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**The Experiences of Persons with Tourette's Syndrome and
their Family Members, as Garnered from the Internet.**

by

Andre Michael Zawallich



**A thesis submitted to the Faculty of Graduate Studies and Research in partial
fulfillment of the requirements for the degree of Master of Education.**

in

Counselling Psychology

Department of Educational Psychology

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Spring, 1997



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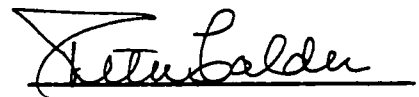
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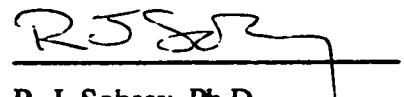
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "The Experiences of Persons with Tourette's Syndrome and their Family Members, as Garnered from the Internet" by Andre Michael Zawallich in partial fulfilment of the requirements for the degree of Master of Education.



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April 16, 1997.

Dedication

I would like to dedicate this thesis to the memories of my mother, Irene Zawallich, and my father, Gustav Zawallich.

Abstract

Electronic discussion forums on the Internet for persons with Tourette's Syndrome (TS) and their family members were monitored and statements were collected about (a) the experience of living with Tourette's Syndrome and (b) the experience of living with a family member who has Tourette's Syndrome. Concept Mapping, a statistical technique for thematically analyzing qualitative data, was used to discern major themes in the experiences of persons with TS and their family members. The experiences of persons with TS fell into five themes: (a) Symptom Management, (b) Positive Aspects, (c) Social Rejection, (d) Misdiagnosis, and (e) Self-Consciousness. The experiences of family members fell into nine themes: (a) Denial/Guilt, (b) Negative Feelings, (c) Social Embarrassment, (d) Intrusiveness of Symptoms, (e) Social Rejection, (f) Search for Solutions, (g) Need for Answers, (h) Positive Concrete Adaptation, and (i) Passive Adaptation.

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I would like to thank my supervisor, Dr. Peter Calder for his very kind support, advice, and direction. I owe him a debt of gratitude I fear I cannot ever adequately repay. I would also like to thank Ms. Jadwiga Speur, who provided many reasons for starting this project and seeing it through.

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Chapter 1. Introduction.

Tourette's Syndrome (TS) stands in contrast to most other chronic illnesses or disabilities as a special problem in psychological and social adaptation. The unwanted movements and vocalizations, known as tics, that characterize TS can vary greatly in their intensity and presentation and are often disturbing or offensive to others. Observers often interpret tics as being intentional and attribute malicious aims to them; if the person exhibiting these symptoms is a child, tics are seen as a sign of poor discipline or neglect on the part of parents. The understanding, sympathy, and concern that may be extended to persons with other disabilities or chronic illnesses are not as likely to be extended to persons with TS or their family members (Cohen, Ort, Leckman, Riddle & Hardin, 1988).

Relatively little has been published about the social and psychological adjustment of persons with the disorder and their family members. Of the few published empirical studies on the social and psychological impact of TS, most have depended upon the use of questionnaires or psychological tests. By definition, such "paper and pencil" instruments are limited samples of behavior (Anastasi, 1982), incapable of capturing the full range of their subject matter—in this case, the experiences of persons living with TS, and the experience of their family members. Restriction of content, however, is an attribute of any research methodology. Webb, Campbell, Schwartz, and Sechrest (1966) cautioned against overreliance on the use of surveys, tests, and interviews in social research. They cited a number of methodological weaknesses and potential sources of bias that stem largely from the awareness of research participants that they were being studied. To counter these, they advocated the use of "unobtrusive" or "nonreactive" research methods, in which the individual being studied is kept unaware of being the object of study.

The global computer network commonly known as “the Internet” provides an opportunity to unobtrusively gather data on the experiences of not only persons with TS, but of a wide variety of other groups. Among the several services available on the Internet are electronic forums, in the forms of electronic mailing lists and Usenet newsgroups. Both provide public forums in which persons interested in a particular topic can exchange their knowledge and opinions. Originally these forums were devoted to the exchange of information among researchers on scientific topics; very quickly they became a method of exchanging information on other topics. There are currently many newsgroups and electronic mailing lists devoted to the exchange of information and emotional support for persons with a number of medical, psychiatric, and psychological conditions. Among these are a newsgroup, alt.support.tourette, and a mailing list, POV-Twitch, devoted to the exchange of information and emotional support for persons with TS and their family members. In order to obtain a report of the experiences of individuals with TS or family members, messages to these electronic forums were monitored for five months to produce the two papers in this thesis. The use of the Internet as a source of research data, instead of as a way of disseminating that data, is relatively new. There is, however, some precedent for the research method employed in these two studies. Ernulf and Innala (1995) unobtrusively monitored a Usenet newsgroup for persons interested in sexual bondage and domination and performed a content analysis on the messages. In the present study messages to the two forums on TS were unobtrusively monitored, and, if relevant to the two research questions (“What is the experience of living with TS?” and “What is the experience of being a family member of someone with TS?”), saved for future reference. The collected messages were then analyzed using concept mapping (Trochim, 1989a, 1989b, 1993). This technique begins with research participant’s

