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Thackeray, Lisa and Eatough, Virginia (2018) 'Shutting the world out': an Interpretative Phenomenological Analysis exploring the paternal experience of parenting a young adult with a developmental disability. *Journal of Applied Research in Intellectual Disabilities* 31 (S2), pp. 179-190. ISSN 1360-2322.

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‘Shutting the world out’: An Interpretative
Phenomenological Analysis exploring the paternal
experience of parenting a young adult with a
developmental disability

Abstract

Background: An in-depth exploration of the
experience of midlife fathers of developmentally
disabled young adults (aged 19-32 years) was
motivated by a dearth of research in this area
(McKnight, 2015).

Method: Five fathers participated in semi-structured
interviews which were subjected to interpretative
phenomenological analysis (Smith, Flowers and
Larkin, 2009).

Results: The final thematic structure comprises four
inter-related themes. They demonstrate a high degree
of concern for children’s well-being; the joy adult
children confer on their father’s lives as well as the
difficulties men experience in response to the limited
opportunities available to their offspring. Importantly
findings also illustrate the way in which men struggle
to contend with painful emotions.

Conclusions: Societal conceptions of masculinity, fatherhood and disability necessarily influence the way fathers experience the world (Yarwood, 2011). It is imperative that service providers recognise the particular challenges faced by fathers, seeking ways to better engage and support them.

Keywords: developmental disability, IPA, fathers, young adults.

Introduction

For researchers investigating parents of children with a developmental disability the dominant focus has been the maternal experience (see McKnight, 2015; Hartley, Seltzer, Head and Abbeduto, 2012). When researchers have employed a participant group of 'parents' they have typically recruited a predominantly female cohort with the result that the paternal experience is under-researched and poorly understood. Importantly existing research has demonstrated that mothers' and fathers' experiences are qualitatively different (see Gray, 2003; Keller and Honig, 2004; Pelchat et al., 2009). This suggests that

the paternal perspective needs to be independently explored in order to enhance both knowledge and understanding.

From a quantitative perspective the focus has typically been stress, well-being, adaptation and coping effectiveness. Further Keller and Honig (2004) argued that findings are inconsistent, with fathers most often appearing in studies comparing their experiences with those of mothers. In a large project exploring factors associated with stress in 120 mothers and 116 fathers of children with intellectual disabilities (age 1-10 years), Salovita, Italinna & Leinonen (2003) reported that the single most important predictor were parents' negative definitions of their situation. For mothers this was associated with the child's behavioural problems while for fathers it was linked to experienced social acceptance of the child, a finding supported by Olsson and Hwang (2001).

Seltzer et al (2009) compared psychosocial and biological markers of stress in midlife parents of adults with 'disabilities' and a control. They found

that the experience was qualitatively different. Parents of disabled children experienced more negative affect, physical symptoms and higher stress levels. For both mothers and fathers more time spent with the adult child resulted in more psychological distress.

Rowbotham, Carroll & Cuskelly (2011) assessed 12 couples, parents of young adult children with intellectual disabilities (ID). Similarly, both partners experienced symptoms associated with stress, anxiety and psychological ill-health with the majority scoring at a clinically significant level. Ha, Hong, Seltzer & Greenberg (2008) examined age and gender differences in aging and midlife parents whose children had either developmental or mental health problems. They experienced significantly higher levels of negative affect, more somatic symptoms and marginally poorer psychological well-being.

A study focusing exclusively on men measured the psychological well-being of fathers ($n=240$) of adolescents and young adults with Down syndrome, Fragile X syndrome and Autism (Hartley, Seltzer, Head and Abbeduto, 2012). In contrast to Rowbotham

et al (2011), they identified symptoms of depression, attributing group differences to fathers' age, maternal depressive symptoms, the child's behaviour and the risk of having additional disabled children. Ultimately they concluded that only a 'modest' portion of the observed difference relates to the child's diagnosis highlighting the need to explore the contribution of contextual factors. In sum, these studies are heterogeneous in approach, report contradictory findings and neglect contextual and environmental factors (Olsson et al., 2001; Pousada et al., 2013).

