

“There is life after the diagnosis”

A comparative exploration of two mothers' experiences of having sons with
Tourette Syndrome

Research Study
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Abstract

The current research study explored the experience of two mothers of boys who suffer from Tourette Syndrome. It looks at the impact of the diagnosis on them and their families, touches on the question of how they are affected by social perception, what feelings are evoked around the issue, and how they feel supported by their son's schools and the medical system. It also briefly takes into account whether there is a place for psychotherapy within a supportive structure for them. Interpretative Phenomenological Analysis was used to elicit the richest themes from the in-depth interviews conducted with both women. While many of the same emotions were evoked on the diagnosis of their sons, both families reacted differently, one acting as a unit or system and the other appearing to separate into individuals coping with the impact. Both women found support from the families they met through The Tourette's Association of Ireland and both became a support for newly diagnosed families. One mother had a very positive experience with her son's school, teachers, psychologist and the medical system in general, the other did not. One woman has been attending psychotherapy as a support for herself, and the other had not ever considered it. This research suggests that treating the diagnosis as 'family diagnosis' rather than an individual's diagnosis may be a beneficial approach for all involved. It also suggests that psychotherapy could be a support for the care-givers who bear the worry, responsibility and at times the sense of isolation associated with Tourette Syndrome, for their children. This study is exploratory in nature, looking at the lives of two mothers in a specific situation, in the hope that the findings will serve as a basis of authentic knowledge from which to develop further Irish studies into what might be supportive to these women and families.

'sometimes we simply have to keep our eyes open and look carefully at individual cases – not in the hope of proving anything, but rather in the hope of learning something!'

Hans Eysenck (1976: 9)

Introduction

Research Context and Rationale:

This research is an exploration of two mothers' experiences of having a child with Tourette Syndrome (TS). TS is becoming a more prevalent diagnosis than it once was, now estimated that 1 in 100 children suffer from this neurodevelopmental disorder (Robertson, 2008). Individuals with TS frequently have wider difficulties in a range of emotional and behavioural domains (Cutler, Murphy, Gilmour and Heyman, (2009) and this affects not only the child concerned, but also the adults in his or her sphere, including parents and teachers. There is research conducted on the treatment of TS (ESSTS, 2011), and many articles on interventions for teachers and schools, (Chowdhury and Christie, 2002; Walter and Carter, 1994), but still relatively little on the impact on the parent or care-giver (Wilkinson, Marshall and Curtwright, 2008; Cooper, Robertson, and Livingston, 2003; Edell and Motta, 1988). It stands to reason that parents are affected by the diagnosis of their child and the subsequent changes, possibly in their child's behaviour and also in managing their lifestyle. As TS is becoming a more prevalent diagnosis, it is important to consider the well-being of the parents, as this in turn will affect the well-being of the child (Comings and Comings, 1985).

As the diagnosis of TS is not usually made until middle childhood and waxes and wanes throughout life, typically at its worst at 12yrs of age, (Leckman, Zang, Vitale, Lahnin and Lynch, (1998), it can be a shock for a family to absorb (Packer, 1997). The symptoms typically manifest unexpectedly, and they can be violent. This can be distressing for the child and the parents who may feel they are past the early developmental stages and therefore 'out of the woods' from a child-rearing perspective.

The current research study explored the experience of two mothers' of boys who suffer from Tourette Syndrome. It looked at the impact of the diagnosis on these women and their families, touched on the question of how they are affected by social perception, what feelings are evoked around the issue, and how they feel supported by their son's schools and the medical system. It also briefly takes into account whether there is a place for psychotherapy within a supportive structure for them.

Method:

The data was acquired by means of in-depth interviews with each woman, using Interpretative Phenomenological Analysis to elicit the richest emerging themes from each case study. Existing Global literature on TS, the impact of TS on the care-givers, and stress in care-givers of children with TS and associated disorders, was referenced in order to contextualize the case study findings. Almost half of individuals with TS will present with at least one comorbid disorder and behavioural difficulties (Budman and Feirman, 2001). These associated disorders can often cause more distress than the tics themselves and are also examined in the existing literature – it is difficult to separate what difficulties are purely related to TS and what might be symptomatic of other disorders.

Objective:

The aim of this exploration was to highlight the impact that a diagnosis such as this has on the mother of the child, and see what it brought up for them; it seeks to explore their experiences and try to understand what has been useful to them as a source of support. The hope is that by conducting a specific study such as this, it may prompt further studies examining TS as a family disorder, which might examine more closely how medical and mental health interventions could include, and support, the parents and family of the child diagnosed, rather than looking exclusively at the child as the individual who has the diagnosis.

Chapter One: A Review of the Literature

1.1. Definition of Tourette Syndrome:

There is a wealth of literature from Britain, America and Europe relating to Tourette Syndrome (TS), and its related disorders or co-morbid disorders. The most comprehensive study of TS has been conducted as recently as April 2011 by The European Society for the Study of Tourette Syndrome (ESSTS, 2011). These are the first assessment guidelines of TS in Europe and are compiled in four comprehensive articles, which review national guidelines and research from available literature. Clinical assessment guidelines of tic disorders and their co-morbid disorders in children and adults are presented, clinically useful screening methods, questionnaires, checklists and neuropsychological tests are assessed and recommended (ESSTS, 2011).

In all the volumes of International literature on TS, a reoccurring name is Uttom Chowdhury, who is Consultant Child Psychiatrist at CAMHS Academic Unit in Dunstable and Honorary Child Psychiatrist at the Neurodevelopmental Disorders Clinic at Great Ormond Street Hospital in London. Chowdhury has written a number of books and articles on TS. His research gives a relevant and clear description to the uninitiated lay-person of what this neurodevelopmental disorder, TS, is. He describes tics as involuntary, rapid, recurrent, non-rhythmic motor or vocal actions and differentiating between simple and complex tics; “An example of a simple tic would be blinking, grimacing, throat clearing or shoulder shrugging. An example of a complex tic would be twirling, bending, touching objects (or others or self), or out of context utterances of words or phrases” (Chowdhury and Christie, 2002:123).

To confirm the diagnosis, children must have multiple motor tics and one or more vocal tics. The tics must occur many times a day for more than one year with no period of remission lasting longer than 2 months (APA, 2000). Coprolalia, where obscene or socially unacceptable words or phrases are uttered involuntarily, is described as relatively rare and suffered by ‘small number of adults’ who may have these complex vocal tics. This is rare in children with TS, and not a specific diagnostic feature of TS (Chowdhury and Christie, 2002). The onset of tics usually occurs around the age of seven but may be

present in earlier childhood. Symptoms become more frequent and variable as the child ages, with tics and associated symptoms generally peaking by about age 12 (APA, 2000).

1.2. Prevalence

In a review of large-scale international epidemiological studies it is suggested that 1% is an appropriate international prevalence estimate for TS in children (Robertson, 2008). Some studies indicate that the rate may be as high as one in 95 boys and one in 759 girls (Comings, Himes, and Comings, 1990). More recently, studies suggest prevalence rates ranging from 0.1% to 3% (Hornsey, Banerjee, Zeitlin, and Robertson, 2001; Kadesjo and Gillberg, 2000; Olson, 2004). A study on the prevalence of TS conducted in a West Essex mainstream secondary school, of year 9 Students (age 13-14yrs) showed a 2.9% incidence of TS in the sample group, that is, 5 children out of a group of 166 pupils, fulfilled the criteria for TS (Mason, Banerjee, Eapen, Zeitlin and Robertson, 1998).

Once considered rare, and as recently as 1973 less than 200 persons in the United States were believed to have TS (Mateševac, 1991), it is now estimated that four in every 10,000 people in the United States have symptoms associated with TS (APA, 2000). The only national, voluntary, health organization for people with TS in America, <http://www.tsa-usa.org/> estimates that some 200,000 Americans have the disorder, with millions more manifesting associated conditions. According to the main website in Britain, dedicated to support, education and research, <http://www.tourettes-action.org.uk/> more than 300,000 people in the UK have TS, including one schoolchild in 100. The TS Ireland site www.tsireland.ie/ is also conservative in its figures, mentioning that Transient Tic disorder affects up to 20% of children at primary school age, this consists of tics that may come and go over the course of one year. About one child in a hundred will develop Chronic Tic Disorder, which is motor tics in one area, which continue over time, and include at least one vocal tic.

1.3 Treatment:

This study has not included the comprehensive treatment of TS, but briefly notes recent literature and its recommendations for treatment. It is held that the most effective treatments for reducing tic severity are antipsychotic medications such as haloperidol,

pimozide and risperidone, although these medications rarely eliminate tics and are often associated with unacceptable sedation, weight gain, cognitive dulling and motor adverse effects (Scahill, Erenberg, Berlin, Budman, Coffey, Jankovic et al., 2006). A comprehensive European guideline on pharmacologic treatment of TS has also recently been developed by the European Society for the Study of Tourette Syndrome (ESSTS, 2011). This work reviewed all studies that document the effect of pharmacological treatment options for TS and other tic disorders between 1970 and November 2010. The ESSTS Guidelines Group provides recommendations for the behavioural and psychosocial interventions of children and adolescents with tic disorders, finding the most evidence for the recommendation of Habit Reversal Training and to a lesser extent Response Prevention. This research recommends behavioural treatment as the first line offer of treatment to patients in most cases but states that it should be embedded within a psycho-educational and supportive context and can be combined with drug treatment. This reinforces suggestions by Cutler, Murphy, Gilmore and Heyman (2009), that education about tic disorders and the provision of support and reassurance to patients and their families should be the cornerstone for all other treatment interventions.

