Parental experience of looking after a child with Gilles De La Tourette Syndrome

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Introduction

Gilles de la Tourette Syndrome (GTS) is a childhood onset inherited neuro-developmental disorder, characterised by the presence of both multiple motor tics and one or more vocal tics, lasting longer than a year (American Psychiatric Association [APA] 2000; World Health Organisation 1992). For descriptive purposes, tics can be divided into simple or complex tics. Simple motor tics are fast and meaningless and include eye blinking, grimacing, shoulder shrugging, coughing and throat clearing, while complex motor tics tend to be slower and may appear purposeful – for example: hopping, kissing, touching objects, echopraxia (imitating movements of other people), copropraxia (obscene gestures) and repeating words. Other complex vocal tics include differences in the articulation of speech, including variation in the rhythm, tone and rate, as well as coprolalia (repetitive use of obscene or socially unacceptable words or phrases).

The onset of tics is usually mild and infrequent and occurs between the ages of 2 – 21, with a mean age of onset around age 7 (Robertson 2000). The tics often increase in severity up to and during puberty, and often reach a relatively stable plateau during early adulthood. The person with Tourette Syndrome is likely to have a number of different motor and vocal tics but head and neck tics are by far the commonest. Coprolalia rarely occurs in young children and only occurs in 10% - 30% of adult clinic populations and thus is certainly not diagnostic (Robertson 2000). Most people can suppress tics for a short period of time only – it is therefore a myth that these tics can be controlled, but unfortunately many professionals and parents still feel that children ‘put on’ their symptoms.

Tourette Syndrome was once considered uncommon, but some recent studies suggest a prevalence rate of between 0.56% and 1.85% of mainstream school children (Kadesjo & Gillberg 2000;
Kurlan et al 2001; Hornsey et al 2001; Khalifa & vom Knorring 2003; Wang & Kuo 2003) and an even higher figure in youngsters with learning disabilities (Eapen et al 1997). It must be acknowledged that the reporting of higher rates has been challenged (Scahill et al 2001), but there do seem to be consistently higher figures reported recently.

Comorbidity has been identified as a common feature of Tourette Syndrome. A study including 3,500 patients from 22 countries, showed that only about 12% of adults and children with TS had no reported comorbidity. The most common comorbid condition was Attention Deficit Hyperactivity Disorder (ADHD), followed by Obsessive-Compulsive Behaviours (OCB) and Obsessive-Compulsive Disorder (OCD). Anger related problems, sleep difficulties, coprolalia and self injurious behaviour tended to be higher in those with co-morbid conditions (Freeman et al 2000).

An uncontrolled study by Wilkinson et al (2001) investigated the impact of Tourette Syndrome on the family with and without comorbid disorders. The results of the study indicated considerable parental burden when Tourette Syndrome symptom severity was greater and comorbid disorders were apparent.

Recent Department of Health documents, such as Valuing People: a new strategy for learning disability for the 21st century (Department of Health 2001) and Family Matters: counting families in (Ward 2001), have emphasised the need for practitioners and local services to provide support for families and involve them in planning services. Service users’ experiences are also emphasised within the clinical governance agenda (Murray et al 2002). With this in mind, we decided to look at the experiences of parents of children with Tourette Syndrome in order to improve the service offered to children and families.

Method

Focus Group:
Following local ethical approval for the study, three consecutive sets of parents with a child with a primary diagnosis of Tourette Syndrome attending the Dunstable and Luton CAMHS clinics were invited to attend an initial focus group. The purpose of the focus group was to explore issues and themes considered relevant in terms of parental experiences and to generate a set of questions for the main part of the study. The group were told that they would play an active part in the study since their opinions on the wording of the questions and the inclusion / exclusion of questions for the interview guide were chosen by them. Such a technique also has the advantage of alleviating any hierarchical relationship between researcher and participant (Morgan 1998 as cited in Mohr & Regan-Kubinski 2001).

The discussion in the focus group was fully transcribed and coded. The four areas that were highlighted were: a) life in the public setting, b) getting a diagnosis, c) education, and d) later life. A set of semi-structured interview questions were then compiled based on these topics.