reports on the phenomenon of interest (e.g., the experience of living with TS). A list of representative unique items is derived from the reports. Participants are then asked to perform card sorts on the items, sorting them in a way that is meaningful to them. Multidimensional scaling (MDS) is performed on the card sorts, resulting in a spatial representation of the items. Cluster analysis is then performed on the resulting map to determine what groups of items which have been sorted together frequently and what groups of items have been sorted together infrequently. Used together, cluster analysis and MDS permit inferences about how participants categorized items and the underlying dimensions of this categorization (Kunkel & Newsom, 1996).

In summary, the two studies in this thesis are the result of a conjunction of factors: the dearth of information on the impact of TS on the persons who have TS and their family members; the existence of a number of electronic forums for persons with TS that could easily, unobtrusively, and ethically be monitored; and the existence of a social science research technique, concept mapping, that could be used to objectively discern major areas of content, or themes, in the data collected. The papers in chapters 2 and 3 are written to stand alone and be ready for publication. For that reason they are relatively brief, keeping in mind the page limitation realities of publications. The reader will probably find some of the articles somewhat redundant with each other. The reason for this, again, is that they have been written to stand alone and be ready for publication in different journals. Chapter 4 concludes with a brief summary of the studies and conclusions reached by the author.

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Chapter 2. The Experience of Living With Tourette's Syndrome, As Garnered From The Internet.

Tourette's Syndrome is a neuropsychiatric disorder characterized by sudden, recurring, rapid, nonrhythmic and stereotyped movements or vocalizations, commonly called "tics." The tics that are the hallmark of the disorder can vary greatly in intensity and complexity. They range from relatively innocuous behaviors such as uncontrolled eye blinking to more disturbing ones, such as the involuntary making of animal sounds and inappropriate swearing. Individuals with Tourettes are typically faced with the problem of living with and attempting to manage symptoms that could lead to social disapproval and ostracization. While a large body of literature exists on the diagnosis and treatment of TS, relatively little appears to have been written on the psychological and social impact of its symptoms. Of the few studies that have been published, most have involved the use of questionnaires (e.g., Jagger et al., 1982; Stefl, 1984) or psychometric tests (e.g., Grossman, Mostofsky, & Harrison, 1986; Robertson, Trimble, & Lees, 1988). Only one study in which persons with TS were asked to freely recount the impact of their symptoms on their lives, (Keiper, 1976) was found.

A case against reliance on questionnaires, tests, and interviews in social research has been made by Webb, Campbell, Schwartz, and Sechrest (1966), who have argued for more use of "nonreactive" measures, in which the active participation of a respondent is not required. The existence of electronic forums for individuals with TS on the world-wide computer network commonly known as the Internet provides an opportunity to unobtrusively gather information on the impact of the symptoms of the disorder on the

daily lives of those who post messages to them. The purpose of this research was to gain a better understanding of the day-to-day experience of living with TS. Two research questions were addressed: (a) what are the reported experiences of persons who have TS? and (b) what are the concepts or themes underlying these experiences? Concept mapping (Trochim, 1989a, 1989b, 1993) was used to discover themes in the electronic mail, and to generate a visual representation of the themes.

