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**A Qualitative Exploration of the Daily Experiences and Challenges Faced by Parents
and Caregivers of Children with Tourette's Syndrome**

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Abstract

Few studies address the daily challenges faced by parents of children diagnosed with Tourette's syndrome. This article reports on a qualitative interview study with 15 parents exploring their experiences, the challenges they face, and the support mechanisms they have found to be most helpful. Thematic analysis identified four core categories which represented shared experiences of the participants: coping with challenging behaviours, misconceptions and lack of understanding, negative experiences of education, lack of support and services for a child with Tourette's syndrome. The research has highlighted a number of recurrent themes, and by highlighting these it is hoped that these findings will be beneficial to parents and professionals alike in increasing the awareness of the challenges that parenting a child with Tourette's syndrome brings particularly with respect to family life and the child's schooling.

Key words: Tourettes's syndrome, Thematic Analysis, daily challenges, support mechanisms, misconceptions

Introduction

Tourette's syndrome is a lifelong neurodevelopmental disorder characterised by both vocal and motor tics which vary in complexity (APA, 2015). Onset typically occurs before the age of 18 years, with boys three times more likely to be affected than girls (Lambert, & Christie, 1998). Parents of children diagnosed with Tourette's syndrome cope with a multitude of problems associated with this condition, as these children often experience significant behavioural, social-emotional, and academic problems (Storch et al., 2007). For example, academic difficulties may include avoiding asking questions or reading aloud in class, as well as having difficulty concentrating and writing. Social difficulties may result from bullying or discrimination from others, and physically, tics can result in difficulties including musculoskeletal physical pain as well as self-injury (Riley & Lang, 1989). These problems are often further exacerbated by commonly occurring comorbid conditions, which may include, among others, Attention Deficit Hyperactivity Disorder, Obsessive-Compulsive Disorder, and various behavioural problems (Robertson, 2012). Yet given the complexity of the syndrome, there is paucity of research addressing the effect of Tourette's syndrome on the caregivers of children with this disorder.

It is well recognized that raising a child or adult with a developmental disability requires exceptional care giving and contributes to higher levels of stress (Dyson, 1997). In addition to dealing with a range of emotional and behavioural issues symptomatic of their child's condition, parents also have to cope with their own emotions often amongst financial and time constraints (Järbrink, Fombonne & Knapp, 2003; McCubbin, Cauble and Patterson, 1982). Caring for a child diagnosed with Tourette's syndrome may be especially stressful for carers due to the complexity of the symptoms that characterize the syndrome.

Primary symptoms of Tourette's syndrome include motor and vocal tics, for which both symptoms must be evident for a period of over a year in order for a clinical diagnosis to be made (APA, 2015). These tics can range from simple behaviours to the more complex. For example, simple motor tics may involve eye blinks, shrugs or grimaces to the more complex gestures, including smelling or touching objects or people. Vocal tics also range from simple to complex, with squeaks, coughs and grunts being common examples of the former, whereas complex vocal tics can include repetition of their own (palilalia) or someone else's speech (echolalia) (Chilvers, Stein & Chowdhury, 2010). In addition to the motor and vocal classification of the tics there is a lot of unpredictability surrounding the symptoms with the part of the body affected by the tics shown to alter over time, and the frequency and severity of the tics to wax and wane (Singer, 2015).

The vast range of behaviours associated with Tourette's syndrome has often lead to the condition being under diagnosed (Comings, 1990) with symptoms ascribed to other conditions, such as nervousness, psychiatric problems, allergies or respiratory or eye problems (Singer & Walkup, 1991). Furthermore, there appears to be a particular lack of understanding by health care professionals over the core symptoms (Choudhury et al., 2007). Doctors often equate Tourette's syndrome with coprolalia, the expression of socially inappropriate or obscene words or phrases, and these symptoms are often required to be present for a diagnosis to be made (De Lange, Olivier, & Meyer, 2003). However coprolalia is not a defining feature of the syndrome and actually occurs in about 20–30% of sufferers, who also tend to be at the more severe end of the spectrum (Jankovic & Kwak, 1993). Similarly, teachers also have a hard time comprehending the educational challenges of a disorder that waxes and wanes, and is often more apparent at home than at school (Schapiro 2002; Lambert, & Christie, 1998). This may leave many caregivers frustrated with the process of gaining a diagnosis and also where to get the appropriate support.