What is interesting, and certainly impacts home life and is later reflected in both case studies included in our discussion, is that “many patients do develop their own strategies to aid relaxation which have a bearing on tic severity” (Robertson and Stern, 2000). Research describes confused parents of children who seem ‘miraculously cured’ in front of doctors, showing no trace of tics that appeared uncontrollable only minutes before in the surgery waiting room (Packer, 1997). It is often the case that children with TS are worse at home compared to school. When children are relaxed at home they can often find it easier to release tics which they might suppress or hide outside the family environment (Robertson and Stern, 2000).

1.4. Co-Morbidities

While most tic disorders require little or no medical treatment, Chowdhury and Christie (2002) conceptualize TS as a spectrum of disorders ranging from mild, transient tics (affecting about 10% of school aged children) to TS complicated by comorbid psychopathology requiring multiple interventions. Research suggests that almost half of

the children with TS present with at least one comorbid disorder (Budman and Feirman 2001). It is estimated that 32–83% of children with TS have Attention Deficit/Hyperactivity Disorder (ADHD) (Comings and Comings 1988). There is also support for high rates of comorbidity between TS and Obsessive Compulsive Disorder (OCD), it is estimated that 30-70% of children with TS have OCD (Carter, Pauls, Leckman, and Cohen, 1994; Geller, Biederman, Griffin, Griffin, Jones, Lefkowitz, 1996; Grad, Pelcovitz, Olson, Matthews, and Grad 1987; Kadesjo and Gillberg, 2000; Nee, Polinsky, and Ebert, 1982; Walkup 1999). It can be these comorbid conditions that may be of more consequence to children and caregivers than TS itself.

Other comorbid problems can result in external behavioural problems at school and at home and therefore not only affect the child but also the parent and teachers in their sphere. These could include oppositional defiant disorder (ODD), aggressive behaviors, conduct problems, and explosive outbursts, depression, and bipolar disorder. It is also reported that 25–35% of children with TS are prone to explosive outbursts, significant temper tantrums, and conduct problems (Budman, Bruun, Park, Lesser, and Olson, 2000; Kadesjo and Gillberg 2000; Stefl 1983). Of students with TS and comorbid ADHD, approximately 23% also presented with a co-occurring learning disability (Schuerholz, Baumgardner, Singer, Reiss, and Denckla, 1996). In addition, children with TS have higher rates of depression and bipolar disorder compared to the general population (Comings and Comings, 1985; Kerbeshian, Burd and Klug, 1995). The presence of depression or bipolar disorder is a major predictor of psychiatric hospitalization and dysfunction (Coffey, Biederman, Geller, Spencer, Kim, Bellordre, Frazier, Craddock, and Magovcevic, 2000). All of the above could influence the quality of life of both the individual with TS and their family unit and caregivers.

1.5 Quality of Life

Evidence also shows that the main comorbid conditions, ADHD and OCD have a detrimental influence on the cognitive performance of children with TS (Como, 2001). TS generally begins in middle childhood, reaching a peak at between 10 to 12 years of age, and is seen at its most severe during these years (Leckman, Zang, Vitale, Lahnin and

Lynch, 1998). It follows that it is not only the child that is affected but also their family and primary caregiver, usually the mother.

Murray, (1997) states that people with TS may need assistance with interpersonal relations, as TS symptoms can lead to peer rejection. He also states that TS sufferers, although having average IQ scores, may have difficulty with concentration, reading and writing. These difficulties could be sufficient in themselves to lower self-esteem and increase the tendency towards depression, loss of control, and a feeling of being different to others. He suggests supporting the parent or Caregiver, stating that that psychological counselling may be needed, as it could relieve the emotional sequelae of an adjustment to the diagnosis of TS for all the family (Murray, 1997).

Wilkinson, Marshall and Curtwright (2008), suggest that parents reported higher levels of stress – to a clinically significant level – when they perceived their child’s academic performance as below that of other students. They also suggest that the correlation between the decline in a child’s academic performance and the number of co-morbid disorders he suffers from is a positive one. Family based interventions can be effective in reducing parental stress (Anastopoulos, Shelton, DuPaul, and Guevremont, 1993; Edell and Motta, 1990). In a more recent study, Conelea, et al., (2010), noted that a significant number of their parent sample reported distress related to their child’s tics, and that improvement of family functioning could occur when parents engage in adequate psycho-education or support.

1.6. Caregivers and Family are affected:

Stress and care demands are expected to be strongest for mothers in two-parent families, compared to the demands on fathers, because of the greater responsibility mothers tend to have for direct child care, (Lamb 1986; Russell, 1986). It has been found that mothers of TS patients had lower self-concepts than mothers in a control group, whose children did not suffer from TS (Edell and Motta, 1988). This finding might also suggest that it is important to consider family members in the treatment of children with TS. Further evidence to support this strain on mothers, can be found in Mash and Johnston’s study (1983a) reporting markedly higher levels of stress in Mother-son dyads of hyperactive children. While this study does not focus specifically children with TS, it highlights that

stress was associated with child characteristics such as distractibility and degree of bother as well as parent characteristics including feelings of depression, self-blame, social isolation and incompetence in parenting skills.

Family members are also stressed by the disorder finding themselves “bewildered” when TS symptoms first appear (Stefl, 1983). Families with a child, a spouse, or a parent suffering from TS report increased marital difficulties, alcohol problems, and substance abuse problems (Stefl, 1983). This study did not separate adults and children when the data was analysed so it is difficult to differentiate family effects when the affected individual is a child versus when the affected individual is an adult (Wilkinson, Marshall and Curtwright, 2008).

Cohen, Ort, Leckman, Riddle, and Hardin, (1988) describe some of the frustrations and limitations that parents feel in their research that directly examines the impact of having a child with TS, noting in particular that parents’ perceptions of their child’s tics are more negative than the perceptions of people outside the family. Furthermore, they reported that the parent–child relationship is influenced more significantly when TS symptoms are accompanied by co-morbid symptoms, especially ADHD and aggression (Wilkinson, Marshall and Curtwright, 2008).

One of the few controlled studies of the impact of TS on caregivers in the UK was conducted by Cooper, Robertson, and Livingston, (2003). This investigation compared a group of children with TS to a group of children with asthma from the same outpatient clinic in London. Results indicated that mothers of children with TS had significantly higher rates of mental health problems and felt a significantly greater burden than mothers of children with asthma. These results suggest that the stresses associated with TS exceed those of a chronic, life-threatening physical illness. Mothers of children with asthma reported that the source of their stress is illness-related, mothers of children with TS reported that the source of their stress was related more to managing the child’s daily activities and to the child’s behavior (Cooper, Robertson, and Livingston, 2003). Such findings underscore the potential effects of comorbid psychopathology on parent stress.

There have been several studies conducted to evaluate how ADHD affects the family. These have focused on the interactions between the parent and child, and researchers have demonstrated that parents of children with ADHD report poor parent–

child interactions and increased maternal depression and anxiety (Barkley and Cunningham 1979; Barkley et al. 1992; Fischer 1990; Mash and Johnston 1983a). The extant literature suggests that the co-morbid mood and behavior disorders, as well as learning difficulties associated with TS contribute to parental stress. Yet previous literature has not adequately examined the reported parental stress experienced in the presence of a child with uncomplicated TS as compared to TS complicated by comorbid conditions (Wilkinson, Marshall and Curtwright, 2008).

1.7.Emotions:

The articles referred to discuss caregiver strain and burden, yet one of the most descriptive passages in all the literature which could indicate the emotions of the family, and in particular the parents or caregivers, is not based on this specific cohort of parents but is an examination of the clinical and psychological aspects of TS. The quotes below give a sense of the battles between the child with TS and their parents and families. The sense of anger and lack of control is pervasive, and affects everybody touched by this disorder. "If there was a single word that best characterized the behavioral problems in TS it would be "anger" Comings and Comings, 1985:442). Many patients were described as having a "short temper" and were "easy to anger" by their families. Typical parental comments were: "every interaction escalates into a major confrontation," "he seems to have been angry ever since the onset of the tics," "unpredictable," "overreacts to minor things," "always finds a negative aspect in every thing," and "life with him is a constant battle." Mothers describe sons as having a "Jekyll-and-Hyde personality" (Comings and Comings, 1985:442). This article discusses how the family life is impacted and clearly states that TS must thought of as a family disorder, maintaining that no one in the household is unaffected. It could be understood that caring for a child with TS who exhibits the behaviour described above, could have the effect of escalating emotions and affecting mothers self perception (Edell and Motta, 1990), and self-esteem and generally contributing to the 'bewilderment' described by Stelf (1983).