In contrast qualitative research typically involves fine-grained analysis capable of providing more nuanced and contextual insight. To this end Gray (2003) compared the coping strategies of 21 fathers and 32 mothers of children (aged 5 to 26 years) with high-functioning autism and identified a qualitatively different experience. Findings demonstrated that responsibilities for domestic tasks were allocated according to traditional gender roles such that women had greater involvement. He also noted that mothers

and fathers typically employed different coping strategies with women relying more on social support. Mothers and fathers of children with cerebral palsy viewed their situation differently and employed different coping strategies (Pelchat, Levert and Bourgeois-Guerin, 2009). While both parents loved their children unconditionally, sharing a common objective, there was a marked difference in the way they pursued and experienced parenting. For example, both parents experienced grief for the 'expected' child along with concomitant feelings of guilt. However for fathers this was experienced on an individual level as a sense of failure. Men also repressed as opposed to expressing emotions and mothers reported that fathers were more likely to use avoidance tactics such as spending more time at work or in leisure activities to avoid being at home. A lack of openness and communication created feelings of isolation for their partners.

Finally, Boström and Broberg's longitudinal study represented the only identified qualitative research

focusing solely on fathers (2014). Exploring the experiences of fathers of children with ID (age 6 months to 10 years) they suggested that, in terms of actual involvement in delivering child care, mothers and fathers are becoming increasingly equal. When fathers assumed the main responsibility for childcare some experienced it as extremely stressful. The researchers thus contend that as the pattern of parenting evolves, more research will be needed to illuminate the paternal experience, particularly in light of the likely need for ongoing support.

Ryan and Runswick-Cole (2008) problematised the fact that mothers are the predominant focus of interest in this context. They pointed to the fact that while all mothers typically assume the overwhelming responsibility for child care, for mothers of disabled children this commitment is often expanded, extending over a longer period. Mothers also tend to be the parent who monitors and takes responsibility for engaging with outside agencies. Thus in light of their greater involvement, mothers' rather than

fathers' parenting skills and abilities are most vulnerable to criticism; as a result they are the 'subjects of scrutiny and surveillance, both by professionals, academics and the wider public more generally' (p.206). Importantly the researchers offer their interpretation not as a derogation of the role of fathers; rather they suggest this imbalance should be redressed. To this end they call for more research exploring the paternal experience.

In light of the established paucity and the heterogeneous nature of the literature it is difficult to garner a comprehensive and coherent understanding of the paternal experience. This is an important issue which, given fathers' integral role in the life of the family needs to be addressed. Effective support should be informed by evidence based research (McKnight, 2015) allowing a systemic approach to supporting families living with disability (Hartley et al, 2012). This necessitates greater inclusivity in terms of the foci of researchers for although the reported findings are divergent, they demonstrate that while the experience of parenting a disabled child

pervades both mothers' and fathers' lives, shared facets are lived differently (Pelchat et al, 2009). Therefore in response to the identified gap, this study focused on lived experience by adopting an inductive qualitative approach. To this end interpretative phenomenological analysis (IPA) was employed to explore contextual experience and the meaning it has in the lives of fathers (Smith et al, 2009).

IPA is interested in garnering a fine-grained and contextual perspective on a particular phenomenon as opposed to representing a population. Smith et al (2009) thus advocate recruiting a homogenous sample. A dearth of literature led us to focus on the experience of English fathers of young adults with developmental disabilities (age 19-31 years). This is the stage at which adult children typically assume independence (Arnett, 1987). However parents of children with disabilities typically continue to be intimately involved in ensuring offspring's needs are met (Jennings, 1987). This represents the second of three related studies exploring the perspectives of mothers (Ref.) and adult siblings (in preparation).

Method

Participants

Once ethical approval was received fathers were recruited through a contact with significant involvement in a number of disability support and advocacy groups. IPA advocates a homogenous sample. Given that we were interested in the phenomenon of fathering a child whose disability precludes a typical developmental trajectory, we took the decision to include conditions defined as developmental disabilities. Five men were interviewed, each the father of a developmentally disabled adult with four of the five also having at least one non-disabled adult child. Participants were given pseudonyms and identifying features recounted during their interviews were changed in order to maintain anonymity (see Table 1).

It is worth noting that in terms of homogeneity the phenomenon we were interested in is parenting an adult child in England. Therefore although Scott is Canadian, he fulfils this criteria as his his children were born and raised here. Further in-depth contextual analysis allows

us to consider the contribution of his Canadian upbringing on his experience.

Data Collection

Interviews were arranged at the participants' convenience and took place between July and October of 2013. They lasted between sixty and ninety minutes.

