelowski (1986). The researcher also utilized these sources for background.

5.4.1 Credibility

A qualitative study is credible when it measures how vivid and faithful the description of the phenomenon is. Credibility also refers to the notion that other people (other researchers or readers) should recognise the experience when confronted with it after having only read about it in a study (Beck, 1993; Sandelowski, 1986).

The credibility of this project was specifically enhanced in three ways. Firstly, the researcher made use of multiple methods to collect material. This strategy is referred to as ‘triangulation of data methods’. Material collected through various means is compared (Beck, 1993; Krefting, 1991; Sandelowski, 1986). The participants were requested to provide a written account of their experience and they were interviewed as methods to collect material. Utilizing more than one method strengthens the confidence in whatever conclusions are drawn (Patton, 2002). Secondly, the researcher utilized peer examination (Krefting, 1991) to validate the research findings. The process as well as analyses of the material was discussed with her colleagues (the Master’s-group). Thirdly, as part of member checking (Beck, 1993; Krefting, 1991; Sandelowski, 1986), the researcher validated the transcriptions of the interviews as well as the analytic categories with the participants.

5.4.2 Auditability

Auditability, according to Guba and Lincoln (1981), refers to the ability of another researcher to follow the decision-making or audit trail used by the researcher in the study. They state that the work of one researcher should be found consistent by another researcher. Another researcher should thus arrive at the same or comparable, but not contradictory, conclusions arrived at by the original researcher's material, perspective and situation.

The auditability of this project was enhanced particularly in three ways. Firstly, the exact strategies used to gather material and to analyse it were described (Beck, 1993; Krefting, 1991; Sandelowski, 1986). Secondly, the characteristics of the participants as well as the processes used to choose them were described (Beck, 1993; Sandelowski, 1986). Thirdly, both my colleagues (the Master's-group) and my supervisor reviewed the study in order to track the processes utilized. They approved for the processes employed (Beck, 1993; Krefting, 1991).

5.4.3 Confirmability

According to Guba and Lincoln (1981), confirmability links with the question of neutrality in a study. The confirmability of this project was enhanced specifically in three ways. Firstly, as discussed in 5.4.2, the audit strategy is the key technique used to establish confirmability (Krefting, 1991). Secondly, as with credibility, the use of multiple methods to collect material aids as a useful tool to strengthen the confirmability (Beck, 1993; Krefting, 1991; Sandelowski, 1986). Thirdly, as already mentioned, both my colleagues and my supervisor were involved during the process of this study. The latter procedure also enhanced the neutrality (Krefting, 1991).

5.5 ETHICAL CONSIDERATIONS

Ethical approval for this project was twofold in nature. Firstly, approval was obtained from the Gauteng Department of Education to be able to work via the Unica School.

Secondly, approval from the Research and Ethics Committee of the Faculty of Humanities at the University of Pretoria was acquired before the research project commenced. The ethical considerations will be discussed in terms of voluntary participation, discomfort and harm, confidentiality and anonymity as well as informed consent.

5.5.1 Voluntary Participation

Participation in this study is completely voluntary (Babbie & Mouton, 2006). It entails the freedom to decide about participation free from any coercion as well as the freedom to withdraw from the research without penalty once it has begun (Whitley, 2002).

5.5.2 Discomfort and Harm

The researcher took precautions not to harm the participants psychologically (Babbie & Mouton, 2006). This study might force participants to face aspects of themselves that they do not normally consider. If, by any chance, a psychological issue surfaces during the interview, the individual will be referred and the data up to that point will be dealt with appropriately. If at any point, during or after the research, therapeutic intervention seems necessary, Dr Lourens Human, my supervisor, will provide the required care.

5.5.3 Confidentiality and Anonymity

In order to protect the subjects' identities, confidentiality (Babbie & Mouton, 2006; Whitley, 2002) and anonymity (Babbie & Mouton, 2006) is of utmost importance. Anonymity is very unlikely in the case of phenomenological research, where close contact with participants is the norm. However, for me it is of utmost importance that the identities of the individuals are never made obvious (Langdridge, 2007). The participants' responses were labelled with case numbers (e.g. Case #1, Case #2, etc.) to ensure the confidentiality of the data upon completion of the interview. A master identification file was created that links case numbers to names to permit the later

correction of missing or contradictory information. This file will only be available for legitimate purposes (Babbie & Mouton, 2006).

5.5.4 Informed Consent

Consent is probably the most essential ethical principle. Working from a phenomenological position, my norm is also to provide the participants with full knowledge about the nature of the research (Langdridge, 2007). The research participants have provided me with written informed consent in order to show their willingness to participate in the research. They are fully informed about the research for which the written accounts and interviews are being used. The researcher highlighted the fact that their privacy and sensitivity are protected. The research participants also know what will happen with the information after it has been recorded (Henning, Van Rensburg & Smit 2004). The interviews were tape-recorded with the consent of the respondents. They were also informed about possible personal and practical issues involved, for example the duration of the interviews as well as the possibility that personal issues will surface during or after the interviews. The findings of this research study were communicated to the participants to involve them in the process of understanding marital relationships in this context.

5.6 RESEARCH RELEVANCE

The value of this research project is fourfold in nature. Its relevance will be addressed in terms of the parents, school, academic and personal domains.

5.6.1 Parents

This project is personally relevant in that (i) it can equip parents who are new to the disorder or provide comfort to such parents knowing that their experience is a shared one (Glass, 2001), (ii) it can provide an opportunity for parents to voice their concerns and/or coping strategies regarding their experience of changes in their marital relationship after the child had been diagnosed with autism (Glass, 2001), and (iii) it can

serve as a tool for individuals in general to appreciate and be more sensitive to those involved in these experiences (Polkinghorne, 1989).

5.6.2 School

This project's relevance for the school as such and the community at large lies in the fact that it can serve as a tool for professionals in a multi-disciplinary context to understand parental relationships better.

5.6.3 Academic

Linking with chapter three, this project is academically relevant in that (i) available and relevant research has been done in the period from 1989 up to 2005. Therefore there exists little recent research on the topic, (ii) there exists limited relevant research in this area in South-Africa, (iii) not much research has been done by psychologists per se, (iv) my project is done from a phenomenological frame of reference, (v) interviews and written accounts have not been the norm for the collection of material before, (vi) findings from literature describes a picture where negative experiences outweigh positive experiences, and (vii) this study can also serve as a reference for further study of and knowledge about autism and inter-familial relationships.

5.6.4 Personal

The value of this project lies in the fact that it provides me with more than just textbook knowledge. Looking at the research-practitioner's model, this study subsequently enhanced my practitioner training. The rationale being that (i) the phenomenological method exposed me to individuals' lived experiences, (ii) the methods for collecting material have similarities to the therapeutic context, and (iii) phenomenological analyses empowered me to search for essences and meaning-units. In general, the value lies for me in the personal growth.

Conclusion

The goal of this chapter was to look at the research method used in this project. This was achieved by exploring the research context, research participants, research material, research quality, research ethics as well as research relevance. The next chapter presents the research findings of the study by describing the themes identified by the researcher during the analysis process.

CHAPTER 6

RESEARCH FINDINGS

Introduction

The goal of this chapter is to present the research findings of the project. This will be achieved by discussing the themes that emerged during the analyses of the material.

The focus of this research is parents' experiences of their marital relationships after their children have been diagnosed as having autistic disorder. As part of the analyses, only themes that have bearing on the research question are presented. The analyses remained loyal to the descriptive nature of the material in order to directly reveal its essential meaning. Themes were not predetermined and were allowed to unfold as the researcher engaged with the transcripts. The information provided here was elicited through the written accounts as well as the interviews.

6. EMERGING THEMES

The themes that emerged from the data analysis were diagnosis, coping, conflict, being different, the outside world, being a couple, partnership, family-life and autism.

For the remainder of this chapter, the following coding system will be employed:

(WA): Written account

(IN): Interview

A(H): Couple A, Husband

A(W): Couple A, Wife

B(H): Couple B, Husband

B(W): Couple B, Wife

C(H): Couple C, Husband

C(W): Couple C, Wife

6.1 THEME 1: EXPERIENCING THE DIAGNOSIS

The focus of this study is on parents' experiences of their marital relationships after their children have been diagnosed with autism. However, the diagnosis surfaced as a prominent theme and will therefore be discussed accordingly.

6.1.1 Introduction

Parents' experiences of their marital relationships were significant both before and after the diagnosis. The theme under discussion surfaced in couples A and C and the following statements are examples provided by participants A(H), A(W), C(H) and C(W) respectively.

6.1.2 Material

Examples that support the parents' experiences before the diagnosis are:

A(H)(WA)

6.1.2.1. "... toe ons geweet het (kind met outisme) is anders, maar nie geweet het hoekom of wat dit is nie."

A(H)(IN)

6.1.2.2. En ek het begin agterkom dat, soos ek gesê het, daar is iets anders met hom, ek is nie seker wat nie... En ek dink wat in my agterkop die heelyd gedraai het, wat ek ook baie vir (vrou) gesê het, is op daai stadium hy is maar nog 'n pap baba. Ek dink enige... My logika het vir my gesê enige 'issues' wat daar dalk mag wees of probleem wat daar mag wees dink ek is vrek vroeg om hierdie bordjie vir lewenslank om hierdie arme ou lyfie se nek te hang, want 'n ou kan... Ons almal weet 'n baba ontgroeï.

A(W)(IN)

6.1.2.3. Ek het verskriklik baie tyd saam met hom spandeer, so ek het dadelik... Ek het net hierdie aanvoeling gekry, maar kyk, hoor hierso, ek moet nie tantrum met hom gooi of met hom raas nie... Want soos met die sjampoe en die seep-eet... Dis nie normale gedrag van 'n kind nie.