1.8. Need for Support:

In the USA Edge-Schoeder and Remer (2007), assert that research has largely focused on the individuals with TS and not on their caregivers. They surveyed 140 caregivers of children who suffer from TS, and their findings suggest that perceived social support was a partial mediator of child's symptom and caregiver strain. Parents may be more susceptible to adverse health consequences because stress related to children's behavior has shown to negatively affect parents' wellbeing (Early, Gregoire, & McDonald, 2002). Caregivers of children with disabilities have even more vulnerabilities to stress which may put them more at risk, than caregivers of children without disabilities (Brehaut et al., 2004; Edell-Fisher and Motta 1990; Fuller and Rankin, 1994). As mentioned earlier mothers of children with TS had lower self-concepts than the mothers of controls, and may feel some guilt and shame, particularly if a pattern of genetic transmission is evident (Edell-Fisher and Motta, 1990). In an earlier study the authors found that the child's perception of parent-child interaction was a significant predictor of the child's emotional adjustment to TS. (Edell and Motta, 1988) This finding in itself prompts a review of what could be of support to this cohort, so that their self-concept may be bolstered and sustained, which would in turn provide them with more internal resources that could aid their child's emotional adjustment to their disorder. The child and the family as a whole could benefit from parents receiving emotional support after diagnosing a child with TS (Packer, 1997).

Joachim & Acorn (2000) discuss the possible stigmatization of having an illness or disorder that differentiates one from the general population, coping with stigma can add to the burden and stress having an impact on the care-giver's self concept, and thus is another contributing factor necessitating a support program for the families of children affected by TS. Parents may feel overwhelmed by the diagnosis and the need to educate school and childcare providers as well as other family members about the diagnosis (Haerle, 1992).

Chapter 2: Methodological Approach

2.1. Design:

The current research study used the qualitative approach of two case studies comprised of semi-structured interviews, analysed by the method of Interpretative Phenomenological Analysis, (IPA). This method is used because of the intensive exploration of the emotional experiences of the participants that is required. The case-study involves in-depth, individual interviews with two mothers of sons who have been diagnosed, and are living with TS. The qualitative method of conducting research is respectful and empowering, allowing the interviewee to construct a narrative, rather than the interviewer constructing it for them (Morgan, 1997).

This is particularly relevant when applying IPA as there is no hypothesis but rather a real exploration of the meaning people make of their lives, in this case the exploration of how these mothers were impacted by the diagnosis of their sons and they what they have subsequently found supportive to them. The dual aim of IPA is to provide an in-depth exploration of people's lived experiences and a close examination of how people make sense of these experiences.

IPA's aim is achieved through interpretative activity on the part of the researcher leading to a dynamic process, whereby the interviewee is making sense of their experience and the researcher has an active role in understanding and deciphering their meaning of what is said. The author holds that this method of analysis, combined with the intimate and detailed insight provided by the case-studies, lends itself beautifully to the purpose of psychotherapeutic research as it echoes the very process of Humanistic psychotherapy; the researcher has to interpret people's mental and emotional state from what they say, Smith and Osborn, (2003) advocate the use of IPA, as it has a theoretical commitment to the person as a cognitive, linguistic, affective and physical being, and assumes a chain of connection between people's talk and their thinking and emotional state. While searching to ascertain an 'insiders perspective', this defines the existence of the 'double hermeneutic', neatly summed up by Smith and Osborn, (2003), when they say that 'the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world.' (2003:53).

2.2. Participants:

With a smaller group, random or representative sampling is less useful than purposive sampling, which this researcher uses. This finds a more closely defined group for whom the research question will be significant (Smith & Osborn, 2003:56). The fact that both mothers interviewed were interested in the subject of TS because they had lived with it first-hand, meant that they were relevant to this study. They were also keen to contribute to any research that may be relevant for others in their situation in the future.

In this case the two participants of this group were found through a gate-keeper; the chairperson of the only TS website in Ireland, who sent an email detailing the nature of the study, and a request to participate to the members of the site (see Appendix B). The topic under investigation is rare, and defines the boundaries of the relevant sample (Smith and Osborn, 2003). This sampling method allowed the researcher to recruit participants from one resource.

The criterion for this study was that the participant was a carer, or member of the immediate family of an individual who has been diagnosed with, and suffers from TS. Both participants of this study are mothers of boys who have been diagnosed with TS. One mother interviewed, referred to as Mother 1, has a son who is 15 years old, and who was diagnosed when he was 8 years, and the other, Mother 2, has a son who is now 24 years old and was diagnosed when he was 9 years.

The size of the sample is also very relevant in IPA Studies and smaller numbers are ideal as the distinctive feature of IPA is its commitment to a detailed interpretative account of the cases included, Smith and Osborn, (2003), refer to this as sacrificing 'breadth for depth'. The sample size of two, while it has its limitations, discussed below, ensures that each participant is given ample opportunity to give a detailed account of her experience. The researcher conducted the research in the homes of the participants, on their agreement, thus ensuring that they suffered no inconvenience of travel, and that they were in familiar surroundings which potentially facilitated their willingness to open up about their experiences.

2.3. Procedure:

2.3.1 Data Collection:

The qualitative method of case studies was used to deeply explore the experience of these two mothers. The interviews were composed of structured and semi-structured, and open questions seeking to elicit a *conversation with a purpose*, Burgess, (1984:102). Thus, unlike traditional phenomenological research that requires the researcher to approach the study by bracketing, or setting aside, her own viewpoints in an effort to minimize their influence on the data collection and analysis, the IPA framework does not consider interviews to be a neutral means of data collection.

Semi-structured interviews are considered the method of choice in IPA research, as they combine the guidance of the researcher to topics under study and the open-ended framework for participants to provide rich data (Smith and Eatough, 2006). They also allow participants to take the discussion in unique directions, permitting them more free range to discuss pieces of experience that are meaningful to them. Participants frequently discuss aspects of their experiences that were not anticipated by the investigator (Shaw, 2001). Both mothers spoke in detail about the impact their son's diagnoses had on individual members of their families, and while this was not the specific research question it was closely aligned and therefore of interest, they as mothers were affected by the impact on every member of the family.

The questions this research used were open and expansive (Smith and Osborn, 2003), and enabled the interviewee to give as descriptive and rich an account of their experience as possible. The input from interviewer was minimal, adopting a Rogerian, person-centred approach, which empathised with, and encouraged the mothers to speak as freely as they felt comfortable to.

2.3.2. Case Study:

Flyvbjerg defends the case study by saying "That knowledge cannot be formally generalized does not mean that it cannot enter into the collective process of knowledge accumulation in a given field or in a society. A purely descriptive, phenomenological case study without any attempt to generalize can certainly be of value in this process and has often helped cut a path towards scientific innovation." (Flyvbjerg, 2004:424)

Bromley (1986) also argues that case studies, although not subject to generalisation, can act as the foundation of scientific research. The case study served to gain a deeper understanding of some of the challenges and emotions of being mother to a child who suffers from TS.

The case studies conducted involved one-on-one in depth interviews. This research was not attempting to test predetermined hypothesis; rather, to explore, flexibly and in detail, the area of concern and interested in the *meaning* of the experience of the individual, (Smith, Flowers and Larkin, 2009). The two mothers spoke about their lives and struggles over the time since their sons had been diagnosed. The information that these mothers gave was authentic and detailed, singling out moments that they have felt particularly supported by individuals along their way through life, and moments when they felt angry, confused and alone.

The researcher therefore designed an individual interview guide (see Appendix A) for the participants. The interview questions correspond with prevalent themes from the review of relevant literature and research. The questions elicit responses to issues such as how the carer has been affected by the diagnosis of their son, and what impact it has had on the family dynamic, and indeed how they themselves cope with the challenges of their particular situation, and upon whom or what resources do they depend for support.

The entire interview, which lasts an hour and fifteen minutes, focused on these questions as starting points. These questions act as a guide, the purpose being to gain a deeper understanding of emotional reactions.

2.4 Data Analysis

The coding of each Interview (Interview 1 and Interview 2) involves several stages derived from the IPA model advocated by Smith and Osborn, (2003). The investigator must engage in an interpretative relationship with the transcript to try to understand the meaning behind the words. While one is attempting to capture and do justice to the meanings of the respondents to learn about their mental and social world, those meanings are not transparently available – they must be obtained through a sustained engagement with the text and a process of interpretation (Smith and Osborn, 2003). As with the

Humanistic Person-Centred therapeutic relationship, the participants were perceived as the experiential expert on the subject under discussion.

IPA is very similar to the thematic analysis approach, advocated by Braun and Clarke (2006). The recordings of the interviews are transcribed and then analysed using thematic analysis. Subsequent to collecting the study data through participant interviews, all audio recordings were transcribed verbatim and reviewed for accuracy by the researcher. In accordance with IPA procedures, each interview was read and listened to three times in order to get an overall sense of it. Thereafter, each interview was analyzed using the IPA steps delineated by Smith, (2004) and Smith and Eatough, (2006). Themes in individual transcripts were highlighted, and then connected across transcripts, and finally, translated into a narrative account.