After collecting demographic information and reiterating the participant's right to withdraw for up to a month following the interview, a semi-structured interview schedule was used to guide the exchange. Interviews were largely participant led so that salient topics introduced by the interviewees could be pursued and further elucidated. Questions included; 'Tell me about a typical day with your daughter/son? ; How does your involvement compare with that of your wife/partner? ; What is your experience of support now that your child is an adult? ; What have you learnt from the experience that you would not have otherwise known? And how do you see the future? Interviews were recorded on a digital recorder and transcribed verbatim.

Analysis

IPA advocates an idiographic approach whereby the participant is positioned as the experiential expert and transcripts are analysed individually (Smith et al, 2009).

The first author began this process by reading the first interview whilst concurrently listening to the recording.

This facilitated immersion in the data such that the participant became the focus of analytic interest. A

commitment to the hermeneutic tradition means that IPA fully embraces the role of interpretation in the analytic process, recognising that both researcher and participant are engaged in this activity as they attempt to make meaning of a given phenomenon (Smith et al, 2009).

Thus descriptive notes were made and salient words and phrases highlighted. Next analysis shifted to a more conceptual level. Conceptual coding is both interpretative and interrogative and involves asking questions of the data in an attempt to identify more abstract and psychological concepts. Smith et al (2009) advocate developing a succinct statement which encapsulates the

meaning of a particular section of transcript. It should capture the psychological essence whilst retaining something of the particular, with the aim of being both grounded and conceptual.

Codes were clustered into associative groups and these become sub-themes which acted to establish patterns of meaning. At this stage of analysis themes were iteratively revised and discussed with the second author as a means of confirming that interpretations were firmly grounded in the data. It was also important to remain mindful of the need to provide a representation which did justice to the data set as a whole. The established sub-themes were then organised into super-ordinate themes (see Table 2).

Results

This study set out to provide a nuanced and contextual account of fathers' experience of parenting an adult child with a developmental disability. The four analytic themes derived from the analysis are illustrated in Table 2 reported in detail below.

(Table 2 here)

'Managing Alice's World': Concernful engagement

There is considerable diversity in the degree to which individual fathers are involved in parenting their child, though all take a very real interest in the intricacies of daily life, maintaining close and loving relationships and experiencing the frustrations of an often unhelpful system. Each asserts his contribution in terms of the tasks he experiences as most important. Two participants see themselves predominantly as breadwinners as exemplified by Alan:

My involvement, cos of her early years cos she had a lot of illnesses, primary care fell to my wife. Still had to work, still had to support.

As the provider Alan asserts a traditional masculine identity predicated on the belief that, as a man, it is his duty to maintain a regular job as a means of providing financial security for his dependents.

In contrast Scott and his partner adapted their lives to allow the flexibility to respond to the individual needs of their four children:

And I still do things with the guys and I've always taken them swimming or doing physical things with them. We have this balance like if it's a lot of things like dealing with applications or forms because Laura had that experience... But if it's something where physically I have to go and pick them up from school or take them this place or get the girls something or sort them out we kind of have a balance.

Interestingly although the couple share responsibilities, they have developed a way of organising their lives whereby Scott's main involvement is with his sons. Further in concentrating on physical tasks he enacts the paternal role in a normatively masculine way.

Managing the often extensive needs of adult children necessarily means interacting with providers of health and social care. For Peter, Rufus and Ben this is experienced as harrowing, with providers perceived as intransigent, making an already difficult situation considerably worse. Alan, who by virtue of his mother's mental health problems has a long association with health and social care, perceives that there has been some

positive change over time. As a native Canadian, Scott recognises a less than perfect system:

...okay even though the NHS isn't what it used to be but our bodies aren't what they used to be. Nothing's what it used to be but you moan, you don't appreciate it.

Scott is appreciative of NHS and social care provision and expresses frustration with British people who decry it.

Peter is vitriolic in his condemnation of social care providers; here he struggles to find the words to convey his palpable rage:

They should be making it easier for you because you've got a problem but they don't. They do exactly the opposite and it's a disaster, it's appalling and you have to be strong in order to fight it and parents of autistic children are prone to divorce and you can understand why because the country gives them more problems. 'You've already got a problem so let's make it worse for you.' Okay that is exactly how they deal with you. It is just so it's a nightmare, it's disgusting, immoral actually is what it is...