Examples that support the parents' experiences after the diagnosis are:

A(H)(WA)

6.1.2.4. "Dit het die dag tot dag lewe in die (van)-huis heelwat makliker gemaak. Omdat die verligting daar was, was daar 'n algemene verligting in stres, konflik en onsekerheid."

C(H)(WA)

6.1.2.5. "It also brought about challenges to us as individuals and as a couple."

A(H)(IN)

6.1.2.6. So dit was eintlik 'n verligting, so asof... Want toe hulle nou vir ons begin verduidelik toe is dit asof... Jy weet, jy stoei met 'n legkaart, jy het die rand nou al mooi aanmekaar en 'n paar stukkies in en jy het die prentjie, maar jy kry die ding net nie lekker reg nie. Maar toe hulle die goed vir ons begin verduidelik en ons ook self meer navorsing doen, toe is dit asof die legkaart net so... Toe begin ons te verstaan, okay, dis hoekom hy so maak en dis hoekom hy hiervan hou en dis hoekom dít werk en dít nie werk nie.

A(W)(IN)

6.1.2.7. Nou verstaan ons. Net om al die punte bymekaar te bring en te kyk waarheen gaan ons nou van hier af, wat is nou die volgende ding wat ons moet doen. Ons het lank nou rondgehardloop, ons eie realiteit geskep in ons gesin om uit te 'figure' hoe om dit te hanteer. Nou weet ons wat is dit. Daar is 'n naam vir dit gegee. Waar gaan ons dan nou van hier af?

6.1.2.8. Weet jy, ek dink nie dit het rêrig 'n effek op my gehad nie... Ek het nou al klaar sover gegaan om aan te pas en om uit te vind en om hom te akkommodeer, want toe hulle nou sê... Toe hulle nou die situasie 'n naam gee het dit nie rêrig aan my gevoel of emosies verander nie, want die situasie was klaar daar. Hulle het net 'n naam gegee. So dit het nie rêrig 'n effek op my gehad nie.

C(W)(IN)

6.1.2.9. It was a relief. Because finally we knew what was going on and at least we knew he was going to get the right help. But at the same time we were having mixed feelings, you know. You are happy and at the same time you are sad because now you are faced with this challenge. You know, like he said, we had plans for him, you know, like any other parents.

6.1.3 Description

When looking at the parents' experiences before the diagnosis, participant A(H) stated that he knew that the child was different, but that they did not know what it was or what caused the difference (6.1.2.1). The same participant also mentioned that together with the awareness of this difference came a fear of exaggeration. This fear stemmed from his concern of stigmatization at an age when the child is powerless (6.1.2.2). Participant A(W) pointed out that, although the child's behaviour was not normal, spending a lot of time with him resulted in her realising that she must not get upset with him. This seemed to assist her in attaching meaning to that what played out in front of her (6.1.2.3).

Turning to the parents' experiences after the diagnosis, participant A(H) mentioned that the diagnosis resulted in a relief of the stress, conflict and uncertainty and thus made the family's daily life more manageable (6.1.2.4). Participant C(H) mentioned that the diagnosis challenged them as a couple as well as individuals (6.1.2.5). Participant A(H) compared the process of the diagnosis to struggling with a puzzle, highlighting how the diagnosis eventually brought about understanding. It appears as if this process of understanding contributed to alternative ways of experiencing and dealing with their child (6.1.2.6). Participant A(W) added that understanding allowed them to take the next step forward (6.1.2.7). The same participant also stated that, because she had already made the necessary adaptations by the time of the diagnosis, it did not really have an effect on her. It appears as if the diagnosis was for her a name given to that what was already experienced. She was already familiar with the situation (6.1.2.8). Participant C(W) highlighted, on the one hand, the relief and happiness associated with the confirmed diagnosis and, on the other hand, the sadness of being faced with reality (6.1.2.9).

6.1.4 Research

I now compare the literature I have reviewed with the theme under discussion. Research by Ross and Jolly (2006) (see 2.5.1) supports the challenges some of these

participants face. An overarching idea is the aspect of the additional stress on these parents.

6.2 THEME 2: EXPERIENCE OF COPING

6.2.1 Introduction

Parents' experiences of their marital relationships were significant in terms of coping as individuals as well as a couple. The theme under discussion surfaced in couples A, B and C. Examples thereof can be seen in the statements by participants A(H), A(W), C(H) and C(W).

6.2.2 Material

Examples that point towards parents' experiences of coping as individuals are:

C(H)(WA)

6.2.2.1. I cried when I was away from my wife. I would not want her to realize how shattered I was, lest I also make things worse for her. (Later it emerged she did the same to protect me from breaking down.)

A(H)(IN)

6.2.2.2. "...het sy op haar eie manier, of my ervaring daarvan, het sy op haar eie manier begin antwoorde soek."

A(W)(IN)

6.2.2.3. Totdat ek die eendag vir my ma gesê het: "kyk, hoor, hierso is vir jou 'n bundel, dis hoe ('n kind met outisme) is op papier, want wat ek vir ma sê wil ma nie verstaan nie. Ma-hulle wil nie hoor wat sê ek nie, so hier, gaan lees, verstaan, ek gaan nie nou meer verder daaroor praat nie. As ma-hulle wil weet oor (ons kind met outisme) kom vra my, maar tot dan toe gaan ons nou maar op ons eie aan."

C(W)(IN)

6.2.2.4. You know, there is a time when you feel a lot of pressure where you feel I cannot do this. There is that point where you feel that this is just too much. But, I don't know, somehow you just, you know, when you just have that time to yourself and you sort your thinking you just happen to get that energy back. You do not know where it comes from, you know.

Examples that point towards parents' experiences of coping as a couple are:

A(H)(WA)

6.2.2.5 Ter voorbeeld het ons standpunt ingeneem en het ek die gesin en ook (my vrou) begin verdedig en beskerm. As die wêreld nie gemaklik met ons Seuna was nie of as hulle hom nie wou aanvaar nie, dan het hulle ons ook nie aanvaar nie. As hy nie welkom is nie dan stel ons nie belang om daar te wees nie.

A(H)(IN)

6.2.2.6. In tussentyd moet ons nou maar net 'n manier kry om te 'cope'. So ek wil amper sê ek het op daai stadium, soos ek gesê het ook, ek het gehelp waar ek kon, ek het probeer ondersteun waar ek kon, maar ek het soort van die teuels aan haar oorgegee, ek het vir haar vrye teuels gegee. Jy weet, ek wil nie te betrokke raak nie. Sy het hierdie goed met my bespreek, ek het my opinie gelug en ons het aangegaan.

6.2.2.7. Weet jy, ek dink hoekom ek sê outisme sal altyd 'n invloed hê op ons besluitneming is dit, dit... (Ons kind met outisme) is outisties, 'let's face it', ons het nou al 'fine' geleer 'cope' daarmee. Ek dink ons doen nogal bleddie goed, al moet ek self so sê.

6.2.3 Description

When looking at the parents' experiences of coping as individuals, participant C(H) stated that a way of dealing with the situation for him and his wife was to hide their emotions with the aim of protecting each other. They coped in this manner without knowing what the other party was experiencing (6.2.2.1). Participant A(H) remarked that, to his understanding, his wife started searching for answers in her own way (6.2.2.2). Participant A(W) explained her way of coping with the extended family as a process where she eventually had to take certain steps. She provided them with the relevant information about autism and felt strongly that she will go on without them until they are willing to accept the situation for what it is and return to her (6.2.2.3). Participant C(W) described that, in the midst of the pressure, she managed to have time for herself and regain her energy (6.2.2.4).

When looking at the parents' experiences of coping as a couple, participant A(H) described that he actively began to defend and protect his family. He reasoned that others' reactions or perceptions towards their child also applied to them as a family and that they would not choose to continue with such relationships (6.2.2.5). The same participant also described the manner in which he and his wife coped with the situation. As a couple his wife had a great deal of the responsibility, however, he participated by also doing what he could and voicing his opinion. It seems that this participant coped by sharing his experiences with his wife and yet allowing his partner to be herself (6.2.2.6). He also acknowledged that, although autism will always have an influence on their decision-making, they are facing the circumstances head-on. They feel that they have learnt to cope very well with the situation and are proud of it (6.2.2.7).

6.2.4 Research

I now compare the literature I reviewed for this study to the theme under discussion. Coping, as a theme of this study, are supported by the research of Tway, Connolly and Novak (2007) who addressed coping of parents of children with autism (see 3.1). This study addressed specific coping strategies of which resilience, the acquiring of information, active coping strategies as well as avoidant coping strategies were utilized by these couples.

6.3 THEME 3: ON EXPERIENCING CONFLICT

6.3.1 Introduction

The experiences of conflict in the parents' marital relationships were a significant theme that emerged. It will be discussed in terms of the factors contributing to conflict as well as the effect of the conflict. The theme under discussion surfaced in couples A and B and it is reflected by the following statements by participants A(H), B(H) and B(W):

6.3.2 Material

Examples that indicate parents' experiences concerning factors contributing to conflict are:

A(H)(WA)

6.3.2.1. Ek weet dit was nogal veral erg vir haar as sy hom met haar broer en suster se kinders vergelyk het en dit het my kwaad gemaak. So al die goed het gevolglik tot baie konflik en frustrasie in ons verhouding gelei.

6.3.2.2. "Na nege jaar van getroud wees gaan konflik uiteindelik in die (hulle)-huis oor die algemene goed soos finansies, binnehuisversiering, vriende en die goed."

B(H)(WA)

6.3.2.3. Ek dink my frustrasie omdat ons geen oplossings kon kry nie, het veroorsaak dat ons baie rusie gemaak het en mekaar selfs kwalik geneem vir die oorsaak van die outisme, en vir die feit dat die behandelings wat duur en moeilik was en ook ons lewe grootliks ontwrig het, nie gewerk het nie.

