



An exploration of fathers' subjective experiences of parenting a child that presents with dyspraxia

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Abstract

Confronting the realisation that one's child may have a developmental disability presents a major challenge for any parent. The body of scholarship in this area however, focused mainly on the role that mothers play highlighting a distinct gap within the literature. In an attempt to address this, the study aimed to highlight the experiences of fathers in parenting a child that presents with dyspraxia. The study adopted an Interpretivist framework using a qualitative approach. Consistent with this approach, 14 semi-structured individual interviews were conducted. Fathers across the Cape Metropole area were purposefully recruited and interviewed regarding their experiences in parenting a child with dyspraxia. These interviews were transcribed verbatim and subjected to Clarke and Braun's version of thematic analysis. Ethics principles as stipulated by the University of the Western Cape were strictly adhered to throughout the research process. The thematic domain of 'experiences' revealed father's expectations; their initial reactions; the periphery of father's emotions; guilt and devastation. Based on the findings of the study, alternative understandings of fathering need to be developed to enable new and more equal ways of being both fathers and men and mothers and women. This is necessary to challenge the limiting essential notions of what is possible for men and women.

Keywords Fatherhood · Masculinity · Children with dyspraxia · Experiences · South Africa · Qualitative study

Introduction

Discussing fatherhood in the absence of acknowledging the roles of both parents in the broad spectrum of parenting is to polarize these subject positions thus hindering a more holistic understanding of what it may mean for fathers to raise a child with a disability.¹ Therefore, to contextualise the role of fathers in rearing a child with a disability it is important to discuss parenting in general, which will highlight the roles of both parents, and ultimately provide a glimpse into the experiences of fathers.

For a number of people, the experience of parenthood is often revered as one of the most fulfilling experiences that life has to offer (Rizzo et al. 2013). First-time parents tend to construct unrealistic expectations about the experiences of

parenting and parenthood (Delmore-Ko et al. 2000). Previous research highlighted these unrealistic expectations through societal ideologies like "intensive mothering" and the 'good mother' (Damaske 2013; Knight 2013; Schmidt 2008). Traditionally, the roles expected of each parent are prescribed with the father being construed as the financial provider of the family while mothers are constructed as nurturers and care givers within the home environment (Brescoll and Uhlmann 2005). As a result of the primacy of mothers' roles within the domain of child development, the role of fathers have often been overlooked and even ignored. This omission thus fails to acknowledge the various concomitant benefits associated with child development when fathers are involved (Hakoama and Ready 2011; Lamb 2004; Rosenberg and Wilcox 2006). These benefits are endorsed by studies that demonstrate that IQ levels and empathy increase for those children who are securely attached to their fathers (Cabrera et al. 2000; Sarkadi et al. 2008). Thus a discussion on fathers, fathering and fatherhood is important in understanding more generally the roles they play, but more importantly in the context of this study how they may experience having a child with a disability.

¹ This study aligns to the United Nations Sustainable Developmental Goals in particular, gender equality (SDG-5) and good health and well-being (SDG-3).

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This paper examines the subjective experiences² of fathers who parent a child presenting with dyspraxia. More specifically, the paper explores fathers' expectations, their initial reactions as well as their emotional responses to having a child presenting with dyspraxia. The argument made in this article is that patriarchy positions men as heads of households with very specific roles and responsibilities. Having a child with dyspraxia challenges these conventional notions of fatherhood as the roles assumed are often determined by the specific needs and context of the child.

Background

Fatherhood

Over the last few decades, research on masculinity and fatherhood expanded drastically (Astone and Peters 2014; Elster and Lamb 2009; Ives 2014; Johnson and Young 2016) and has been described as being 'in crisis' a 'work in progress' and there have been numerous questions on the 'future of fatherhood' (Freeman 2003; Hobson 2004; Miller 2011). Traditional conceptualisations of fathers as the financial providers, breadwinners and disciplinarians of the family who are emotionally absent have subsequently shifted to include the various roles that are played by fathers across different cultures and contexts (Gregory and Milner 2011). These shifts may be attributed to the changing roles expected of both men and women in society (Schooreel and Verbruggen 2016). Within the current context of the twenty-first century the term 'father' refers not only to the man who fathered a child but also to someone that has assumed those responsibilities and roles (Hobson 2004). Contemporary conceptions of what it means to be a father may refer to someone that is more than capable to care for his children, irrespective of his marital status, age, sexual orientation, employment status or whether he is a step or adoptive parent (American Psychological Association 2013).

Through defining what it means to be a father, the distinction should be made between father, fatherhood and fathering. The term father is used to refer to the individual man while fatherhood seeks to describe the broader context within which fathering occurs (Graham et al. 2016). The concept of becoming a father is therefore more complex and multidimensional and is largely influenced by various social and cultural processes. These processes include interactions between the father and his child, his spouse, the family as well as his community at large (Marsiglio et al. 2005; Schacht et al. 2009). The practices of fathering and the role of fatherhood can

therefore be seen as a fluid construct that is socially influenced and fluctuates through time and context (Richter and Morrell 2006).

