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Father experiences of sleeping problems in children with autism

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Abstract

Purpose: This study aimed to explore the role of fathers in the management of sleeping problems in children with autism and their perspectives of the impact of these difficulties on family life. **Methodology**: Semi-structured interviews with 25 UK based fathers of children with autism were undertaken. **Findings**: Two thirds of fathers reported that their children experienced severe sleeping problems in the areas of bed-time resistance, sleep onset and night-time waking. Fathers were significantly involved in the management of these difficulties and reported a range of associated deleterious impacts on the family, including significant negative effects on paternal and maternal health, father employment, couple relationship and sibling experiences.

Research limitations: The interview sample cannot be said to be representative of all fathers of children with autism since the backgrounds of those taking part were relatively homogeneous in respect of ethnicity, marital status and level of education.

Practical implications: Improvements in effective, family-centred provision are urgently needed which employ a co-parenting, gender-differentiated methodology.

Social implications: Given the severity and frequency of difficulties, sleeping problems in children with autism should be viewed as a significant public health concern. **Originality/value:** This is one of the first studies, qualitative or quantitative, to explore the role and perspectives of fathers of children with autism in the important area of sleep management.

Keywords: autism; children; fathers; sleeping problems; health; couple relationships; siblings

Introduction

Amount and quality of sleep is known to be strongly associated with general well-being, with impact on cognitive development, levels of stress and immune responses (Gallagher, Phillips, & Carroll, 2010). Bruni, (2010) noted that ensuring good sleep in childhood should be viewed as a preventative measure designed to ensure a healthy adult life. It has been estimated that between 40% - 80% of children with autism experience problems relating to sleep, believed to be twice the rate found in typically developing children (Polimeni, Richdale and Francis, 2005). Difficulties include bed-time resistance, sleep onset, night waking, sleep anxiety and low sleep efficiency (Kotagal & Broomall, 2012). Sleep problems in children with autism were not reported to be associated with gender, age, IQ, parental occupation or learning ability, but were linked to the severity of autism symptoms (Mayes, Calhoun, Murray, & Zahid, 2011). Chronological changes in the nature of sleeping problems have been reported, with younger children on the autism spectrum experiencing greater bed-time resistance, parasominias, night wakings and sleep anxiety while in adolescence problems related to falling asleep, shorter periods of sleep, and tiredness during the day (Goldman, Richdale, Clemons, & Malow, 2012). A number of elements are believed to be causally associated with sleep dysfunction in autism, including genetic, environmental and neurological factors (Devnani & Hegde, 2015).

Sleep problems result in a range of negative consequences for individuals with autism, such as reduced social ability compared to individuals with autism without sleep problems (Lambert et al., 2016), greater communication problems and stricter adherence to rigid routines (Schreck, Mulick, and Smith, 2004). Poor sleep patterns have also been linked to poorer health related quality of life (Delahaye et al., 2014),

increased behaviour problems in both children (Goldman et al., 2011., Hirata et al., 2016) and adults with ASD and intellectual impairment (Matson, Ancona, & Wilkins, 2008).

The impact of sleep problems on families is pronounced. Parents of typically developing children have been found to be at increased risk of stress, problems with their own sleep and negative interactions with their children (Polimeni, Richdale and Francis 2005). In children with autism, poor sleep has been found to predict levels of maternal stress (Herrmann, 2015; and fatigue (Giallo, Wood, Jellett, & Porter, 2013); parental sleeping patterns (Meltzer, 2008) and maternal and paternal symptoms of depression (Meltzer, 2011). Findings from the online survey of 306 fathers, associated with this study (XXX) found that 31% of fathers experienced a little stress associated with children's sleeping problems, 27% a moderate amount and 24% "a great deal of stress".

Treatments for sleeping problems in children with autism are reported as limited (Tilford et al., 2015), consisting of behavioural approaches where parents are educated in the use of sleep hygiene strategies, such as consistent bed-time routines (Turner & Johnson, 2013); pharmacological interventions, especially the use of melatonin (Goldman et al., 2014) and complementary therapies such as massage or the use of weighted blankets (Devnani and Hegde, 2015). The use of sensory strategies such as optimising noise and light levels have been reported as having some positive impact (Jan, 2008), as have the use of aerobic exercise and motor skills (Brand, Jossen, Holsboer-Trachsler, Pühse, & Gerber, 2015).