B(H)(IN)

6.3.2.4. En nou kry ons sulke toetse om te doen. Nou moet... Ons sit, ek en sy en haar pa en haar ma en elkeen en ek sê nee dis normaal en dat is normaal en dan verskil ons toetse so hemelsbreed met mekaar dan begin ons baklei daaroor. Dan sê ek op haar 'score' val hy binne die outistiese spektrum, maar op my 'score' dan val hy nie daar nie.

6.3.2.5 Maar ons het twee totaal verskillende maniere om goed wat ons pla te verwerk. Sy moet meer daaroor praat en ek moet glad nie daaroor praat nie. Hoe meer iemand daaroor wil praat, hoe moeiliker is dit vir my om daarmee te 'deal'. So, dan voel dit vir my hoe meer ek daaroor wil praat hoe minder kan ek 'actually' my interne meganisme laat werk so dit het nou nog verder ons laat argumenteer... Uhm: Spanning....

Examples that indicate parents' experiences concerning the effect of the conflict are:

A(H)(WA)

6.3.2.6. Ek het maar eerder begin onttrek, want dinge by die huis was net te veel. Bly maar eerder besig en stil as om daar te wees of iets te sê en dit eindig in rusie. Ek dink dit is een van die redes hoekom

(my vrou) altyd moeg en afgemat was want sy moes met (ons kind met outisme) 24 uur 'n dag 'cope'. Dit was natuurlik nog slegter vir ons huwelik.

B(W)(WA)

6.3.2.7. “Ek was baie maal in die middel en deur albei onder kruisverhoor geplaas oor die ander se opinie. Ek dink daar was...is baie opstand in my daaroor.”

6.3.2.8. “... want ek dink lateraan raak die argumente nie meer gefokus op die beste antwoord nie, maar 'n ‘tug-of-war’ vir die magsposisie. (Wat my ma onregverdiglik by (my man) probeer wegvat het).”

6.3.3 Description

When looking at the parents’ experiences concerning factors contributing to conflict, participant A(H) mentioned that, although it was hard for his wife to compare their child with the extended family’s children, it made him angry. This led to a lot of conflict and frustration in their relationship (6.3.2.1). The same participant also stated that, after being married for nine years, conflict in their household is eventually about general aspects like finances, interior decorating, friends and other aspects of a general nature (6.3.2.2). Participant B(H) stated that the frustration of not finding a solution caused a lot of conflict in their relationship and even resulted in them blaming each other for the cause of autism as well as the fact that the treatment was unsuccessful (6.3.2.3). This participant also discussed a disagreement between himself on the one hand and his wife and her parents on the other. It was about a test evaluating the child, where his score reflected that of normality but his wife’s indicated that the child was in the autism spectrum (6.3.2.4). The same participant also discussed the opposing ways they dealt with things that bother them. Whereas his wife wants to talk about the subject, talking makes it even more difficult for him to deal with it. This difference in dealing with situations caused even more arguments and tension between them (6.3.2.5).

Looking at the parents’ experiences concerning the effect of the conflict, participant A(H) stated that the conflict between them resulted in him withdrawing. It was safer for him to keep his peace and be busy on his own. This, as well as his wife’s exhaustion because she had to constantly deal with the child, had a harmful effect on their marriage (6.3.2.6). Participant B(W) remarked that she was the person in between having to field

the opinions of others. Being in this position generated a revolt in her (6.3.2.7). She also added that arguments were eventually not focused on the best resolution any more, but that it became a fight for a position of power (6.3.2.8).

6.3.4 Research

I now compare the literature I reviewed for this study with the theme under discussion. Conflict, as a theme of this study, is supported by the research of Ross and Jolly (2006) where the experience of withdrawal (see 2.5.1) was also described. As can be seen in the section on parents' experiences concerning factors contributing to conflict, stress in the marriage is highlighted in research by Blair et al. (1996), Hutton and Caron (2005) and Shelly (2004) (see 3.2.6).

6.4 THEME 4: ON BEING DIFFERENT

6.4.1 Introduction

Parents experienced being different or being unique as having a positive effect on their marital relationships. The theme under discussion surfaced in couples A and B, as can be seen in the responses by A(W) and B(H):

6.4.2 Material

An example that supports the parents' experiences of being different is:

A(W)(WA)

6.4.2.1. "Ons verhouding het so verbeter en gegroei, want ons die een ding in gemeen, en die een verantwoording wat ander mense nie het nie. "

A(W)(IN)

6.4.2.2. Die ding wat my en (my man) sterker as enige deursnee persoon... As jy iemand kry met wie jy rêrig iets in gemeen en net julle, net daai paartjie of net daai twee persone het hierdie een ding, hierdie 'treasure' waaroor hulle saamwerk en saam bou... Dit maak daai verhouding sterker... Dit gee vir my en (my man) sekuriteit. Dit gee vir ons vrede, want ons weet dit is wat ons verantwoordelikheid. Dit is...Dit is... Jy weet, dit is (ons kind met outisme)...

B(H)(IN)

6.4.2.3. Is so anders in ons huwelik wat ons nou oor sekere goed sal lag of trots wees wat in ander gesinne 'n heeltemal ander reaksie sou gekry het. En dit maak jou verhouding uniek. En wanneer jou verhouding uniek is dan dink ek, uhm, dan is daar meer hoop. Dis soos mense wat van die rugbyspan hou, dit gee vir jou 'n anker.

6.4.3 Description

Participant A(W) commented that because they have this one thing in common and this one thing to be responsible for which others do not have, their relationship grew and became stronger (6.4.2.1). Linking to what participant A(W) had stated in the written account, she further explained that is what made them as a couple stronger than the average person. She described a commonality that only they share – their child. She sees their child as a treasure they both work on together and invest in. Having sole responsibility for this commonality provide them with security (6.4.2.2). It seems as if participant B(H) described a uniqueness of their own because they can be happy and be proud about certain things which would have evoked a different reaction in other families. He added that a relationship being unique adds hope and compared that to people who like the same rugby team – it provides an anchor. It seems as if this experience has added to the couple's closeness (6.4.2.3). Looking at these descriptions, the experience of being different seems to have had a powerful impact on the couples – almost as a factor binding them together.

6.4.4 Research

The literature sources that I have reviewed for this study does not correspond with the contents of the theme of being different as I have found it.

6.5 THEME 5: EXPERIENCING THE OUTSIDE WORLD

6.5.1 Introduction

Parents' experiences of their marital relationships relating to the outside world were another significant theme that emerged. This section will address both the negative and the positive outcomes the outside world had on the participants. The theme under discussion surfaced with all three the couples and is reflected in the statements of A(H), A(W), B(W) and C(H).

6.5.2 Material

Examples that indicate parents' negative experiences regarding the outside world are:

A(H)(WA)

6.5.2.1. "Ewe skielik was almal kenners op die gebied en is ons gebombardeer met voorstelle, spesialiste en raadte. As maar nog jonggetroudes, mense en ouers het ons maar party dae verlore gevoel."

A(W)(IN)

6.5.2.2. Ek het aan die begin baie raas gekry - by hom, by my ma-hulle, by almal, my vriende, by almal. By verskriklik baie mense het ek ongelooflik baie uittrap-berade gekry, omdat ek hom toegelaat het om sekere goed te doen.

B(W)(IN)

6.5.2.3. "Kan nie eers ons eie huwelik nie... Maar sy was so deel daarvan gewees. Hierdie ding van keuses, dat as sy die keuses vir jou wegvat wat jy naderhand verantwoordelikheid ook wegvat. ... Ek het net eenvoudig teruggetree."

6.5.2.4. Ek kan 'actually' terwyl julle nie kyk nie 'fine' goed doen. En om op 'number 99' in te storm en oor te neem en te sê laat ek tog net die situasie red, want jy kan nie 'cope' nie, terwyl ek nog tot op daai stadium ge-'cope' het en miskien nie op die konvensionele manier soos wat julle almal... Maar ek wou dit nog nooit gedoen het soos my ma nie. Ek wou nog nooit daai spanning en druk en al daai goed gehad het in my gesin en...

6.5.2.5. “B(H): Wat het die grootste impak op ons lewe, ons huwelik, negatiewe invloed op ons huwelik gehad, jou ma of outisme? B(W): Moet ek kies tussen die twee? My ma.”

C(H)(IN)

6.5.2.6. You know, I will tell you it even tests your relationship as far as how you relate to your own family. If there is somebody in my family that cannot tolerate him then it upsets my wife, you know. And it is natural for me to try to be the neutral party. And if... From her family, if somebody does not tolerate him, it obviously upsets me more than... You know what, so it is challenges the way also relate to our own families as well and in-laws as well, you know. It is one of those things.

Examples that indicate positive outcomes regarding the outside world are:

A(W)(WA)

6.5.2.7. Daar was in die begin nogal baie frustrasies en woede teenoor mense en die gemeenskap wat hulle mening en opinies gelug het oor (ons kind met outisme), maar deur dit alles het ek en (my man) gegroei in ons ouerwees en in ons huwelik.

A(H)(IN)

6.5.2.8. “...waar almal nou alles te sê het, dis nou ons teen die wêreld.”

6.5.3 Description

When looking at the parents’ negative experiences concerning the outside world, participant A(H) stated that suddenly everyone were experts about the subject and bombarded them with advice and opinions which resulted in them feeling lost at times. It seems as if the significance of their own voice as a couple and as parents has been taken away by others (6.5.2.1). Participant A(W) experienced being scolded at by, among others, her husband, parents and friends because it seems as if her actions went against the generally accepted norms (6.5.2.2). Participant B(W) described her mother’s involvement in their marriage and that she took their choices and responsibility away, which resulted in the participant withdrawing from the situation (6.5.2.3). She also stated that others treated her as being incompetent by wanting to rescue a situation and take over while she could actually cope really well by that stage. She added that she might not have done things like others would, but she also never had the desire to do it like her mother. She never wanted that tension in her family (6.5.2.4). It seems as if in both

(6.5.2.3) and (6.5.2.4) the feeling of incompetence surfaced. The same participant also responded to a question of her husband that her mother had a more stressful influence on their marriage than autism (6.5.2.5). Participant C(H) said that the manner in which they related to the extended families, also tested their relationship. The husband described that when the families from both sides could not tolerate their child it also challenged them as a couple (6.5.2.6).