In terms of more traditional constructions of fatherhood, or rather hegemonic fatherhood, the concept of the 'good' father consists of three core functions:

- Provision: He must provide for his family and furthermore he needs to be the sole provider/breadwinner.
- Protector: He should be the primary protector of not only his children but his home thereby displaying qualities of strength, bravery and responsibility.
- Authority: He needs to serve as the authority within the family particularly as judge and disciplinarian. (Ruddicks 1997).

However, when a father is expected to display qualities that are more nurturing, he will experience 'role strain' which is fundamental to the concept of hegemonic fatherhood (Ruddicks 1997).

Men who are confined and constrained to the roles accrued with hegemonic masculinity or hegemonic fatherhood can cause severe internal conflict or dissonance. Through this, the concept of a new man that incorporates a more child-oriented masculinity is being considered (Cable 2017). This is illustrated in considering the core functions of child-oriented fatherhood which includes the following:

- Direct interactions between a father and his child through both playing and care-taking.
- The aspect of accessibility and how he makes himself available when his child needs him.
- He should demonstrate responsibility or managing and providing of resources for his child (this may be in the form of doctor's appointments, daily routine tasks etc.).
- And how a father provides a support network for his children as they continue to grow. (Pleck and Masciadrelli 2004; Marsiglio et al. 2000).

Although some men seek to include newer constructions of masculinity, in particular the child-oriented masculinity and thereby reject some traditional constructions of hegemonic masculinity, they may experience a sense of apprehension as a result of societal expectations. A study conducted in South Africa determined that men are still confronted with widespread pressures to express their manhood in various traditional ways and are fearful of being mocked by other men and women for performing household chores and displaying caring or more nurturing duties towards their children (Jain et al. 2011).

The constructions and understandings regarding what it means to be a man and a father in South Africa is shrouded in inconsistency and ambivalence for many men. Many of

² Experiences in this study refers to the subjective process of making meaning in parenting a child that presents with dyspraxia and connecting these meanings with personal life experiences (Wong et al. 2015).

them are confronted by various social laws and policies which in one sense limits their interactions and levels of involvement within the lives of their children, yet in another sense they are constructed as uninvolved, emotionally distant and absent (Richter et al. 2012; van den Berg et al. 2013). Given the ambiguity that many fathers may experience it is imperative to redefine the role of men in general and fathers in particular. These challenges mentioned may present a major burden to many men who have ‘normal’ children and may be exacerbated for those fathers who have children who present with some kind of disability, for example those who present with learning disorders like Dyspraxia.

Dyspraxia

At specific ages children are expected to overcome certain milestones such as being able to crawl, being able to reach for toys, recognising objects from a distance, eat with a spoon etc. However, for many children these expected developmental milestones (walk, talk, read, run, write and even play sport) may not be achieved at these typical ages (Prado et al. 2014). The inability to achieve these milestones may be indicative of a learning disorder. In South Africa learning difficulties affect roughly 11.2% of children (Department of Social Development / Department of Women, Children and people with Disabilities/UNICEF 2012). Learning disorders can affect a child in terms of their social, psychological, physical and educational environments (Foulder-Hughes and Prior 2014).

The more commonly researched learning disorders are Autism and Attention Deficit-Hyperactivity Disorder (ADHD) due to the fact that the incidence/prevalence in the past was fairly high. However, other learning disorders seem to be emerging at quite a rapid pace, highlighting the need to focus on some of these learning disorders or difficulties like Developmental Coordination Disorders (DCD) of which Dyspraxia is one (Cortiella and Horowitz 2014).

The construct of dyspraxia has been shrouded in a variety of definitions from various fields of study. Put simply, the disorder has been described to refer to abnormal motor behaviours or difficulties experienced with regard to motor movements (Tanaka et al. 1996). More aptly the disorder has been described as difficulties associated with motor movements that are exacerbated by various perceptual difficulties. In addition, dyspraxia is considered to refer to impairment in or difficulty associated with planning, organising and executing various physical movements which may have various implications for parents to consider. The disorder is subsequently considered to be developmental in its origin as opposed to a disorder that is acquired (Gibbs et al. 2007).

Previously the concept of Developmental Coordination Disorders (DCD) and dyspraxia have been used interchangeably and mistakenly so. The concept of DCD was rather

understood by many to refer to a range of disorders involving coordination difficulties of which dyspraxia was one (Peters et al. 2001). Further to this DCD was used to refer to a range of disorders that are fundamentally developmental in nature and therefore its definition has been closely linked to dyspraxia. Dyspraxia however was referred to as the impairment in organising various motor movements and in some cases perception, language and thought processes as well (Steinman et al. 2010).