Instead of easing a challenging situation providers serve to exacerbate it, adding an additional layer of difficulty to family life. The words Peter chooses powerfully express his feelings conveying the calamitous nature of his situation; it caught him unawares, subsumes him in its horror and worse, he is unable to escape. He finds it difficult to accept that this is the way things are; in contravention of his world view he has learnt that the only way to attain the support his son needs is to adopt an adversarial approach and this is something he experiences as abhorrent.

Similarly Rufus experiences a social care system predicated on the need to minimise expenditure as opposed to responding to the diverse needs of vulnerable members of society. He refers to employees as 'sleek PR men' conveying the notion that they operate on the same terms as commercial businessmen, attempting to hoodwink unsuspecting parents into believing their rhetoric:

...they occasionally go for the cheapest option ... They had that sleek air of PR men, would say anything provided that it got

you into their clutches and they were building a place for both disabled children of Amy's kind but also for autistic children. Now Amy can't resist pressure, autistic children can be quite violent so it was the worst possible option but the council kind of found it convenient because it was a nice easy money saving exercise.

He perceives the system as uncaring and he feels threatened by a local authority which has no interest in Amy as a unique human being, a system whose primary aim is to save money. Ultimately the notion that support services cannot be trusted means that participants maintain a state of vigilance and are prepared to fight in order to ensure that their children's best interests and well-being remain the issue of central concern.

'You'd rather have a normal child': An unexpected paternal journey

Recognition of the limitations conferred by disability represent a source of ongoing grief, a process intimately related to acceptance. The temporal unfolding of family

life serves to reiterate what is lost in terms of opportunities to reach typical milestones; leaving home, starting a career, achieving independence. For these fathers the expected order was disrupted and they have had to come to terms with an unanticipated reality. Acceptance is experienced at both a personal and societal level with Rufus, Scott and Ben referring to acceptance in terms of personal experience while Alan and Peter invoke societal attitudes and response to disability.

Ben and his partner were not aware of Alice's difficulties until a friend pointed out that her development was slow. Consultation with paediatricians confirmed this and for Ben it seemed as if the daughter with whom he had 'fallen in love' was snatched away:

...what it seemed like to me is that she actually spent many of her early years not having a clue what the world was or who was in it or had no understanding of it at all. She obviously had some but that's the way it seemed like she didn't know what she was looking at. You didn't even know if she was looking cos you weren't sure what she could see properly or focus but then very gradually it seemed like she was able to make sense of and

feel safe in the world and then of course she then started to interact with it and interact with people so she grew and it was so but it was, in the early years it was like nothing, she was nothing, nothing...

There is dreamlike quality to this extract as if Alice were no longer fully present as a sentient human being and for Ben she seemingly ceased to exist. One possible interpretation is that he was so traumatised by the diagnosis that he dissociated from his daughter as a means of containing overwhelming grief. However with time he came to see that all was not lost and his reference to Alice's increasing sense of security and sense-making may also reflect his own psychological adjustment.

Peter finds the way in which other people respond to his son deeply problematic. Throughout the interview he reiterates the fact that British people are particularly inept when faced with disability:

In London they stare or they look away, okay. They are not, in other words people in the UK are just not as receptive to people with difficulties. You can see it in their faces.

People's attitudes are reflected in their faces; when they stare it highlights the fact that there is something different about Toby; when they purposefully look away it suggests his presence is in some way disturbing. This serves as permanent reinforcement of the stigma associated with disability, and as a father Peter is affronted. Further in tarnishing his son they threaten his sense of self-esteem.

For Alan, Patricia's arrival threw the expected order into a state of flux. The birth of a baby is typically a cause for celebration but the arrival of a baby with a disability is generally regarded as a tragedy. The effects of societal hostility are myriad and Alan asserts "*I mean you'd rather have a normal child*". Acknowledging the desire for a 'normal' child does not mean that Alan does not value Patricia as a unique human being. He is simply expressing the parental desire for one's child to enjoy a healthy and ultimately independent life.

Grief is closely aligned to acceptance, although it has a more visceral quality, evoking feelings of sorrow and loss. It is multifaceted, experienced in relation to different

aspects of their lives and their adult children's. It is not always to the fore but in different ways Peter, Scott and Alan live with a sense of loss for the life that might have been.

For Peter there is grief for the typical father/son relationship he and Toby will never share; grief for lost opportunities and sorrow in recognising that he will not always be able to keep his safe. He contrasts his feelings about his daughter leaving home with the way he feels about Toby:

...the girls can fend for themselves. They're able-bodied, common sense. I mean they're great. The only help Emma needed was putting stuff in her car. Toby wouldn't be like that, okay.