Interview:
Information sheets and invitations to take part in the study were sent to 13 sets of parents with a child under 16 with Tourette Syndrome.
Tourette Syndrome attending the CAMHS clinics in Bedfordshire and Luton, and 4
sets of parents with a child under 16
attending the Tourettes Clinic at the
National Hospital for Neurology and
Neurosurgery, Queens Square, London.
Ten different parents responded and
agreed to take part. The interviews were
all carried out by the same researcher
(DC) and interviews were carried out at
the parent's home or local clinic. All
interviews were audio-taped. The
interviews were conducted according to
Arksey and Knight's (1999) four stages of
the interview process: the first stage is
the opening of the interview – the key
features are to assure confidentiality,
explaining the length of the interview and
being friendly and polite; the second
stage is during the interview, which
involves attentive listening and
maintaining eye contact; during the
closing of the interview (third stage), the
interviewee is made to feel that his/her
contributions were valuable and they are
informed that they will have access to the
results; after the interview (fourth stage),
the interviewee should be thanked by
letter.

Data Analysis:
Each interview was transcribed and a
content analysis was conducted in
relation to Grounded Theory, a term
coined by two sociologists, Glaser and
Strauss (1967). Rather than a theory,
Grounded Theory is an approach to
theorising about data. Coding is at the
centre of qualitative data analysis
(Strauss and Corbin 1998): line by line
coding was first applied followed by
paragraph by paragraph coding when
some of the transcript did not reveal any
dimension; axial coding (Strauss and
Corbin 1998) was used to code the data.
This coding technique aims to reveal the
structure among categories or describe
the process of actions / events. Thus
categories and their pertaining
subcategories were identified along with a
core category or emerging storyline.

Findings
Five main themes emerged:
1. Time taken to obtain a
diagnosis
2. Immediate response to a
diagnosis
3. Impact of diagnosis on the family
4. Negative educational experience
   before a diagnosis
5. Symptom severity as an indicator
   of the child’s future

Time taken to obtain a diagnosis
On average, parents reported that they
waited approximately two years until they
received a certain diagnosis for their
child. Parents described initially feeling
apprehensive about going to their general
practitioner. The majority were initially
reassured and told that things would
settle down but, later, parents asked for a
referral to a specialist since symptoms
persisted and they felt their child had a
disorder of some type which had not been
diagnosed. A mother described that ‘she
knew something was wrong because
there is already somebody in the family
with Attention Deficit Hyperactivity
Disorder (ADHD)’ and this is what made
the mother determined to seek an
assessment. Another mother had an
assessment from a specialist since the
child’s father already had a diagnosis of
Tourette Syndrome. In one case, a
mother had insisted that her child was
seen by a local psychiatrist and although
the local psychiatrist did not make a
diagnosis, some form of help was offered.
The majority of parents generally felt that there was a lack of knowledge regarding Tourette Syndrome at primary care level. Parents reported looking up information on the Internet as a result of a lack of support provided prior to diagnosis.

Immediate response to a diagnosis
Most parents experienced conflicting emotions, which were positive, negative or neutral. Parents talked about initially feeling relieved that there was ‘a reason for their child’s behaviour rather than the fact that he’s just naughty or has not been brought up properly’. This was a common theme in that parents often felt blamed by others for their child’s behaviour. One parent felt the diagnosis had reinforced her feelings of being blamed, with her comments being ‘is it my fault? Has it come from my family?’. In many cases, parents tried to make sense of their child’s diagnosis and keep things in perspective by making comparisons with children who have other more extreme disabilities. Some parents took a neutral stance since they really did not know much about Tourette Syndrome. One mother who had waited several years for a diagnosis was extremely angry when a diagnosis was finally made and felt that their ‘daughter’s childhood was taken away’ because of the late diagnosis.

Impact of diagnosis on the family
The impact of diagnosis on the family has been contrasted with life before diagnosis and life after diagnosis. All parents felt that their lifestyles were affected by their child’s condition. Prior to diagnosis, a mother described her concerns about social stigma and ‘who could hear’ her child’s verbal tics. Parents often felt others were being judgemental of them and thinking they were ‘bad parents’. Some parents would not take their child shopping because of the perception of others. Having a diagnosis changed a lot of parents’ attitudes towards their child’s behaviour and symptoms. Parents felt more comfortable in public explaining their child’s behaviour and letting others know s/he had Tourette Syndrome. Having a diagnosis also had a big impact on getting help within schools: ‘giving the behaviour a label helped, otherwise no one would listen to you’.

Parents commented on the fact that they could now research the Internet to seek further information and gain a better understanding of the condition to help them and their child cope. Parents realised that stress was a potential trigger to tics and thus families adapted by avoiding stressful situations. Families said that they ‘pulled together’ to deal with the difficulties with Tourette Syndrome. Humour was often used as a way of coping.