As this project involves two participants, the transcript of Interview 1 was looked at in detail before moving on to examine Interview 2 (Smith, 2004). Particular themes started to emerge; the way the family coped with the diagnosis, the emotions these mothers felt, the support of professionals or organisations, sometimes the frustration or lack of support was alluded to by the manner in which they spoke about situations; the pitch of their voices and the unfinished sentences, rather than the words they used. When a participant finds it difficult to express their thoughts and feelings, the IPA researcher's role is to interpret their mental and emotional states from what they do say. Such inferences are made with recognition of the participant's contextual and cultural background (Reid, Flowers, and Larkin, 2005).

The natural progression of both stories covered very similar topics, such as their boy's schooling, medication and interests, but the differences lay in the experience of each mother. By remaining aware of what had come before, it was possible to identify what was new and different in the subsequent transcript and at the same time find responses which further articulated the extant themes. Care was taken to distinguish clearly between what the respondent said and the analyst's interpretation or account of it (Smith, 2004:76).

A table was created which listed all themes from of the participants' transcripts in rows, with two columns representing the two participants (Appendix E). The researcher began by listing all themes from participant one and two, until all themes from both

subjects were listed; a chronological master-list of themes is presented in the sequence in which they appeared in the data. Smith and Osborn (2004:70) describe a magnet with some of the themes pulling others in and helping to make sense of them, these are 'superordinate' concepts or themes. During this process, certain themes were discarded if they did not fit into the overall structure, or if the evidence in the transcript was not rich enough to develop them.

In this study it was found that the analysis, and the writing up of the results of the analysis, informed one other and therefore the results and the discussion are incorporated into one comprehensive chapter.

2.5. Ethics:

According to the The Belmont Report of Ethical Principles and Guidelines for the protection of human subjects of research, outlined by The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in April 18, 1979 there are three main principals that are relevant to the area of research involving human subjects; Respect for persons, Beneficence and Justice.

Respect for Persons incorporates at least two ethical convictions: firstly, individuals should be treated as autonomous agents, and secondly, that persons with diminished autonomy are entitled to protection. Qualitative research such as this, where the questions are open ended and the participants can choose where they wish to take the conversation takes account of this.

In 2012, an ethical committee reviewed the research proposal and made the suggestion that the initial research proposal be refined in order to exclude individuals who suffered from TS and therefore eliminate any risk of traumatising a vulnerable population unintentionally. In this study only willing participants who were directly relevant to the question were approached as subjects. This would also protect participants under the code of Beneficence cited below.

The code of Beneficence outlines that Persons are treated in an ethical manner not only by respecting their decisions and protecting them from harm, but also by making efforts to secure their well-being.

The British Psychological Society (2002) states that participants in psychological research have the right to have the information they provide remain anonymous. The use of pseudonyms (e.g. Mother 1 and Mother 2) in the present study enables the participants to remain anonymous. The researcher has removed any identifiers (e.g. place names, other people's names) from vignettes that are used in the present dissertation. An information sheet and consent form (see Appendix C and D) is used to inform the participants of anonymity, of the right to withdraw and of their right to have any information removed from the study. Participants have also been made aware of the potential risks of collaborating in this study. Due to the personal nature of their stories and the possibility that the discussion may evoke an unexpected emotional response within them, that may be and upsetting, details of psychotherapists willing to provide a free session to the participants were provided for them to avail of if necessary.

Before the interviews are conducted, participants are given time to familiarise themselves with the information sheet and consent form and given the opportunity to ask any questions. Participants were informed of their right to disclose or withhold personal material at their own discretion.

2.6. Limitations:

One of the main limitations of the use of the open ended interview technique is that it might be difficult to replicate (Coolican, 2004). Another limitation that this researcher sees is that the style of interviewing reduces the control over the situation, takes longer to carry out, and is harder to analyse (Smith & Osborn, 2003). Another potential limitation of this study is that it only includes two cases. Smith, (2004) has argued the case for the single case study, but recommends three as an ideal number for the sample, and on reflection, due to the very different responses of the individuals interviewed in this study, a third perspective may have provided a more balanced view. However, these arguments can be countered by the fact that there is a vast amount of information which is generated and the analysis needs to penetrate this sufficiently to be a relevant IPA study.

Chapter Three: Analysis of Results and Discussion

3.1. Themes:

The experiences of two mothers' of sons diagnosed with TS, were so rich and varied that the superordinate themes which emerged from the analysis of the two case studies each included a number of subordinate themes. The main themes were Family Attitude, Support, and Emotions. It was not necessary for each interviewee to display evidence of all themes, nor have they necessarily been selected on the basis of prevalence. Factors such as the richness of the accounts, or how certain themes illuminated other aspects of the account, were all considered important for the development of these themes.

Under the theme Family Attitude, the Impact of the Diagnosis and Social Stigma were important sub-themes. If we take into account that 'no man is an island', then this statement is true nowhere more so, than in one's family of origin. Even if connections are not apparently close, the family operates as a system and each member impacts on the other. One of the central premises of family systems theory is that family systems organize themselves to carry out the daily challenges and tasks of life, as well as adjusting to the developmental needs of its members (Minuchin, 1974). Individual family members are mutually influenced by, and mutually dependent upon one another. What happens to one family member, or what one family member does, will influence the other family members.

Both Mothers expressed emotions through what they said and the way in which they relayed their stories. Some of their emotions were expressed clearly and some were left to interpretation. The emotion with which they described their individual scenarios was imbued with meaning. If the text was to be looked at through a psychotherapeutic lens, the language and pitch they used while being interviewed, the roles that they and others played, and the possible defence mechanisms that these mothers used unconsciously, would also be rich sources of data, the aim of this research was to adhere as closely to their stories, and their own meaning of their situations as possible. Emotion was intrinsic to their stories as they were describing their and their family's lives. Fear, worry, relief, anger, guilt, responsibility and loneliness were just some of the emotions that surfaced and were spoken of during the interviews.

Although at the outset, this study did not have a set hypothesis, the question of support had reappeared in the literature pertaining to mothers of children with TS and associated disorders. These mothers cited family and extended family among their sources of support, along with psychologists, psychotherapists, doctors, teachers and the educational system, the support members of the Tourette's Association of Ireland, and other mothers and families in similar situations.

The role of psychotherapy and whether or not, it was used, or even considered, as a support mechanism for these women is briefly discussed in this chapter. It is a form of support and research cites the need for support for the families of children with TS. Both women's perceptions of psychotherapy are discussed below.

As the results and analysis informed one other and therefore are incorporated here into one comprehensive chapter, a summative overview of the results of the case studies can be found at the end of this chapter.

Presented below are excerpts from the transcribed interviews as exemplars of the context of the themes within the interviews. The participants' names (and possible identifying details) have been changed to preserve anonymity. Mother 1, Son 1 and Dad 1 refer to Interview 1, and Mother 2, Son 2 and Dad 2 refer to Interview 2. The letter "T" denotes the interviewer.

3.2. Family Attitude

It was difficult to pin-point the reasons why certain events in each case took a particular direction. Similar situations of two mothers of boys diagnosed with TS, at a similar age resulted in two very different experiences for each family. This research examines the possibility of core family beliefs and values, which have remained unspoken, influencing what this research will call 'Family Attitude'. This broad term will include what might define success and achievement. It will try and understand the sense of each family functioning as a unit, looking inwards for support and sustenance, or whether support is perceived as something that comes from an external force.

3.2.1 Impact of Diagnosis

As TS is not usually diagnosed until mid childhood, at about 7-9 years of age, (Chowdhury and Christie, 2002) it can be a frightening thing for parents to come to terms with if they have no prior knowledge of TS. It is worth considering that it can also be a relief to hear a diagnosis that explains their child's often overnight changes (Packer, 1997).

Mother 1; ...he had a full neurological exam. We went early in the morning and she came to us about one o'clock and she said 'Tourette's is usually diagnosed over a period of time as in they have to be recurring and consistent' and you know and she said 'but I strongly suspect he has Tourette's syndrome' and we came out of the hospital and Dad started crying.

Mother 1... I was relieved...Because all I could think of was epilepsy, a tumour. ...Yeah so I can live with Tourette's... If he has Tourette's I don't care, we'll get through Tourette's. Dad was devastated.

Mother 1 had prior knowledge of TS and had a background in Special Needs Teaching with exposure to disorders in children – it is interesting that she cites her initial reaction as relief when her husband who has no prior knowledge of TS is 'devastated', this would support the view that the reassurance and education of families around TS after their diagnosis is the cornerstone of all treatment (Cutler, Murphy, Gilmore and Heyman, 2009). Minuchin's family systems theory (1974), also can explain how hard Dad 1 takes the news as he has been influenced by the history of mental illness in his family.

Mother 1: he was very upset because he started thinking of mental illness and depression and suicide and his brother before he committed suicide was diagnosed with paranoid schizophrenia. He had a first cousin with schizophrenia and he thought this is the rocky, slippery road to schizophrenia, you know, paranoia and so on. Now he knows that's not the case but then...