The implications of one’s child receiving a diagnosis may be vast and triadic. The first of which is the experience of dysfunction felt by the child him/herself, the family that has been affected and the larger external environment within which the disability has manifested. The realisation that one’s child may have a developmental disability may be regarded as a crisis and one of the most difficult experiences for any parent (Heiman 2002). Families of a child with a developmental disorder are vulnerable to high levels of stress and ongoing challenges. Additionally, research within these contexts has primarily focused on mothers rather than on fathers highlighting the importance of the current study (Al-Yagon 2015).

In a study exploring the social impact of living with dyspraxia, researchers found that in many cases mothers tended to be more informed about disorder and were able to answer many of the questions relating to it (Payne et al. 2013). In contrast, fathers were unable to understand what was happening with their children and the unique challenges that they faced. As such, fathers were less tolerant, perhaps owing to a sense of powerlessness, which would result in tension between both parents, however; in some cases children who were diagnosed with dyspraxia (aged 13) expressed that their fathers were positive role models in providing support and understanding (Payne et al. 2013).

Theoretical Framework

The underpinning theories for this study are Bowen’s *Family Systems Theory* and *Family Resilience Framework*.

Family systems theory provides a lens to examine how communication or dialogues are used within families through which past and future experiences are constructed (Smith-Acuna 2011). Family systems theory emphasise that families should be considered as systems. A system can be defined as a unit comprised of interacting and reacting parts that reciprocally influence and communicate with one another. (Bregman and White 2011). A system comprises of interrelated elements and objectives, that exhibit coherent behaviours, engage in regular interactions and exist interdependently of one another (Haefner 2014). These interrelated elements refer to the individual members within the family structure that inevitably co-construct a family structure and environment (Berryhill et al. 2016).

The family resilience framework seeks to explore the ways in which a family has the ability to heal, grow and recuperate from specific adverse life challenges (Becvar 2013). The framework also suggests that challenges and crises impact the family unit in its entirety and the subsequent processes that mediate recovery of not only the family member but their relationships as well (Saltzman et al. 2013). The framework further extends to examining the organising and communication processes within the family unit.

Families are often faced with diverse challenges and therefore they are expected to organise their households in various ways in order to meet these challenges. Social and economic resources, a flexible structure and a sense of connectedness can strengthen a family's resilience. Concurrent to this, families need to counterbalance and buffer against disruptive changes in order to re-establish stability. In addition, resilience is fostered when there is shared support, corroboration and a commitment to endure hardships together (Walsh 2012).

Communication assists families in forging resilience by adding informative clarity to critical situations, fostering collaborative problem solving while encouraging a greater sense of emotional sharing. Disruptive crises may easily breakdown communication and affect a family's ability to function (Walsh 2016). Secrecy, denial and covering-up impede recovery whereas a shared sense of truth and acknowledgement may foster healing. Ambiguous or mixed messages may fuel anxiety whereas clear information may facilitate informed decision-making, future planning and meaning making. A sense of trust, tolerance or differences and empathy may enable family members to express a multitude of feelings that may be aroused in a crisis situation or in instances of chronic stress (Becvar 2013).

Theoretically the two frameworks complement each other and allow for an in-depth analysis by examining how fathers interact with all the interrelated elements of the system and how they affect him in turn. In addition, family resilience framework provides one with a schema to understand how fathers adapt to and ultimately cope with parenting a child with a disability (Baum 2007; Haydon-Laurel 2011; Kaur and Scior 2009).

In light of the above, and due to the limited research on fatherhood and dyspraxia, this study is critical as it may inform various interventions while highlighting a largely neglected area of research.

Method

Research Design

The overarching aim of this study was to explore the subjective experiences of fathers parenting a child that presents with dyspraxia in the Cape metropole area. A qualitative approach

utilising an exploratory design was employed to understand and provide in-depth information about fathers' subjective experiences of parenting a child that presents with dyspraxia. This design offers the opportunity to explore the current phenomenon in an open and organic way where limited information is available (Mack et al. 2005). Data was collected using semi-structured individual interviews with fathers.

Research Context

The study was conducted in the Cape Metropole area. In the Western Cape, South Africa The final sample of 14 fathers ranged across the following widespread areas; Parow, Durbanville, Bellville, Belhar, Table View, Bonteheuwel, Paarl and Boston. These areas are not only diverse in geographical space but also vary in socio-economic status ranging from affluent to lower-income, resource constrained communities.

Participants and Sampling

The study employed a non-probability sampling method. Consequently, the participants were selected on the basis that they possessed the specific qualities or experiences required for investigation (Terre Blanche et al. 2011). The study was open to all types of fathers that had demonstrated presence and involvement in their child's life. Fathers were purposefully selected based on this criteria and identified through an expert within this focus area. Participants were sampled from various non-profit organisations, centres and schools that focus on children with learning difficulties whereby parents were informed about the nature of the current study and those who were willing to participate, provided their contact information.