Looking at the positive outcomes concerning the outside world, participant A(W) stated that, although the opinions of others regarding their child caused a lot of frustration and anger, she and her husband grew through it all in being parents and in their marriage (6.5.2.7). Participant A(H) experienced that regardless of all the opinions, it was them against the world. It seems as if this statement highlights the notion of protecting the family (6.5.2.8).

6.5.4 Research

I now compare the literature I reviewed for this study with the theme under discussion. The outside world, as a theme of this study, is supported by research. DeMyer (1979) stated that parents every so often feel more stress than assistance from families (see 2.5.3). As Tilton (2004) also stated, comments generally made out of goodwill can yet be critical and contribute to the stress. However, as can be seen above, the same author also mentioned that a positive experience is most common for parents of children with autism and their extended family (see 2.5.3).

6.6 THEME 6: ON BEING A COUPLE

6.6.1 Introduction

Parents' experiences of their marital relationships relating to being a couple were also a significant theme. This section will address the challenges and the factors that led to positive outcomes in being such a couple. The theme under discussion surfaced in

couples A, B and C and is reflected by the following statements by participants A(H), A(W), B(W), C(W).

6.6.2 Material

Examples that illustrate the challenges of being a couple are:

A(H)(WA)

6.6.2.1. “Ons het meestal dae as individue sowel as 'n egpaar nie geweet waar om te vat en waar om te los nie en het mekaar meestal van die tyd helemal gemis.”

C(W)(WA)

6.6.2.2. “Our hopes and dreams were shattered because we came to realize that he will never be self-sufficient and should be supervised at all times as he cannot recognize danger.”

A(H)(IN)

6.6.2.3. En soos (my vrou) gesê het, sy het haar dae gehad. Dan sien ek sy is moeg, dan dink ek, OK, kom ons doen moeite. Maar, soos ek vir jou gesê het, daar is 'n paar 'kites' wat net nie gevlieg het nie. En ek moes net, ons moes net agterkom, weet jy, ek kan dissipline toepas en ek kan met (ons kind met outisme) deel en speel en... Maar daar is sekere tye en op 'n sekere punt waar ek net moet los, ek moenie betrokke raak nie en dis beter vir my om om te draai. ... Dis net daar waar “mamma” dan draai ek om en ek loop - dis beter vir almal.

B(W)(IN)

6.6.2.4. Ek dink ek is gefrustreerd oor die feit dat ek baie meer sal wil uitgaan en baie meer dinge wil doen en ek verstaan hoekom jy nie wil nie. Aan die een kant verstaan ek presies waar hy vandaan kom en ek ervaar die frustrasies. Ek is iemand wat... Ek sal baie meer met hom uitgaan en goed doen met hom en ek weet hoe moeilik dit is. Hy raak weg by winkelsentrums, as jy weer sien is hy weg. So ek ken daai spanning en daai frustrasie. Dis vir my frustrerend. Ek meen dis nie meer soos ons vroeër was nie, veral nie soos jy vroeër was nie. Ek sal nog steeds graag dinge wil doen en plekke gaan en naweke weggaan en vakansie wil hou. Ek het besef dit is so moeilik en dit veroorsaak frustrasie. Ek verstaan intellektueel hoekom jy nie wil nie. Ek verstaan dat die logistieke, die frustrasie daarvan, maar emosioneel is ek...

Examples that illustrate the factors that led to positive outcomes in being a couple are:

A(H)(WA)

6.6.2.5. Die was ook die draaipunt waar, soos wat ons verhouding verbeter het, die stryd nie meer tussen ons as individue was nie, maar waar ons saam as 'n gesin aan die ding begin werk het en die stryd nou was tussen ons en die buitewêreld. ... so het ons gesinsband versterk en ook ons huwelik.

A(W)(WA)

6.6.2.6. Ons het vir twee jaar rond gesoek vir hulp en niemand kon ons raad gee, oor hoe, en wat presies 'fout' is met (kind met outisme) nie. As gevolg daarvan het ons mekaar bygestaan en geweet dat ons eie ding gaan moet doen.

A(W)(IN)

6.6.2.7. Ek en (my man) praat verskriklik baie oor hierdie goeters. Dit is ons, ons hou nie terug van mekaar nie. As daar iets is wat ek wil weet dan praat ons daaroor en soos ek sê die laaste ruk is ons so oop boek laat ons presies weet waar staan ons in die verhouding met (ons kind met outisme), waar staan hy in sy rol en ek in my rol presies. ... Ons het nou al so in ons eie roetine ingeval laat ons weet presies waar staan ons met mekaar, wie doen wat en wanneer...

6.6.2.8. "Weet jy, ek dink die verskil... Die verskillende maniere hoe ons dit hanteer het en hoe ons die inligting gekry het, het mekaar gekomplementeer en mekaar aangevul."

B(W)(IN)

6.6.2.9. Nou in 'hindsight' het jy altyd baie antwoorde, maar... Dis hoe ons gekom het waar ons nou is, dis die lesse wat ons geleer het en dan daaruit te bou ... dan gaan ons almal beter en voller mense wees - 'happier' mense wees, meer gebalanseerd wees. Dan kan ons saam beter 'function' want daar is...

6.6.2.10.B(W): Maar hierdie jaar het ons begin. Van die goeters het ons net eenvoudig... Dinsdae-aande uitgaan, gaan koffie drink êrenste en dis 'amazing'. Die begin het ons uitgegaan en baklei en toe het ons maar besluit om te gaan flik, want dan kan ons nie baklei nie. En dis 'actually' nou 'fun'. Nou kry ons tyd om met mekaar te kan praat sonder een of ander krisis wat 'interrupt' en dis 'amazing' - dis 'genuine'. B(H): Mmm... Dit doen nogal ons verhouding baie...

6.6.3 Description

Turning to the parents' challenges of being a couple, participant A(H) mentioned that, as individuals and as a couple, there were days where they felt so lost and bypassed each other in the process (6.6.2.1). Participant C(W) stated that the realisation that their

child would never be independent shattered all their hopes and dreams (6.6.2.2). Participant A(H) said that although he put in an effort when he saw that his wife was tired, it was not always easy. He had to recognise what his roles in terms of their child were as well as to know when to step aside and let his wife handle their child (6.6.2.3). Participant B(W) stated that she is understanding of her husband's position as well as his tension and frustration with regards to dealing with their child. However, the frustration she experienced concerning the difference in their current way of being and that her husband's conduct is taking out of her (6.6.2.4).

Turning to the factors that led to positive outcomes in being a couple, participant A(H) stated that the turning point in their marriage and their family relationships was when the battle was no longer between them as individuals. They became more resolute and stood together as a family - it would now be them against the rest of the world. It seems as if this turning point enabled them to cooperate when dealing with their circumstances. This may have assisted them in discovering their unique outcome (6.6.2.5). Participant A(W) mentioned that their search for assistance with their child resulted in them supporting each other. In the process they also came to the conclusion that they would have to resolve all matters as they arose (6.6.2.6). The same participant added that she and her husband communicate openly without holding back. They know exactly where they stand with their child and each other as well as in their roles and duties (6.6.2.7). She also mentioned that the different ways in which they handled the situation with their child complemented each other (6.6.2.8). Participant B(W) remarked that, when looking back, the lessons they learnt bought them to where they are currently. Building on those experiences would make them more content and balanced individuals, allowing them to function better together (6.6.2.9). The same participant also stated that, as from the beginning of this year, they began to do things together. At first they had to go out for a movie as it would minimise the potential for conflict. However, they are now able to go out for a coffee and spend time together without any mutual recriminations. She experiences this change as fun and amazing and that it means a lot for their relationship (6.6.2.10).

6.6.4 Research

I now compare the literature I reviewed for this study with the theme under discussion. Being a couple, as a theme of this study, is supported by DeMyer (1979) where experiences of frustration (see 2.5.1) is addressed, in Ross and Jolly (2006) the loss of expectations the parents had for the child (see 2.5.1) are raised and in Woodgate (2008) the partners' different feelings (see 3.2.6) are highlighted. However, DeMyer (1979) (see 2.5.1) and Blair et al. (1996) (see 3.2.6) also noted the positive outcomes as stated above.

6.7 THEME 7: ON PARTNERSHIP

6.7.1 Introduction

Parents' experiences of their marital relationships as being partners were another significant theme. Partners' perceptions of each other surfaced for all three couples and are described in the statements by participants A(W), B(H), B(W), C(H) and C(W).

6.7.2 Material

Examples that demonstrate the challenges in their partnerships are:

B(H)(WA)

6.7.2.1. (My vrou) het op (ons kind met outisme) se eerste verjaarsdag begin bekommerd raak oor die gebrek aan sekere mylpale en abnormale gedrag. Sy het dit met my bespreek en ek het gedink sy oorreageer en dat seuns maar stadiger ontwikkel as dogtertjies. [(Ons kind met outisme) se sussie was toe 3 jaar oud].

B(W)(WA)

6.7.2.2. "Maar daar is nie meer troos by my man nie. Ek kan hom nie troos nie. En hy kan my nie troos nie."