The period of time between the onset of symptoms and formal diagnosis has been shown to be particularly taxing on parents of Tourette's syndrome (Cohen, Detlor, Shaywitz, & Leckman, 1982). Children's complex tics and compulsions may engage in behaviour and rituals that are difficult for parents to comprehend (Handler, 2004; Wilensky, 1999). For example a child may consistently bang a glass on a table, in order to get just the right feeling or sensation (Schapiro, 2002). For many parents, the unanswered questions surrounding their child's symptoms, may leave them doubting their own parenting skills (Edell-Fisher & Moto; 1990), with families worried that they are viewed as obsessed with or even exaggerating their child's symptoms (Riviera-Navarro, Cubo & Almazan, 2009).

For families who then have to adjust to a diagnosis of Tourette's syndrome, part of the process of adjustment is learning to understand, reinterpret, and accept typical behaviour.

These are often the habits that they have spent time trying to encourage a child to suppress (Leckman, King, Scahil et al., 1999). In addition, the fact that the heritability for Tourette's syndrome is high (Mataix-Cols et al., 2015; Burd, Kauffman and Kerbeshian, 1992), can also leave parents with a feeling of guilt and to feel they are to blame for their child's difficulties (Kidd, Prusoff, & Cohen, 1980).

The few studies that have been conducted on the strain of caregivers of children with Tourette's syndrome, have all shown parenting a child with this condition to be extremely stressful. For example, Cooper, Robertson, and Livingston (2003) studied the differences in mental health and caregiver burden between parents of children with Tourette's syndrome compared to parents of children with asthma. They found that parents of children with Tourette's syndrome experienced greater caregiver burden and were at greater psychological risk than parents of children with asthma. Research has also found families with Tourette's syndrome are more likely to experience stress on family relationships, higher levels of parenting aggravation, difficulties with child care and finances, and less consistency in family

routines compared to typically developing control children (Wilkinson et al. 2001; Robinson, Bitsko, Schieve and Visser, 2013; Stewart, Greene, Lessov-Schlaggar, Church, & Schlaggar (2015).

With relation to treatment, unlike other disorders, there are no specific guidelines for Tourette's syndrome issued by the National Institute for Health and Care Excellence (NICE) body. However Tourette's syndrome is mentioned in the guidelines for difficulties with which it has a high co-morbidity rate: ADHD (NICE, 2006); violence (NICE, 2005) and Autism (NICE, 2014). This leads to the information available on how to treat Tourette's syndrome specific symptoms to be very limited, with pharmacological interventions often the treatment of choice. In fact, pharmacological interventions are commonly available for tics and are often offered to a families; however these may offer only modest effects (Swain, Scahill, Lombroso, King, & Leckman, 2007), and may lead to serious adverse side effects such as weight gain and diabetes (Robertson, 2012).

Therefore it is evident from the literature that Tourette's syndrome can present a range of challenges to the individuals and their family. However there is a distinct lack of research exploring the experiences of parents with Tourette's syndrome compared to other developmental disorders (Harrington, Patrick, Edwards, & Brand, 2006). A recent study (Riviera-Navarro, Cubo & Almazan, 2009) using focus groups identified communication difficulties about the symptoms of Tourette's syndrome between clinicians and parents as a problem, and both parents and their children also reported experiences of stigma. The aim of this paper was to further explore the daily experiences of parents raising a child with Tourette's syndrome with a view to describing and assessing the impact of the disorder on family life, identifying particular challenges the parents might face and to also evaluate their experiences with support services.

Method

Participants

Participants in the current study were recruited via Tourette's Action; the leading support and research charity for people with Tourette's syndrome and their families in the UK. The study was advertised nationally on the Tourette's Action website. Participants were therefore a self-selected sample and recruited nationally from a variety of geographical areas including the North West, East, South East of England and Wales.

