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Fathering a Child with Autism Spectrum Disorder: An Interpretative Phenomenological Analysis

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Abstract

Raising a child with an autism spectrum disorder (ASD) is a stressful experience and has been associated with poor maternal mental health and increased maternal emotional distress. However, the experiences of fathers of children with ASD are largely unexplored and the coping strategies these men employ to cope with the challenges they face have received little research attention. This research aimed to explore the phenomenological experiences of fathers of preschool children with ASD by gaining a better understanding of the manner in which these individuals attempted to cope with their situation. A multiple, single-case study design was employed and five participants were recruited via two local paediatric practices. Semi-structured interviews were conducted with the participants and data were analysed making use of Interpretative Phenomenological Analysis (IPA). This analysis yielded three superordinate themes, which were labelled as follows: (a) the experience of fathering a child with ASD, (b) challenges of fathering a child with ASD, and (c) coping with fathering a child with ASD. The results suggest that the fathers of children with ASD experience their parental role as stressful. The participants in the current study related the stress they experienced to a number of challenges associated directly with their children's behaviour, as well as to the effects that parenting a child with ASD had on their own wellbeing and functioning. The participants reported making use of a number of coping strategies in order to deal with the challenges they faced. The participants used both problem-focussed and avoidant coping strategies. The results are discussed and recommendations made with regard to future research.

Introduction

The past decade has witnessed a dramatic increase in the number of children diagnosed with Autism and Autism Spectrum Disorders (ASD). According to Moore (2008), 1 in 1000 children were reported to be diagnosed with ASD in 1994, while Pottie and Ingram (2008) reported ASD prevalence as high as 6.7 children in every 1000 in the United States of America during 2007. Furthermore, evidence from a number of European countries including Denmark (Lauritsen, Pedersen, & Mortensen, 2004) and England (Baird et al., 2006), as well as from countries across Asia (Sun & Allison, 2010) suggests that the past 10 years have witnessed a noteworthy global increase in the prevalence of ASD diagnoses. It is debatable whether or not the actual incidence of ASD is on the rise. However, what appears obvious is that ASD diagnoses are being made more frequently worldwide. Matson and Kozlowski (2010) noted that while numerous theories have been formulated regarding the increase in ASD diagnoses, the broadening of the diagnostic criteria, improved assessment methods and a heightened awareness of autism symptoms appear to be primarily responsible for the increased prevalence of ASD diagnoses.

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Dimensional conceptualisation of ASD

The international increase in the prevalence of ASD diagnoses may, in part, be due to a shift from the categorical conceptualisations of ASD as presented in the DSM-IV and ICD-10 classification systems to a more dimensional understanding of these disorders (Volkmar, State, & Klin, 2009). The dimensional conceptualisation of ASD proposes that the core features of ASD, namely (a) social skills deficits, (b) communication difficulties, and (c) restricted interests and repetitive behaviours, occur along a continuum rather than being indicative of discrete, independent syndromes or disorders (First & Tasman, 2004). Support for the dimensional approach to conceptualising ASD can be found in the research literature. For example, following a meta-analytic study Macintosh and Dissanayake (2004) concluded there was insufficient evidence to support the validity of Asperger's syndrome as being distinct from High Functioning Autism. In addition, Szatmari and colleagues (2009) reported that individuals diagnosed Asperger's syndrome exhibit similar with developmental trajectories from early childhood through adolescence to those trajectories shown by individuals diagnosed with autism. Furthermore, Posserud, Lundervold and Gillberg (2006) reported that 2.7% of a non-clinical sample of 9430 Scandinavian children between the ages of seven and nine years were classified as having achieved high scores on certain domains of the Autism Spectrum Screening Questionnaire (ASSQ) as rated by their teachers and parents. These authors concluded that symptoms characteristic of autism are thus more common in the general, typically-developing paediatric population than was previously thought.

The view that ASD may occur along a continuum as opposed to being composed of a series of related, yet clearly differentiated, developmental disorders would appear to be borne out in recent research. It could thus be reasoned that individuals diagnosed with autism or another ASD and their families may be expected to have similar experiences and face similar challenges. Consequently, in the ensuing literature review, as well as in the remainder of the article, no differentiation will be made between autism and other ASDs. The term ASD will also be used to refer to individuals diagnosed with any autism spectrum disorder.

ASD related difficulties in children's functioning

Deficits in social interaction and communication, as well as evidence of an atypically restricted range of interests, are often already apparent in toddlers with ASD (Charman & Baird, 2002; Charman et al., 2005; Landa & Garrett-Mayer, 2006; Lubetsky, Handen, McGonigle, 2011; Yirmiya & Charman, 2010). However, it is most often during interaction with institutions and networks outside of the family environment that the full impact of ASD-related difficulties on the child's functioning becomes evident. A disproportionately high prevalence of learning difficulties has been reported amongst children with ASD (Nicholas et al., 2008). In addition, Baird and colleagues (2006) found that from an early age, children with ASD generally performed below their scholastic potential even when controlling for IQ and learning difficulties. These learning deficits or impairments appear to be specifically associated with ASD and can generally not be attributed to disruptions of cognitive systems or causes aside from ASD (Meirsschaut, Roeyers, & Warreyn, 2010). The difficulties that individuals with ASD experience in acquiring basic scholastic competencies are further complicated by problems in other functional domains. Children with ASD frequently find it difficult to effectively regulate their behaviour and emotions (Bromley, Hare, Davison, & Emerson, 2004; Posserud et al., 2006) and are generally less effective at comprehending the finer nuances of spoken language, less effective at interpreting social cues and have difficulty asserting themselves socially (Szatmari et al., 2009). As a result these children may find it particularly difficult to function effectively within the rule-governed and socially complex environment that characterises most formal educational settings. These behavioural difficulties, combined with elevated rates of learning difficulties and scholastic under-performance, often result in children with ASD being suspended from mainstream education or dropping out because they are unable to function effectively within the system (Ashburner, Ziviani, & Rodger, 2010; Prior, 2003).

Parenting children living with ASD

Children with ASD face numerous challenges in various domains of their functioning. These challenges appear to impact upon these individuals from childhood, through adolescence and into adulthood. Consequently, parenting a child with ASD is usually very demanding. Liptak, Stuart and Auinger (2006) found that parents of children with ASD reported a higher frequency of paediatrician visits for health problems unrelated to ASD than were reported by parents of children who did not suffer from ASD. Long-term medication regimens and the practical implications of having to administer medications on a daily basis have also been identified as placing particular demands on the time and financial resources of many parents of children with ASD (Lee, 2009). These parents also often have additional responsibilities with regard to ensuring that their children receive an array of specialist interventions and adjunct therapies (Koydemir & Tosun, 2009; Myers, Mackintosh, & Goin-Kochel, 2009).

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The daily tasks of limit setting, promoting autonomy and facilitating communication between the child and others have been found to place particular strain on parents, specifically mothers, of children with ASD (Osborne, McHugh, Saunders, & Reed, 2008). Parents of children with ASD may also find that the demands of caring for their children cause them to live a routine, rigid and socially-isolated existence that prevents them from pursuing fulfilment in other areas of their lives (Meirsschaut et al., 2010). In addition, the restricted social interaction skills and behavioural difficulties that many children with ASD exhibit make it difficult for parents to interact with their children, thus limiting the fulfilment that parents experience during these interactions (Konstantareas & Homatitus, 1992; Sukhodolsky et al., 2007). Parenting a child with ASD confronts individuals with particular challenges that have been associated with elevated levels of caregiver burnout (Tehee, Honan, & Hevey, 2008), reduced psychological wellbeing (Kuhn & Carter, 2006), increased social isolation and lower levels of perceived family cohesion (Higgins, Bailey, & Pierce, 2005).

The available literature thus suggests that parenting a child with ASD could be considered to be a source of significant and chronic stress (e.g., Higgins et al., 2005; Kuhn & Carter, 2006; Meirsschaut et al., 2010; Osborne & Reed, 2010; Tehee et al., 2008). A few studies indicate that parents of children with ASD report higher levels of stress and parenting burden than is reported by the parents of children without ASD. Weiss (2002) compared the levels of selfreported stress of parents of children with ASD, parents of children with mental retardation and parents of typically developing children. In this study, the parents of children with ASD reported similar levels of parenting stress to those of the parents with mentally retarded children, both of which were significantly higher than the levels of stress reported by the parents of the typically developing children. However, the parents of children with ASD reported significantly more negative effects of stress than was reported by the parents in the other two groups. Similarly, mothers of children with ASD have been found to report both higher levels of parenting stress and higher levels of psychological distress compared to the mothers of children with non-ASD related developmental delays (Estes et al., 2009). In a large population-based study conducted by Montes and Halterman (2007), parents of children with ASD were reported to be more highly stressed than parents in the general population. It would thus appear that parenting a child with ASD is a uniquely challenging and stressful experience.