This family seems to function as a close unit, that sees support coming from within, but that can also be received and accepted from outside their microcosm.

Mother 1:like when we were there first and this is a really big thing. When we had Tourette's first it was a huge thing in our lives. (Raised voice)... Huge (raised voice).

Of note in this passage is that she speaks in the First Person Plural ‘we’, ‘when we had Tourette’s first’ and it was a huge thing in ‘our lives’. This is in contrast to a number of later excerpts from Interview 2, where Mother 2, although having a close relationship and marriage to her husband, seems, from her description of events, to be coping with the diagnosis alone. Comings and Comings (1985), suggest that for the complete treatment of TS, it must be thought of as a family disorder since no one in the household is unaffected. After the diagnosis Mother 2 relates;

Mother 2: Dad was very scared but he would go off to work during the day and escape a lot of it whereas I was at home with the baby and him and Brother 2 as well and thank God I had an au pair around the house because I think I would have been driven demented but anyway the diagnosis was made at Christmas.

Here she mentions that Dad 2 ‘escapes’, It is difficult not to notice the contrast between the Family Attitudes towards the diagnosis of TS just received. While they mention the devastation and fear of the fathers, respectively, which are similar, one couple seems to be closely involved, and the other dealing with it each in their own way. This feeling of separateness could also be implied from the way that Mother 2 tells her son that that something is wrong with him and that they will find a solution to help him.

Mother 2: So I just explained it to him (Son 2) that we were going to sort it. That this was something that was really, really frightening him and ...and we were going to find the doctor that was going to help him. We didn’t say fix him but we said help him ...

Relating back to Minuchin’s family systems theory (1974), it is possible that this turn of phrase could appear to be making the son into the scapegoat, or vehicle for the problems of the rest of the family, and thus enabling them to each define their roles around his having TS. What is also of note in the above passages is that Mother 2 refers to ‘his’ diagnosis and the first family call it ‘our’ diagnosis. If we are to look at TS as a family diagnosis then the impact is shared, and it is less ‘his’ diagnosis but rather the whole family’s diagnosis, this in itself may relieve some of the strain from the mother alone. It could be important to look at the role of the family in the treatment of the individual, based on the view that the family is a self-regulating unit; stress in one part of the family is seen as affecting all other members (Minuchin, 1974).

3.2.2. Social Stigma

Cohen et al., (1988) note that parents perceptions of their child's tics are more negative than the perceptions of people outside the family. Parents imagine them to be worse than they are. TS is a disorder that has very obvious physical manifestations that differentiates one from the general population, this can cause stigma ,and coping with stigma can add to the burden and stress having an impact on the care-giver's self concept (Joachim and Acorn, 2000)

Mother 2: ...and then you start looking for tics. The ones that they (the websites) were describing, you were imagining he was having even though he hadn't got them (laughs). He had enough going on, believe you me.

Mother 2 is imagining tics he does not have, therefore perceiving them as worse, or more than they are. What is noticeable is the sense of isolation and possibly social stigmatization that both mothers feel.

Mother 1: ... we occasionally go out for a meal as a family and there was a couple of times when he was very bad in fifth class, we stopped going out actually because he could not control it and it used to upset Dad 1 when people used to stare and Dad 1 used to get annoyed with people in a restaurant that would stare. We used to go into this particular pub ... because they had booths and we felt we had a bit of hmm...Privacy or like it was a kind of a barrier between us and other people, you know, but people even walking by would make comments, you know, not comments, they'd stare, you know.

In the above passage the impact on family life is clear, they stop going out for family meals for a period while their son's TS is bad, Dad 1 is annoyed, upset and protective of his son as others (outside the family and their 'private booth') stare in. They segregate themselves, and choose their venue due to its ability to section them off from the outside world. Possibly they feel TS as the barrier between them and other people.

There is description of Mother 2 falling and breaking her elbow in a car park, shortly after her son's diagnosis. She describes herself more concerned about the security guard's impression of her distressed son whose tics were 'exploding', than her own situation, this highlights that even in acute pain Mother 2 was concerned about what the perception of her son might be.

Mother 2: I was sort of making excuses for him because he all over the place now (raises voice). The ticks were really after exploding. I said 'Just don't pay attention to my son', I said 'God help him' I said 'He's just had a recent diagnosis of Tourette's'.

She goes on to explain that the English Security Guard helping her has heard of TS

Mother 2: I was more conscious of him (Son 2) than I even was about my elbow (laughs).

3.3. Emotions

As we look at the variety of emotions that are mentioned throughout both interviews a range can be noted but there is an underlying theme of worry about their sons in both women's stories. As we have seen from extracts above, after the diagnosis fathers are described respectively as devastated and scared. Other children are mentioned with little traces of concern through the interviews, yet when they speak of their sons with TS there is a sense of the mother's paving the way for their sons, be that calling parents of school friends ahead, or talking to the kick-boxing instructor before her son joins, or calling Irish college ahead to make sure a son's condition had been noted;

Mother 1: ...and in fact I make a point of highlighting, I will phone them and say just in case you did not get a chance to read the application forms, he has Tourettes.

Mother 2 describes telling her son's pals mothers unbeknownst to him, because she wanted to prevent him being bullied or picked on;

Mother 2: ... He didn't want anybody to know....So it was close family and what I did was because I needed him to be, not to be bullied by kids ...I decided to tell their parents..... And like I felt that I was doing the right thing. I didn't think I was betraying confidentiality. I felt that I was looking after him. You know preparing the road. I was like a road sweeper you know (laughs).

This 'road sweeper' analogy could possibly fit with what Mother 1 does not say when she is describing when Son 1 when to secondary School and "I went ahead and I sort of... ", 'paved the way' or similarly, 'prepared the road' could also fit here. Their attitudes to their sons are similar, their worry and the desire for them not to be bullied or singled out

urges them go ahead and prepare the way for them. Responsibility for their child seems to weigh heavy on these women's shoulders,

Mother 2: And I suppose the very fact that Son 2 is now living away from home, that's a good thing because I know he's twenty-four but even when he was twenty I was probably still, you know, concerned, worried, you know.

The results of Cooper et al., (2003) indicated that mothers of children with TS had significantly higher rates of mental health problems and felt a significantly greater burden than mothers of children with asthma. Mothers of children with TS reported that the source of their stress was related more to managing the child's daily activities and to the child's behavior. These results suggest that the stresses associated with TS exceed those of a chronic, life-threatening, physical illness, which was asthma in this particular case (Cooper, Robertson, and Livingston, 2003).

Mother 2: So maybe did I try to put him in a box in each part of his life, do you know what I mean? Did I find for a space for him? Did I try to control what he was doing? Did I try to control to outcome? I know I certainly did control whoever he met, that would have understood his condition but did that kind of go on a pace a little bit too much, you know.....Did I want him to get that result and if he didn't do that work he wasn't going to get that result so was I trying to control what he was doing next....?

Both Mothers strongly express moments of guilt and self-blame about their son's condition reflecting Mash and Johnson's findings of parent's feelings of self-blame. Their research examined Mother-son dyads (1983a) and reported markedly higher levels of stress than parents of normal children. Stress was associated with child characteristics such as distractibility and degree of bother as well as parent characteristics including feelings of depression, self-blame, social isolation and incompetence in parenting skills, which is echoed in the self-questioning of Mother 1 and 2;

Mother 1: And you know even I like, I remember thinking what did I do to give my son Tourette's. What did Dad 1... did we do something to give our son Tourette's, you know, and you know all that guilt initially and I remember I didn't know I was pregnant with Son 1, when I was pregnant and we went, you know, we'd a very busy social life ...I went out a couple of nights and I'm sure I had lots

to drink. And I kept thinking was it because, you know, it's something to do with, you know, foetal alcohol syndrome. Did I give my son foetal alcohol syndrome.

Mother 2 asks herself was she a bad parent;

Mother 2: and then of course I remember thinking Jesus I did something wrong, like I mean I'm a really bad parent here. What went wrong, you know.

Responsibility and guilt are the interconnected when she says that her guilt dissipates when she realizes that her son has to 'do it himself', she relinquishes responsibility for an entity beyond her control and it stops her feeling 'guilty'.

Mother 2: So that was hard to hear but it stopped me then feeling guilty about why he wasn't achieving. Son 2 would have to do it himself if he was ever going to achieve.

This mother was notably upset when she discussed her son's academic achievements and the fact that she felt he had so much potential that was untapped at school. She wanted him to do well so that he would not find his future difficult. Wilkinson, Marshall and Curtwright (2008), suggest that parents reported higher levels of stress – to a clinically significant level – when they perceived their child's academic performance as below that of other students.