B(H)(IN)

6.7.2.3. B(H): As jy sou sê... Kyk 'obviously' is ons opsies minder met (ons kind met outisme). Ons

kon klomp goed nie doen nie wat ander gesinne doen, maar... Uhm, sou jy sê, laat ek dit nou reg stel, dat die opsies waarna jy soek in ons verhouding... Neem jy my kwalik vir die feit dat daar nie opsies... Laat ons nie daai opsies het nie? Is jy kwaad vir oor (ons kind met outisme)? B(W): Hmu (skud kop)

B(W)(IN)

6.7.2.4. Daar is 'n paar goed. Dis eenkant die werk-situasie. Dit begin nie by hom nie, maar ek dink hy is in die 'loop' daarso. Verstaan jy, ek het half vir hom gewerk en ek het besluit om my eie ding te doen en...en dit werk net nie. ... En dan raak ek eintlik opstandig teenoor hom, want my besigheid kon gewerk het as daar iemand was wat my met ander goed kon help. En ek werk al weer by hom.

Examples that demonstrate the positive experiences in their partnerships are:

B(W)(WA)

6.7.2.5. Verstaan my reg, ek dink (my man) is 'n 'amazing' pa en ek kan onomwonde sê dat ek nie sonder (hom) deur die aanvanklike 'turmoil' van outisme sou gekom het nie. Al is jy in jou 'sadness' so alleen en eensaam, sou ek, as ek fisies op my eie was, nie dit gemaak het nie.

C(H)(WA)

6.7.2.6. "It is amazing how my wife is willing to break her back to make a good living for my 'CHAMP' hence strengthening me as well."

C(W)(WA)

6.7.2.7. My husband can deal with (our child with autism's) condition better than I do because he is calm and patient whereas I sometimes feel a lot of pressure and even snap at times but on these days he takes over and allows me to have time to myself. This really helps because after some time I become energetic and hopeful that I can deal with this challenge.

A(W)(IN)

6.7.2.8. Ek dink ek en (my dogter) het die vinnigste, wat sy taal aanbetref, by hom aangepas ... met hom begin kommunikeer sodat hy ons kan verstaan, want ons is die meeste van die tyd in sy geselskap gewees. ...dan sal hy met my begin praat dan sal (my man) hom so aanloer. Sien jy, ek bedoel nou dit ge-'translate' nou maar so vir (my man), wat sê hy, wat bedoel hy.

6.7.3 Description

Looking at the parents' challenges in their partnerships, participant B(H) said that his wife's concern about their child started at his first birthday realising his inability to reach certain milestones as well as observing his abnormal behaviour. However, when discussing this, her husband saw her concern as an overreaction, rationalising that boys develop slower than girls (6.7.2.1). Participant B(W) remarked that there was no more comfort within her husband. She could not comfort him and he could not comfort her (6.7.2.2). Participant B(H) was concerned whether his wife blamed him for the fact that there were less options in their relationship – that they could not do things that other families do. However, after careful probing from his side she answered in the negative. It appears as if participant B(H)'s uncertainty about his role in their relationship troubled him and that he needed confirmation concerning his position (6.7.2.3). Participant B(W) stated that her feelings regarding her work situation are closely related to her husband. She worked for him before she decided to start her own business. The fact that it failed made her rebellious because her business could have worked if there had been someone who could have assisted her with the other things. She is currently again working for her husband (6.7.2.4).

Looking at the parents' positive experiences in their partnerships, participant B(W) remarked that her husband is an amazing father and that she would not have survived the initial confusion connected with autism without him. Although she experienced being alone in her plight she added that she would not have made it being physically alone as well (6.7.2.5). Participant C(H) mentioned that he was supported by his wife's willingness to take the trouble to make a good living for their child (6.7.2.6). Participant C(W) remarked that her husband alleviates the pressure of their child from her by taking over at times and thereby allowing her to have time to herself. This helps her to recharge her attitude and to gain perspective (6.7.2.7). It appears as if both statements (6.7.2.6) and (6.7.2.7) are examples of the spouses praising each other. Participant A(W) stated that she and their other child adapted to their child with autism's language the quickest. This provided her with the opportunity to explain to her husband what the child's conversation meant (6.7.2.8).

6.7.4 Research

I now compare the literature I reviewed for this study with the theme under discussion. Partnership, as a theme of this study, is supported by DeMyer (1979) where experiences of sadness are addressed (see 2.5.1) and in Woodgate (2008) the partners' different feelings that led to them "not always being on the same wavelength" (see 3.2.6) are mentioned. Nevertheless, as was also pointed out in the previous theme, DeMyer (1979) (see 2.5.1) and Blair et al. (1996) (see 3.2.6) acknowledge the positive outcomes concerning such partnerships.

6.8 THEME 8: FAMILY LIFE

6.8.1 Introduction

Parents' experiences of their marital relationships relating to their family life was another significant theme that emerged. This section will address both the challenges and the positive experiences of the participants. The theme under discussion surfaced in couples A and B and is reflected in the statements by A(H), B(H) and B(W).

6.8.2 Material

Examples that illustrate the challenges relating to their family life are:

B(H)(WA)

6.8.2.1. "Dit was 'n ontugtering om te besef dat my huwelikspad en gesin se drome so vroeg van spoor af gaan en al my pogings om dit te red is vergeefs."

A(H)(IN)

6.8.2.2. Ek dink in die begin was dit vir my frustrasie ... In die begin was daar hierdie verskriklike, glo vir my, dit is eintlik simpel om te sê, maar daar was hierdie helse 'power struggle' tussen my en hierdie klein stukkie lyfie, uhm, helse kompetisie oor (my vrou) se aandag en emosies.

Examples that illustrate the positive experiences relating to their family life are:

B(W)(IN)

6.8.2.3. Ek dink dis belangrik om daarop te fokus en om dit te 'cherish' en daaraan vas te hou en bymekaar te staan - amper met jou rue in 'n sirkeltjie na mekaar toe dat jy bymekaar is en dan in die samelewing. Ek dink nie jy kan uit die samelewing gaan nie. Ek dink nie jy kan uit die lewe...

6.8.3 Description

Looking at the parents' challenges relating to their family life, participant B(H) remarked how hard it was to realise that his dreams for his marriage and family were being crushed and that all his efforts to rescue them were all for nothing (6.8.2.1). Participant A(H) described his frustration about the competition between him and their child with autism for his wife's attention. It seems as if this competition could have left him feeling neglected (6.8.2.2).

Looking at the parents' positive experiences relating to their family life, participant B(W) mentioned that, although one cannot leave the community, standing together as a family unit is of utmost importance. She compared it to standing, within the community, back-to-back, facing fearlessly outward (6.8.2.3).

6.8.4 Research

I will now compare the literature I reviewed for this study to the theme under discussion. Family-life, as a theme of this study, is supported by Kingston (2007) and Ross and Jolly (2006) who recognised both the positive and negative experiences among family members (see 2.5.1).

6.9 THEME 9: EXPERIENCING AUTISM

6.9.1 Introduction

Parents' experiences of their marital relationships in relation to autism also emerged as

a theme in this study. This section will address the effects of autism as well as the positive outcomes the participants experienced. The theme under discussion surfaced for all three couples and is reflected in the statements of A(H), A(W), B(H), B(W), C(H) and C(W).

6.9.2 Material

Examples that indicate the effects of autism on the participants are:

B(H)(WA)

6.9.2.1. Ek sien nou in retrospek dat die gebeurtenis my minder laat konsentreer het op ander goed in my lewe soos werk, gesondheid, my huweliksverhouding en ander verhoudings, my geestelike lewe, ens. Ek het swakker oordeel aan die dag gelê. Ek het nie veel aandag gegee aan my huweliksmaat se behoeftes en seer nie, omdat ek my pyn en hartseer probeer verwerk het.

B(W)(WA)

6.9.2.2. “Outisme beëindig ‘life as we knew it’, dit ontspoor alles en gooi jou in ‘n ander wentelbaan waar ander reëls geld.”

A(H)(IN)

6.9.2.3. Het nie geweet waar om te vat of om te los nie. En ‘n ou sit nou maar en dink by jouself, weet jy, ek is nou die man van die huis, dit is my kind so ek moet seker moeite met hom doen en seker uitvind wat gaan met hom aan. Dit help nie ek sê vir almal hulle weet nie waarvan hulle praat nie, maar ek spandeer self nie genoeg tyd met hom nie. ... ‘n ou voel verantwoordelik.

B(W)(IN)

6.9.2.4. Jy kan nie daar verby kom nie. Dit gaan nie weggaan nie. Dit gaan nie verander nie. ... Jy weet, hy word nie groter nie hy word nie beter nie. Jy sit heeltyd in ‘n gevangenskap. Jy sit die heeltyd... Jy kan nie aangaan nie.

6.9.2.5. “Letterlik jy gaan oorlewings -‘mode’. Jy dink nie aan wat wil jy graag doen of waarna toe wil jy graag gaan of waarvoor wil jy graag spaar of iets nie, want jy spaar vir daai...”

C(H)(IN)

6.9.2.6. So even it stifles our social life because you also have to think, not just myself but also as a couple, you can’t just go anywhere. You can’t just go anywhere. You have to think about when you

sit in a restaurant you have to limit your time because just now he is going to get restless. He is going to peoples tables. You have to think about those things. You cannot use public transport. You don't know what he wants to do inside the bus. He may want to lie down and if he feels he wants to lie down he will lay down on the seat and there could be somebody who has to use it. So it starts with the way your life runs. You cannot... You have to plan everything. You cannot just decide, 'Ah, today we are using the bus'.

Examples that indicate the positive outcomes relating to autism are:

A(H)(WA)

6.9.2.7. "Die laaste sal wees die nabye verlede en huidiglik waar ons gemaklik is met outisme, ons situasie en waar ons vandag is."

C(W)(WA)

6.9.2.8. "...his condition bought us closer as a couple, and we were prepared to face the challenge head-on."