The elevated levels of stress that are reported by parents of children with ASD have been widely associated with a higher incidence of mental health problems, elevated psychological distress and lower levels of wellbeing (Benson, 2010; Benson & Karlof, 2009; Davis & Carter, 2008; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Estes et al., 2009; Hastings et al., 2005; Meirsschaut et al., 2010; Montes & Halterman, 2007; Pakenham, Samios, & Sofronoff, 2005; Phelps, McCammon, Wuensch, & Golden, 2009; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008). This situation is not unique to the parents of children with ASD as the connection between stress and reduced psychological wellbeing has been widely documented in the broader psychological literature (e.g., Dyson & Renk, 2006; Hatch, Mishra, Hotopf, Jones, & Kuh, 2009; Morrison & O'Connor, 2005; Turner & Lloyd, 2004). However, exposure to chronic life challenges or stressful events does not necessarily result in reduced psychological wellbeing or negative mental health outcomes (Bergdahl & Bergdahl, 2002; Morris, Ciesla & Garber, 2010). Lazarus and Folkman (1984) have proposed that the manner in which individuals appraise situations that they are faced with largely determines the levels of stress they experience, the manner in which individuals attempt to cope with the challenges they face, and the impact that the specific situations have on their psychological wellbeing.

An integrative conceptual framework of stress and coping

Building on the work of Lazarus and Folkman (1984), Moos and Holahan (2003) proposed an integrative conceptual framework of stress and coping in which dispositional and contextual aspects of the coping process are considered to be complimentary. Dispositional views of coping are those that emphasise the "individuals' habitual interactions with their environment as well as the cognitive and behavioural coping responses or skills individuals employ to manage specific stressful encounters" (Moos & Holahan, 2003, p. 1387). In contrast, contextual perspectives on coping "assume that more transitory, situation-based factors shape individuals' coping appraisals and their choice of specific coping responses" (Moos & Holahan, 2003, p. 1388). The framework of stress and coping proposed by Moos and Holahan (2003) consists of a number of systems that are thought to function in a transactional manner. Two primarily dispositional systems, namely the environmental system and the personal system, form the basis of this particular conceptual framework. The environmental system is made up of stable conditions outside of the individual such as finances, social support networks and ongoing environmental stressors. The personal system is characterised by the enduring personal characteristics of the individual, which are thought to mould the specific coping responses they employ. Specific components of the personal system may include preferred coping styles

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and personality traits, as well as cognitive abilities and preferences. The environmental and personal systems are hypothesised to act as a backdrop for the third component of the framework, namely transitory environmental conditions. Moos and Holahan (2003) claimed that transitory environmental conditions "provide opportunities for learning and the potential for personal development or decline" (p. 1293). It would thus appear that life events, educational or selfdevelopment opportunities and situational changes provide the context within which the more enduring elements contained in the environmental and personal systems influence how individuals attempt to cope with the challenges they encounter. These components of the framework (i.e., environmental system, personal system and transitory conditions) are all viewed as influencing the specific cognitive appraisals individuals make regarding stressors, as well as impacting upon the specific coping behaviours and strategies these individuals implement.

The role of cognitive appraisals in the reported stress and coping of parents of children with ASD

The integrative conceptual framework of stress and coping (Moos & Holahan, 2003) provides a useful theoretical context for understanding how parents and caregivers of children with ASD cope with their situations. A number of studies have highlighted the role of cognitive appraisals in the stress that parents of children with ASD report, as well as the effect that this stress has on their wellbeing. Self-perceptions with regard to parenting competence and coping ability have been shown to be directly related to levels of parental stress in mothers of children with ASD (Phelps et al., 2009). Stuart and McGrew (2009) reported that negative appraisals of caring for a child with ASD were strongly associated with increased caregiver burden and marital distress. In addition, a study comparing the functioning of mothers of children with ASD, mothers of mentally retarded children and mothers of typically developing children suggested that positive perceptions of control and self-efficacy increased the coping ability of the mothers of children with ASD or mental retardation (Weiss, 2002). The appraisals that parents of children with ASD make about the challenges that face them, as well as their appraisals of how effectively they are equipped to meet these challenges, would appear to have an effect on the levels of stress and emotional distress experienced by these parents.

Transitory environmental conditions as a component of Moos and Holahan's conceptual framework of stress and coping

The literature makes very little reference to variables that could be classified as transitory environmental conditions (Moos & Holahan, 2003) in relation to parental stress and coping in ASD. However, Pakenham et al. (2005) report that temporary increases in stress predict maternal distress. Benson and Karlof (2009) noted that stress proliferation or "the tendency for stress to create additional stressors" (p. 350), mediated the effect of the severity of children's symptoms on maternal depression in a study of mothers of children with ASD. The chronic nature of ASD may make the role of transitory environmental conditions in parental stress and coping less obvious than in situations where exposure to stressors is more time limited.

The environmental system as a component of Moos and Holahan's conceptual framework of stress and coping

According to Moos and Holahan (2003), the environmental system (one of the primary dispositional systems in their framework) consists of stable conditions within the individual's environment such as ongoing environmental stressors, the availability of financial resources and social support networks. Hastings et al. (2005) noted that parenting a child with ASD is a source of chronic stress, especially as there is very little that the parent can do to impact directly upon the stressor. In addition, parents of children with ASD are confronted by the same educational, behavioural and social challenges their children face (e.g., Ashburner et al., 2010; Nicholas et al., 2008). The many challenges associated with parenting a child with ASD would thus seem to represent an ongoing environmental stressor. This view is supported by the finding that child problem behaviours were found to be strongly predictive of maternal stress levels, as well as predicting maternal emotional distress (Pakenham et al., 2005).

The interaction between stressors and coping has also been hypothesised to be influenced by the physical resources that individuals are able to access (Moos & Holahan, 2003). However, very little attention appears to have been paid in the literature on coping and parenting a child with ASD to the impact of physical resources such as socioeconomic status and access to support services. In one study investigating coping in mothers of children with ASD, Pakenham and colleagues (2005) found that age and socioeconomic status were predictive of maternal adjustment. Older mothers and mothers of higher socioeconomic status were found to report higher levels of emotional wellbeing and lower incidences of mental health problems.

Moos and Holahan (2003) highlighted social support and social networks as an aspect of the environmental system that may significantly impact on coping. Social support has been reported to have a positive

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impact on the wellbeing of parents of children with developmental disabilities in general and ASD in particular. Weiss (2002) found that higher levels of social support were related to a reduction in incidences of negative stress effects amongst mothers of children with ASD and mental retardation. Dunn et al. (2001) found that social support moderated the relationship between stress and negative mental health outcomes in both mothers and fathers of children with ASD. Higher levels of social support were associated with lower levels of marital distress. Similarly, Pakenham et al. (2005) reported that higher levels of social support strongly predicted better marital adjustment in their sample of women with ASD children. Social support has been reported to influence parental emotional wellbeing at various stages of parenting children with ASD. Stuart and McGrew (2009) found that higher levels of social support were directly related to reduced family and parental burden in a group of parents whose children had recently been diagnosed with ASD.

The personal system as a component of Moos and Holahan's conceptual framework of stress and coping

The final component of the integrative framework of stress and coping proposed by Moos and Holahan (2003) is the personal system. This system consists of enduring personal characteristics including an individual's preferred coping styles. A number of studies have explored the effect of different coping styles in the parents of children with ASD. Coping styles or coping responses generally appear to have an influence on the wellbeing of parents of children with ASD. Dunn et al. (2001) found that coping styles moderated the relationship between the stressors associated with parenting a child with ASD and negative outcomes in both mothers and fathers. Pakenham and co-workers (2005) reported that coping strongly predicted emotional wellbeing among mothers of children with ASD. Coping would thus seem to influence the effect that stress has on the emotional and psychological functioning of individuals raising children with ASD.