3.4. Support

Support is something that everyone needs from time to time, and a concern of the working psychotherapist for their client would include 'what support structure does this person have around them?' Support can be perceived, or actual, it can come in the shape of family or friends, a Medical System, a School System, or an unknown kindly individual. The support, and lack of it, that these women describe comes as all of the above. There are parallels and differences in what each found supportive. Both describe a loving and supportive husband and both mention siblings and friends. For the participant of Interview 1, the key areas of support were the Medical System and the individuals she encountered therein, The School and teachers, some of whom she singles out as 'wonderful' individuals. While Mother 2 sees that both these structures should have been a support, she appears to feel like they were not, the interviewer had a sense of her disappointment and her feeling isolated and let down. The Tourette Syndrome

Association of Ireland (TSAI) has also been a support network for both, through which they were introduced to other families with TS who met and advised them after the initial diagnosis, and through which they subsequently met and advised others at the earlier stages of their diagnosis. Mother 1 says she depended on the contacts made through TSAI.

Mother 1: I have to tell you really that initially I depended on people like X and Y, and other parents for support.

Okay.

Mother 1: And I have now become that source of support for other people.

Mother 2 describes her first realisation that TSAI existed and how she felt;

Mother 2: I...and I contacted this girl and she came over to the house, explained about her own son, that he had it and all of a sudden then it was well its not just not us, you know, there are lots of other people ... 'There's people locally here' she says 'Who have children with Tourette's' and I go 'Right, wow'.

The 'Its not just us' here that hints at the isolation she might have been feeling, and her astonished gasp of 'wow' when she realised there were families closer than she imagined. In previous studies, when parents of children with TS believed that social support was available to them their sense of well-being improved, perceived social support has been found to be a partial mediator of child's symptom and caregiver strain (Edge, Schoeder and Remer, 2007). She describes how supported she felt when they met as a group;

Mother 2: It was the physical support or the mental support of having four or five other people who were 'God did you go through that before? ... and what did you do there?' or even a phone call, you know, to be able to ring somebody and sort of chat about what it was like for them when they were going through that and what did you do then, you know.

The support felt by Mother 1 is further described by how her son's secondary school catered to his specific requirements, it is clear she is in close communication with them as she reads out an extract from a letter from the school describing the arrangements they have made for her son:

I: The school sounds like it was supportive

Mother 1: Yeah and then he went into secondary school. I went ahead and I sort of... The big thing with Son 1 actually was that he had a place to go.... (reading letter from school) ...”We’ve organised a new timetable with him so he can go out three times a day”. ... Now I can tell you they cleaned out the store room. They filled it with posters and put in a little beanbag in there....He could leave the class-room and he could go in there, and he could bark and shout and roar and yell all he wanted and then when he was ready he would come back into class.

Research suggests that some children appear to benefit from having permission to leave the classroom briefly to release or "let out" tics, which they have been suppressing. Permission to take short breaks may diminish class disruption as well as the child's anxiety (Walter and Carter, 1997). When discussing the support she felt while her son was at school Mother 2 is of the opinion that if you get an empathic teacher in National School “you are made, you know they’re like the mammy in the class anyway”, but the experience of Secondary School was difficult, dismissive and appears to have had an impact both on her self-esteem and her relationship with their child.

Mother 2: But now we’re dealing with a whole different scenario where you have, you know, maybe older type teachers who wouldn’t take any kind of, ah that’s poppy cock type of crap and then the other teachers who are ‘Yeah, yeah, yeah’, they do the nodding but they don’t do the giving.

Walter and Carter, (1997) also warn that a negative emotional reaction is likely to make a child afraid, upset, or hostile and it is worthwhile to bear in mind that most children are extremely frustrated by and embarrassed about their tics. Tics tend to be sensitive to stress and may become worse as the child becomes more frustrated or fearful. The teacher is a model for the children in the class.

Mother 2: for all of Son 2’s school in secondary school, no matter how many times... I mean, I’d a path worn out to the school trying to hear what they were saying and Son 2 wasn’t, it was all negative, nothing positive. Negative, negative, negative, negative and of course now what’s that doing to me. I’m starting to turnout like them and I’m starting to judge him and say ‘You must concentrate in

school, you must, you must, you must'and I remember to the stage where I went to my own GP and I said 'I can't cope with this anymore'.

The sense of overwhelm is palpable here and the description above of a path worn to the school reflects findings of Haerle (1992), who suggested that 'parents may feel overwhelmed by the diagnosis and the need to educate school and childcare providers as well as other family members about the diagnosis'. Because of the potential stigma involved, the management of the information about the TS diagnosis - whom to tell, how, and when - can be quite stressful for children and families (Joachim & Acorn, 2000). This mother goes to her GP because she can no longer cope. In the following extract her frustration and sense of helplessness and disappointment with the school system, surfaces as she describes a discussion she had with the principal after her son had left the school;

Mother 2: 'You know', the Principal said to me 'We never really gave up on him', and I said 'Yeah, hello' (laughs). I said 'You wore me down'. I said 'You should have been able to in far better control than I am', I said. 'I'm not as educated from an educator's point of view'. I said 'I'm a parent and a mother and I'm you know trying to encourage and support and whatever but you have the skills to support him. You even had psychologists who could have supported him but you didn't', you know so. Look, you know, he's out of school. He's out of that mode.

With regards to the Medical System, both women encountered very different experiences. Mother 1 describes her son's psychiatrist with fondness and appreciation that transcend the expected relationship of Doctor/Client, which can be explained by what a caring and engaged support she found him to be:

Mother 1: Ah he was wonderful. I think what I really liked about him was that he was genuinely interested in all aspects of Son 1's life.....So yeah he was great. He was a wonderful psychiatrist. I can't even tell you what wonderful care Son 1 got from this man.

How supported she, and her family, has felt from the care of their psychiatrist, is illustrated in her despair at hearing he was due to retire;

Mother 1: He said 'I'm taking early retirement' and I said 'Oh that's wonderful, that's great' and you know we chatted about that for a few minutes and I went to the loo and closed the door and I cried for twenty minutes.

Mother 1... it was such a positive experience.

When Mother 2 describes how her son came off his medication, she says he felt like a guinea pig, a far cry from the support and interest that Son 1 felt in his life from his Doctor,

Mother2: ...he felt that he was a guinea pig he told me and they (the doctors) hadn't a clue what they were talking about

Yet Mother 2 seems to be able to use the visits where she brings her son to see his psychiatrist, as a source of support for her, almost like she was in therapy.

Mother 2: Whilst I felt when I would go to visit her, I felt that it was my way of letting out a lot of my fear or my stress or my whatever.

Mother 2: So I actually felt that I was actually maybe in therapy (laughs) rather than him, you know.

This is a complex dynamic as she is aware that the resource is for her son, but it seems that she too needs an outlet. This concept of her need for support is indicated in research that suggests caregivers should be supported (Edell and Motta, 1988; Murray, 1997). While gaining some relief by this method of therapy 'by proxy', there are times when she does not feel supported or heard;

Mother 2: They were supporting him and ... I used to often feel that I was probably going in with such negative feelings myself about how it was affecting him and I didn't think they heard that a lot of the time. All they could see was that Son 2 is a remarkable guy and was managing his tics so well because he wasn't the drama queen. He wasn't the having the explosive type of, I don't know, scenarios where you might have a kid who totally goes off the rails but in a way maybe that was privately going on between him and I all the time.

Her use of the term 'drama queen' could suggest that she felt she was perceived as a Drama Queen, if so that would not seem supportive or empathic and could compound her sense of isolation and possibly frustration. The word 'explosive' appears here and reappears throughout her dialogue. This tranche of text evokes the description of the

difficult parent-child dynamics described by Comings and Comings, (1985). The explosive anger they discuss is mentioned and the private dynamic between mother and son. They mention a “Jekyll-and-Hyde personality”, which is exactly what she says she feels her son sometimes has. Her frustration is again palpable later says that she does not feel her son had a good experience within the Medical System:

Mother 2: ...I don't think he had a good experience within the system right. He felt that first of all there was no continuity in the service, he was lucky he had who he had for a couple of yearsbut it was always somebody new coming in and asking him the same questions.

I: The same questions?

Mother 2: Ah Christ if they asked him about his medical history I think he'd strangle them, you know....Why the hell, they can f***ing read the brief, you know. Sorry now to be rude.

3.5. The role of Psychotherapy:

Mother 2 does not receive support from psychotherapy but does allude to her many external civic and parental association duties as a support to her, she also describes a close family, with a degree of ‘volatility’ which she believes has had a part to play in their continued closeness – in that emotions are expressed and “are out there.” Volatility is an expression that is closely aligned to some of her expressions to describe the family unit and her relationship with her son. It is, after a brief conversation about her own opinion of psychotherapy where she says she thinks it's great, that the above passage follows about her son feeling like a guinea pig in the system, and her exasperation about doctors and psychologists not reading the brief and repeating questions – this is the only time in the interview that she uses the ‘f’ word and then apologises for being rude.

Mother 2 has never considered Psychotherapy, yet she seems to have been able to use her son's psychiatrist to release her fears and worries to. Psychotherapy was not even considered as an option of support that she could attend and use for herself. Although Mother 2 describes herself as having a positive view of psychotherapy, her skepticism and distrust may be implied from what she says about her second son finishing a short period of attending a psychotherapist. She mentions that as he is an adult she is “not part

of that intervention”. What is telling is that when she says he has only been attending for a couple of weeks it is immediately reinforced by “it wasn’t too bad” as if maybe attending for longer could be perceived to be something ‘too bad’. There is a sense of her exclusion from the process and querying “what’s this all about”. She also is under the impression that he has been ‘directed’ to go somewhere (emotionally).