Review of Literature

Tourette's Syndrome has an onset in childhood or early adolescence, and is usually lifelong in duration. The symptoms change over time, in both the intensity and the nature of the tic; periods of remission are not uncommon. The disorder occurs in 4 to 5 persons per 10,000, and is approximately 1.5 to 3 times more frequent in males than in females. The susceptibility for inheriting TS appears to be genetic (American Psychiatric Association, 1994). The tics that are the hallmark of TS vary greatly in intensity and complexity. "Simple" tics involve only one group of muscles, causing a brief, isolated, jerk-like movement, or a single, meaningless sound. Examples of simple motor tics include an eye blink, head jerk, or shoulder shrug. Examples of simple vocal tics include sniffing, throat clearing, grunting, or making of animal sounds, such as barking or quacking. "Complex" tics consist of coordinated sequences of movements involving several muscle groups. Examples of complex motor tics include seemingly nonpurposeful movements such as headshaking or trunk bending. Seemingly purposeful movements such as hitting, throwing, or jumping, as well as making obscene gestures (copropraxia), or imitating gestures (echopraxia) are also examples of complex motor tics. The uttering

of syllables, words, phrases, or full sentences are examples of complex vocal tics, which may also include the shouting of obscenities or profanities (coprolalia), the repetition of someone else's speech (echolalia) or the repetition of one's own speech (palilalia) (Fahn, 1993; Jankovic, 1992; Singer & Walkup, 1991). Tics may be completely involuntary, or they may occur in response to an urge to perform a movement or vocalization to relieve an unpleasant sensation. In the latter case, the individual having them may experience the tics as being under voluntary control and may attempt to suppress them. Except in the most severe cases, most persons with tics can suppress them for varying lengths of time, leading to a buildup of inner tension and discomfort which can only be relieved by an increased outburst of tics (Tourette Syndrome Classification Study Group, 1993).

There is often a significant delay between the onset of symptoms and the diagnosis of Tourette's syndrome or tic disorder. For persons who developed the syndrome prior to the 1980's, a simple lack of information about the disorder among health care professionals may have been a major factor. Goggin and Erickson (1979) identified an almost complete absence of discussion of Tourette's Syndrome in the professional literature of medicine or psychology at the time. Although information about the disorder has become more widespread, lack of familiarity with it is likely still a major reason for missed diagnoses or misdiagnoses (Wand, Shady, Broder, Furer, & Staley, 1992), as is the misconception that coprolalia must be present for the diagnosis to be made (Comings & Comings, 1985; Shapiro, Shapiro, Young, and Feinberg, 1988). Persons with mild or moderate Tourette's Syndrome are able to suppress their symptoms for up to several hours at a time; some do so when being examined by health care professionals, again

possibly leading to a missed diagnosis (Comings & Comings, 1985; Bruun, 1984; Golden, 1977). Tics presenting as chronic coughing, sniffing, and throat-clearing may be interpreted as indicating respiratory problems or allergies (Golden, 1977). Symptoms of the onset of Tourette's Syndrome may be confused with transient tics of childhood (Golden, 1977); differential diagnosis between the syndrome and other neurological conditions may also pose a challenge (Bruun, 1984).

An individual may simply be unaware of the symptoms; in a study of 54 members of a single family who had a tic disorder of some kind, Kurlan et al., (1987) found that 30 percent were unaware of their condition, and only 19 percent had sought medical attention for it. McMahon, Leppert, Filloux, van de Wetering, and Hasstedt (1992) studied 161 related family members with TS, none of whom had ever been diagnosed with TS or OCD, concluding that this may have been a reflection of the mildness of the tics, as well as a "remarkable tolerance for the 'family twitch'" (p. 164). Those individuals who are aware of their symptoms frequently diagnose themselves. Bruun (1984) noted that the majority of the 300 patients who had been referred to her had made the diagnosis of Tourette's Syndrome themselves, using information disseminated by the Tourette's Syndrome Association. Wand, Shady, Broder, Furer, and Staley (1992), in a survey of 462 Canadian persons with Tourette's Syndrome, found that the mean number of years between onset of symptoms and medical diagnosis was 7.8 years. Only 33 percent of their respondents reported receiving their first information about Tourette's Syndrome from physicians; seventy-three percent reported an initial misdiagnosis by physicians.

Although only the presence of motor and vocal tics for at least one year, arising before age 18 and not attributable to other disease processes or the ingestion of substances, is required to make a diagnosis of TS (American Psychiatric Association, 1994), it is generally agreed that a variety of other disorders are often seen in persons with TS (Lombroso et al., 1995). These may include obsessive-compulsive disorder (OCD), attention-deficit hyperactivity disorder (ADHD), anxiety, depression, learning disabilities, sleep disturbance, speech problems, and a variety of behavioral and impulse control disorders. The nature of the relationship between these disorders and TS remains an ongoing controversy. Whatever the nature of the relationship, the associated symptoms are often more a source of distress than the tics themselves. (Bruun & Budman, 1992; Erenberg, Cruse, & Rothner, 1986; Lombroso et al., 1995).