Forms and styles of coping and their effects on parental wellbeing

A body of research in ASD has focussed on the effect that different forms of coping or different coping styles may have on parental wellbeing. Problemfocussed coping has been linked to increased maternal wellbeing (Smith et al., 2008). Problem-focussed coping has also been shown to predict weakly, yet significantly, maternal psychological adjustment (Pakenham et al., 2005). Not making use of problemfocussed coping has also been associated with increased marital distress in both mothers and fathers of children with ASD (Dunn et al., 2001). In addition, employing avoidant means of coping has been associated with reduced parental wellbeing and poor mental health outcomes. Avoidant coping styles have been related to increased parental stress and negative mental health outcomes (Hastings et al., 2005), as well as strongly predicting negative maternal wellbeing (Pakenham et al., 2005; Smith et al., 2008). Furthermore, Smith and colleagues (2008) reported that mothers of children with ASD who make relatively little use of avoidant coping styles report higher levels of positive maternal wellbeing than those who engage in predominantly avoidant styles of coping. Literature suggests that one form of problemfocussed coping, namely reframing or positive reinterpretation, may be particularly effective in coping with the challenges of parenting a child with ASD. Positive reframing has been defined as "attempts to construe and restructure a problem in a positive way while still accepting the reality of the situation" (Moos, 1993, p. 15). Smith and colleagues (2008) found reframing to be strongly predictive of maternal wellbeing, while Hastings and co-workers (2005) reported that reframing was associated with lower levels of depression in both fathers and mothers of children with ASD.

Research demonstrates, however, that problemfocussed coping is not consistently superior to avoidant coping. Hastings and colleagues (2005) found that problem-focussed coping was not significantly associated with parental stress or mental health in parents of children with ASD. Similarly, Stuart and McGrew (2009) reported that while avoidant coping predicted marital difficulties amongst parents of children with ASD, it was not predictive of individual caregiver burden.

Parenting a child with ASD is considered to be a stressful undertaking that is purported to negatively impact on parental wellbeing and increase the risk of negative mental health outcomes. In addition, the manner in which parents attempt to cope with the challenges they face would seem to influence their wellbeing. Furthermore, theoretical frameworks such as the integrative conceptual framework of stress and coping proposed by Moos and Holahan (2003) appear to be useful for understanding the research literature on stress and coping in parents of children with ASD. However, the efficacy of various approaches to coping in the context of parenting a child with ASD is not clear. Lazarus and Folkman (1984) considered problem-focussed coping to be a more effective means of dealing with stressors than avoidant coping. However, while the literature on coping amongst parents of children with ASD reviewed in this article suggests that problem-focussed coping, particularly reframing, is associated with more positive parental wellbeing than avoidant coping, this trend is not

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consistently evident. Hasting et al. (2005) also cautioned that the established conceptualisations of coping on which many coping questionnaires are based may not be adequate for fully understanding the range of coping strategies employed by parents of children with ASD.

The need to explore meaning-making and specific coping methods of fathers of children with ASD

The role of coping and its effect on the psychological wellbeing of parents of children with ASD appears to be well established. However, it seems that the specific processes involved in coping with parenting a child with ASD are less clearly understood. In addition, the vast majority of studies investigating stress and coping amongst parents of children with ASD have made use of predominantly female samples. Moreover, the few studies investigating gender differences in this regard have tended to be inconclusive or contradictory (e.g., Davis & Carter, 2008; Gray, 2003; Hastings et al., 2005). The need thus exists to develop a better understanding of the manner in which parents, particularly fathers, of children with ASD make sense of their situation and to gain further insight into the specific coping methods employed by these individuals. In addition, given the dearth of ASD-related research in South Africa, research that is specific to the South African context is required. Consequently, this study aimed to explore the phenomenological experience of South African fathers parenting children with ASD, with specific reference to the challenges they face and the ways in which these men attempt to cope with their parenting challenges.

Method

Design

The research aimed to explore the phenomenological experience of fathering a child with ASD. The study focussed particularly on the challenges that fathers face and how they attempt to cope with these challenges. Through sharing experiences people reveal truths and, in that process, the telling of stories gives meaning and interpretation to experience and the world around us. The lived experiences of others encourage personal reflection and provide the basis for the generation of theoretical implications (Sinner, 2004). Such phenomenological enquiry amounts to a focus on the way in which the experience is given directly through the participants' expressions, prior to the interpretation of those expressions (Knight & Bradfield, 2003).

Stones (1986) in his article titled "Phenomenological praxis: A constructive alternative in psychology" advocated that psychology should aim more at being

a descriptive science rather than an explanatory one. This stance is considered to be compatible with both phenomenological and behaviourist approaches to research in psychology. There is much debate in phenomenological circles as to the method of research one should use in a phenomenological enquiry. Phenomenological researchers agree that there is no single method that will suffice for each and every enquiry and suggest that the approach to a phenomenological method design should be flexible and adapted to suit the phenomenon that is studied (Holroyd, 2001). For this study, a multiple, singlecase study design was employed. Smith and Eatough (2007), as well as Smith (2004) and Yin (1989) contended that case study designs are well suited to qualitative research in a number of psychologyrelated fields. This is because case study designs offer the opportunity for in-depth analysis and thus provide individual or unique perspectives on participants' experiences and intrapersonal processes. The combination of a case study method with a phenomenological stance can thus be described as a phenomenologically informed case study (Bradfield & Knight, 2008). According to Giorgi and Giorgi (2008), Interpretative Phenomenological Analysis (IPA) offers an adaptable praxis for qualitative research purposes in the same way as therapists practice individualised procedures. IPA is a method for undertaking a phenomenological interpretive strategy. In this phenomenologically informed casebased study the conceptual framework for case-based research proposed by Edwards (1998) was used for guiding the broad process or phases of the case study research. In addition, guidelines offered by Smith, Jarman and Osborn (1999) regarding the implementation of IPA were also used.

Participants

Five fathers of children with ASD were recruited via purposive sampling from two private paediatric practices in Bloemfontein, South Africa. Smith, Flowers and Larkin (2009) suggested that samples of three to six participants are best suited for Interpretative Phenomenological Analysis (IPA) studies. In order to ensure a degree of homogeneity, participants were required to be married to the mother of their child with ASD. Only fathers of children aged between four and seven years of age were included in the sample. This decision was based on literature suggesting that ASD diagnoses are being made at earlier points in childhood (e.g., Charman & Baird, 2002; Yirmiya & Charman, 2010). In addition, relatively little research has been conducted concerning children with ASD who are in the foundation phase of their education and their family members. Fathers of children who had been diagnosed with mental retardation or a physical disability in addition to ASD were excluded from the

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sample. Furthermore, in order to obtain a more normative impression of fathering a child with ASD rather than exploring the experience of adjusting to the initial diagnosis, fathers of children who had received a diagnosis of ASD less than one year prior to the data collection were excluded from the sample.

The average age of men in the sample was 40.6 years, while the average age of the children diagnosed with ASD was 4.6 years. Three of the participants were Caucasian, while two were Black. All five participants were employed. The majority (80%) of the sample reported that their children were in preschool at the time of their respective interviews. The gender of the children with ASD was fairly evenly distributed (2 girls; 3 boys). The time that had elapsed since the participants received their child's ASD diagnosis ranged from 12 months to 36 months with a mean of 24 months.

Procedures and ethical considerations

Ethical clearance to conduct the study was obtained from the Research Committee of the Department of Psychology at the University of the Free State (UFS), Bloemfontein, South Africa. Two paediatricians specialising in neurodevelopment identified potential participants from their patient records. The paediatricians provided the researcher with the contact details of fathers of children with ASD who met the inclusion criteria mentioned previously. These individuals had been informed as to the purpose of the study by their paediatrician and had consented to be contacted by the researcher as potential participants in the study. The researcher contacted eight individuals telephonically and five agreed to participate in the study. All five participants were interviewed at the University of the Free State's Department of Psychology. Written informed consent was obtained from each participant prior to being interviewed. Participants were assured that their anonymity would be guaranteed and were informed that the research was being conducted in partial fulfilment of the requirements for an academic qualification. Participants were also informed that the findings of the current study may be submitted for publication in a peer reviewed journal. All interviews were conducted by the researcher. Interviews lasted between 45 and 90 minutes. The interviews were semi-structured and were conducted according to an interview schedule developed by the researcher. The interview schedule was compiled with the overarching aim of exploring the participants' experiences of parenting a child with ASD. The interview schedule also aimed to explore (a) the experience of fathering a child diagnosed with ASD, (b) the challenges that fathering a child with ASD presents, and (c) how these men go about coping with these challenges. In keeping with the guidelines set

out by Smith and Eatough (2007), open-ended questions were used to explore the experiences of the participants. Prompts and follow-up questions were then used to further explore the participants' experiences or to gain clarity on certain issues. Interviews were conducted in English. All interviews were recorded electronically and transcribed verbatim prior to analysis.