Mother 2: He was only going for a couple of weeks....You know it wasn’t too bad, but he said ‘But I’m not ready to talk to you about it’ and I said ‘Okay fine and whenever you’re ready’.’ I don’t think I will ever be able to talk to you about it’ and I go oh right Jesus what’s this all about and then you’re trying to sort of, you’re thinking what is it about? Is there something that I need to know or is it something that he doesn’t want to tell me or is it something that I need to know at all or maybe it’s nothing.

I: Is he still going?

Mother 2: No he stopped going.....And I thought he stopped going because he didn’t maybe want to go wherever he was being directed to go.

Mother 1 uses a psychotherapist as a place where she first went to address her own past, not for anything related to her son having TS. She initially used therapy as a place to ‘just cry’. She describes how it serves as just ‘time for her’ and is ‘a very positive experience’, where she feels fully supported, to the extent that her therapist offered to drive back from another part of the country to see her when she was in a crisis. She describes the safety she feels in the ‘small, little, cosy room’ as empowering her and enabling her;

Mother 1: At being a better parent and a better, not just a better parent just a better me really, you know.

The emotions and attitude of Mother 1 seem to the researcher to be flexible and adjusted, she displays resilience and balance in her demeanor and the way she describes her family and the care and support she has received. As described by Mother 1, her family unit appears cohesive and close, with many family interests and activities referred to throughout the interview.

Edell-Fisher and Motta, (1990) found that the mothers of children with TS had lower self-concepts than the mothers of controls. In an earlier study (Edell & Motta, 1988), the authors found that the child's perception of parent-child interaction was a

significant predictor of the child's emotional adjustment to TS. These findings and the experience of other clinicians (Packer, 1997) suggest that the child, and the family as a whole, could benefit from parents receiving emotional support after diagnosing a child with TS.

3.6. Overview of Results:

Mother 1 found the school and teacher to be a support, referencing correspondence at different stages of her son's schooling outlining an appropriate intervention strategy from the school. Mother 2 does not find the school supportive and seems to think that it was from her son's entrance to secondary school that her relationship with him declined.

Mother 1 found her doctor, psychiatrist and the medical system in general supportive on the whole, with the exception of two individuals singled out as unhelpful, the exception rather than the rule. Mother 2 found the psychiatrist helpful possibly as a place where she felt able to release her own concerns, but there is ambiguity around this, as indicated in the text above, as she sometimes feels she may not always have been heard. She does not single out anyone in this system as having provided 'wonderful care' and on the whole seems more disillusioned than supported by this system where questions to her and her son were often repeated by changing staff, and she felt treatment was based on a system of 'trial and error'. Both mention courses of Cognitive Behavioral Therapy (CBT); Mother 1 finding it useful for allaying her son's anxiety but with regards to his tics the impression was that he had figured out himself to 'head one tic off' with another and that the treatment specifically for this purpose was 'a long way to drive'.

Mother 1: There was one time there was therapy involved and it didn't work out.

I just felt it was a long way to drive for therapy.

Mother 2 does not find this intervention useful either and feels her son did not have a very good therapist.

I: And the CBT, Did that work well?

Mother 2: No but I don't think he had a good therapist.

Still under the medical umbrella, the same medication was mentioned by both mothers, Mother 2 weans her son off almost immediately saying that it made him worse and Mother 2 finds it is the only thing that takes the edge of the tics but later describes how it

caused bloating in her otherwise thin son, and also she describes anecdotal evidence that it is like having a net curtain over you and makes everything 'kind of blurry'.

The support of the TSAI was useful and supportive to both mothers, both saying they depended on it and the information from parents who had been through what they were going through, in the early years after the diagnosis. They have both gone on to become that source of support for parents who are new to their child's diagnosis, meeting and calling them telling them what to expect and reassuring them that "there is life after the diagnosis". One mother does this because she is grateful for the support she received and 'it is not a big deal in the end' and the second mother enjoys giving support because "I actually got a buzz out of being able to contact someone and talk them through where I am now" and sees it as a source of meaning and support for herself:

Mother 2: "I sometimes feel when you can help others, you help yourself"
Over the passing of time since both have had the diagnosis, 8 years and 15 years respectively, what is interesting is that once-off encounters, and the kindness or knowledge of specific individuals stands out for both women – gestures from individuals have had a meaningful impact on these women's lives and have stood out enough to be mentioned in each interview. What is important now is the same as what is important for any mother with a son, that they have aspirations and have friends, are doing well in school, have a job, that they are happy.

Mother 1: What is a big deal is that your son or daughter is now socially active and is physically healthy, enjoys life, has goals, dreams and aspirations, you know.

There is a sense of both mothers moving on with their lives;

Mother 1: There's a point of where you hand it over to them. You can't be mothering them for the rest of your life ...

Mother 2: He went off and he found a job and then he tried FAS courses and he did various different things and he's currently working and he's happy. He's, as I said not living at home. He has an income, he has a car, he drives it around, he feeds himself and puts petrol in his car (laughs) and he has a social life. He has his friends.

And finally Mother 1 sums up her son's concerns when she says;

Mother 1: I mean.....In the grand scheme of things like.....That's what he's worried about....whether we're going to allow him to go a disco or not!

Conclusion: “There is life after the diagnosis”

This study explored the experiences of two mother’s lives after their son’s diagnoses of TS. What was important to them was the impact this diagnosis had on their family, and the subsequent relationship their son had with them and the world outside the family unit. They described their emotional responses and their support systems. The conclusion to this exploration it is that the diagnosis of TS affects the whole family, not just the individual diagnosed. The findings of this study indicate that there is a need for the parents of the diagnosed to be taken into consideration throughout the interventions with the child, and to be provided with knowledge, reassurance, support and coping skills. In addition this study also suggests the inclusion of psychotherapy as a source of support for the mother or care-giver, as a haven for them to come to terms with the sense of guilt, worry, and responsibility that is inevitably evoked in them after the diagnosis of their child. What is initially a ‘huge deal’ for parents and families, with the right care can diminish to become just ‘thing’, a characteristic of their child, like their eye-colour, a part of their make-up;

Mother 1: That’s it, you know, you’ve Tourette’s you know. I’ve blue eyes you know lets get on with it, you know.

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APPENDIX A

Interview Questions

Research Questions – Susan Duffy MA Psychotherapy – 2012

- Briefly describe your family unit to me...
- Who suffers from TS?
- What age are they now?
- When were they diagnosed? What age were they at the time?
- In your opinion, how long before their diagnosis did they display symptoms?
- What was your reaction to the diagnosis / what did you know about TS at the time?

- How does TS affect them? *Physically / emotionally / lifestyle?*
(*How do they manage*)

- Are they on medication – sometimes/ always?
- Have they been to therapy – what sort of therapy? For how long?
- How was that? (*did it make a difference- in what way - Was the experience a positive / negative one?*)
- Generally what do you feel would be a support to X?

- Describe your relationship with X
- What words come into your mind when you think about X?
(*i.e. tenderness, love, fear, worry, frustration, guilt etc.*)

- Do you feel supported generally; *family/ socially / teachers / community*
- What do you feel could be of support to you?

- Have you considered therapy?
- If yes – did you go? (*at what point in your life?*)
- Could you tell me a little bit about what that experience was like for you?
- If you decided not to go, could you explain why? Would you go?
(*doubts/ fears / perception of therapy/ reflection on coping skills / stigma*)
- Would any other family members consider therapy?

Extra consideration if time allows;

- Do you think X having TS impacts the family? *How?*

APPENDIX B

Email Requesting Participation

Email Script to recruit participants

Recently you kindly sent out requests to professionals who had worked with TS Sufferers to see if they would grant me an interview, it seems there has been no response, which leaves me at a glaring halt in my research! However, I have been thinking that maybe the following might be something that I am altogether more comfortable with, and curious about, and could be the way forward for my piece of work.

I would like my thesis to explore, and maybe give voice to the fears, anxieties and frustrations of the parents or carers of children /adolescents diagnosed with TS and consider what it is like living with a child with TS, and what they feel, as the closest to the sufferer, may be the best ways to care for, and in some cases, and if even for temporary periods, eliminate tics. This could have implications for the use of psychotherapy as part of a multi-faceted approach for treating patients, and also possibly and eventually, as a source of support for the parents / carers... it would be an open question rather than starting off with the premise that it may be of help...but in my mind it is certainly worth exploring.

Might you be able to introduce me to a couple of parents /family who might be willing to speak to me...it would of course be confidential, and not take up more than an hour of their time, and I would travel to wherever is convenient for them to speak to me.

I would be thrilled if you would consider it yourself, if you felt comfortable to do so?

It would involve 1 meeting of approx 1 hour with me - where I would ask approx 8 open questions and let each parent/carer give me their experience in a safe and non-judgmental environment.

After completion of the interview, I may request to contact the participants by telephone or mail if I have any follow-up questions.