Sleeping difficulties in children with autism are both under-recognised and under-treated (Tilford et al., 2015), with qualitative studies exploring the impact of such

problems on families extremely limited. Russell & McCloskey, (2016) suggested that such a methodological approach can serve to illuminate omissions in practice and support the development of service models which are capable of addressing articulated family needs. Paternal perspectives in the field of autism are especially rare, with most data collected from mothers (Donaldson et al., 2011). A meta-analysis of 404 studies in the field reported that mothers outnumbered fathers by 8 to 1 as research participants (Braunstein, Peniston, Perelman, & Cassano, 2013). Proposed explanations for father exclusion include on-going presumption of maternal care (Flippin & Crais, 2011), difficulty in recruiting fathers to research studies (Johnson & Simpson, 2013) and a more general deficit model view of father competence in the nurturing of children (Brotherson, Dollahite, & Hawkins, 2005). In relation to sleep, a comprehensive literature search could discover no qualitative studies which focused on paternal experiences of the sleeping problems of their children with autism.

Braunstein et al., (2013) argued that failure to include fathers of children with autism undermines applied research efforts, since paternal treatment and support needs have been found to differ from those of mothers in various ways. For example, in a study of parental perception of unmet need, Hartley et al., (2015) found that although there was significant agreement between fathers and mothers, fathers were more likely than mothers to identify parental self care as an area where support was lacking. In addition, Papageorgiou & Kalyva, (2010) reported that fathers are much more likely than mothers not to disclose their child's autism to colleagues at work, and as a result reported receiving less support and understanding overall. It is such

omissions, regarding qualitative approaches and paternal perspectives in the critical area of sleep which the current study seeks to address.

Findings presented here are drawn from a wider study of fathers of children with autism (XXX). Research questions relevant to this article, were:

To what extent do children experience problems with sleep?

What is the nature of any sleeping problems?

What is the impact of children's sleeping problems on families?

Methods

Research design

This paper utilises data from a two year mixed methods study. The first phase consisted of an online cross sectional survey of fathers of children with autism, autism spectrum disorder or Asperger syndrome (hereafter referred to as ASD) and during the second phase, 25 semi-structured interviews were undertaken to explore survey themes in greater depth.

Participants and procedure

Sampling

A convenience sample of 306 fathers was recruited to an online survey of fathers/male carers (namely biological, adoptive, foster or step-fathers) of children with ASD, aged up to 19 years and living in the UK. Fathers were recruited through major UK autism charity websites, e-mail invitations sent out to over 80 local autistic

societies, an advert in a national autism publication for parents and flyers to autism specific schools.

Fathers were asked if they would agree to be interviewed within the survey and 185 fathers did so. A maximum of 25 interviews was specified in the research design in the light of time and resources available. Fathers were chosen for interview purposively with a view to exploring paternal experiences which might be affected by age, socio-economic, ethnic and educational backgrounds, as well as differences in children's age and ability (see Table 1). Not all of the 185 men who agreed to be interviewed in the survey, remained willing or able to take part and therefore further purposive sampling was undertaken until 25 interviews had been arranged.

Procedure

Interviews lasted 1-2 hours and occurred at a place and time convenient for fathers. Most fathers were interviewed in a neutral venue, during the day and near their place of work. Fathers were asked to talk about their involvement in caring for their child/ren with autism, parenting challenges and ways of coping (see XXX, forthcoming) and pertinent here, to discuss sleeping patterns, any associated difficulties and the impact of sleeping problems on family members.

Participants

The majority of fathers completing the survey were white (95%), aged over 40 (80%) and married (79%). Most worked full-time 62%) and just over half (52%) were educated to degree level or above.

Characteristics of the survey sample appear in Table 1.

INSERT TABLE 1 ABOUT HERE

Most fathers interviewed were white (n=24), aged 40 or over (n=19) and married (n=23). Seventeen men were educated to degree level or above. Most children were boys (n=20) and 15 were aged 10 years or below. Eight children had a diagnosis of autism, 12, ASD and five, a diagnosis of Asperger Syndrome. Complete characteristics of the interview sample are presented in Table 2.