Analysis

Smith et al. (2009) stated that Interpretative Phenomenological Analysis (IPA) is "concerned with understanding personal lived experiences and thus with exploring persons' relatedness to, or involvement in, a particular event or process" (p. 40). It has been argued that IPA can be best understood as "a perspective from which to approach the task of qualitative data analysis" (Larkin, Watts, & Clifton, 2006, p. 104) rather than a prescriptive method of analysis (Smith & Eatough, 2007; Smith & Osborn, 2008). This perspective emphasises the importance of developing an understanding of the individual's experience and sense-making regarding a particular situation or event (phenomenology), as well as making reflective interpretations of these experiences and meanings (interpretation) (Shinebourne & Smith, 2009; Smith, 2004; Smith & Eatough, 2007; Smith et al., 2009). The IPA approach has its origins in those fields of enquiry, such as phenomenology and symbolic interactionism, which hold that "human beings are not passive perceivers of an objective reality, but rather that they come to interpret and understand their world by formulating their own biographical stories into a form that makes sense to them" (Brocki & Wearden, 2006, p. 88). Brocki and Wearden have cautioned that structuring analyses in IPA according to existing theoretical frameworks may emphasise the perspective of the researcher rather than that of the participant. However, Smith et al. (2009) emphasised that IPA is a non-prescriptive and dynamic method of analysis. Moreover, according to Larkin et al. (2006) the interpretative aspect of IPA is "informed by direct engagement with existing theoretical constructs" (p. 104). It would thus appear that IPA is a suitable method of analysis for the current study, as it allows for the phenomenological understanding of the participants' experiences of fathering a child with ASD, as well as for a theoretically informed analysis of their coping efforts. The data analysis in the current study followed the guidelines provided by Smith and colleagues (2009). First, each transcript was closely read a number of times, noting points of interest and salient statements. Second, themes capturing the participants' lived experiences emerging from the transcripts were documented. Third, these themes were consolidated and given descriptive labels. Fourth, theme labels were compared across the five transcripts and

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consolidated into a table of comparative themes. Finally, a master table of superordinate themes was compiled across all five transcripts.

Results

Three superordinate themes emerged during the analysis. The first theme reflects the personal experiences of the fathers participating in the study. More specifically, this theme reflects the cognitions and emotions reported by these individuals in relation to having a child with ASD. The second theme deals with the specific challenges that the participants experience as fathers of children with ASD. Two subordinate themes emerged within this superordinate theme, namely challenges that are directly associated with the child and challenges related to the participants' own wellbeing and functioning. The final theme that emerged during the analysis was related to the methods of coping employed by the participants.

The experience of fathering a child with ASD

The participants generally appear to be overwhelmed at having to come to terms with their children's ASD, as well as the realities of parenting these children. The excerpts below clearly show that most of the participants reported feeling anxious, overawed, confused and disappointed.

"The first thing, when he [the paediatrician] mentioned all this terminology, you become scared. The worries are, I never got a clear picture, is that [ASD] something with your mind, do you think straight? Is it a substance in your brain? I do not know." – EF

"I was also worried." - AD

"I am confused, I do not know what to expect." – BT

"...it was a disappointment that my child might not grow up, or be able to function properly or normally. That is the biggest emotion that I felt." – CD

One father, CD, expressed concern that he may have been genetically responsible for his daughter's condition, and thus for her difficulties.

"...because there is a genetic predisposition, one worries that where – where does she get it, who is to blame for it. You wonder how responsible are you for the child?" – CD

The intensity of the emotions experienced in having to come to terms with having a child with ASD is reflected in the difficulty that LF, the father of a boy diagnosed with ASD 18 months prior to the study, appears to experience in relation to accepting the diagnosis. LF appears to fluctuate between wanting to get the best possible help for his child and being unable to fully accept that his child suffers from ASD.

"I do not believe it; I do not believe that he has it. I believe he is terribly overactive and he can never sit still. I believe what they *[healthcare practitioners]* are telling me and I respond to them, but I still don't believe he has autism, or ADHD." - LF

Anxiety, confusion and a sense of being overawed were, however, not the only emotional states experienced by the fathers participating in the study. Some fathers expressed relief at being able to attribute their child's difficulties to a specific diagnosis, while others seemed generally positive regarding their child's outcomes.

"Initially relieved, compared to not knowing what *[was wrong]*." – CD

"I was also worried, but I was having hope that things would get better. I still have hope that he will be fine" – AD

The fathers participating in the study thus seem to experience a number of emotions, both negative and positive, regarding their children, the role they are to fulfil as parents and what the future may hold for them and their children. In addition, most participants articulated experiencing their children's ASD as stressful and challenging.

"There are challenges, and we face *[them]* on a daily basis. My patience is tested each day, but it makes me a better person." – BT

"It [ASD] brought a stress on our family, we did not cope." – CD

"With my first child, my daughter, things were smooth. But with this boy, it has become tough..." – AD

Challenges of fathering a child with ASD

Most of the participants experienced fathering a child with ASD as challenging. A number of these challenges and concerns appeared to be related specifically to their children's behaviour, social skills and scholastic functioning. This subtheme was labelled child-specific challenges. A second subtheme emerged in relation to the participants' experiences of

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the ways in which parenting a child with ASD impacted upon their social interactions, marital relationships, and wellbeing. This subtheme was labelled direct paternal impact.

Child-specific challenges

The fathers participating in the study reported that their children's behaviour was one of the most significant challenges they faced. A number of the participants experienced their children as having poor emotional regulation, most often evident in temper tantrums and inappropriate or excessive aggression. The excerpts below reflect the participants' understanding that their children's aggressive behaviour is generally an expression of frustration.

"It is difficult sometimes, [e]specially when he loses his temper, he can't understand some things, he is very challenging..." – LF

"She sometimes gets aggressive. I take it as it comes. That is a challenge." – BT

The children's high levels of physical activity and apparent noncompliance with parental instructions were additional child-specific challenges reported by the participants.

"...he wants to run all the time. He does not see danger, he just like [s] to go on. He sees everything as fun, and he does not listen to me when I say: do not do that!" – EF

"He would like to do things his way. But when you give him activities, like saying "this is serious, we do this now" he won't [engage in the activity]." – AD

Severely limited interests and stereotypical or perseverative behaviours are characteristic features of ASD. The fathers in the current sample reported that these behaviours presented difficulties, not only in relating to their children, but also as sources of paternal frustration and possible triggers for the temper tantrums and aggressive behaviour discussed above. In addition, one father, AD, found his son's lack of emotional expression particularly frustrating, as this made it impossible for him to judge his son's mood and level of contentment.

"As I said, sometimes he get[s] stuck on stuff, when I want to watch the weather, he wants to watch Barney, and that is where the screaming begin[s]. So it is very difficult." – LF

"He constantly repeats everything, he got stuck on a subject ... he will ask you a hundred times what the cat's name is \dots " – LF

"And then, I think the other challenge is to keep him satisfied. That is a big challenge. We never know when he is happy or not happy. We never know when he is happy." -AD

The participants also identified limited or underdeveloped social skills as significant childspecific challenges. The fathers in the study specifically expressed a desire for their children to become more socially competent, as well as expressing concern at their lack of age-appropriate friendships and their inability to establish ageappropriate personal boundaries or exhibit contextappropriate social behaviour.

"...she has to learn to interact socially." – $\ensuremath{\mathsf{BT}}$

"...he likes to play with *[by]* himself a lot, he does not have a lot of friends, he likes to play with *[by]* himself." – LF

"...[child's name] does not have personal boundaries, not scared of anything, will go to any person in the street. We can't go to church with her. If we sit with her in the mother's room, she will be playing with all the kids, [and] all the mothers..." – CD

Due to the composition of the sample, most of the participants had not yet come into contact with formal mainstream educational systems. However, the one participant (AD) whose son was engaged in mainstream education at the time of the study, expressed concern at his son's poor scholastic progress.

"One big challenge is the slow progress, slow academic progress. This is the big challenge..." – AD

Direct paternal impact

In addition to concerns relating to their children's poor emotional regulation, stereotypical behaviour and poorly developed social skills, participants noted that their personal functioning and wellbeing had been impacted by their roles as fathers to children with ASD. Three of the five fathers participating in the study related that their social interaction with others had been negatively affected by their children's behaviour or by uncertainty regarding how their children might behave in certain situations.