The 15 participants (11 females and 4 males) included three couples who were interviewed separately and they were either a parent or caregiver of a child with TS (aged between 7 and 17 years). Tourette's syndrome is often accompanied by co-morbid conditions and a large proportion of parents reported that their child had co-morbid difficulties (9 out of 12 children) including ADHD, anxiety, Oppositional Defiant Disorder, and Autism Spectrum Disorder.

Development of an interview guide and data collection

A semi-structured interview schedule was developed with consideration given to previous similar studies which focused on similar neurodevelopmental disorders. Factual questions including how long their child has had a diagnosis of Tourette's syndrome, and whether their child had any additional diagnoses were asked initially in order to build a rapport and trust between the interviewer and interviewee, before moving on to potentially more difficult or sensitive areas. The questions were checked for the appropriateness of the wording with Tourette's Action and a parent of a child with Tourette's syndrome prior to interviews commencing.

The following core questions were asked:

- 1) As a parent of a child with Tourette's syndrome can you tell me about the challenges you face?

- 2) Can you tell me about the support you have received?

- 3) What support or services have you found helpful?

Due to topics raised during the first interview, an additional question was added to subsequent interviews which enquired about whether the parent felt the challenges which they face have changed over time as their child has got older. Questions were deliberately broad with the aim of eliciting detailed responses, allowing the interviewee scope to expand on their answers. . Probes were utilised to ensure that all the intended topics are covered in depth, and unexpected points mentioned by the interviewee were also given attention and integrated into the interview (Jacob & Furgerson, 2012).

Full ethical approval was obtained from the ethics committee of the University of Hertfordshire in accordance with procedures outlined by the BPS. Data was collected via semi-structured face to face interviews in order to elicit rich descriptions of parents' subjective experiences. All interviews were carried out by a researcher (RB) experienced in conducting semi-structured interviews, and the interviews were carried out at interviewees' homes.

Prior to commencing the interview, participants were provided with an information sheet about the aims of the study and assured of their confidentiality and anonymity and that

participation was entirely voluntary before they then were asked for their written informed consent. The interviews were carried out over a three-week period and ranged in duration between 30-75 minutes. No-one withdrew from the study and no incidence of distress during the interviews occurred.

Thematic Data Analysis

Interviews were recorded and transcribed verbatim. Transcripts were then analysed using the techniques of thematic analysis (Braun & Clarke, 2006), with the aid of NVivo software for analysing and managing data. Transcripts were first read in full so as to get an overall sense of the course of each interview and thereafter coded to capture the essence of parents' descriptions, explanations, comments and views in relation to the focal questions of the study. Codes were then condensed into to a list of initial themes within and across transcripts and memos were written to provide a reflective account of the process of forming and labelling themes representing the views of the participants. To ensure rigour of the analysis, extensive revision of the emerging themes was undertaken by renaming, splitting or merging themes through an iterative process. The credibility of the final major themes was checked independently through audit trails conducted by two of the researchers (AL, JS). In reporting results, a detailed description for each major theme is provided along with pertinent quotes to illustrate specific aspects of its content.

Results

Initial coding produced 80 codes that were then allocated to 20 sub-themes. In the next stage of the analysis further explorations of the content of those themes in terms of similarities and

links as well as their relevance for the focal questions of the interview were undertaken which resulted in four major themes (see Figure 1) representing the essence of the participants' views in relation to the core questions of the study.

Coping with challenging behaviours

Parents have to deal with the many challenging symptoms of Tourette's, including tics, anger/rage attacks and behaviour issues which can have a huge impact on daily quality of life. As well as managing symptoms, parents of children with TS often feel responsible for other people's responses and reactions to their child's display of unusual behaviour.

As tics are the main feature of Tourette's syndrome, almost all parents (14 out of 15) reported finding it difficult to cope with the tics their children displayed. In particular, dangerous, rude and loud tics were all identified as being the most difficult to deal with, and several children were identified by their parents as regularly causing themselves self-injuries through their tics.

She's got a tic where she wants to put her hand in fire and will go to the gas ring, and not until that's nearly happened we've realised that the danger is there. Grabbing us from behind when we're driving, opening the door while the car's moving, things like that (Sarah).