INSERT TABLE 2 ABOUT HERE

Data Analysis

Copies of transcribed interviews were made available to all fathers to address issues of trustworthiness (Mason, 2012) by providing participants with a further opportunity of verifying that the narrative given accurately reflected their views and experiences. Analysis was guided by aspects of a grounded theory approach (Strauss & Corbin, 1998) where theory is "inductively derived from the study of the phenomenon which it represents" (Ezzy, 2002, p.12). This approach involving a 'constant comparison' (Dey, 2004) of data on a line by line basis, leads to the development of meaning and new understandings, by identifying patterns of similarity or difference. NVIVO 10, a Computer Assisted Qualitative Data Analysis Software programme (CAQDAS) (Bazeley & Richards, 2000) was employed during this process. Hutchison, Johnston, & Breckon, (2010) reflected on the limitations of CAQDAS approaches in terms of generating interpretations while acknowledging that such software can facilitate the systematic handling and organisation of significant amounts of qualitative data by enabling a rigour in the sorting, matching and connecting of data, which leads to the formation of categories and sub-categories. Some aspects of analysis were informed

by a priori themes identified in the literature, especially relating to the conceptualisation of sleeping problems. Other themes emerged inductively from the data, such as those relating to impacts on families.

Ethics

The research received ethical approval from XXX University. Participants completing the online survey were given information concerning research aims, provided with assurances of confidentiality and anonymity and were made aware that should they go on to complete the survey, consent would be assumed. Fathers interviewed received further information, pertaining to their right to decline to answer any question and to withdraw from the research at any time without consequences. None did so.

Findings

All names used are pseudonyms and each father has been assigned a numeric code: (F1 = Father 1) etc.

Sleep associated problems

Two thirds of fathers interviewed reported a range of significant problems associated with their children's sleeping patterns. These are categorised below.

Bed-time resistance

Half of fathers reported significant difficulties in getting children into bed, often despite the range of strategies intended to facilitate this process (see below): '*And then it may be a bath, watch a bit of telly, and then get him to bed - which is a lot more challenging than getting him up in a morning'. (F17).* The transition to bed was

specifically highlighted by one man: *'It's getting him to move from doing whatever he's doing to getting ready for bed.' (F12).* The bed-time routine was often a lengthy one for parents: '*When Ethan's at home, I'm persuading him to go to bed at about eleven... The 'going to bed' routine takes about 40-45 minutes' (F10).* Fathers described the growing frustration involved in the evening as they themselves became more tired: '*So, half past eight, he won't go to bed. Half past ten, he still won't go to bed. Half past ten…, you're getting irate, you're tired, you've been up and down the stairs a million times'. (F9).*

Sleep onset

A number of fathers described problems children experienced in falling asleep once they were in bed: '*You have to sit with him…otherwise he'll just get out of bed again and wander round…eight or nine times out of ten'(F7)*. Several described how children's difficulties in falling asleep had led to them sleeping in parents' beds: '*At the beginning of our relationship [my partner] used to sleep in the bed with Helen to get her to sleep' (F14).* Sometimes complex routines had developed so that children could fall asleep in the parents' bed before being moved back to their own, which in some cases had become difficult to modify. '*Simon gets into our bed, reads for a while and falls asleep…And it has to follow the same pattern…but if you ask him not to do that, if I'm on an earlier shift, and I actually wanted to go to bed, it's. "oh, no, no, no, no, no" (F18).* For a minority of families, the situation was more extreme, with one father stating: '*some nights he just doesn't go to sleep' (F20)* and another: '*So at the time when he was 3, 4, 5 years old, he could go three, four days and nights without sleep' (F10.*

Night waking

One of the most problematic aspects of children's sleeping difficulties, discussed by two thirds of fathers, was their inability to sleep for long periods through the night, often waking very early. Such disrupted nights could occur frequently: *'He will wake up very often – it could be any time between three o'clock in the morning and five in the morning' (F24).* Once awake, children could stay awake for long periods: *'she'll be up for about four hours. So last night she woke up at about ten, finally went down at about half past two' (F5).* For several families, acute problems with sleeping had been going on for a number of years*: 'when he was 3, 4, 5 years old, he could go three, four days and nights without sleep… now - he's 14, he goes to bed at eleven. He falls asleep between one and two. He's up again at five.'(F10).* Several fathers reflected on the impact of caring for children through the night as well as during the day: *'With an autistic child there's no break. Yeah, you sleep, but you're half asleep and half awake, because if he wakes up, all the lights are on, all the curtains are open, and you're in bed upstairs' (F11).*