"Yes, I have no social life. There is nothing of the sort, because you do not know when

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my daughter will do something that will offend other people, or the other way round. We avoid it completely." – BT

"So yes, the biggest social in the community we have cut, for her sake and because other people do not understand her..." -CD

"...the relationship with our neighbour[s], we do not want this boy to play with our [the neighbour's] kids. That is when [the] relationship with our neighbours becomes tough, very tough sometimes." – AD

Some participants noted that parenting a child with ASD had impacted upon their relationship with their spouse, as well as affecting their perception of their role as parents or the manner in which others in the family perceive them.

"...he is so stubborn with the mother, and if I am not around sometimes it annoys me when they make me a monster – "I am going to tell your daddy!" – EF

"...because of the situation [his son's limited interests and behavioural perseveration] I lose my temper sometimes and I end up screaming, because of the situation and then everyone blames everyone in the family. And me and my wife start fighting." – LF

Coping with fathering a child with ASD

The preceding analysis suggests that the participants experience a number of their children's behaviours and limitations as challenging or stressful. Furthermore, parenting children with ASD seems to have challenged these men's perceptions of themselves as fathers. Further analysis of the semistructured interviews revealed that the participants employ a number of coping strategies in an effort to deal with the challenges they face. In keeping with the theoretical framework proposed by Moos and Holahan (2003), the coping strategies reported by the participants were broadly grouped as either problemfocussed or avoidant.

Problem-focussed coping

The participants reported making use of a number of problem-focussed coping strategies when addressing the challenges presented by parenting a child with ASD. Two of the participants found that practical interventions aimed at either reinforcing positive behaviour or facilitating the child's disengagement from disruptive stereotypical behaviours were the most effective means of consistently coping with their children's problematic behaviours.

"Saying to him do this, and then I am going to reward this. I think that has worked to my advantage..." – AD

"I have to get [him] to change his mindset, to get him interested in something else, more interesting than the current situation. He has a fascination with keys ... I use the keys as a deterrent when he loses his temper." – LF

One participant found that specific problem-focussed coping strategies implemented at a more general or systemic level were also useful. These strategies included making changes to existing discipline strategies within the home so as to accommodate the specific needs and characteristics of the child with ASD. In addition, this participant was prepared to relocate the family in order to gain better access to the services his child requires. However, implementation of these strategies was not without difficulties, as the wellbeing and ambitions of the rest of the family needed to be taken into consideration.

"She [the child with ASD] has a different disciplinary way with her compared to the other children. They [other family members] bought into the picture. My little girl is 10 years and she is four – six years difference - she was not jealous. We could not hit [child's name], it did not have any impact." – CD

"We are prepared to move to a different area or school, where it will be the best for her, and taking the other children into consideration as well." -CD

Gathering information and learning more about ASD, as well as possible treatment opportunities surfaced as a theme in the coping responses of the participants. This is reflected in the excerpt from the interview with BT below. In addition, another participant, EF, believed that periodically consulting his son's paediatrician in order to gain information regarding his son's development and progress would help him cope more effectively with the challenges he experienced.

"I think one should obtain as much information as possible, there will be certain things you will never understand. Just be there for your child and learn about it, try to obtain information." -BT

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"Personally, I would like him to see, maybe we could go back to [paediatrician's name], where he could do an assessment, is [child's name] okay, I would like to hear how he is now." – EF

Having access to information and specialist care also seemed to provide some participants with reassurance regarding their child's current welfare and future prognosis. Seeking expert medical input and following the recommended treatment regimens appears to be another information-related form of problem-focussed coping. These strategies appeared to be employed primarily by the two black participants.

"It was okay, I took my chance with the doctor. He gave good medication ... he is now okay." - EF

"I think there is still time to improve, because of the professional assistance we are busy getting for the boy. I think there is still time for this boy to improve. I am not much worried, because of the professional assistance." – AD

The participants also used positive reframing in order to cope with the challenges of parenting a child with ASD. CD appears to have dealt with his wife's role as primary facilitator in their daughter's management/ treatment and his somewhat more removed role as primary breadwinner, by reframing his role with regard to his child's ASD as one of supporting his wife and empowering her to focus on their child. Another participant (BT) seems to have conceptualised the challenges his child with ASD confronts him with as opportunities for positive selfdevelopment. He seems to view facing the challenges of raising a child with ASD as providing the opportunity to develop character which, in turn, enables him to deal more effectively with these challenges.

"If she stays on the *[autism]* spectrum, we will be fine with it. It will be challenging, each day of the week is a new challenge. I believe at the moment, because my wife has much more impact and working with her, I see my role more than *[as]* supporting my wife and make sure she copes..." – CD

"My patience is tested each day, but it makes me a better person. It also builds my character, it makes me better. It is not really that much of a challenge. I still live." -BT

Avoidant coping

In addition to the problem-focussed coping strategies reported above, the fathers participating in the study also appear to employ a number of avoidant coping strategies. One participant appears to minimise the seriousness of the challenges facing him as the parent of a child with ASD by not taking the situation too seriously and viewing the child's condition as transient. CD thus appears to intentionally avoid thinking realistically about the situation with which he is confronted. However, he does seem to be aware of the avoidant nature of this particular strategy. BT also appears to employ cognitive avoidance as a coping strategy by attempting to concentrate on the present and not thinking too much about the future.

"And because we are not taking the diagnosis too seriously, there is a part of you that thinks that it [is] just a phase. We have a[n] ostrich technique – bury your head in the sand." – CD

"Tomorrow will sort itself out. I do not think about it. Tomorrow's worries is tomorrow's worries. This is how I see it. I handle everything on a daily basis." - BT

One participant reported making extensive use of religious coping in order to deal with the challenges of raising a child with ASD. Religious coping involves trusting in supernatural influences or a deity to help one deal with the challenges one faces.

"...at the end of the day, I am a believer, and I believe that it is God's will to cure my child. So, it does not matter which disorder it is, I have prayed about it and God will handle the situation." -BT

A father participating in the study related two situations in which he felt he had raised the awareness of his co-workers with regard to ASD. He seems to find meaning in being able to alert his co-workers to possible signs of developmental delay that their own children may display. These discussions may also serve to provide this participant with some degree of social support. Irrespective of the specific function of the interactions recounted below, they seem to provide him with the opportunity to use the situation he is confronted with to have a positive impact on the lives of others. These interactions could thus be classified as examples of seeking alternative rewards.

"It is very interesting at work, when I started to give details about the growing of this boy, people became interested. They started to think about the activities of their own children. There was one lady who said "You know, my boy used to do those

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things, I have to consult a specialist, whether my child is having that particular disease"." -AD

"I am telling the guys, when we are working together, I become ... Because somewhere I am going to assist, somebody who will not be able to recognise the illness *[ASD]* that maybe is in his or her boy, I think that part of the education I am driving. I think that is the positive part that helps." – AD

Discussion

Analysis of the data revealed that fathering a child with ASD results in the experience of a number of emotions. In this particular study participants reported emotions ranging from guilt and anxiety to hope and relief. However, the fathers participating in the study tended to report more negative than positive emotions with regard to their parental roles. Although no attempt was made to quantify the emotional distress of the participants or to determine whether the emotions they experienced were indicative of specific clinical syndromes, it would appear that the findings lend further support to a trend in the literature that suggests that parents of children with ASD tend to report elevated levels of emotional distress when compared to parents of non-ASD children (e.g., Benson, 2010; Davis & Carter, 2008; Dunn et al., 2001; Estes et al., 2009; Phelps et al., 2009; Seltzer et al., 2003). However, the participants did not experience having a child with ASD as entirely negative. What the respondents actually articulated was that within the negative experience of having a child with ASD there was some relief and sense of usefulness. Some reported feeling relieved at being able to attach a label to their child's problem. They also expressed hope that with the problem having been identified and the appropriate help received, their children's chances of enjoying better outcomes had improved. Nevertheless, all the participants related experiencing their paternal role as stressful or challenging. This finding is in keeping with literature highlighting elevated levels of stress in the parents of children with ASD (e.g., Estes et al., 2009; Higgins et al., 2005; Kuhn & Carter, 2006; Meirsschaut et al., 2010; Osborne & Reed, 2010; Weiss, 2002).

Participants in the study identified specific aspects of their children's behaviour and certain impacts that fathering a child with ASD had on their personal functioning as significant sources of stress. Behavioural difficulties and poor emotional regulation were the most frequently reported childspecific challenges. Participants also expressed frustration at their children's stereotypical and perseverative behaviours. Only one participant expressed concern regarding his child's poor scholastic progress. However, this participant's child was the only child of school-going age included in the sample. The apparently low valence of school-related and cognitive developmental concerns or stressors reported by the participants is thus probably due to the composition of the sample rather than indicating that these ASD-related problems are not viewed as challenges by the fathers of these children.