Owing to the prevalence of various co-morbid disorders surrounding dyspraxia and the lack of clarity surrounding the disorders' definition (Colley 2006; Gibbs et al. 2007; Jongmans et al. 2003; Miyahara and Baxter 2011; Peters et al. 2001; Steinman et al. 2010; Zwicker et al. 2012) a diagnosis is problematic. It is noteworthy that not all children in this study aligned completely to the criteria as outlined in the DSM-V but rather, how they presented with the disorder.

The sample consisted of 14 fathers who were individually interviewed (Payne et al. 2013; Foulder-Hughes and Prior 2014). The sample size was considered appropriate for the current study in accordance with the criteria outlined by Malterud et al. (2016). According to their five steps in determining information power, owing to the nature of the current study and its contribution to a largely neglected area of research concerning fathers perceptions of parenting and furthermore, concerning the area of Dyspraxia, a much smaller sample size is required to produce sufficient information power. Rather the emphasis is placed on depth of information particularly when the focus of the study is quite specific (Malterud et al. 2016).

Given the diversity of fathers in South Africa, a varied sample across age, race, culture and income was recruited. The participants had a mean age of 41, where eight identified as ‘white’, five identified as ‘coloured’, and one identified as ‘indian’.³ Thirteen fathers had sons who presented with dyspraxia and one father had a daughter. 86% of fathers in this study were married, 14% were divorced, and they had varying educational backgrounds ranging from Matric (Grade 12) to various tertiary degrees.

Data Collection

Upon receiving ethics approval from a University in Cape Town, subsequent recruitment, gaining of informed consent, the interviewing process took place. 14 semi-structured interviews were conducted, which were guided by an interview schedule that was designed in relation to various literary articles, the theoretical position of the current study and the recommendations and suggestions of the aforementioned articles. Each interview was approximately 45–75 min at each participant’s convenience and the discussions therein developed organically from the semi-structured interview schedule. Examples of some of the questions were: ‘what are some of the more positive experiences you have had with your child?’, ‘what are some of the more difficult experiences you have had with your child?’ etc. A pilot run was conducted with the interview guide to ensure that it was appropriate and effective in addressing the research question, language used, and the timeframe allocated. None of the participants who participated in the pilot were used in the main study. A debriefing session was held with each participant after their interview which allowed for an open dialogue to impart knowledge about their experiences, attitudes and beliefs regarding the research process and to clarify their emotional expression of the experiences shared (Houghton et al. 2013; Sharpe and Faye 2009). The debriefing session allowed the researcher to identify those who may have felt the need for psychological support, and appropriate referrals were made where necessary. Although referral was emphasised, all participants refused the offer.

Data Analysis

Data collection and analysis took place simultaneously and the analysis unfolded inductively rather than deductively in conjunction with the data collection process itself (Visagie 2010). The individual interviews with fathers were analysed using Clarke and Braun’s (2013) six-phase guide to conducting a thematic analysis. Phase one included

familiarising ourselves with the data which was characterised by reading and re-reading the transcripts, in all cases together with the audio-recordings. Phase two encompassed generating initial codes by grouping similar ideas together. Once this had been completed an external reviewer, a PhD in Psychology candidate reviewed the initial codes and corresponding excerpts to confirm eligibility of the identified codes and to minimise bias on behalf of the researcher. Phase three aimed to identify themes based on the initial codes where Phase four aimed to review and refine these themes. Phase five each theme was defined and named with the assistance of a second external reviewer with a PhD in psychology. Phase six of the analysis produced the thematic domains, themes and sub-themes of the study. Each transcription was read and re-read which culminated into 27 broadly defined codes. A data extraction table was used in order to manage and guide the process of coding and also assisted in grouping the 27 codes into 5 themes which were encapsulated into the overarching thematic domain of “experiences”. The coding and grouping of codes into themes was verified by three additional psychology researchers. The mechanisms employed to ensure the credibility and trustworthiness of the study were peer-debriefing (PhD and PhD candidate in Psychology), audit trail (all decisions and processes followed were document in detail in the dissertation, (see Jackson 2017) and providing a thick, rich description (describing the setting, participants and themes in detail) (Terre Blanche et al. 2011).

Procedure and Ethics

The researcher contacted various fathers through email, text-message or a telephonic call in order to discuss the study. In some instances, the information provided was of mothers who parent a child that presents with dyspraxia. In these cases, mothers would either arrange dates, venues and times on behalf of their husbands or alternatively provide the information to contact their husbands directly. Each telephonic discussion focused on the purpose of the study and to arrange a possible date to meet at the participant’s earliest convenience. Each venue was discussed separately and therefore ranged between various coffee shops, restaurants, home and employment environments.