He had a particularly disgusting spitting tic when he was 10 or 11, and we had just no help in how to cope with that. You see him doing it out on the street and people judge really harshly. (Ellie)

Several parents raised not knowing how to respond to their child's relevant tics as being particularly distressing (10 out of 15). Examples given were feeling guilty

for having been frustrated and angry at their child's behaviour, when many of these behaviours could be actually ascribed as a tic. For example Cathy wondered

What do you do? Do you take her out of the situation, do you leave her in the situation, do we go to synagogue that day do we not? Because...we don't wanna be taking her out but equally how do you sit there with it going on?"

And when you find out that you've been shouting at a child to stop doing something that he cannot stop, the guilt just, it's just awful. (Cathy)

In addition parents highlighted how these challenging behaviours impact on their daily life or work commitments. For example, numerous and wide-ranging daily struggles were highlighted, including being able to hold down a job due to the difficulty with finding appropriate child-care for complex needs, or having to leave a public places like supermarkets when the tics are aggravated. Parents even discussed changing social activities and holidays to less public places to avoid less attention. However, it was the everyday activities like brushing teeth, eating and going to bed that was raised as being consistently problematic due to the nature of the tics (8 out of 15)

We have tea earlier than we would normally because...if we had tea later and her tics are really bad and she couldn't physically eat. (Helen)

Misconceptions and lack of understanding

Whilst TS does not affect intellectual ability, it is a puzzling disorder to understand, even for medical professionals and the lack of knowledge surrounding this complex inherited neurological disorder, is often further exacerbated and distorted by the media. The lack of such knowledge is one of the most disabling aspects for those living with a child with TS.

Many parents (12 out of 15) talked about how when they share with others that their child has TS, there will automatically be an assumption that they have coprolalia. Some parents related this to the media portrayal of Tourette's syndrome.

I know it's probably funny to watch on the TV when they're shouting out, you know, swear words...I think some people, you know, take the mick but...it's so tiring and when you see your son in that much pain because of it, erm, and he's just worn out...it's making people understand that it's not that funny. (Rose)

Importantly, it was not just the misunderstanding by the lay public that was raised as concern, but several parents talked about how even the professionals seem to lack an accurate understanding of Tourette's syndrome; for example Ellie recalled talking to a Doctor; “*when we said our son's got Tourette's, he went 'oh, swearing.' And that's a medical professional (laughs).*” A number of interviewees also expressed that some family members lacked understanding about Tourette's syndrome (6 out of 15), particularly the older generation; for example Steve stated that his father-in-law “*will maybe snap and disapprove*”. Similarly, Tom said “*I think the older generation find it hard to take, like my mum and dad.*”

Negative experiences with schools

For many students with TS, school is a challenging environment. Very often whilst in the school, students have to concentrate to suppress their tics, which is both exhausting and compromises their concentration in class. Therefore negative experiences of school and education is made up of many challenges such as concentrating in class, unhelpful responses by school staff to their tics and difficulties with fellow students. The theme of education was discussed by many of the interviewees, with parents expressing frustration with the lack of support in mainstream schools. In some cases (2 out 15) it has led to children not attending

school. For example; Sarah and Tom's daughter stopped attending school at the age of 14 due to a lack of support. Sarah recalled:

We wanted extra time for her when she come to do some exams and studying, she found it difficult to read...off a board because she were doing her eye tics and it were asked if they could make notes for Emma, you know just minor adjustments like that, which they didn't really carry through.

Many parents experienced a lack of willingness to get appropriate statements in place. Most parents raised frustration at the number of meetings they had with schools and SEN to get extra support and reported that even what was agreed and discussed was rarely followed-through, often due to lack of communication with the different teachers involved in the children's care. The majority of parents' felt that raising awareness in schools of the special needs of TS children could make a significant impact on the lives.

The importance of the school was highlighted by, Charlotte, for example, stating that they had received an excellent provision which offered a good balance between giving her son the appropriate level of support without singling him out too much as being different. She explained that the school had put into place a number of interventions to support her son including a card which he could hold up if he needed to leave the classroom for a period of time, and being able to take assessments in a separate room to other pupils.