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It is interesting, however, to note that only one father identified his child's lack of emotional responsiveness as a challenge and that none of the participants noted communication difficulties as a source of paternal stress. ASD tends to be characterised by deficient verbal communication, poor eye contact and limited emotional responsiveness (Landa & Garrett-Mayer, 2006; Nicholas et al., 2008; Szatmari et al., 2009; Yirmiya & Charman, 2010). These symptoms are reported to be particularly evident in preschool children (Baird et al., 2006; Charman & Baird, 2002) and it was thus expected that these symptoms would be identified as a challenge by the fathers in the current sample. However, it is possible that the children of the fathers in the current sample represent cases of ASD at the higher or more verbal end of the spectrum. Alternatively, given that all the fathers in the sample hold fulltime jobs, it is possible that the children's mothers or teachers are more directly impacted by their poor communication skills as they are required to deal with the children more intensively on educational and communication-dependent tasks (e.g., Benson, 2010; Bromley et al., 2004; Gray, 2003; Kuhn & Carter, 2006; Osborne et al., 2008). Finally, fathers in the sample may be more inclined to fulfil a disciplinary role, while the children's mothers are more inclined to facilitate learning and communication skills development. Consequently, the higher valence of behaviour-related stressors amongst fathers may be more reflective of their parental role than of the children's abilities and deficits.

Participants perceived parenting a child with ASD as having an impact on their social lives, affecting their relationships with their spouses and influencing the way they view themselves as fathers. The fathers participating in the study viewed their children's behaviour and the potential reactions of others to this behaviour as limiting the extent to which they were able to socialise with others or go out in public with their children. Some participants also viewed negative reactions or a lack of understanding on the part of their neighbours as potentially socially isolating. These findings are in line with the parental social isolation or poor perceived social support reported in a number of other studies in the ASD literature (e.g., Benson & Karlof, 2009; Dale, Jahoda, & Knott., 2006; Stuart & McGrew, 2009). The participants also felt that their relationships with their spouses had

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changed as a result of having a child with ASD in the family. Disruptions or changes in family dynamics have been highlighted in other studies on parenting children with ASD (e.g., Pakenham et al., 2005; Smith et al., 2008; Stuart & McGrew, 2009). The participants in this study perceived themselves to be in conflict with their wives more regularly, particularly on issues involving their child with ASD. Some fathers also perceived themselves as somewhat isolated from the families. They viewed themselves as outsiders who did not experience the same quality of contact with their ASD children as that experienced by their wives. The fathers in the current study thus appear not only to perceive a lack of social support with regard to their communities, but also with regard to their spouses and families.

A specific aim of the study was to gain greater insight into the manner in which the fathers of children with ASD attempt to cope with the challenges they face. These coping strategies or behaviours are reflections of the dispositional personal system proposed in the integrative framework of stress and coping (Moos & Holahan, 2003). The participants reported making use of both problem-focussed and avoidant means of coping. Practical interventions aimed at reducing problem behaviours or increasing child compliance were one form of problem-focussed coping used by the participants. Systemic changes to the way the family functioned or dealt with issues such as discipline also proved helpful to some fathers. These strategies represent direct attempts to reduce the effect that a particular stressor has on the individual, and are often referred to as problem solving coping responses (Moos, 1993). Given that the participants mostly highlighted behavioural difficulties related to their children's ASD as stressors, it would seem logical for them to employ a number of strategies aimed directly at addressing these behaviours. The sample was also composed of the fathers of preschool children with ASD. This is considered to be a developmental period during which behavioural difficulties are particularly prevalent in children with ASD (Baird et al., 2006; Charman & Baird, 2002; Landa & Garrett-Mayer, 2006; Szatmari et al., 2009; Yirmiya & Charman, 2010). Consequently, practical coping strategies aimed at addressing problem behaviours could be expected to be more commonly employed by parents at this stage than during other developmental periods.

Participants reported attempting to cope with the challenges presented by their children with ASD by gathering additional information regarding their children's condition, as well as information regarding alternative treatment or management options. Knowing that they had consulted the appropriate medical and affiliated professionals and that they were following the recommendations of these professionals seemed to reassure some of the participants. The above-mentioned attempts at seeking guidance and support are considered to be forms of problem-focussed coping (Moos, 1993; Moos & Holahan, 2003). It should be noted, however, that many of the participants did not appear to be very knowledgeable with regard to the nature of ASD, the available treatment options or the most probable outcomes associated with the condition. This strong focus on information gathering and professional reassurance may thus have occurred in response to a lack of adequate information regarding the condition rather than as a preferred coping strategy.

Much of the research conducted on parenting children with ASD appears to suggest that problem-focussed coping is preferable to avoidant coping (e.g., Dunn et al., 2001; Hastings et al., 2005; Pakenham et al., 2005; Smith et al., 2008). However, some authors suggest that problem-focussed coping may not necessarily always be superior to avoidant coping (e.g., Hastings et al., 2005; Stuart & McGrew, 2009). Furthermore, Smith and colleagues (2008) have suggested that avoidant coping may prove effective in situations where individuals have little direct control over stressors, as is the case with a chronic condition such as ASD. In addition, the problem-focussed/ avoidant coping dichotomy has been criticised as being too rigid and simplistic to reflect the complex nature of the coping process (Amirkhan & Auyeung, 2007; Moos & Holahan, 2003). Participants in the current study reported engaging in cognitive avoidance in order to more effectively deal with challenges they encountered.

It would thus appear that the fathers of children with ASD participating in this study experienced the characteristic symptoms of their children's condition, such as behavioural difficulties, stereotypical behaviours and poor social skills as particularly stressful. Restricted social lives, marital conflict and changes to their paternal roles also appear to provide these individuals with specific challenges. The aforementioned stressors generally seem to be related to unpleasant emotional states such as anxiety, guilt and feelings of being overwhelmed. The participants employ both problem-focussed and avoidant coping strategies in an attempt to deal with challenges that face them. The respondents did report making use of reframing although this did not appear to be one of their primary means of coping. This finding appears to be contrary to much of the literature on parental coping in ASD (e.g., Dunn et al., 2001; Hastings et al., 2005; Smith et al., 2008). However, this finding could possibly be a result of the age of the participants' children, in that younger children may provide mainly behaviourally-related challenges, thus eliciting primarily behaviour-focussed means of coping in their fathers. Alternatively, reframing may

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be considered to be a less active, more defeatist form of coping and thus considered to be less masculine. The possibility should also be considered that reframing may be more readily employed by the parents of older children with ASD, as parents come to accept the chronic nature of the condition over time and view reframing as a more effective means of coping. The participants did not seem to experience their social isolation as a stressor with a particularly high valence. Furthermore, with the possible exception of one individual, none of the participants appear to have sought social support as a means of coping. A possible explanation may be that studies highlighting social support as an important means of coping with raising a child with ASD focus on specific contextual support as is found in dedicated ASD parent support groups, thus underplaying the effectiveness of non-contextual social support (e.g., Benson & Karlof, 2009; Dale et al., 2006; Pakenham et al., 2005; Weiss, 2002). However, this finding may also reflect gender differences regarding the need and preference for social support, particularly as most studies conducted in this field have tended to make use of either exclusively or predominantly female samples.

Limitations and Recommendations

A number of limitations to the study must be highlighted. First, the sample was drawn from a small, principally homogeneous group from a specific geographic location. This limits the extent to which the findings of this study may be generalised beyond this specific context. Second, no attempt was made to control for the severity of the ASD symptoms experienced by the participants' children. This constitutes a limitation as other studies have revealed that symptom severity is associated with both parental stress and coping preference (e.g., Benson, 2010; Davis & Carter, 2008; Dunn et al., 2001; Estes et al., 2009). Third, no attempt was made to specifically establish or quantify the emotional distress that the participants experienced as a result of fathering a child with ASD. Consequently, while the current study may provide insight into the coping strategies employed by the fathers of children with ASD, no conclusions can be reached regarding the effect of these coping strategies on paternal emotional wellbeing. Finally, the current study provides a somewhat developmentally specific view of the experience of fathering a child with ASD. These findings can thus not be generalised to fathers of children with ASD in other developmental phases, nor can these findings be viewed as representative of the experiences of fathers who have been subjected to the stressors of raising a child with ASD over a more extended period of time.