Confidentiality: Notes about the research and any form participants may fill in will be coded and stored in a locked file. This means that all data kept on participants will be de-identified. All data that has been collected will be kept in this confidential manner and in the event that it is used for future research, will be handled in the same way. Audio recordings and transcripts will be made of the sessions but again these will be coded by number and kept in a secure location. Participation in this research would be voluntary, and any volunteers are free to withdraw at any point of the study without any disadvantage.

Let me know what you think and if you would prefer for me to give you a call to discuss this with you in person?

Kind regards, Susan

APPENDIX C

Interview Information

Information Form

My name is Susan Duffy, I am a student with Dublin Business School and am undertaking an MA in Psychotherapy. As part of my course I am required to undertake a research paper and am requesting your participation in this.

My research will explore, and give voice to the feelings of the parents of children /adolescents diagnosed with TS, and consider what it is like living with a child with TS in Ireland. In addition to considering what they feel, as primary carer to the individual with TS, also tentatively exploring what they consider to be the best ways to care for sufferers of TS and their families. This could have implications for the use of psychotherapy as part of a multi-faceted approach for treating patients, and also possibly, as a source of support for the parents and families. This is an open question for exploration, with no preconceived hypotheses.

What is involved?

Participation in this study involves 1 meeting of approx 1 hour with me - where I will ask approximately 20 closed and open questions and let each parent give me their experience in a safe and non-judgmental environment. After completion of the interview, I may request to contact the participants by telephone or mail if I have any follow-up questions.

Risks

I would like to draw attention to the sensitive nature of this research. It is possible that during the course of the session distressing or painful issues may be evoked for you. I would ask that you be mindful of this and recommend that you put in place some time for self-care and reparative measures after our interview. Should you require it, an hour of free counselling is available to you in the follow up to our meeting. These counsellors are trained in Humanistic and Integrative approaches and are in the pre-accreditation phase of their career.

North Dublin, Brid; 087 2385118

North Dublin City and South County Dublin, Caroline; 085 7179117

Dublin City Centre, Irene; 087 6576487

Confidentiality

Notes about the research and any form participants may fill in will be coded and stored in a locked file. This means that all data kept on participants will be de-identified. All data that has been collected will be kept in this confidential manner and in the event that it is used for future research, will be handled in the same way. Audio recordings and transcripts will be made of the sessions but again these will be coded by number and kept in a secure location. Participation in this research would be voluntary, and any volunteers are free to withdraw at any point of the study without any disadvantage.

APPENDIX D

Informed Consent Form

CONSENT FORM

Protocol Title:

An exploration of the concerns of mothers of boys who suffer from Tourette Syndrome, and considerations of what may be of support to them, looking also at their perceptions of psychotherapy and experience of the same.

Please tick the appropriate answer.

I confirm that I have read and understood the Information Leaflet attached, and that I have had ample opportunity to ask questions all of which have been satisfactorily answered.

Yes
No

I understand that my participation in this study is entirely **voluntary** and that I may withdraw at any time, without giving reason.

Yes
No

I understand that my identity will remain confidential at all times.

Yes
No

I am aware of the potential risks of this research study.

Yes
No

I am aware that audio recordings will be made of sessions

Yes
No

I have been given a copy of the Information Leaflet and this Consent form for my records.

Yes
No

Participant _____
Signature and dated

Name in block capitals

To be completed by the Principal Investigator or his nominee.

I the undersigned, have taken the time to fully explained to the above participant the nature and purpose of this study in a manner that he/she could understand. We have discussed the risks involved, and have invited him/here to ask questions on any aspect of the study that concerned them.

Signature

Name in Block Capitals

Date

APPENDIX E

Master List – A Sample of Some of the Participant Themes

MASTER THEMES	
Participant 1	Participant 2
Family description – goes back unprompted to start of her relationship dating/ husbands background.	Ticks at 8 – grunting getting really pronounced – I was pregnant – was my pregnancy making tics worse
Dates wrong /few attempts	Was it attention seeking / said to teacher
Describes move from US to Ire kids 3 and 6mths Transition / back to husbands profession / building house / up and down to family in other parts of country Big change. “Tough going”	Tics occasional up to pregnancy/ mannerisms – when pregnant grunting and arm action
Dad’s back gave out / stop working Mum starts looking for work / US qual not recognized paperwork to do – took couple of years	Excuses – hope that it was not something serious thought his arm was going up in triumph – games intense affect on a child “we were looking for every excuse”
Mum happy in career “never looked back”	Pregnancy – difficult pregnancy – lying down a lot convinced he’s looking for attention / doc advises ignore them could be transient / colicky baby born tics worse head jerking prompted mum to take seriously knew that this was not on purpose
Dad home with kids for year or two then set up part-time business 10 years ago and works in another job part time too	Control - Whole body jerking out of control / frightening Teacher says tics sometimes in class
Own home – no mortgage (less stress financially) we’re ‘blessed’ pg 3	Exploded in car after school / erupted
Older parents / later starters conscious of kids through college	Mother angry – how can you be like this – how can a teacher cope with you “I don’t do it in school mam” Oh you devil” this is all about you and me – you are doing this to affect me – conflict purpose
Happy life goes on to say despite ‘tragedies’ corrects this to ‘sadness’	GP – don’t talk in front of him – sthg serious not to be ignored Internet descriptions could have his name in front of them Horrible forums Scary
Describes suicides in dad’s family (brother and mother)	Mothers belief – rude not to reply to emails
History of mental illness / Dad anxiety	Dad escaped to work Without au pair I would have bene driven demented

Best friend dies in Iraq	Christmans – boy did not want to see anyone or anyone to see him this way Shame embarrassment confusion
Home to be with Dads father and he dies not long after	Extended family support (brother psychologist) calmed parents down
Wonderful Family despite all this (reiterates pg 4) pg 5 V positive experience	Defining it – making tics where they may not have been “imagining he was having tics even though he hadn’t got them”
Describes differences between hub and self ‘co-exist with very different interests’ R. feels -love harmony balance	Neurologist – team of people will be assigned – wants action now Met lovely lady – individuals stand out in these stories -
Describes Dads interests trees rocks music movies travel in USA cats	When? Frightened He was so bad I couldn’t send him to school
Mums interests dogs books classical music cooking – mix has been great for our kids they love everything	Protection – PG 5 Fear of bullying How will people perceive it Swear words started Mum – This is unacceptable- I can’t deal with it, How am I going to cope with this? (whatever about the other tics)
And swimming – R. swimming come up a lot throughout	Social perspective Fall in car park – mums elbow broken but she is making excuses for her somn – tics exploding “don’t pay any attention to him God help him he’s just had a recent diagnosis of TS” “I was more conscious of him (son) than I even was about my elbow”
Mum describes her family – tentative no detail – 6 siblings all married ‘5 brothers and they’ve been, you know’ – drifts to ‘parents still alive’	Life events family illness – life and death Concern over telling son – should she shield him / protect him Worrying how events might affect my son Horrendous year
Son – language difficulty before he went to school /articulation problems eg.s pg 6 Reversed sayings	Brother best child in the world - au pair took him off
Dad had difficulties in school / mum feels dads were emotional(?) Dad ‘puts himself down’ – described earlier as ‘worry wort’ Difficulties when a child reading	Medication – 2 weeks effect – like someone switched off a switch – tics subsided Guilt around giving medication – never sick previously – only gave him calpol and

	antibiotics – whisper – guilt???
Child with TS very like his dad –w alks talks looks like him	Conflict – relief v’s medication No idea of long term effects – “I wanted quick fix “ Normality restored – back to school “Detox” him during summer – R detox interesting word
Mum kept him back at playschool for a second year	Comes in to tic - friends don’t know – KEY DIFFERENCE in studies
Mum against sending kids to school at 4	He did not want anyone to know – mother decided to tell their parents – felt I was doing the right thing “I don’t think I was betraying a confidentiality. I felt I was looking after him” R – does she maybe feel like she was – word betray - evocative
Support services - When he went to school he was referred to Speech and language service for 2 years for articulation problems Mum working with him at home – got over reading difficulties because of individual time mum put in with him reading each nightp7	Mum – paves way – prepares the road -
Stutter and stammer / squeeze eyes and blink – grunting –arms moving – and a whole lot of rituals	Sport plays a part – here kick boxing – masks tics releases energy PIANO in both cases
Teacher 2 nd class TEACHER Suggested more than stammer	Anger – frustration Felt his body had been taken over by a monster
long time ago – in the past have to remember details (R. less important in life now)	Support begins for mum – TSAI Suddenly not just us – lots of others – dawning realization
rituals from age 5yrs– counting and cleanliness not touching dirty things incessant hand-washing	Others the experts – why did other mum with experience not notice my boys tics – external locus of control Relinquish ability and power to others R
dad says mum has given him a complex – blame? Pg.8	Tv – release tics -
Anxiety /forms including OCD anxious about being late – anxious about sister missing – trauma when he was young where she did go missing – managing anxiety / coping skills / worrier	Post diagnosis - Mum realizes that it is involuntary – anger dissipates - empathy / sympathy – god love him how could he concentrate all day in school

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