Night-time roles

The roles of fathers and mothers in managing sleep associated problems differed between families, for a variety of reasons, including the relative demands of parents' employment, health issues, other caring responsibilities and parents' relative ability to cope with sleeplessness. Mothers and fathers often shared the task of taking their children with autism to bed: '*At the moment we have got an alternate going on, where it's one night me, then it's [my wife]' (F20).* However, as children grew older, the undertaking could became increasingly problematic for some mothers: '*With [my wife]… he's as big as she is, and it's a harder battle for her.'(F16).* One father

explained his central role in the bed-time routine in relation to his wife's other caring tasks: *'we have certain routines that have to be done for him to go downstairs, and so I tend to take that on at night because Julia's had it all day, by and large, and she's just about spent'. (F21).*

In ten families, fathers had taken the lead in managing children's night-time waking for various reasons. One father cited his wife's job as key: *'some days he would get up at four, five o'clock every morning - I would get up with him, because I realise my wife [as a teacher] has got thirty kids all day' (F9).* For another family, ~~family~~ finances and health problems influenced role decisions at night: *'It has to be me, because my wife is an assistant head and [suffers from] fatigue so her sleep is sacrosanct… she's the breadwinner in the house'. (F10).* In some instances, carer's own sleeping patterns was central to role division: '*I'm not the best sleeper myself, so it just made more sense that I did that particular duty. It just made it easier for my wife' (F24).* Another man felt that he could cope better with night-time supervision duties: '*I do most of it, because my wife doesn't cope very well with being woken up in the night' (F5).* A separated father of children with autism explained his process of decision-making regarding getting his children up in the mornings: '*If I get up at six o'clock.., I'm going to be shattered by two. And it means it's going to be difficult...because it's just me on my own looking after [children] with additional needs, so that's quite hard.' (F19)*

Impact on families

Fathers discussed a range of significant negative effects on their own health and working life, the quality of their partner relationship and the life experiences of their non-disabled children.

Health

Lack of sleep for parents was the most significant health issue raised, with its associated negative impact on daily functioning. Both parents were often affected: *'A few years ago we were getting no sleep. Literally two or three hours' broken sleep a night' (F16)*. One father referred to the range of effects of sleep loss on himself and his wife: *'we were physically and mentally drained. That sleep deprivation thing' (F18).* For one man, the impact of chronic sleep deprivation over a number of years had resulted in profound consequences for his mental health: *"I had sleep deprivation-induced psychosis, which sounds pretty bad but it was actually worse than it sounds. It was something else'. (F10).* The potential consequences of sleep loss had affected one father's view on his own life expectancy:

> *'There'd been almost daily articles in the press about how lack of sleep is going to kill you… I made rather more life insurance arrangements than a lot of people would, because there is the very real prospect that I won't see retirement' (F5).*

Employment

Seven fathers reported that their children's sleeping issues had caused significant problems in their working lives. One father described how extreme mental health problems associated with sleep deprivation had led to early retirement. Others

discussed the impact of long-term interrupted sleep on their performance in the workplace.

> *'But from [when he was] four to seven, I'd say, some days I was going in to work and I was absolutely drained, absolutely drained - and having a full day's work ahead of me' (F9).*

One father described how he had learnt to manage sleep loss and full-time employment over a number of years:

> '*For the past fourteen years…we've just adjusted as time goes on. The guys at work don't understand how sometimes I can function, because I come in, I'm tired as anything, you know' (F20)*.

Sometimes fathers explained how colleagues had accommodated their difficulties:

> '*But a few years ago we were getting no sleep. Literally two or three hours' broken sleep a night. And I'd be going in to work… and [colleagues] would just go 'Bad night with Seth?' and... If I fell asleep while I was parked up somewhere it would just be like 'Mike's had a bad night with Seth'. (F16)*.

Another father explained that his employer's response to his extreme tiredness due to his child's night-time waking could be variable:

> '*And they say to me 'What can we do to help?' I say 'The main thing I need is tolerance. Because there are days when I will make mistakes and days when I'll struggle…and people will seem sympathetic until you're a bit slow or you make a mistake. In which case it's 'Why haven't you...?' (F5).*