Once rapport was established, the researcher provided each participant with an information sheet comprising of the nature and details of the study. The purpose of the study, the rights of the participant, confidentiality and anonymity were all discussed with each participant. Furthermore, consent forms were handed out to each participant to sign as agreement and understanding of what the study entailed, their rights as participants, how the findings of the study would be used and their agreement to participate voluntarily. Each interview was conducted by the primary researcher.

³ Statistics South Africa continues to classify people into population groups, since moving away from the past apartheid-based discrimination. This classification uses a population group-based classification system that is no longer based on a legal definition, but rather on self-classification (StatsSA 2015).

Results

Particular focus was placed upon the knowledge, understandings, difficulties and care experienced by fathers. A number of sub-categories or themes were identified which translated into the emergent thematic domain which will be discussed to provide a comprehensive description of fathers experiences when parenting a child that presents with dyspraxia.

Father Expectations

In contrast to fathers' understandings of the developmental difficulties experienced by their children, it appeared that they battled with their preconceived expectations of what it means to be a father to a child with this disorder. This was highlighted by Keller et al. (2014) where fathers expressed their desires to share in intergenerational experiences that their fathers had with their own children. This included playing sports, riding a bike together, travelling together on a road trip and sharing knowledge (Keller et al. 2014). This theme highlights the need for fathers to reconstruct their expectations and perceptions of fatherhood.

In a number of the interviews that were conducted, fathers tended to create certain expectations when fathering a child which are discussed by the following extracts. In some cases they had to re-evaluate and adapt their expectations in light of the fact that their child experienced particular limitations as a result of the disorder. This was revealed by a father (Participant 8 p.14) when exclaiming that:

“you not even focusing on the rugby or the cricket or something like that but those are some of the things you should be doing so in terms of the father, in terms of sport you also you know, I'm might have liked him to be more involved in sports or something you know ... and we sort of, I accept it as a father. And then obviously I'm looking past the other things like you know it really like to sit with him and built a go-cart and built this and stuff but uhm its just things that we accept you know that I accept actually as a father”.

This was further explained by another father (Participant 5 p.15) that in some cases “... *fathers like to live vicariously through their kids*” but these activities are often put on the “*backburner*” which can often be a very difficult thing for fathers to accept. Instead the participant (Participant 5) suggests that fathers should be encouraged to focus on their child's own path and to concentrate on getting them to the next developmental milestone, such as dressing themselves, tying their shoes etc.

“if you keep that in front of you, you never know where you might end up if you are going to sort of just be sad for your kids all the time, you are going to be doing them and yourself a huge sort of injustice because you are never going to move forward”.

Additionally, it was evinced by one of the participants (Participant 5 p.9) where other family children did not want to play with his son and the participant explained “*yeah it's not a nice thing. You know you sort of weep for your child when you see things like that*”. This relates to the expectations that fathers have of their children based on their own inter and intrapersonal interactions and development with other children. However, this process is hampered where other children prefer to play with those children who are able to engage and interact more easily. This form of social exclusion further exacerbates issues around social development for the child while simultaneously foregrounding fathers preconceived notions of parenting, shifting these notions from goal-directed activities, to a more supportive and sensitive role.

Fathers are therefore faced with the disparity between traditional role expectations and a more nurturing role within the family. Fathers generally develop an ‘ideal’ sense of how they will begin to develop the attachment between themselves and their children while the children are in utero. The process of attachment thus seems disrupted for fathers as a consequence of this disorder. This was described by one father (Participant 9 p.1):

“I have missed of that quite a substantial part of his life where the child say, daddy is going to the beach um I want to go, or daddy is going wherever and I want to go with but because he is still so attached to his mommy because of these issues so now as a father I have now missed a large part of it and I am still missing a large part of it and it becomes now for me on a personal level more of a provision type of role um and making sure that he has everything that he has rather than to enjoy my child as he is still young”.

This highlights the fluidity between fathers' child-oriented expectations and their lived realities, by being cast back into the traditional providing role.

The first paragraph emphasized the expectation of fathers to engage practically and share experiences and knowledge with their children. This was proceeded by the expectation that their children would develop relationships with other children and the expectation of forming a close bond and attachment with their child. However these expectations were disrupted and therefore having a child who presents with dyspraxia compelled fathers to constantly rethink and renegotiate their roles and responsibilities (Seligman and Darling 2007).

Initial Reaction

The initial reaction was experienced in an array of ways ranging from complete denial to experiencing the diagnosis as a crisis. What is evident is that fathers' initial experiences hinged on denial as expressed in the quotes below.

Fathers expressed that their initial reaction was characterised as being more relaxed but through introspection it may have been a sense of denial in an attempt to cope with the diagnosis of their children. This sense of denial was experienced in a number of external environments from grandparents

“I mean people always like to give advice ... with coming from an older person like an aunt, an uncle, a [his] mom or [his] dad, whatever the case may be, that this is just years of experience that they are just passing down to you, but when you have this kind of issue they don't have that kind of experience to give, so they are not qualified to make that call, yet um the struggle is trying to get that across and not seem ungrateful or whatever.”),

teachers (“...all of his teachers were, well he will come right, he will come right...”) and family (“... I mean he is going to come out of it, he is going to snap out of it, maybe after he turns 4 he can talk properly or whatever...”) and in some cases parents had to go out of their way to prove that there was a problem with their child (Participant 5, p.6).