Many children with TS are described as having difficulty with peer relations (Cohen, Friedhoff, Leckman, & Chase, 1992). Jagger et al., (1982) found that 3 out of 4 children between 8 and 18 with TS they surveyed had been teased about their symptoms by classmates in school. Nearly one half of the students had found their teachers to be “unfair or difficult to deal with” (p. 276) and nearly one quarter had been ridiculed by teachers. Hagin, Beecher, Pagano, and Kreeger (1982) found that their sample of students with TS were frequently not chosen by their peers for projects, sports, or after school activities. The parents of the children, their teachers, and the children themselves noted that they were socially isolated. Stokes, Bawden, Camfield, Backman, and Dooley (1991) measured the peer relationships of 29 students with TS by asking their classmates to rate them on a sociometric scale, the Pupil Evaluation Inventory. Almost half of the students

with TS were rated as being significantly more withdrawn than their classmates: over a third received the lowest rating on one or more factors measuring aggression, likeability, and popularity. These ratings were not related to the severity or frequency of tics, or to whether the students were receiving medication. Friedrich, Morgan, and Devine (1996) found that third and fifth graders rated a boy with symptoms of TS, portrayed by a child actor on video, less positively than a boy without TS, even when information about TS was presented to them. Dykkens et al., (1990) administered the Vineland Adaptive Behavior Scales to a group of 30 children with TS, and found that they had a lower level of social functioning in interpersonal relationships, use of play and leisure time, and coping skills than would be expected for their chronological ages. The TS children were also significantly weaker on a scale measuring domestic living skills, a weakness that appeared to be related to their lack of compliance with requests to complete domestic chores, and parental difficulties in dealing with noncompliance.

Problems in social functioning do not necessarily translate into lower self-concept for children with TS. Edell-Fisher and Motta (1990) administered the Piers-Harris Children's Self-Concept Scale to 30 children with TS and 30 children without TS, matched for age and sex; they also administered the Tennessee Self-Concept Scale to parents of children in both groups. There was no significant difference between the two groups of children on global self-concept, although children with Tourette's Syndrome acknowledged more behavior disturbances than the children in the control group, and the level of behavior disturbance correlated significantly with the severity of the disorder. The parents of the children with TS, however, had significantly lower self-concepts than

the parents of children in the control group. Edell and Motta (1989) found that parental self-concept was not significantly correlated with the self-concept of children with TS. They did, however, find that the child's perception of parental behavior as being accepting was a predictor of the child's self-concept. They also found that the degree to which parents were perceived as using guilt or hostility to control a child's behavior was negatively correlated with the child's self-concept and positively correlated with the child's level of trait anxiety. Edell and Motta (1989) speculated that parental overprotectiveness and anger at the diagnosis may lead to the use of guilt or hostility to control the child's behavior. In a prospective study of children at risk for TS, Carter, Pauls, Leckman, and Cohen (1994) found that children with tic disorders were not significantly different from unaffected children in social or emotional functioning, with two exceptions: lower ratings of perceived attractiveness, and higher perceived maternal acceptance. The children with Tourette's Syndrome also appeared to have had a higher frequency of other psychiatric disorders. Carter et al. (1994) speculated that this may have been due to increased stress within families of children with TS.

Among adults, the presence of TS alone does not necessarily seem to be associated with either self-consciousness or lowered self-concept. Adults with both TS and significant obsessive compulsive symptoms, however, appear to have a higher level of social anxiety and lower self-concepts than does the general population (Thibert, Day, & Sandor, 1995). Grossman, Mostofsky, and Harrison (1986) administered the Minnesota Multiphasic Personality Inventory (MMPI) to a sample of 29 adults with TS and 29 adults without TS, matched for age and sex. They found that the TS group had, in

comparison to the control group, more preoccupation with physical and bodily functions. more depressive affect, and more preoccupation with anger and guilt, as well as rumination. The adults with TS also showed a pattern of scores suggesting a strong sense of social alienation, as well as occasional bizarre perceptions and disturbances of ideas. Item analysis suggested that the adults with TS felt victimized, and had a fear that their impulsive outbursts would occur at critical or embarrassing moments. Their social withdrawal and tiredness, as reflected by their MMPI scores, suggested that a great deal of vigilance and energy was required to suppress their symptoms. Robertson, Trimble, and Lees (1988) reported a higher incidence of depressive symptoms in TS patients, a finding they attributed to the effects of having a chronic stigmatizing illness. Robertson, Channon, Baker, and Flynn (1993) compared TS patients to patients with major depression and to a control group with neither TS nor depression. The TS patients were more depressed than controls, but less depressed than patients with depression. The TS patients also showed the same pattern of results on measures of anxiety.