It is the mundane, everyday activities which throw his loss into sharp relief so that helping his daughter load the car as she prepares to leave home highlights his son's limitations. Toby's life will always be compromised and for Peter this represents a source of ongoing sadness.

As children become adults, fathers continue to find themselves challenged. As life unfolds they are confronted anew with the opportunities which are not available to their sons and daughters. Although many issues are resolved, acceptance, particularly in relation to societal attitudes and behaviours, continues to be something participants grapple with.

'It's family': Parents, not carers

Despite the difficulties these fathers face, they are at their most animated when talking about the happiness their children bring into their lives.

Alan is offended by those who refer to him as a carer, contending that the parent/child relationship does not end once your child reaches adulthood:

... as a father you're a father for life regardless of the condition of the child so I'm still a father to my oldest daughter. I still help her ... so it's not that you stop being it after a certain age. So it's the same for any parent that you ask that cares for a learning difficulty will tell you they're a parent first. The tendency is for people to put carer. I'm not struck by that word. You're a parent ...

In describing him as Patricia's carer, Alan feels that people diminish the relationship by suggesting it is unequal, predicated on obligation. He does not recognise a differentiated experience; it is simply that Alan responds to Patricia's greater need, something he characterises as a fundamental and inherent feature of being a father.

During the week Scott's sons attend educational provisions. However at the weekend the boys cannot be left unsupervised and as a result their parents are responsible for keeping them occupied:

And on a Saturday I'll have the boys so she can do whatever she wants, take time off, and on a Sunday she has the boys. So on a Saturday I tend to have them here. They have this thing called (name) at (name) Park where they go bike riding so I tend to take them and (name) is between twelve and four so I tend to take them about two and we go bike riding for about an hour then I come back home, I give them a bite to eat and then we go swimming and then I come back home and then we chill out...

Scott refers to his wife taking 'time off', a term usually employed when referring to breaks from paid work. Its use is illustrative of the incessant demands made on the couple in caring for their sons. They have agreed a system whereby they spend one day at the weekend with Courtney and Idris allowing each to experience personal time and space. Their situation necessitates this structured approach and whereas for most parents this level of involvement is transitory, for Scott it endures.

With Toby's diagnosis Peter, experienced himself as 'a rudderless ship', metaphorically adrift. The world had shifted on its axis and he was no longer able to orient himself to the future. At a young adult Toby continues to need a high level of care with the result that Peter's life is limited:

We have found a carer who will babysit. I hate calling it babysitting because it's not babysitting is it? Minding, right. So but that's expensive. You know going out to the cinema will cost thirty odd pounds before we've bought the cinema tickets so it makes an expensive evening right so that's another thing...

He is frustrated that the English language does not provide an appropriate word to describe care delivered to a young adult in these circumstances. 'Babysitting' diminishes Toby's adult status, infantilises him, and perhaps most importantly, points to the enduring nature of the situation. The impact is manifold and cumulative and such are the implications that the opportunity to be spontaneous is stifled.

For three participants the effects of supporting their families had serious implications for their careers and in this respect it changed the course of their lives. For example, Ben and his partner found continuing in their chosen careers impossible:

*What happened was we **both** in fact gave up work, we were both teachers in one form or another and we both ended up in careers in which we were more able to control our time. I ended up as a plumber and she ended up as a reflexologist but it wasn't possible to be brutally honest to do any kind of, to look after Alice and work in any conventional sense.*

'(E)nded up' suggests that being a plumber is not an occupation he would have selected by choice. Alice's

diagnosis shifted Ben's experiential horizon such that she became the focal point, the controlling factor and he was no longer the arbiter of his own time. He was unable to commit to work in the way that a 'career' demands and this had important implications in terms of his ability to generate income.

In the beginning fathers' expectations were coloured by fear of the unknown, and now that their children are adults other people are inclined to perceive their continuing involvement as a burden. However it is apparent that their children bring immense happiness.

When asked about the best aspects of parenting all were effusive in expressing the pleasure they experience. Peter describes Toby as 'wonderful', 'fantastic', 'lovely' and 'adorable' while for Alan, Patricia has always been a 'joy'.

Here Rufus describes the enormous pleasure he derives as the recipient of his daughter's unconditional love:

... and you've learnt that there are rewards in doing it in terms of the affection that Amy and dare I say complete passion, for all of us, she has for all of us.