A(W)(IN)

6.9.2.9. My geduld geleer. Baie erg geduld geleer. Dis definitief die grootste ding wat ek bekom het, is geduld. Daar is dae wat ek verskriklik geïrriteerd raak. Wat ek dink is nou maar net... Jou bekertjie kan net soveel vat dan het ek net nodig om te ontlaai. (My man) verstaan ook nou al. Dan ontlaai ek en ek laat gaan en ek baklei en ek doen wat ek moet doen. Dan is ek weer 'fine'. Dan gaan ek weer vir 'n paar weke of wat ook al aan. Maar ek dink dit het ons verhouding... Ek het rustiger geword. Ek het baie rustiger geword. Weet ek het geleer om te gaan stilstaan, kalm te raak en van alle hoeke af 'n ding te bekyk, nie net van "Dis hoe ek dit sien" nie.

6.9.3 Description

Turning to the effects of autism on the parents, participant B(H) described certain consequences of autism. He concentrated less on other aspects of his life such as his work and health, his marital relationship, other relationships and his spiritual life. He used poor judgement and paid less attention to the needs and hurt of his spouse because he tried to deal with his own pain and grief (6.9.2.1). Participant B(W) mentioned that autism brought all that was familiar to a halt, resulting in the unknown being thrown at her (6.9.2.2). Participant A(H) also described that he felt lost. Having the responsibility

of being the man of the house, he realised that he had to spend more time with his child to personally find out what the situation was before judging others' opinions (6.9.2.3). Participant B(W) described autism as something one cannot escape. Being trapped it does not change or go away. That her child was not getting any better resulted in her feeling as if being imprisoned – sitting there and being unable to go forward. It seems as if the limitation of her freedom played a great role (6.9.2.4). The same participant also stated that she experienced being in a survival mode and not giving her own needs and wishes free rein (6.9.2.5). Participant C(H) remarked that their social life was being hampered. It appeared as if autism controlled their options in many different ways. Having to always take their child into account, as when going to a restaurant or using public transport, they have to do careful planning for everything that involves their child with autism (6.9.2.6).

Turning to the positive outcomes relating to autism, participant A(H) stated that they have recently become comfortable with autism and their current situation (6.9.2.7). Participant C(W) mentioned that the outcome of their child's condition is twofold. It brought them closer as a couple and equipped them to deal with challenges head on (6.9.2.8). Participant A(W) remarked that it taught her patience. The couple also now know how to effectively go about when things become too much. The participant mentioned also turning out to be more relaxed which equipped her to view circumstances from all the angles (6.9.2.9).

6.9.4 Research

I now compare the literature I reviewed for this study with the theme under discussion. Autism, as a theme of this study, is supported by DeMyer (1979) where emotional experiences connected to autism were addressed (see 2.5.1). As noted previously, DeMyer (1979) (see 2.5.1) and Blair et al. (1996) (see 3.2.6) acknowledged the positive outcomes relating to autism.

My intention with this research study was to explore parents' experiences of their marital relationships after their children have been diagnosed as having autistic disorder.

Seeing that the results are reflective specifically of the three couples who participated in the study, one can argue that the researcher was able to present a representative account of their experiences. The analysis of the research material provides a range of experiences parents in these circumstances might be familiar with.

Conclusion

The goal of this chapter was to present the research findings of this project. This was achieved by discussing relevant themes (diagnosis, coping, conflict, being different, the outside world, being a couple, partnership, family life and autism) that emerged during the analyses of the material. The next chapter will summarise and integrate previous and present research on autism. Limitations and recommendations will also be addressed.

CHAPTER 7

DISCUSSION AND CONCLUSION

Introduction

This is the concluding chapter and the goal is to summarise and integrate the relevant literature with the research findings. This chapter also discusses the limitations of the study and provides recommendations for future research.

7.1 SUMMARY

This section will provide summaries pertaining to autism, research on autism and research findings on autism. Previous research on autism as well as the results coming from this study will also be integrated.

7.1.1 Summary of Autism

Autistic Disorder, listed under the developmental disorders of PDD, is characterized by impairment in the nature and quality of social skills, communication and/or a restricted and repetitive repertoire of behaviours and interests. Deficits in social interaction are varied and are usually the most severe in the preschool years. Impairments in communication are often deeper than just language and can effect both verbal and nonverbal skills. Impairments in repetitive, restricted and stereotyped patterns of behaviour may be seen in the preoccupation with one or several facets which are abnormal either in their focus or intensity.

The etiology of autism describes a complex picture involving genetics, biology and neurology in combination with a number of environmental factors. Among the medical causes, genetic issues have increasingly suggested that autism is highly heritable. Genetic analysis concluded that a combination of genes and pre-existing factors are likely to be involved in autistic disorder. Medical conditions, such as genetic conditions, viral infections, metabolic conditions and congenital anomaly syndromes

have been identified in some cases as playing a role in the development of autism. Looking at the neurobiological cause of autism, neuro-anatomical findings revealed abnormalities in brain regions such as the limbic areas, brain stem, hippocampus, temporal and frontal lobes. However, uncertainties exist as no abnormality has been found in post-mortem brain studies. As for the neuro-chemical findings, the only brain chemical that has clearly been found in abnormal levels in individuals with autism is the neurotransmitter serotonin. There are also various suggestions regarding neuro-physiology as a causal factor in autism. Environmental causes have also been suggested as a factor contributing to autism. Pregnancy, as an environmental factor, may function in combination with genetic or other factors, or merely indicate the presence of abnormalities already existing in the infant. Although not unique to autism, infections may also be regarded as a possible cause of autism. Also under investigation, pollutants and toxins like lead poisoning, has shown a link with autism.

Treatment of autism highlights that a combination of various approaches as well as the provision of treatment on multiple levels are often required. Behavioural treatments can be highly effective in symptom management in individuals with autism. Some effective behavioural approaches are Applied Behavioural Analysis (ABA), Discrete Trail Training (DTT) and Differential Reinforcement Pivotal Response Training (PRT). Some educational interventions are TEACCH and the SCERTS model. Pharmacological treatments are also used for symptom management. Examples of valuable pharmacological treatments are neuroleptics, Selective Serotonin Reuptake Inhibitors (SSRIs), opioid antagonists as well as several anticonvulsant medications. Other treatments worth mentioning are speech and language therapy, occupational therapy, adapted physical education and music, dance and art therapy.

The impact of autism on the family can be described in terms of parents' experience in general, the experience of siblings, the experience of the extended family as well as the experiencing by parents of their marital relationship. Noteworthy is the fact that these experiences can both be seen, on the one hand, in terms of the challenges or negative aspects surrounding it, and on the other hand, as having a demonstrable positive and remedial aspect.

7.1.2 Summary of Research on Autism

Research on the topic of parents of children with autism focuses on parental stress, the support and/or coping of parents with a child with autism as well as the parental marriages (as seen in 3.1). Motivating the topic of my study is the fact that literature specifically linking the marital relationship and children with autism is relatively scarce and at times only raises it briefly. Research pertaining to the topic of this study has been done between the period 1989 to 2008 and most of these studies have been researched and implemented abroad. Of these studies only one (Roderigue in Roderigue et. al., 1990) researcher explicitly stated that it is from a psychological background. The majority of the studies also utilized questionnaires as their method of gathering material. With reference to their theoretical position, only one (Woodgate et al., 2008) study confirmed using hermeneutic phenomenology. The findings of these studies confirmed in the main that having a child with autism added stress to the parents' marriages, lowered levels of marital intimacy, resulted in less marital satisfaction as well as a feeling of detachment between each other. However, there were also some parents who felt that their marriages had been strengthened by their experience.

7.1.3 Summary of Research Findings on Autism

Various significant themes emerged from the data analysis of this study. Looking at the diagnosis, parents' experiences of their marital relationships were significant both before and after the diagnosis. As an experience of coping, the parents' experiences concerning their marital relationships were significant in terms of coping as individuals as well as cooperatively as a couple. Experiences of conflict in the parents' marital relationships had meaning both in terms of the factors contributing to conflict and the effect of the conflict. Parents experienced being different or being unique as having a positive effect on their marital relationships. External influences had both negative and positive effects on the parents and their marital relationships. Being a couple was experienced as both a challenge as well as the presence of factors that led to positive

outcomes in being a couple. Parents also highlighted their perceptions of their partners when looking at their marital relationships. When addressing the theme of their family life, both the challenges and the positive experiences of the participants surfaced. Parents' experiences of their marital relationships in relation to autism were evident both in terms of the effects of autism as well as the positive outcomes the participants experienced.

7.1.4 Integration of Previous and Present Research on Autism

This section will demonstrate an integration between the above-mentioned themes that surfaced in this study as well as in research addressed earlier in chapters 2 and 3. Participants' experiences of the diagnosis of their child correspond with previous research in terms of the challenges and stress these parents face. Experiences of coping are reflected in similar coping strategies used by parents of children with autism. Experiencing conflict is comparable when actions such as withdrawal are described. Parents' experiences concerning factors contributing to conflict are supported by research on stress in these parents' marriages. Noteworthy is that the theme of being different did not correspond with previous research reviewed by the researcher and that all the couples in this study experienced being different as positive. Experiences of the outside world correspond with previous research in terms of added stress as well as probable positive outcomes. Parents' experiences of being a couple are supported by previous research where feelings like frustration, the spouses' different feelings and the loss of dreams for their child, are highlighted. Parents' positive outcomes also received attention. Experiences of their partnership linked to earlier research where experiences of sadness and the feeling of not being on the same level, are mentioned. Similar to experiences of being a couple, positive outcomes concerning the partnership are also acknowledged. Experiences of their family life are supported by literature describing both the positive and negative experiences among family members. Experiences regarding autism are backed by literature describing both the emotional experiences connected to autism as well as the positive outcomes relating to autism.