The researchers recognise this was a qualitative study and that the research cannot, and does not, seek to generalise. Lincoln and Guba (1988) proposed transferability as an alternative to external validity in recognition of the fact that not all qualitative studies can be generalised. Transferability is a qualitative criterion of trustworthiness which is used to judge the extent to which findings may be applied to other contexts (De Vos, 2005). In order to achieve a level of transferability, thick descriptions should be provided (Rudestam & Newton, 2001) to aid in the interpretation of the complex issues addressed. This allows those readers who want to conduct further research to make a transferability judgement (De Vos, 2005) about the appropriateness of applying the findings in other settings.

Future research should attempt to investigate the efficacy of the specific coping strategies employed by fathers of preschool children with ASD by determining the perceived impact of different coping strategies on paternal psychological wellbeing and functioning. Single case studies should be employed to obtain a richer and more idiographic impression of paternal experiences in ASD. Comparative studies may be employed to identify possible gender differences regarding the experiences of parenting a child with ASD.

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References

- Amirkhan, J., & Auyeung, B. (2007). Coping with stress across the lifespan: Absolute vs. relative changes in strategy. *Journal of Applied Developmental Psychology*, 28(4), 298-317. doi: 0.1016/j.appdev.2007.04.002
- Ashburner, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. *Research in Autism Spectrum Disorders*, 4(1), 18-27. doi: 10.1016/j.rasd.2009.07.002
- Baird, G., Simonoff, E., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., & Charman, T. (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: The Special Needs and Autism Project (SNAP). *Lancet*, 368, 210-215. doi: 10.1016/S0140-6736(06)69041-7
- Benson, P. R. (2010). Coping, distress and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders*, 4(2), 217-228. doi: 10.1016/j.rasd.2009.09.008
- Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders*, 39(2), 350-362. doi: 10.1007/s10803-008-0632-0
- Bergdahl, J., & Bergdahl, M. (2002). Perceived stress in adults: Prevalence and association of depression, anxiety and medication is a Swedish population. *Stress and Health*, *18*(5), 235-241. doi: 10.1002/smi.946
- Bradfield, B. C., & Knight, Z. G. (2008). Intersubjectivity and the schizophrenic experience: A hermeneutic phenomenological exploration. *South African Journal of Psychology*, 38(1), 33-53.

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- Brocki, J. M., & Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 2(1), 87-108. doi: 10.1080/14768320500230185
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders. *Autism*, 8(4), 409-423. doi: 10.1177/1362361304047224
- Charman, T., & Baird, G. (2002). Practitioner review: Diagnosis of autism spectrum disorder in 2- and 3-year-old children. *Journal of Child Psychology and Psychiatry*, 43(3), 289-305. doi:10.1111/1469-7610.00022
- Charman, T., Taylor, E., Drew, A., Cockerill, H., Brown, J-A., & Baird, G. (2005). Outcome at 7 years of children diagnosed with autism at age 2: Predictive validity of assessments conducted at 2 and 3 years of age and pattern of symptom change over time. *Journal of Child Psychology and Psychiatry*, 46(5), 500-513. doi: 10.1111/j.1469-7610.2004.00377.x
- Dale, E., Jahoda, A., & Knott, F. (2006). Mother's attributions following their child's diagnosis of autistic spectrum disorder. *Autism*, 10(5), 463-479. doi: 10.1177/1362361306066600
- Davis, N. O., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, *38*, 1278-1291. doi: 10.1007/s10803-007-0512-z
- De Vos, A. S. (2005). Qualitative data analysis and interpretation. In A. S. De Vos, H. Strydom, C. B. Fouché, & C. S. L. Delport, *Research at grass roots for the social sciences and human service professions* (3rd ed., pp 333-349). Pretoria: Van Schaik.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff -Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, *37*(1), 39-52. doi: 10.1023/A:1026592305436
- Dyson, R., & Renk, K. (2006). Freshmen adaptation to university life: Depression symptoms, stress and coping. *Journal of Clinical Psychology*, 62(10), 1231-1244. doi: 10.1002/cjlip.20295
- Edwards, D. J. A. (1998). Types of case study work: A conceptual framework for case-based research. *Journal of Humanistic Psychology*, *38*(3), 36-70. doi: 10.1177/00221678980383003
- Estes, A., Munson, J., Dawson, G., Koehlo, E., Zhou, X-H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, 13(4), 375-387. doi: 10.1177/1362361309105658
- First, M. B., & Tasman, A. (2004). DSM-IV-TR mental disorders: Diagnosis, etiology, and treatment. West Sussex, England: John Wiley & Sons Ltd. doi: 10.1345/aph.1E447
- Giorgi, A. P., & Giorgi, B. M. (2008). Phenomenological psychology. In C. Willig & W. Stainton-Rogers (Eds.), *The SAGE handbook of qualitative research in psychology* (pp. 165-179). Thousand Oaks, CA. Sage.
- Gray, D. E. (2003). Gender and coping: The parents of children with high functioning autism. *Social Science & Medicine*, 56(3), 631-642. doi: 10.1016/S0277-9536(02)00059-X
- Hastings, R. P., Kovshoff, H., Brown, T., Waed, N. J., Espinosa, F. D., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-aged children with autism. *Autism*, 9(4), 377-391. doi: 10.1177/1362361305056078
- Hatch, S. L., Mishra, G., Hotopf, M., Jones, P. B., & Kuh, D. (2009). Appraisal of stressors and common mental disorder from early to mid-adulthood in the 1946 British birth cohort. *Journal of Affective Disorders*, 119(1), 66-75. doi: 10.1016/J.JAD.2009.03.021
- Higgins, D. J., Bailey, S. R., & Pierce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), 125-137. doi: 10.1177/1362361305051403

The *IPJP* is a joint project of the Humanities Faculty of the <u>University of Johannesburg</u> (South Africa) and <u>Edith Cowan University's</u> Faculty of Regional Professional Studies (Australia), published in association with <u>NISC (Pty) Ltd</u>. It can be found at <u>www.ipjp.org</u>

- Holroyd, C. (2001). Phenomenological research method, design and procedure: A phenomenological investigation of the phenomenon of being-in-community as experienced by two individuals who have participated in a community building workshop. *The Indo-Pacific Journal of Phenomenology, 1*(1), 1-10.
- Knight, Z. G., & Bradfield, B. C. (2003). The experience of being diagnosed with a psychiatric disorder: Living the label. *The Indo-Pacific Journal of Phenomenology*, 3 (1), 1-20.
- Konstantareas, M. M., & Homatitus, S. (1992). Mothers' and fathers' self report of involvement with autistic, mentally delayed, and normal children. *Journal of Marriage and the Family, 54,* 153-165. doi: 10.1016/0163-6383(94)90053-1
- Koydemir, S., & Tosun, U. (2009). Impact of autistic children on the lives of mothers. *Procedia Social and Behavioural Sciences*, 1(1), 2534-2540. doi:10.1016/j.sbspro.2009.01.447
- Kuhn. J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, *76*(4), 564-575. doi: 10.1037/0002-9432.76.4.564
- Landa, R., & Garrett-Mayer, E. (2006). Development in infants with autism spectrum disorders: A prospective study. *Journal of Child Psychology and Psychiatry*, 47(6), 629-638. doi: 10.1111/j.1469-7610.2006.01531.x
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative analysis. *Qualitative Research in Psychology*, *3*(2), 102-120. doi: 10.1191/1478088706qp062oa
- Lauritsen, M. B., Pedersen, C. B., & Mortensen, P. B. (2004). The incidence of pervasive developmental disorders: A Danish population-based study. *Psychological Medicine*, *34*, 1339-1346. doi: 10.1017/S0033291704002387
- Lazarus, R. S., & Folkman, S. (1984). Stress, appraisal, and coping. New York, NY: Springer.
- Lee, G. K. (2009). Parents of children with high functioning autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities*, 21, 93-114. doi: 10.1007/s10882-008-9128-2
- Lincoln, Y. S., & Guba, E. G. (1988). *Criteria for assessing naturalistic enquiries as reports*. New Orleans, LA: American Educational Research Association. (ERIC Document Reproduction Service no ED297007)
- Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders*, *36*(7), 871-879. doi: 10.1007/s10803-006-0119-9
- Lubetsky, M. J., Handen, B. L., & McGongile, J. J. (Eds.). (2011). Autism spectrum disorder. Pittsburgh, OH: Oxford University Press.
- Macintosh, K. E., & Dissanayake, C. (2004). Annotation: The similarities and differences between autistic disorder and Asperger's disorder: A review of the empirical evidence. *Journal of Child Psychology and Psychiatry*, 45(3), 421-434. doi: 10.1111/j.1469-7610.2004.00234.x
- Matson, J. L., & Kozlowski, A. M. (2010). The increasing prevalence of autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 418-425. doi: 10.1016/j.rasd.2010.06.004
- Meirsschaut, M., Roeyers, H., & Warreyn, P. (2010). Parenting in families with a child with autism spectrum disorder and a typically developing child: Mother's experiences and cognitions. *Research in Autism Spectrum Disorders*, 4(4), 661-669. doi: 10.1016/j.rasd.2010.01.002
- Montes, G., & Halterman, J. S. (2007). Psychological functioning and coping among mothers of children with autism. A population-based study. *Pediatrics*, 119(5), e1040-e1046. doi: 10.1542/peds.2006-2819
- Moore, C. (2008). Thoughts about the autism label: A parental view. *Journal of Philosophy of Education*, 43(3-4), 493-498. doi: 10.1111/j.1467-9752.2008.00652.x