Couple relationship

Nine fathers described a range of negative effects of sleep problems on their partner relationships. The issue of bed-time resistance resulted in a lack of time for parents to spend together in the evenings: *'we never get any time to ourselves. We can't sort of sit and watch a late-night film because Jo is likely to just sort of wander down' (F2).* A father of a teenager with autism and obsessive compulsive disorder reflected on the impact on stressful bed-times over years on his partner relationship: '*When you're still faced with having to put your son to bed… every night, and that can take up to an hour, there's not a lot of time in the evening for socialising and relaxing… And so it has put a strain on our relationship in many respects. (F21).* For one couple, the strain caused by their child's sleeping problems almost resulted in the breakdown of their relationship: *'And it got to the stage where we were on the point of divorce. We'd literally reached the point where we had no life' (F18).* Several fathers reported that children's sleeping difficulties affected not only the couple relationship inside the home but also their opportunities for socialising together outside it: '*We've never been able to have a night out since probably Charlie [now aged 12] was born' (F4).* The result of co-sleeping meant that some couples experienced long periods where they could not share a bed: *'I would sleep on a chair in his room. Simply because that was the only option' (F10).* Some couples often shared a bed for only part of the night due to the need for one parent to supervise their child with autism during the night: *'It could be any time between three o'clock in the morning and five in the morning. At which time I usually go into his room. There's a bed made up next to his bed' (F24.)*

Siblings

Four fathers described the ways in which the sleeping problems of their children with autism had affected their other typically developing children. In some cases, bed-time resistance issues resulted in lack of quality time to spend with other children, for example: *'You feel quite sad because you miss out on that time with her'. (F20).* Night-time waking in children with autism also sometimes resulted in interrupted sleep for siblings: *'It usually has a knock-on effect, Hayley (child with autism) will wake Ethan up, Ethan will wake Sadie up....' (F14).* One father spoke of the way in which sleep loss was affecting the education of his typically developing children: *'her sister is missing a lot of sleep because of her, and so she's behind at school' (F5).* Another man explained the need for special arrangements for his typically developing daughter at school: '*And the teachers are aware that there are these issues with sleep going on at home. Ellie [sibling] is allowed to sleep at her convenience..at school' (F10).*

Discussion

This study extends our knowledge of the nature of sleeping problems in children with autism and their impact on the daily experience of family members. It appears to be one of the first to explore father involvement and perspectives in this important area.

Fathers reported a range of significant sleep-related difficulties in bed-time resistance, sleep onset, sleep duration and night-time waking and emerged as closely involved in the management of these, both here and in an associated large scale survey (XXX), often sharing or taking lead responsibility for supervising bed-times and periods of night-time waking. Such findings resonate with a growing evidence base which highlights the important, though often overlooked, contribution

of fathers of children with autism in areas of personal care (XXX; (Meadan, Stoner, & Angell, 2015); leisure (Mitchell & Lashewicz, 2015) and education (XXX). More research is needed which explores the roles of both mothers and fathers in managing sleep. In addition, fathers must be included in co-parenting approaches to maximise the impact of such interventions. Braunstein et al., (2013) noted that many parent interventions in the field of autism, as in others, fail to report the sex of participants, thereby seeming to imply that gender is not a significant factor in parental response, when in fact, comprehensive meta-analytic studies have shown that men and women may respond differently to the methodology of parent education programmes (Panter-Brick et al., 2014; Scourfield, Cheung, & Macdonald, 2014). In the area of sleep management, Malow et al., (2014), found the use of a parent education approach to be effective in improving sleep onset in 80 children with autism, although since neither the sex of participants was reported, nor a gender-differentiated analysis undertaken, it cannot be assumed that the intervention was or would be equally as effective with both parents.

Fathers reported significant negative physical and mental health effects of children's sleeping problems. In several instances, these were acute, with fathers struggling to cope with on-going sleep deprivation, alongside the daily demands of paid employment. Such findings resonate with those of previous studies which reported that sleeping problems in children with ASD were found to be related to poorer mental health (Hodge et al., 2013) and increased stress (Hoffman et al., 2008; Levin and Scher, 2016) in mothers and, in addition, raise questions regarding assertions that mothers may be at greater risk of negative effects of children's sleeping problems compared to fathers (see Polimeni et al., 2005, for example). Tilford et al., (2015) argued that further research is needed regarding the impact of sleeping

problems on the health of caregivers of children with autism and we would argue that such investigations must include fathers, to gain a more comprehensive understanding of impacts within families and associated gender-differentiated carer needs. Hodge et al., (2015) found that

Greater focus on the effect of sleeping problems on siblings of children with autism and implications for practice, is also required. Difficulties reported here are in keeping with those of other studies where typically developing siblings of children with autism have been shown to have an increased risk of sleeping problems (Chou et al., 2012). Qualitative studies undertaken with siblings themselves would prove especially insightful in understanding the nature and extent of impacts on their lives.