An integration between the relevance of this research (as discussed in 5.6) and the results of this study will now be addressed. Referring to the relevance of this study for the parents, the themes that emerged indicated a broad spectrum of experiences. This study provided parents with the opportunity to voice their experiences in this regard. As one participant remarked, she realised “we think the same thing”. One can trust that the documentation of these individuals’ experiences would better equip others in the same or similar situation. As for the school and the community at large, the experiences that emerged may facilitate better understanding of such relationships. For me, as the researcher, this study added to my research-practitioner training and personal growth. The relevance of this study for me will be discussed in more detail in the post-reflection.

7.2 LIMITATIONS AND RECOMMENDATIONS

With reference to the research methodology, some limitations have been identified. However, in addressing the limitations, certain recommendations have been formulated. Both the limitations and recommendations of this study will now be addressed.

Firstly, it is important to acknowledge that this study’s sample size only consisted of three couples. Although for the purpose of this study sufficient saturation of the material was achieved, more participants could provide more information on parents’ experiences regarding this phenomenon.

Secondly, only one school for children with autism was included in this study. It might be that findings are unique to the school. Including more schools may ensure that results are not school specific.

Thirdly, purposive sampling was utilized as methods for selecting participants. This may raise the question as to whether or not the sample is representative of the population as it is not really feasible to garner a random sample (Langdridge, 2007). Utilizing additional methods for sampling may contribute to the participants being more representative of the population.

Fourthly, as the sample in this study was homogeneous the research findings are specific to the participants. More diverse participants may provide more information of parents' experiences of their marital relationships having a child with autism.

CONCLUSION

This study provided valuable information on parents' experiences of their marital relationships having children with autism. This study may contribute more to understanding these parents' experiences. In this chapter a summary and integration of the relevant literature was provided. Limitations of the study as well as recommendations for the future were also explored.

POST-REFLECTION

This section will address my stance while looking back at this project evaluating the difference that this research project made on me as a person and as a therapist.

The process of writing the literature review as well as the chapters on the research position and methodology provided me with a certain level of understanding of the research question and the theoretical framework. However, only the practical implementation of the research unleashed deeper understanding. The opportunity to have been able to experience every phase of the process directly, equipped me with very valuable practical experience.

Out of the eagerness to learn and not knowing what to expect, grew learning experiences. Some of these encounters were the individuals' willingness to be part of the process and these couples' way of living, reading their written accounts, listening to their feedback regarding the interviews as well as my experience of the interviews.

The interviews allowed me to yet again recognize certain characteristics in myself that are of utmost importance in therapy situations. Renewed realization of my flexibility and adaptability stood out.

The value of risking my comfort zone surfaced on several occasions during the study. Some were instances where interaction with the participants and other role-players involved empowered me, unaware at that stage, in tackling personal challenges. As I became more open to their ways of being, I stood amazed at the process of growth that took place in me. I take from this the confidence to venture risks, to be open to experiences and to continue treasuring relationships in life.

Looking at how this study enhanced my research-practitioner's training, exposure to the phenomenological methodology and analysis made me more attentive to individuals' lived experiences – how they make sense of their world. Such an attitude assists me in developing a better understanding of the meaning attached to experience(s) as well as in

exploring the essence(s) of core meanings. Focusing on individuals' experiences also makes it easier to stay with people's stories within the context where it takes place. Working and living close to this position empowered me to describe individuals' experiences more accurately.

Just as the meaning of experience of phenomenology is relevant to therapy, it is also applicable to life. Looking at the meaning of events in terms of a certain context adds value to how one understands it. The manner in which I live by focusing attention on others' and my own experiences of situations correlates with the level of those relationships. I even venture making the statement that the memories one has of experiences in relationships are so valuable that it remains alive long after either the experiences itself or the people involved have ceased to be. Treasuring the meaning of life-experiences (be it positive or negative) has an immeasurable significance in the cycle of life.

Turning to my personal experiences with couple-relationships, this research definitely did not leave my perceptions regarding marital relationships untouched. Having had the opportunity to be part of these participants' worlds was, on both therapeutic and personal levels, an empowering process.

Utilizing both the written accounts and the verbal interviews as methods for collecting material provided me with an understanding of the full impact thereof on individuals. Observing the value thereof supports me in my manner of doing therapy. One particular participant remarked that writing was for him the most valuable as it was insightful to take time to reflect on the topic at hand. The interviews were, on various levels, positive experiences for all the participants.

The impact of reading through the participants accounts had a very marked impact on me. Initially, it touched me in an unexpected way. It provided me with the opportunity to share in aspects of the participants' being. Aspects such as how they made sense of the changes in their lives as well as that of their partners, the phases through which each individual went and its impact on him or her as well as on the couple as a couple were

some of the moments which stood out for me. Being forced to experience emotions, I came to a renewed understanding of the value of becoming quiet at times in life – and in therapy. For me, to see and acknowledge other individuals and situations clearly for what they are have a direct influence on the journey of life that we all participate in.

The process of documenting the study as well as my involvement with the role-players left me with admiration for the strength that lies within each individual. Not only do I look back at my personal growth throughout this process, but also at the strength in others. I yet again recognized the potential each parent possesses as well as the driving force behind Unica school, the Department of Education and the University of Pretoria for creating opportunities for growth.

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APPENDIX A

PARTICIPANT INFORMATION SHEET AND CONSENT FORM



26 March 2009

Dear Parent,

RE: REQUEST TO PARTICIPATE IN A RESEARCH PROJECT

I am a Master's student in Psychology at the University of Pretoria and currently doing my research project. The aim of this project is to describe parents' experiences of their marital relationships after their children have been diagnosed as having autistic disorder. The project is therefore titled "Parents' experiences of their marital relationships after their children have been diagnosed as having autistic disorder".

Participation in this project will require that you first provide a written account how you experience your marital relationship after your child has been diagnosed with autism. Thereafter, interviews will be conducted jointly with both parents. Each interview with me (on the premises of the Unica School, Pretoria, if possible) will take approximately one and a half to two hours. The researcher will make contact with the participants telephonically in order to arrange meetings with them.

In order to participate in this study the following criteria need to be met:

- (a) the participants must be parents of a child with autism and the child is a learner at the Unica School, Pretoria;
- (b) the participants must be able to supply first-hand information how they experience their marital relationships after their children have been diagnosed as having autistic disorder;
- (c) both parents must be willing to participate in the study; and
- (d) the child must have a medical and / or clinical diagnosis of autism.

The value of this research project lies in the fact that it can equip parents who are new to the disorder or provide comfort to such parents knowing that their experience is a shared one. It can provide an opportunity for parents to voice their concerns and/or coping strategies regarding their experiences of changes in their marital relationships after a child has been diagnosed with autism. This study can serve as a tool for professionals in a multi-disciplinary context dealing with these issues as well as providing a reference for further study of and knowledge about autism and inter-familial relationships. The findings of this study will be communicated to the research participants.

The researcher will take precautions not to harm the participants psychologically. This study might force participants to face aspects of themselves that they do not normally consider. If, by any chance, a psychological issue surfaces during the interview, the individual will be referred and the material up to that point will be dealt with appropriately. If at any point, during or after the research, therapeutic intervention seems necessary, Dr Lourens Human, my supervisor, will provide the required care.



Participation in this study is voluntary. It entails the freedom to decide about participation free from any coercion as well as the freedom to withdraw from the research without penalty once it has begun. It must be understood that this study intrudes on the participant's private life therefore the freedom of choice whether to participate or not.

In order to protect the subjects' identities, confidentiality and anonymity is of utmost importance. The participants' responses will be labeled with individual case numbers (e.g. Case #1, Case #2, etc.) to ensure the confidentiality of the data upon completion of the interviews. A master identification file will be created that links case numbers to names to permit the later correction of missing or contradictory information. This file will only be available for bona fide research.

The participants will, at all times, have access to the researcher's material. The researcher will provide the transcriptions as well as the analyses of the information to the participants. This thesis, as well as any other form of publication resulting from it, will be made available to the participants before making it public.

Kind regards

Ms. Carin Davel
Student
072

Dr Lourens Human
Supervisor
082



**Faculty of Humanities
Department of Psychology**

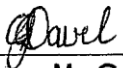
25 March 2009

CONSENT PERTAINING TO RESEARCH

As parents you play a vital role in the child's life and it is important that your experiences are documented. Your participation in this study will be highly appreciated. If you are willing to participate, you will be contacted telephonically to schedule a suitable date for contact and to clarify any additional information you may require.

Please indicate whether you would like to participate in this study by making the appropriate statement:

I agree to participate	
I decline to participate	

Participant's Name	Signature	Date	Place
 Ms C.G. Davel	Researcher	20 April '09 Date	Pretoria Place
 Dr L.H. Human	Supervisor	26 Mar '09 Date	Pretoria Place
 Prof D.J.F. Maree	Acting HOD	26 Mar '09 Date	Pretoria Place

APPENDIX B

REQUEST FOR PERMISSION TO LIAISE WITH SCHOOL FOR THE RESEARCH PROJECT



100
1908 - 2008



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Humanities
Department of Psychology

Mrs. C. D. Koudstaal

**REQUEST FOR PERMISSION TO LIAISE WITH SCHOOL A FOR
RESEARCH PROJECT
INFORMATION PERTAINING TO RESEARCH**

I am a Master's Psychology student at the University of Pretoria and currently doing my research project. The aim of this research study is to describe parents' experience of their marital relationship after their child has been diagnosed with autism. The project is therefore titled "Parents' experience of their marital relationship after their child has been diagnosed with autism".

Participation in this study will require that the parents first provide a written response about their experiences of their marital relationship after their child has been diagnosed with autism. Thereafter, interviews will be conducted with both the parents jointly. Each interview will be approximately one and a half hours with me on the school premises. The researcher will make contact with the participants telephonically in order to arrange a meeting with them.

In order to participate in this study the following criteria need to be met:

- (a) the participants must be parents of an autistic child at Unica School, Pretoria;



- (b) the participants must be able to supply first-hand information about their experiences of their marital relationship after the birth of an autistic child;
- (c) both parents must be willing to participate in the study; and
- (d) the child must have a medical and / or clinical diagnosis of autism.