The initial reaction of parents when receiving the diagnosis can be described as a particular crisis within the lives of each parent (Heiman 2002). Typically it has been assumed that mothers tend to experience greater stress when their child has a disability while other studies refuted this inference (Yamada et al. 2012). More commonly the initial reaction can be linked to that of bereavement and therefore tends to be more negative in nature. Based upon the ideas that fathers held, they created an ideal life that they hoped to share with their children. Fathers therefore experienced a sense of grief at the possibility of not being able to live out those ideals with their children, thereby reworking their initial ideals. Notwithstanding, families process and approach adversity differently and therefore either adapt more flexibly and spur into action whereas others may resist the diagnosis and ultimately become less effective in their approach (Poslawsky et al. 2014).

The Periphery of father's Emotions

An important theme that emerged encompasses the emotional responses of the fathers stemming from their experiences with their children. The emotional responses ranged from fathers' reporting that their needs, both emotionally and cognitively are secondary to that of their child, to guilt and devastation.

When interviewed, one of the fathers (Participant 1 p.8) described that in his view (“*I think it affects him more than if affects us*”), being afflicted with this disorder, affected his child more and therefore his emotional responses should be secondary to the emotional experiences of his child. This was further emphasised by another father (Participant 9 p. 2), who had been diagnosed with a chronic disorder when he reported:

“There is less that I can do but there would have been more that I could have done with him if he could interact with me. Then he could explain to me and I could explain to him, I could tell him ok Daddy is a bit tired now and I can't carry you now but for example he would come to me and say that I want to jump and but with my condition, even in my chest my muscles are inflamed and my breathing capacity is not that of a normal human being...”.

Additionally, another father (Participant 3, p.9) who indicated that “... *I think to myself you know like what is he going through if I am getting frustrated and I can't understand him, how much more frustrated is he getting that he can't convey the message over to me...*” and therefore, as mentioned by Participant 8, p.14: “... *I'm looking past the other things like you know, I'd like to sit with him and build a go-cart and build this and stuff but uhm its just things ... that I accept actually as a father*”. Traditionally, as children develop, they may demonstrate greater understanding of the needs of their parents. However, as a result of their disorder, this possibility is now either delayed or non-existent.

One father (Participant 9 p. 4) indicated that the needs of his child become central in the daily functioning of the family,

“he has had to attend speech therapy, occupational therapy and various other therapies you know um and it has been very challenging for us as a family and therefore the end result has sort of brought us to a cross roads”.

The consistent urgency in maintaining the needs of their child thereby circumvents the needs of the entire family into the periphery. Through this, fathers experienced neglect in terms of their own needs, thereby experiencing a sense of frustration, inter-spousal conflict and burn-out.

Guilt

On the other hand, a father (Participant 1 p.14) compared his experiences with how other families might be coping with having a child with a disability. This participant described his feelings of guilt in the sense that:

“I am just feeling quite guilty about it that it wasn't really or isn't really all that bad ... but I know that with

a 10% change it would have been such a different ball game. If it was 10% worse it wouldn't have just been 10% different”.

The excerpt above may be explained by drawing on a phenomenon experienced when one experienced a particular traumatic event by ‘surviving’ while others may not. *Survivor guilt/syndrome* refers to an instance whereby one experiences a sense of guilt as a result of ‘surviving’ a particular adverse event (diagnosis) where others may not (“*isn't really all that bad*”) (Zoja 1995). The participant describes feeling a sense of remorse and sorrow towards other families who may experience more significant disruptions within their family systems (Khatri and De Sousa 2015). This further directly challenges the stereotypical ideal that fathers may respond with avoidance and withdrawal when their child has a disability by not only indicating an involved presence in the life of his child but an emotional response connected to the disorder itself (Novak et al. 2011). Furthermore, symbolically a father survives being unscathed whereas his child is left ‘injured’. Although his child survives, it is how they have survived that creates a sense of guilt within the father. This further represents the death of the ‘normal child’ as evident by another father (Participant 9 p. 7):

“so yeah we saw him sitting on his own um playing by himself while all the other children where interacting with each other, talking, laughing and sharing the toys, ... and that is when we realised that this is his life at school day in and day out because he can't communicate”.

Experiencing the disorder as ‘not all that bad’ indicates the ways in which fathers begin to rationalise and minimise their experiences in order to cope and re-establish their sense of resilience.

Devastation

In conjunction to this, a participant (Participant 2 p.1) revealed that:

“as a male um you don't show it because the partner is very very when we find out about it she was obviously devastated but being a male you mustn't show it's just the wrong way”.