His efforts are rewarded with gratifying shows of love and appreciation. Rufus' greatest pleasure and surprise relates to the fact that Amy is indiscriminate in demonstrating affection for all the members of her immediate family. This is something special, a unifying experience which transcends expectation.

The data demonstrates that fathers continue to respond to the particular needs of their children and this makes significant demands with the result that in different ways lives are constrained. However, paternal support is typically delivered with acquiescence and viewed as a natural response to additional need. Importantly given the prevailing negative conceptions, fathers were at their most animated when talking about the happiness children bring into their lives.

'Shutting the world out'

Bridling difficult emotions is a strategy employed by all five fathers, though for each it is lived differently. The following passage demonstrates how Peter's feelings

about Toby's future make it extremely difficult for him to contemplate the prospect of his son leaving home:

I view it personally as a disaster cos I will miss him terribly. I cannot stand the thought of it. I cannot, and I have my friends saying to me, 'You've gotta get your head round this. They all move out at some stage or another and Toby's got to'. And Jenny has always said to me 'You don't wanna be in your seventies, if you're still alive and have your 40 year old living here and then he can't fend for himself'. And you know he has to have his own life and you've got to bite the bullet, well I have to bite the bullet. Certainly I am going to find it horrific.

Peter is explicit in conveying how he is terrified of relinquishing his son to the care of others; the prospect is so painful that he simply cannot entertain it. 'Biting the bullet', is a metaphor derived from the practice employed by soldiers of holding a bullet between their teeth during surgery in the absence of anaesthesia. It perfectly encapsulates Peter's experience whereby extreme pain must be endured and nothing can ameliorate his suffering.

Anxiety is a pervasive aspect of Alan's parenting experience, fearing that he may lose Patricia at any time:

You're always waiting for something to go wrong. So every illness was heart failure or I mean she didn't get colds she got hospitalised every time. She still does occasionally so there is a fear that once you've got that in the back of your head there's a fear that every time, I mean from my point of view. I can't speak for my wife. It's the same fear all the time. You live with that.

Living in a continual state of anxiety means that Alan remains alert and once he perceives potential threat his mind races ahead, imagining the worse. He feels unable to escape these painful emotions, and having never felt able to share them he negotiates them alone.

Conversely Scott is proactive in his approach to managing his feelings:

t's just you can look and it looks all rosy but it's just not that. And I think I'm old enough to realise that as I said to my daughters, life isn't fair. If you understand that you will get on with it....I have to tell myself that too. I have to tell myself

'Scott, okay come on, you don't deserve a pat on the back, just get on with it.'

Key to Scott's approach is recognition of his agency and acceptance that life simply 'isn't fair'. Observing other people's lives from the outside can create the impression that all is perfect. However, Scott understands that things are not always what they seem and that making assumptions serves to increase his own feelings of injustice.

Fathers typically find it difficult to fully engage with issues which induce painful emotions and thus Rufus' concern for Amy's safety and well-being is tacit:

I'll tell you what there is, there's also the worry. I don't think this is Amy so much because she's not mobile, she might put herself in a dangerous position. She might be taken advantage of. I don't think she has been. I don't think she will be but it's a thought at the back of your mind...

This statement is contradictory, reflecting the difficulty Rufus experiences when contemplating the possibility that his daughter may be at risk. He negotiates these

painful thoughts by attempting to reassure himself that abuse has not and will not occur. However, by articulating his fears Rufus reveals his anxieties about the future which is perceived as a precarious and terrifying prospect.

In contrast Ben is candid in expressing the anxiety he experiences when thinking about Alice's future:

The future, that's a thing that always is scary. There's a lovely poem written by a friend of mine, Emma, who has a learning disabled daughter and it goes something along the lines of you know, what do I leave her and she looks round the house she sees all these things that she's got that have belonged to her parents which are no good to her and then she ends up saying something like a big dog to care for her and guard her. Well that's it.

Ben asserts the futility of passing on material possessions when they have no intrinsic value and the dog metaphor is extremely powerful. Dogs are construed as devoted companions whose love and commitment is unconditional: a relationship analogous to that of parent and child. The sentiment eloquently conveys a deeply

felt, and unrealisable longing to live secure in the knowledge that his child will always be protected by a fierce and devoted guardian.