Support and services

The interviews highlighted a number of sub-themes relating to the support and services received by families who have a child with Tourette's syndrome. The first subtheme was a shared experience that services are inadequate for children with Tourette's syndrome and their families (14 out of 15). David, for example, described the support they had received as "*minimal and begrudging and inadequate to be honest.*" Further to this, many parents

described feeling as though they had to ‘battle’ to receive support. Rose recalled trying to access Child and Adolescent Mental Health Services for her son;

I shouted it from the rooftops, kicked and screamed, wrote snotty emails, sent them a handwritten letter.

Others reported feeling dismissed by professionals and services when attempting to receive a diagnosis for their child’s difficulties. Andrea, for example, sought professional help for her son for six years, and was continually told that nothing was the matter with her child and to just ignore it. It was only until she saw a television programme that she realised her son had Tourette’s syndrome. She was then able to specifically ask to be referred for a specialist assessment of this, to be told he showed classic signs of Tourette’s syndrome.

Additionally, some (5 out of 15) found that their child’s difficulties are somewhat trivialised by professional staff by comments such as that the child was ‘fine’ when they were in the care of others; David stated:

Teachers will say... ‘oh he’s been fine all day’... an implied rebuke... in that we are making too much of a fuss and as a consequence making it worse for him by going on about it all the time, because actually he’s fine we’re just being fussy parents.

He went on to say that he therefore thinks it is extremely important for parents to be confident in their own judgement about their child, regardless of dismissive attitudes they may experience from some.

Ten out of the 15 interviews raised the lack of support for Tourette specific symptoms. Here, parents mentioned how the support they received from, particularly via CAMS, were focused on some of the comorbid disorders, such as Asperger’s syndrome and ADHD. However guidance for help with Tourette specific symptoms was perceived as minimal (6 out of 15),

and many felt disappointed and frustrated that the main support on offer was via the medication route at best with very few alternative treatment options.

It was very disappointing when they seemed to just offer medication or nothing.

You know, their sessions were very much just listening sessions where the counsellor would just listen and repeat and make notes and that was it. (Steve)

When asked about advice they would give to parents of a child newly diagnosed with Tourette's Syndrome, most interviewees emphasised the importance of building networks with other parents. Ellie stated that she felt a sense of isolation after her son's diagnosis, and advised others to "*Speak to other parents, yeah. Try and find a support group, realise you're not out there alone, yeah definitely.*" Many parents discussed support groups, with some finding them helpful, for example Jane stated "*its two mums running a support group for other parents and people with Tourette's, and that's been the biggest support we've had.*" Other parents have had reservations about attending particularly with bringing their children along.

Actually it'd be nice if there was a children's group, but because it was a mixed group with adults and children present, that didn't really meet our needs. Erm I don't think she would have been able to deal with some of the more extreme adults that were there. (Cathy)

Discussion

Caring for a child diagnosed with Tourette's syndrome is considered to be especially stressful for carers due to the complexity of the symptoms that characterize Tourette's syndrome and the lack of understanding that surrounds the disorder by both the public and health care professionals (Choudhury et al., 2007; Schapiro 2002; Lambert, & Christie, 1998). The

interviews with the parents revealed a number of wide-ranging challenges including the difficulty or even inability to cope effectively with their child's tics, and feeling helpless which caused considerable distress. Parents discussed issues relating to services and the support offered which were often found to be unresponsive and of little help, with many highlighting difficulties knowing where to get advice and support both pre and post diagnosis. In particular medical professionals and teachers were two groups identified as needing to receive more formal training on the symptoms of TS. Parents also identified misconceptions about Tourette's syndrome, and practical difficulties that they have been presented with on a daily basis.