In some cases you may experience a sense of “*devastation*” but in terms of being a male you cannot reveal the devastation you experience. In opposition to this,

“So I dunno, I guess, do I feel sad at times, yes I do I cry, ... I mean you don't weep for hours but you have your moments where you really feel sad about, that this had

to happen, not to me, it's not self-pity its actually, I dunno what it is, how do you describe it, it's not self-pity for you it's actually uh it's like almost an empathetic sadness” (Participant 11 p.7).

The above excerpts indicate the dissension between the stereotypical socialisation of men as logical, task-oriented and unemotional and the expressive, nurturing, caring and vulnerable father. The extracts above foreground the contradictions as well as the ambiguity around fathers and how they father. On one hand a father reports that his emotions should be viewed as secondary to the experiences of his child whereas on the other hand a father explains how his emotions need to be withheld.

Maintaining the strong and silent or tough-guy script can have a profound impact on the father-child relationship resulting in the father becoming less involved, distanced and experiencing problems with intimacy (Al-Yagon 2015). Through suppression of his emotions, a father may subvert the ‘mourning process’ and fail to adapt to the disability of his child. He may experience this as an inability to protect his child thereby affecting his self-esteem and respond by suppressing his emotions, preventing resolution of this burden (Seligman and Darling 2007).

Discussion and Conclusion

In line with family systems theory and the family resilience framework, the emphasis is placed on families existing within a complex and interactive system that operates with interconnected behaviours and objectives. Additionally the needs and experiences of one member may in turn affect other members within that system. These behaviours may refer to the ways in which parents engage with their children, how families experience routine behaviours such as eating or sleeping to more complex and vital needs such as survival.

Fathers are therefore influenced not only by the system within which they exist with their children but also the system from past experiences when they were children engaging with their own fathers. This was demonstrated in the current study by the ways in which fathers interacted with their children through their own particular ideas of what their interactions with their children should be. Our study demonstrates that having a child with dyspraxia interfered with important processes for fathers relating to their parenting expectations. The preconceived ideas held by fathers were disrupted with the realization that their child was unable to engage in joint activities with them as their own ‘typical’ childhood experiences taught them and they consequently expected the same of their child.

Secondly, it highlighted how they understood their attachments to be disrupted. Fathers had to withdraw from attaching

to their child due to the disability causing an intense reliance on the mother. This illustrates that a disruption in the family system causes fathers to re-evaluate and shift their roles in order to adapt to the changing family environment so that homeostasis within the ‘functioning’ family unit can be re-established. These scenarios positioned participants as supportive and sensitive on the one hand, while simultaneously leaving fathers to question what their respective roles should be on the other hand. As mentioned earlier, one of the fathers resigned himself to being the provider as that was the only way he felt he could make a meaningful contribution at that time. Having a child presenting with dyspraxia seems to compel fathers to reframe their initial expectations as they had to adapt and attune to their child needs.

The initial reactions fathers displayed can be described in terms of rationalization, minimizing their own feelings while others expressed complete devastation. In terms of family resilience, experiences of adversity or prolonged crisis places undue pressure on the family unit and therefore the behaviours that develop in order to maintain healthy family functioning may differ substantially from one context to the next. It is therefore noteworthy that as families evolve and as various challenges emerge, processes responsible for optimal family functioning and well-being of the family members may vary over time. Having a child with a disability could be explained as being a ‘crisis’ for some of the participants. The participants dealt with their situations in various ways so as to make sense of them. Thus some fathers expressed that their situations were not as bad as other families, while other fathers inadvertently seemed to experience survivor guilt. Whatever emotions were expressed, they point to the fact that these participants were deeply affected, while they remained involved and emotionally connected.

This therefore challenges stereotypical notions of men being cut off from their emotions and emotionally distant. One father expressed how devastated he felt but did not show it because he wanted to ‘protect’ his wife who openly expressed the devastation she felt. So for fathers in this study their emotions were secondary not only to that of their children’s, but also to that of their spouses/partners. A family that displays openness to adaptive change to meet new challenges and constructs a newer structure to meet these challenges thereby indicates flexibility which serves as a core process in the development of resilience. Concurrent to this, families need to counterbalance and buffer against disruptive changes in order to re-establish stability. In addition, resilience is fostered when there is shared support, corroboration and a commitment to endure hardships together (Walsh 2012). In this way fathers seemed to re-organise the structure of their family unit, whilst re-evaluating their roles as fathers to meet these challenges however, this may place undue pressure and hardship on

fathers and without re-establishing stability they significantly increase their chances of burnout, stress and mental illness.