Discussion

The participants' adult children had a variety of diagnoses, the consequences of which varied in terms of severity and this may have impacted individual's experiences. Analysis thus illustrated how, to varying degrees, fathers struggle to accept the implications of their child's disability, particularly in light of negative societal conceptions. However, providing ongoing support is typically construed as a natural paternal response to meeting individual need. While sons and daughters represent a source of joy, participants are confronted with the difficulties and limitations faced by their vulnerable adult children. As a result fathers are subject to painful emotions. The data suggests that the men in this cohort typically resist fully engaging with thoughts and feelings which evoke anxiety. In situations where they are not able to protect sons and daughters these feelings are potentially overwhelming and as a

means of protecting themselves they adopt different coping strategies, fearful of being subsumed. In light of this the future represents a particularly difficult prospect and is anticipated with apprehension.

Given societal conceptions of masculinity and fatherhood, it is inevitable that pre-existing ideals and stereotypes colour participants' engagement with the world. They are committed to caring *for* and caring *about* their disabled child and yet they must do so in an often hostile environment. Circumstances have thrown the masculine roles they anticipated for themselves into disarray. They must reconcile their sense of themselves as men, and what that means in terms of their own and others' expectations, at the same time responding to their need to fulfil existential commitments. Thus we propose that a thread of masculinity runs through the themes, facilitating understanding of how fathers both live and make meaning of their very particular situation.

Harré and Gillet (1994) point to the pervasive influence of social discourse and context in shaping behaviour and facilitating certain experiences, whilst simultaneously precluding the opportunity for others. Butler points to

the role gender plays in regulating ways of being a woman or a man:

'Genders, then, can be neither true nor false, neither real nor apparent. And yet, one is compelled to live in a world in which genders constitute univocal signifiers, in which gender is stabilized, polarized, rendered discrete and intractable. In effect, gender is made to comply with a model of truth and falsity which not only contradicts its own performative fluidity, but serves a social policy of gender regulation and control' (Butler, 1988, p. 528).

Butler acknowledges the constitutive nature of gender formation and enactment, while eloquently conveying the inherent contradictions in implying stability when in reality the way in which gender is enacted is fluid.

Similarly, Yarwood (2011) argues that while the reality of men's lives are both more fluid and complex than the predominant discourse suggests, the breadwinner father continues to be an enduring dominant construct which is linked to conceptions of what it means to be a good father. A corollary of a hegemonic masculinity is that men typically have greater earning potential than women and this is normative in sustaining the notion that

mothers assume the main responsibility for familial care. This further informs the way in which men perceive their roles; the ways of being and doing fathering that are available to them:

Whilst patriarchy has been brutalising to both men and women, it has sustained its hegemony by emphasising the right way to be a man and by the suppression of other forms of masculinity. (Nunokoosing, 2002, p.36).

Against this backdrop it is not surprising that participants' experiences are imbued with conceptions of the right way to be a father. Nunokoosing (2002) suggests that resisting the cultural control of hegemonic masculinity is risky, while Butler (1988) argues that the 'performative accomplishment' of gender identity is compelled by social sanction and taboo (p.520). Like the men in Yarwood's cohort, these fathers are expected to be more than financial providers, indeed in light of their children's additional needs they are subject to increased demands in terms of providing support. They must find a way of negotiating the many roles they fulfil, at the same time as dealing with their own emotions. These emotions

reflect the fact that while there is nothing inherent in disability which discredits the individual, it is devalued by society. Children with disabilities are thus born into a hostile world and this makes life difficult for families (Nunkoosing, 2002). This is exemplified by an incident recounted by Rufus whereby a man said, "It must be difficult having a dud child"

It was this distressing revelation that facilitated an understanding of fathers in terms of what it means for their sense of themselves as men. The statement implies that in fathering Amy, Rufus failed, he produced a 'dud'. Dud is defined as a 'thing that fails to work; a useless thing' (OED). This represents a serious threat to his masculinity, besmirching his ability to successfully father a healthy child. Importantly it is a threat experienced by all these fathers. They embarked upon the paternal journey assuming they would be raising a 'normal' child. The arrival of a son or daughter whose development transcends the typical pattern threw them into a world they never anticipated and given negative stereotypes the implications are pervasive. This supports Salovita et al's

(2003) finding that social acceptance of their child is a predictor of fathers' stress and Pelchat et al's (2009) contention that men experience guilt and personal failure about fathering a disabled child.