Negative effects of a diagnosis included the stigma associated with Tourette Syndrome as well as dealing with medication and possible side effects. One family reported experiencing a conflict within the family in terms of dealing with the non-affected sibling’s reactions and understanding.

Negative educational experience before a diagnosis
Parents expressed that their child had experienced difficulties at school, ranging from peer relationship adjustment, the teacher’s lack of understanding and bullying to academic problems in the classroom. Numerous children were viewed as ‘a nuisance and a naughty child.’ Parents said that there was little recognition by teachers of the behavioural difficulties that children with Tourette
Syndrome may have or recognition of associated difficulties such as ADHD.

The diagnosis of Tourette Syndrome led to the application of positive learning strategies. One parent said that her child’s class teacher suggested that the child could ‘suck on a cough sweet’ so that he could suppress his vocal tics. Some parents commented that teachers were sent on a course. In contrast, there are other parents who have been waiting for some time to get extra support for their child’s needs. Parents indicated that teacher training on Tourette Syndrome was crucial. A mother recognised how a smaller class size ‘wouldn’t [make her daughter] nervous, that means the noises wouldn’t come out as much’. Some parents also disclosed that despite the diagnosis, schools had not altered their approach to teaching, although other parents said that bullying was now being addressed.

**Symptom severity as an indicator of a child’s future**

Parents expressed concerns about their child’s future focusing around symptom severity. If the symptoms were mild or under control then the future was anticipated to be positive – for example, the child would have had a good education, a successful job and a long-term romantic partner. A negative future was expected in the case of symptoms increasing in severity. Negativity was defined by not ‘being capable of living independently’, a lack of education and no life partner. Most parents claimed that their child’s life partner ‘would have to be someone very understanding’. All parents expressed that their desire was for their child to be ‘as normal as possible’ and this depended on severity.

An emerging theme was parental emotional responses. During the analysis, it became clear that parent’s emotions vary according to what stage of the ‘Tourette Syndrome journey’ they are at. These stages are: a) prior to diagnosis; b) initial reactions to diagnosis; c) coping after diagnosis; and d) planning for the future. The range of emotions includes anger, anxiety, relief, and guilt.

**Discussion**

Although we only interviewed 10 different parents of children with Tourette Syndrome, it was clear that all had concerns with the lack of understanding and knowledge that professionals had about the condition. Parents felt that primary care workers, such as general practitioners, could have made an earlier diagnosis or at least referred to specialist clinics earlier if they had recognised the signs and symptoms.

Concerns about school life were also important. Many parents felt that recognition of their child’s difficulties within school would have a major outcome on their child’s adjustment and well-being. A recommendation was made that more should be done to educate teachers and doctors.

As with many conditions which have behavioural symptoms, many parents feel a degree of guilt and blame. A greater public understanding is also important to decrease levels of stress amongst parents.

Parents had mixed feelings when the diagnosis of Tourette Syndrome was finally made. However the majority felt that the diagnosis helped them to ‘shift’ away from an attitude of blaming their
children to one of empowerment, where one felt they could educate others openly. It also allowed parents to read more widely around the subject and thus again feel more in control of the situation.

Parents experience a range of emotions depending on where they are on the assessment stage. Given the range of complex symptoms and challenging behavioural problems, it is not surprising to see that emotions include anxiety and guilt. Cooper et al (2003) looked at mental health and caregiver burden in parents of children with Tourette Syndrome and compared this with parents of children with asthma. They found that parents of children with Tourette Syndrome were more likely to suffer from psychological difficulties and experience greater caregiver burden. One recommendation is that parents should get some support at the time of diagnosis. This may take the form of follow up clinics, more explanation and/or information sheets. A support group for parents may be helpful as this allows parents to learn from each other and also make them feel less isolated.

The limitations of the current study include the small sample size. We were also aware that we did not obtain the child’s view of him / herself or an objective measure of severity of symptoms. There may have been selective bias in that parents who chose to respond to the invitation for interview were parents of children who were more challenging than most. A further limitation is that no standardised schedules or interviews were used.

Conclusion
Parents of children with Tourette Syndrome experience a range of difficulties which involve a professional and public misunderstanding of the condition. Recommendations involve better education of all professionals who come into contact with the child and a support group for parents. The neurodevelopment service at Bedfordshire and Luton CAMHS is currently considering ways of raising the awareness of Tourette Syndrome amongst health and education professionals.

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