In conclusion, having a child with a disability, disrupts notions of the ‘ideal child’ which leads to feelings similar to those expressed when grieving loss. This loss of the ‘ideal’ or ‘normal’ child sets many dynamics in motion calling on these fathers to confront their own notions of what it means to be a father. This thereby indicates that fathering a child with a disability further subjugates the construction of parenting and dismantles the traditional roles of both mothers and fathers when rearing a child with a disability. The study further illuminates the disconnect between conventional constructions of fatherhood in South Africa that positions fathers in a rigid and fixed role that is presented in a negative light (Conway 2008; Makusha and Richter 2015; Mavungu 2013; Shefer et al. 2010). Fathers’ roles are inextricably more complex, shifting between more traditional conceptions such as the provider towards the all giving and nurturing carer. This in-turn disrupts the entire family structure and function as roles subsequently become more blurred rather than clearly distinct and defined. Fatherhood in this context is fluid and is shaped by the needs of the child, the immediate family and the systems they interact with. The emotions of fathers are experienced as secondary leaving these men once again in an emotional state but not feeling able to express these emotions for fear of upsetting their partners. Fathering a child with such a disability suggests a precarious trajectory for these fathers if their situations remain unacknowledged and the necessary support is not put in place to assist them through these challenging moments.

Limitations

Owing to the nature of dyspraxia, obtaining participants whose child had received an ‘official’ diagnosis proved to be challenging. As such the study aimed to include fathers of children who rather present with dyspraxia. Upon review of the demographics of the participants within the current study, a more diverse sample of fathers as well as fathers with female children that present with dyspraxia may have added to the findings of the study. It is also noteworthy that all the children of the fathers within the study were either engaged within a treatment intervention or had received some kind of therapy prior to each interview. As a result, participants were more likely to be more resilient as opposed to a father that has less financial stability or access to health services, professionals and therapeutic interventions. In addition, we caution against assuming that this kind of knowledge can be applied to the greater population of parents’ who have a child with a disability, however, a qualitative methodology does not assume generalisability, but rather to elucidate the in-depth lived experiences of fathers’ who have a child with a disability (Leung 2015).

Recommendations

In light of the limitations of the study, some considerations for future research as well as some practical suggestions as indicated by the fathers within the study.

Future studies should consider adopting a masculinity-focused framework in order to determine the influence that learning disorders have in constructing and challenging traditional gendered constructions of what it means to be a man and subsequently a father. Therapists and various health professionals should be acutely aware of the impact that learning disorders have on the entire family unit. As such it should be standard practice to ensure that options are made available to assist families who may be struggling to cope with and adapt to the diagnosis of their child thereby providing family systems therapy.

Although there has been an increase in research examining the experience of siblings when a child has been diagnosed with a learning disorder, within the South African context this is still an under-researched area. As such future studies should examine the experience of siblings especially as revealed within the current study, the importance of the sibling interaction and support function that siblings offer to parents. Moreover, a number of studies focus solely on the experiences of one particular member within the family unit and perhaps future studies should seek to examine the family unit in its entirety. Conducting focus group discussions with fathers, mothers and siblings may shed some much needed light in developing various treatment options that families may utilise in assisting their child with a learning disorder.

Future research should also examine how mothers and mothering informs and influences the role of fathers and fathering and visa-versa. Developing alternative understandings of mothering and fathering may prove to be critical especially in light of the fact that these understandings will enable new and more equal ways of being fathers and mothers and more generally men and women as well. This is necessary in order to challenge various essentialist notions that limit what it means to be a man, a woman and more specifically a father and a mother. Encouraging workshops that focus specifically on facilitating greater dialogues between mothers and fathers may best assist in developing these alternative understandings.

In a number of interviews, participants indicated various practical suggestions to better assist parents with children with dyspraxia. The first of which indicated that health professionals should seek to contain parents' initial reactions as it may play a pivotal role in the ways in which the family unit is able to cope and mobilise into action.

Fathers within the study also suggested that a "less clinical", more informal support network needs to be developed to better assist parents. This was emphasised by one father (Participant 8 p.13) "I think there's a, there's a wealth of

information out there that people just don't have the forum really to share it with so ja. I think it's a good idea, its finding the right forum I like the clinical side not out, so I think a lot of people just want to speak honestly you know like I struggled with my child in this area and this is what I did with it you know. I mean my child couldn't go to a normal school he was chucked out of some school once or twice, this is what we did, this is what works." As such it was suggested that creating a network hub or forum to share information and practical suggestions between parents that health professionals also had access to would be key in this regard. This was further indicated by the same participant where he highlights the value of the knowledge that parents have obtained through their own experiences; "I mean if you think about it a lot of people actually take 2 years before they, they sort of, sort of find the right people. It would be nice to know that there's some people that you can talk to from day 1 and possibly save your child 2 years of battling and you just going sideways and not forward." This may in-turn facilitate a practical guide for parents to utilise in treatment of their child at home, and instead of indicating what parents should not do, rather indicating what parents can do.

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Compliance with Ethical Standards

Conflict of Interest On behalf of all authors, the corresponding author states that there is no conflict of interest.

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