The value of this research project lies in the fact that it can equip parents who are new to the disorder to cope or provide comfort to such parents knowing that their experience is a shared one. It can provide an opportunity for parents to voice their concerns regarding their experience of changes in their marital relationship after the birth of the autistic child. This study can serve as a tool for professionals in a multi-disciplinary context dealing with these issues as well as providing a reference for further study of and knowledge about autism and inter-familial relationships. The findings of this research study will be communicated to the research participants.

The researcher will take precautions not to harm the participants psychologically. This study might force participants to face aspects of themselves that they do not normally consider. If, by any chance, a psychological issue surfaces during the interview, the individual will be referred and the data up to that point will be dealt with appropriately. If at any point, during or after the research, therapeutic intervention seems necessary, Dr Lourens Human, my supervisor, will provide the required care.

Participation in this study is voluntary. It entails the freedom to decide about participation free from any coercion as well as the freedom to withdraw from the research without penalty once it has begun. This study intrudes on people's lives and disrupts the participants' regular activities. Voluntary participation in this study will be emphasized because of the intrusion into the subject's private life.

In order to protect the subjects' identities, confidentiality and anonymity is of utmost importance. The participants' responses will be labeled with individual



case numbers (e.g. Case #1, Case #2, etc.) to ensure the confidentiality of the data upon completion of the interviews. A master identification file will be created that links case numbers to names to permit the later correction of missing or contradictory information. This file will only be available for bona vide research.

The participants will, at all times, have access to the researcher's material. The researcher will provide the transcriptions as well as the analyses of the information to the participants. This thesis, as well as any other form of publication resulting from it, will be made available to the participants before making it public.

Regards

Carin Davel
072 3 33 33

C. G. Davel
Researcher

C. Davel
Signature

11 April 2008
Date

Pretoria
Place

Dr L. H. Human
Research supervisor

[Signature]
Signature

11 April 2008
Date

Pretoria
Place

Prof. M. Marchetti-Mercer
Head of Department

[Signature]
Signature

14-04-2008
Date

Pretoria
Place

APPENDIX C

PERMISSION FROM THE PRINCIPAL OF UNICA SCHOOL TO CONDUCT RESEARCH



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

UNICASKOOL

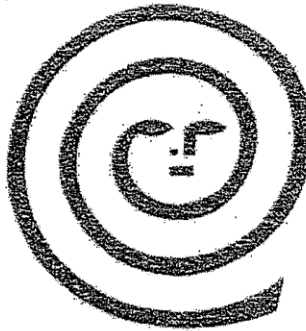
VIR LEERDERS MET OUTISME

Principal/Skoolhoof:
Mev./Mrs. C.D.Koudstaal

Borgliggaam/Sponsoring Body:
Vereniging vir Outisme
Association for Autism

Fondsinsamelingsnommer/Fund Raising Number
02-200082-000-0

Reg Nr. TS D4 211177



*Together we understand
and manage Autism better!*

UNICA SCHOOL

FOR LEARNERS WITH AUTISM

Posbus/P.O.Box 35182
Menlo Park 0102
Pretoria Suid Afrika/South Africa
Tel. (012)4606539
(012)3461103
Koshuis/Hostel (012)3290647

Faks/Fax (012)4606324

e-pos/e-mail: autism@mweb.co.za

13 Mei 2008

Me C.G. Davel
Universiteit van Pretoria
Departement Sielkunde

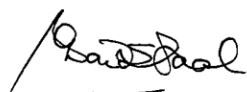
Me C.G. Davel

NAVORSING : UNICA SKOOL

Hiermee verleen ons toestemming dat u u navorsing van stapel mag stuur.

Daar word van u verwag:

- Gereelde interne skakeling met Unica-skool.
- Hulpverlening slegs per afspraak.
- Afskrif van u verhandeling aan Unica-skool.
- Samewerking van ouers word nie deur Unica-skool gewaarborg nie, maar moet deur u self bewerkstellig word.


C.D. KOUDSTAAL
Hoof

Die Spiraal simboliseer lewe en groei. Die binnewaartse beweging dui op ons begrip vir die persoon met outisme asook ons strewe na die voorsiening in sy reg tot toepaslike effektiewe onderrig en ondersteuningsgeleenthede. Die Buitewaartse beweging dui op die resultaat van daardie omvattende dienste: die volle verwesenliking van elke individu se potensiaal.
The Spiral symbolizes life and growth. The inward movement points to our striving to understand and provide the person with autism the right to appropriate and effective education opportunities and support. The outward movement is indicative of the outcome of all these all-embracing services: the full actualisation of the individual's potential.

APPENDIX D

REQUEST FOR PERMISSION FROM THE GAUTENG DEPARTMENT OF EDUCATION



Director Policy and Planning Gauteng Department of Education

**REQUEST FOR PERMISSION FROM GAUTENG DEPARTMENT OF
EDUCATION FOR RESEARCH PROJECT
INFORMATION PERTAINING TO RESEARCH**

I am a Master's Psychology student at the University of Pretoria and currently doing my research project. The aim of this research study is to describe parents' experience of their marital relationship after their child has been diagnosed with autism. The project is therefore titled "Parents' experience of their marital relationship after their child has been diagnosed with autism".

Participation in this study will require that the parents first provide a written response about their experiences of their marital relationship after their child has been diagnosed with autism. Thereafter, interviews will be conducted with both the parents jointly. Each interview will be approximately one and a half hours with me on the school premises. The researcher will make contact with the participants telephonically in order to arrange a meeting with them. The time frame of this research project is estimated to be completed not later than the end of 2009. The researcher will personally conduct the research at Unica School as from July 2008 until March 2009.

In order to participate in this study the following criteria need to be met:

- (a) the participants must be parents of a child with autism at Unica School, Pretoria;



- (b) the participants must be able to supply first-hand information about their experiences of their marital relationship after their child has been diagnosed with autism;
- (c) both parents must be willing to participate in the study; and
- (d) the child must have a medical and / or clinical diagnosis of autism.

The value of this research project lies in the fact that it can equip parents who are new to the disorder or provide comfort to such parents knowing that their experience is a shared one. It can provide an opportunity for parents to voice their concerns and/or coping strategies regarding their experience of changes in their marital relationship after the child has been diagnosed with autism. This study can serve as a tool for professionals in a multi-disciplinary context dealing with these issues as well as providing a reference for further study of and knowledge about autism and inter-familial relationships. The findings of this research study will be communicated to the research participants.

The researcher will take precautions not to harm the participants psychologically. This study might force participants to face aspects of themselves that they do not normally consider. If, by any chance, a psychological issue surfaces during the interview, the individual will be referred and the data up to that point will be dealt with appropriately. If at any point, during or after the research, therapeutic intervention seems necessary, Dr Lourens Human, my supervisor, will provide the required care.

Participation in this study is voluntary. It entails the freedom to decide about participation free from any coercion as well as the freedom to withdraw from the research without penalty once it has begun. This study intrudes on people's lives and disrupts the participants' regular activities. Voluntary participation in this study will be emphasized because of the intrusion into the subject's private life.

In order to protect the subjects' identities, confidentiality and anonymity is of utmost importance. The participants' responses will be labeled with individual case numbers (e.g. Case #1, Case #2, etc.) to ensure the confidentiality of the



data upon completion of the interviews. A master identification file will be created that links case numbers to names to permit the later correction of missing or contradictory information. This file will only be available for bona vide research.

The participants will, at all times, have access to the researcher's material. The researcher will provide the transcriptions as well as the analyses of the information to the participants. This thesis, as well as any other form of publication resulting from it, will be made available to the participants before making it public.

Regards

Carin Davel

072 48131



CONSENT PERTAINING TO RESEARCH

Mrs C. D. Koudstaal, the principal at Unica School, is willing to give me tentative permission to conduct the research at their school. I herewith request your permission to proceed with my research project as planned. I urgently need your consent letter as it has to be submitted, together with my research proposal, at the Ethics Committee of the Faculty Humanities.

Yours faithfully

C. G. Davel

Researcher


Signature

23 April 2008

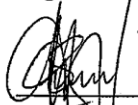
Date

Pretoria

Place

Dr L. H. Human

Research supervisor


Signature

23/4/08

Date

Pretoria

Place

Prof. M. Marchetti-Mercer

Head of Department


Signature

23-04-2008

Date

Pretoria

Place

APPENDIX E

PERMISSION TO CONDUCT RESEARCH FROM THE GAUTENG DEPARTMENT OF EDUCATION



UMnyango WezeMfundo
Department of Education

Lefapha la Thuto
Departement van Onderwys

Enquiries : Shadrack Phele MIRMSA

Tel. no. : [+2711] 355 0285

06/05/2008

Ms Davel Carin Gratia
Suite 134
Private Bag X1
Menlo Park
0102

Dear Ms Davel Carin Gratia

PERMISSION TO CONDUCT RESEARCH: PROJECT

The Gauteng Department of Education hereby grants permission to conduct research in its institutions as per application.

Topic of research : "Parent's experiences of their marital relationships after their children have been diagnosed as having autistic disorder".

Nature of project : M.A. [Counselling Psychology]

Name of university : University of Pretoria

Upon completion of the research project the researcher is obliged to furnish the Department with copy of the research report (electronic or hard copy).

Wish you success in your academic pursuit.

Yours in Tirisano,

p.p. Shadrack Phele (MIRMSA)

TOM WASPE
CHIEF INFORMATION OFFICER
Gauteng Department of Education



Office of the DDG: IS & KM (CIO)

Room 1807, 111 Commissioner Street, Johannesburg, 2001
Tel: (011) 355-1514/1507 Fax: (011) 355-0734/0833

P.O.Box 7710, Johannesburg, 2000
E-mail: tomw@gpg.gov.za or elridar@gpg.gov.za