Several targets for intervention are indicated here, relating to increasing the effectiveness of sleep management strategies and minimising the impact of difficulties on family members. Regarding service provision, Ryan, Burton, & Bromley, (2014) testified to the general shortage of sleep support services in the UK, which represents a major shortcoming in view findings presented here. The development of greater expertise amongst primary health care professionals is needed, since as noted by Caulfield, (2011) health professionals have been slow to recognise the importance of identifying and managing sleeping difficulties. The greater use of nurse-led community-based sleep clinics where staff receive intensive and specialist training has been found to be effective in improving quality of life for families having children with learning disabilities and sleeping problems (Ryan et al., 2014) and the further use of such an approach should be investigated for families with children with autism.

More father inclusive parent education approaches are required. Honaker & Meltzer, (2016) argued for the development of technological approaches in this area such as web-based modules or apps. Such approaches may be especially user-friendly for fathers who are often less able to access face to face provision available during the working week (Cutress & Muncer, 2014) and who may prefer online support and information (Flynn and Stana, 2012; Seymour-Smith, 2013; Watkins & Jefferson, 2013).

Limitations of the current study should be noted. Since the sample consists of men who were from an almost exclusively white ethnic background, two thirds of whom were educated to degree level or above, it cannot be said to be representative of all fathers of children with autism. Further research is needed which is effective in recruiting fathers from more diverse ethnic and educational backgrounds. In relation to ethnicity, for example, Waheed (2015) recommended greater use of a wider range of engagement activities including face-to-face presentations in local community venues and a strategic distribution of flyers. In addition, as noted above, survey data associated with this study indicated that 81% of fathers reported some degree of child sleep-related stress which rose to 100% of fathers interviewed. If we take such stress as a proxy for children experiencing sleeping problems, then fathers having children with such difficulties may be over-represented in both the survey and interview sample, although the rate of sleeping problems in the population of children with ASD could be high, estimated at 40%-80% of children (Polimeni, Richdale and Francis, 2005). Despite these limitations, it is argued that the current study does serve to extend knowledge, given the scarcity of father perspectives in autism and sleep management.

In conclusion, the present study found that the nature of sleeping problems in children with autism resulted in a number of substantial negative effects on fathers, mothers and siblings. Fathers were often closely involved in the management of difficulties. Given the frequency of problems and the scale of negative impacts on families, it is argued that sleeping problems in children with autism should be regarded as a significant public health concern in the UK, urgently warranting an increase in both research and family-centred service provision.

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Table 1: Characteristics of survey sample

Characteristic	*N (%)*
Age	
21-29	11 (4%)
30-39	51 (17%)
40-49	159 (52%)
50-59	77 (25%)
60-69	8 (3%)
Number of children with autism	
1	257 (84%)
2	40 (13%)
3	8 (3%)
4	1 (1%)
Relationship to child with autism	
Biological father	287 (94%)
Step-father	13 (4%)
Adoptive father	4 (1%)
Foster father	2 (1%)
Marital status	
Married	242 (79%)
In a partnership	38 (12%)
Separated/Divorced/widowed	21 (6%)
Single	5 (2%)
Educational background (highest level)	
Completed primary/secondary school	26 (9%)
Passes at GCSE/ A level	61 (20%)
Vocational qualifications	59 (19%)

Degree/ postgraduate qualifications	160 (52%)
Employment status	
Full-time	190 (62%)
Self-employed	42 (14%)
Retired/Not in paid work	46 (15%)
Part-time	27 (9%)
Ethnicity	
White	286 (95%)
Mixed heritage	6 (2%)
Black or Black British	5 (2%)
Asian or Asian British	2 (1%)
Chinese	1 (1%)

Note percentages may not add up to 100% due to rounding. Some values were missing.

Table 2: Characteristics of interview sample

Characteristic	*N (%)*
Age	
21-29	2
30-39	4
40-49	12
50-59	7
Number of children with autism	
1	20
2	4
3	1
Relationship to child with autism	
Biological father	23
Step-father	2
Marital status	
Married	23
Living with partner	1
Separated/Divorced	1
Educational background (highest level)	
Passes at GCSE/ A level	1
Vocational qualifications	7

Degree/ postgraduate qualifications	17
Employment status	
Full-time	11
Self-employed	6
Retired/ Not in paid work	3
Part-time	5
Ethnicity	
White	24
Black or Black British	1