How participants perceive the paternal role affects their engagement as fathers, the ways in which they provide care and support, and the way they experience self and relationships. For example, fathers typically have lesser involvement with service providers which may in part be explained by the assumption of providers that fathers do not wish to be involved (Nunkoosing, 2002). This is a corollary of the fact that in a society which conceptualises mothers as bearing the main responsibility for familial care, fathers are afforded greater opportunity to absent themselves. Most have positioned themselves as the family's main financial provider, a role which typically necessitates going out to work. This reflects Pelchat et al's (2009) finding that men are more likely to use avoidance tactics such as spending time at work. Scott represents an exception here in that he has adapted his working life in such a way that he fully shares the commitments

involved in supporting his adult children in equal measure with his wife. However, he still assumes responsibility for securing the financial future of his family. He also places high value on his ability to provide a masculine perspective in determining issues relating to the ways in which his sons are treated:

I see a lot of mothers, especially when they have the boys they'll be doing certain things that if the boys were normal they wouldn't do where I try to keep the balance. Even sometimes I'll say 'Come on, they're young men. You can't do that.'

Here Scott illustrates his belief that there is a specifically gendered component to parenting such that fathering a son is qualitatively different to fathering a daughter. The contribution of a male role model is deemed crucial in responding to the particular needs of young men.

The fact that men absent themselves, physically and emotionally, may represent an attempt (either conscious or unconscious) to protect themselves from being subsumed in a potentially painful and anxiety provoking response. This is a finding reflected in a number of studies cited above. For example Pelchat et al (2009)

found that fathers have a tendency to repress rather than express emotions and to avoid situations they find difficult by spending additional time in work or leisure activities. Mahalik et al (2005) suggest that in conforming to masculine norms including self-reliance, emotional control and primacy of work, other people, particularly family members, may perceive men as emotionally distant. This suggests a complex interplay between felt emotion and the ability to express the accompanying feelings in a society where people react negatively to those who transgress gender role norms. This phenomenon is more marked in relation to men's transgressions than women's (Mahalik et al, 2005) suggesting that men are under greater pressure to conform and thus contain their emotions.

In conclusion we contend that societal conceptions of masculinity and fatherhood imbue the paternal experience and are key to understanding this particular phenomenon. Illustrating how this operates in practise helps us to think about how this might be challenged by alerting service

providers to the ways in which their approach typically marginalises fathers.

Limitations and Future Research

This study is limited in that it employed a small homogenous sample of midlife English men. However we concur with the view expounded by Haug that if ‘a given experience is possible it is also subject to universalisation’ (1987, p.44). On this basis an in-depth approach facilitated careful engagement with fathers’ accounts illustrating the ways in which societal discourse imbues paternal experience. Given the fact that we are all subject to the influence of our cultural and historical environment this suggests that other fathers of disabled adult children may share similar experiences. Further while not seeking to make formal generalizations, IPA studies allow us to think about transferability and re-contextualisation, moving beyond the sample. Thus the findings may also be helpful in understanding the experience of fathers

whose children experience, for example, chronic illness.

It is apparent that the failure of researchers to explore the paternal experience reflects a broader issue in that their perspective is often neglected by those working with families of disabled children. This study has shown that avoidance and eschewing painful emotions are not indicative of a dearth of concern.

Rather it is a response which in many ways conforms to societal expectations. Current service provision typically seeks to engage with and support mothers rather than fathers and this has serious implications for the well-being of men. This is a matter which demands serious attention.

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Participant	Participant Age	Participant nationality	Adult child / children	Child's age	Diagnosis
Alan	63	English	Patricia	31	Down syndrome
Ben	61	English	Alice	27	Severe learning difficulties with autistic features
Peter	59	English	Toby	19	Autism
Rufus	70	English	Amy	29	Abnormal Rhett's syndrome
Scott	58	Canadian	Courtney	32	Autism
			Idris	21	Autism

Table 1: Participant information.

Master themes	Sub-ordinate themes		
Theme 1 'Managing Alice's world': Concernful engagement	Sharing versus relinquishing responsibility	Negotiating a dispassionate system	
Theme 2 'You'd rather have a normal child': An unexpected paternal journey	Issues of acceptance	Continuing grief	
Theme 3 'It's family': Parents, not carers	Being a father: Different by degree	A life constrained	A source of great joy
Theme 4 'Shutting the World out'	Bridling difficult emotions	The future: A frightening prospect	

Table 2: Master and sub-ordinate themes.