The *IPJP* is a joint project of the Humanities Faculty of the <u>University of Johannesburg</u> (South Africa) and <u>Edith Cowan University's</u> Faculty of Regional Professional Studies (Australia), published in association with <u>NISC (Pty) Ltd</u>. It can be found at <u>www.ipjp.org</u>

- Moos, R. H. (1993). Coping Responses Inventory Youth Form (CRI Y) Professional Manual. Lutz, FL: Psychological Assessment Resources Incorporated.
- Moos, R. H., & Holahan, C. J. (2003). Dispositional and contextual perspective on coping: Toward an integrative framework. *Journal of Clinical Psychology*, 59(12), 1387-1403. doi: 10.1002/jclp.10229
- Morris, M. C., Ciesla, J. A., & Garber, J. (2010). A prospective study of stress autonomy versus stress sensitization in adolescents at varied risk for depression. *Journal of Abnormal Psychology*, *119*(2), 341-354. doi: 10.1037/a0019036
- Morrison, R., & O'Connor, R. C. (2005). Predicting psychological distress in college students: The role of rumination and stress. *Journal of Clinical Psychology*, 61(4), 447-460. doi: 10.1002/jclp.20021
- Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). "My greatest joy and my greatest heart ache": Parent's own words on how having a child in the autism spectrum has affected their lives and their families' lives. *Research in Autism Spectrum Disorders*, *3*(3), 670-684. doi: 10.1016/j.rasd.2009.01.004
- Nicholas, J. S., Charles, J. M., Carpenter, L. A., King, L. B., Jenner, W., & Spratt, E.G. (2008). Prevalence and characteristics of children with autism-spectrum disorders. *Annals of Epidemiology*, 18(2), 130-136. doi: 10.1016/j.annepidem.2007.10.013
- Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). The effect of parenting behaviours on subsequent child behaviour problems in autistic spectrum conditions. *Research in Autism Spectrum Disorders*, 2(2), 249-263. doi: 10.1016/j.rasd.2007.06.004
- Osborne, L. A., & Reed, P. (2010). Stress and self-perceived parenting behaviours of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders*, 4(3), 405-414. doi: 10.1016/j.rasd.2009.10.011
- Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger's syndrome. *Autism*, 9(2), 191-212. doi: 10.1177/1362361305049033
- Phelps, K. W., McCammon, S. L., Wuensch, K. L., & Golden, J. A. (2009). Enrichment, stress and growth from parenting an individual with an autism spectrum disorder. *Journal of Intellectual & Developmental Disability*, 34(2), 133-141. doi: 10.1080/13668250902845236
- Posserud, M. J., Lundervold, A. J., & Gillberg, C. (2006). Autistic features in a total population of 7-9-year-old children assessed by the ASSQ (Autism Spectrum Screening Questionnaire). *Journal of Child Psychology and Psychiatry*, 47(2), 167-175. doi: 10.1111/j.1469-7610.2005.01462.x
- Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modelling approach. *Journal of Family Psychology*, 22(6), 855-864. doi: 10.1037/a0013604
- Prior, M. (2003). Is there an increase in the prevalence of autism spectrum disorders? *Journal of Paediatrics and Child Health*, 39(2), 249-263. doi: 10.1046/j.1440-1754.2003.00097.x
- Rudestam, K. E., & Newton, R. R. (2001). Surviving your dissertation: A comprehensive guide to content and process (2nd ed.). Thousand Oaks, CA: SAGE.
- Seltzer, M. M., Krauss, M. W., Shattuck, P. T., Orsmond, G., Swe, A., & Lord, C. (2003). The symptoms of autism spectrum disorders in adolescence and adulthood. *Journal of Autism and Developmental Disorders*, 33(6), 565-581. doi: 10.1023/B:JADD.0000005995.02453.0b
- Shinebourne, P., & Smith, J. (2009). Alcohol and the self: An interpretative phenomenological analysis of the experience of addiction and its impact on the sense of self and identity. *Addiction Research and Theory*, *17*(2), 152-167.
- Sinner, A. (2004). Chronic pain and returning to learning: Exploring the lived experiences of three women. *The Indo-Pacific Journal of Phenomenology*, 4 (1), 1-15.

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- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1(1), 39-54. doi: 10.1191/1478088704qp004oa
- Smith, J. A. & Eatough, V. (2007). Interpretative phenomenological analysis. In E. Lyons & A. Coyle (Eds.), *Analysing qualitative data in psychology* (pp. 35-50). Thousand Oakes, CA: Sage.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, methods and research. London, UK: Sage.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp.218-240). London, UK: Sage.

Smith, J. A. & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (pp. 53-80). London, UK: Sage

- Smith, L. E., Seltzer, M. M., Tager-Flusberg, H., Greenberg, J. S., & Carter, A. S. (2008). A comparative analysis of well-being and coping amongst mothers of toddlers and mothers of adolescents with ASD. *Journal of Autism and Developmental Disorders*, 38, 876-889. doi: 10.1007/s10803-007-0461-6
- Stones, C. R. (1986). Phenomenological praxis: A constructive alternative in research in psychology. South African Journal of Psychology, 16(4), 117-121.
- Stuart, M., & McGrew, J. H. (2009). Caregiver burden after receiving a diagnosis of an autism spectrum disorder. *Research in Autism Spectrum Disorders*, *3*(1), 86-97. doi: 10.1016/j.rad.2008.04.006
- Sukhodolsky, D. G., Scahill, L., Gadow, K. D., Arnold, L. E., Aman, M. G., Mcdougle, C. J. ... Vitiello, B. (2007). Parent-related anxiety symptoms in children with pervasive developmental disorders: Frequency and association with core Autism symptoms and cognitive functioning. *Journal of Abnormal Child Psychology*, 36, 117-128. doi: 10.1007/s10802-007-9165-9
- Sun, X., & Allison, C. (2010). A review of the prevalence of autism spectrum disorder in Asia. Research in Autism Spectrum Disorders, 4(2), 156-167. doi: 10.1016/j.rasd.2009.10.003
- Szatmari, P., Bryson, S., Duku, E., Vaccarella, L., Zwaigenbaum, L., Bennett, T., & Boyle, M.H. (2009). Similar developmental trajectories in autism and Asperger syndrome: From early childhood to adolescence. *Journal of Child Psychology and Psychiatry*, 50(12), 1459-1467. doi: 10.1111/j.1469-7610.2009.02123.x
- Tehee, T., Honan, R., & Hevey, E. (2008). Factors contributing to stress in parents of individuals with autism spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, 22, 34-42. doi: 10.1111/j.1468-3148.2008.00437.x
- Turner, R. J., & Lloyd, D. A. (2004). Stress burden and the lifetime incidence of psychiatric disorder in young adults: Racial and ethnic contrasts. *Archives of General Psychiatry*, 61(5), 481-488. doi: 10.1093/aje/kwq283 Retrieved from: http://archpsyc.ama-assn.org/cgi/full/61/5/481
- Volkmar, F. R., State, M., & Klin, A. (2009). Autism and Autism Spectrum Disorders: Diagnostic issues for the coming decade. *Journal of Child Psychology and Psychiatry*, 50(1-2), 108-115. doi: 10.1111/j.1469-7610.2008.02010.x
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6(1), 115-130. doi: 10.1177/1362361302006001009
- Yin, R. (1989). Case Study Research (rev. ed). Newbury Park, CA: Sage.
- Yirmiya, N., & Charman, T. (2010). The prodrome of autism: Early behavioral and biological signs, regression, periand post-natal developments and genetics. *Journal of Child Psychology and Psychiatry*, 51(4), 432-458. doi: 10.1111/j.14697610.2010.02214.x

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