Receiving a diagnosis is known to be a particularly challenging and difficult time for the families. Parents with a range of childhood conditions often feel they have to fight for a diagnosis, with their child's difficulties perceived to be dismissed by professionals and services when seeking help (e.g. Harrington et al., 2006; Ludlow, Skelly, Rohleder, 2012). Unsurprisingly then, parents with Tourette's syndrome also reported the same frustration when seeking initial diagnosis and emphasize the common misconceptions surrounding the characteristics of the disorder to hamper this process (Jankovic & Kwak, 1993). For many parents this compounds the stress of an already difficult period and leaves them feeling helpless, and that they are even made to believe that they are exaggerating their child's difficulties (Edell-Fisher & Moto; 1990), Riviera-Navarro, Cubo & Almazan, 2009). The findings reported here support previous research over a lack of understanding by health professionals about the core symptoms of Tourette's (Choudhury et al., 2007; De Lange et al., 2003) and the need to improve communication channels between the parents and the professionals involved in the initial diagnosis.

In addition to the shared experiences that parents of children with disability face, parents will also have to deal with unique symptoms that their child displays. For parents with Tourette's

syndrome, learning how to deal with tics tends to be one of the main concerns with those that have social (rude, loud) and/or physical (dangerous) consequences reported to be the most troublesome. These have a huge impact on both the child academic and social life as well as impacting on parents being able to establish daily routines (Wilkinson et al. 2001; Robinson, Bitsko, Schieve and Visser, 2013). It is important to be aware of the challenges concerning family life and school education that arise from developmental disorders in general, and those that are more syndrome specific, in order for parents to get the appropriate help and support.

Many parents expressed their concern that the support and services available for people with Tourette's syndrome were largely inadequate. More specifically, there appears to be lack of services tailored to Tourette's syndrome and those that exist largely relate to comorbid disorders (NICE 2014). In addition, parents raised their frustration and disappointment at the fact that medication was often offered to their child with very few alternative treatment options (Swain et al., 2007). Again this emphasizes the lack of knowledge that surrounds Tourette's syndrome and the need for more specific services and medical guidelines to be dedicated to this condition.

An essential component of effective management of Tourette's syndrome is educating the person affected and the people around them about the condition i.e. family members, teachers and peers (Swain et al., 2007). The experiences of adolescents with TS at school are often found to more negative when teachers do not have sufficient knowledge and understanding of the condition. Psycho-education to school staff may include practical advice such as arranging for extra time in exams, or deciding on a place where the child can go to tic (Robertson, 2012). In the current study, parents who had reported more positive experiences of living with Tourette's syndrome were those who have had the opportunity to explain Tourette's syndrome to other parents and pupils.

In addition to some of the challenges faced by parents, there were many positive experiences parents wished to share. Many parents emphasised the importance of building networks with other parents of children with Tourette's syndrome. Previous studies have also highlighted the benefits support groups can be to parents with children with disabilities, such as the offloading of negative emotions, for sharing common experiences, and in obtaining specific information about care and treatment (e.g. Bennett, DeLuca & Bruns, 1997; Smith, Gabard, Dale, & Drucker, 1994). Whilst support groups were not favoured by all parents, having access to a wide range of social support was essential to parent's ability to cope (Stewart et al., 2015; Lee, Chen, Wang and Chen, 2007). In addition, parents who concentrated on their child's achievements and distilling confidence in their child, also reported having an easier time.

There are several limitations to the study, which are important to note. The use of a self-selective sampling method may have meant that parents who had more negative experiences were more likely to volunteer. However, participants were recruited from various locations across the UK, and therefore our findings should be fairly reflective in the amount of support available nationwide. Finally, the different experiences of fathers and mothers were not explored here. This may be important to address in the future as mothers of children with developmental disabilities have been identified as being at particular risk from physical and emotional strain (Estes et al., 2009).

Whilst our qualitative study lacks generalizability of its main findings, the in-depth exploration of parents' experiences raising a child with Tourette's syndrome provided a detailed, subjective account of the essence of their day to day life and the difficulties they face. The burden of care and associated stress for the parents is considerable, as very few guidelines exist surrounding the development and management of the symptoms of Tourette's syndrome. The lack of knowledge surrounding this disorder is often further

exacerbated and distorted by the media, with lack of such knowledge identified as one of the most disabling aspects for those living with a child with Tourette's syndrome. It is hoped that by increasing the knowledge about the support that parents find to be helpful or unhelpful, more tailored services could be developed for these families.

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