Champion, Fulton, and Shady (1993) surveyed 210 persons with TS, or their parents if they were children or adolescents, on the impact their symptoms had on social functioning. More than 40 percent of respondents reported problems with dating and making and keeping friends. Over one third of respondents reported moderate to significant problems in coping, with another 47 percent reporting at least mild problems in coping. Stefl (1984) surveyed 431 persons with Tourette's Syndrome and found that over half had sought counseling for problems related to their symptoms, and that the majority did not perceive this counseling as being helpful. Respondents rated their mental

well-being significantly lower than did randomly selected respondents from the same geographical area. Erenberg, Cruse, and Rothner (1987) reported that 30 of the 58 patients (52%) in their follow-up study had sought mental health counseling; only 17 (35%) had felt this counseling was helpful. Keiper (1976), in her qualitative study of the experiences of 5 adults with TS, also reported that her respondents had difficulties in coping with school or work, in spite of having attained relatively high levels of achievement. They also reported social isolation and loneliness, combined with feelings of pessimism about the future.

Although many persons with Tourette's Syndrome experience a diminution or remission of their tic symptoms as they get older, a significant number suffer profoundly from either associated disorders or from the social sequelae of their childhood tics (Bruun & Budman, 1992). Bruun and Bruun (1994), citing data from the Stefl (1984) survey reported that, of adult respondents, 36 percent were employed full-time and 15 percent were employed part-time, at a time when the national unemployment rate was between 7.6 and 9.6 percent. Asam (1982) and Robertson, Trimble and Lees (1988) have reported evidence that suggests persons with Tourette's Syndrome are at risk for "downward drift" into lower social classes than that of their parents. There is reason to believe that this is not an inevitable consequence of Tourette's Syndrome: Goetz, Tanner, Stebbins, Leipzig, and Carr (1992) surveyed a sample of 58 Tourette's patients and found that, although the majority of the respondents had experienced problems in school, as adults, 98 percent were high school graduates and 90 percent were working full-time or were full-time students in higher education programs--an above-average level of educational

achievement. However, even those with optimistic views of the life prospects of Tourette's patients, such as Shapiro et al., (1988), concede that Tourette's Syndrome can impair psychosocial functioning and that the exact effects will be dependent on the emotional and intellectual resources of the individual.

The Internet

Originally conceived as a method for researchers and academics to exchange information, the worldwide computer network commonly known as the Internet has, in recent years, been the object of increasing interest among members of the general public. This has resulted in explosive growth in the number of persons using the Internet, and a shift away from its focus as a means of disseminating academic research to a method of popular communication (Badgett & Sandler, 1993). One of the more popular services provided over the Internet is a large collection of discussion groups, known as Usenet newsgroups, each devoted to its own particular topic. Once a message has been posted to a newsgroup, that message, and any responses to it, are sent to all other Internet sites carrying that newsgroup. There are a number of newsgroups devoted to the exchange of information and support for persons with various medical and psychiatric conditions; among these is a newsgroup ([alt.support.tourette](#)) for persons with TS.

Less popular than Usenet newsgroups are mailing lists, which also provide forums for discussion of particular topics, but only to those subscribing to the list. Any piece of electronic mail sent to a mailing list is sent to all the other subscribers. Among mailing lists devoted to the exchange of support and information for persons with medical or psychiatric conditions is [POV-Twitch](#), a list for persons with TS and their family

members. Both the mailing list and the newsgroup were monitored in this study to gather data on the experience of living with TS. Although this means of gathering data is relatively new, it is not without precedent. At least one group of researchers, Ernulf and Innala (1995) have already gathered data by unobtrusively monitoring communications on a Usenet newsgroup.

Concept Mapping

The data from monitoring the Internet discussion groups and mailing lists was analyzed using Concept Mapping (Trochim, 1993). The technique, as described by Trochim (1989b) entails asking a group of participants to generate as many ideas as possible about a given topic. A list of unique statements about the topic is generated from the participants' contributions. Participants are then asked to sort the resulting list of unique statements into logical, homogeneous groups, with each group representing a particular aspect or theme of the topic. The sorts are then analysed using multidimensional scaling and cluster analysis. Trochim (1993) originally marketed his system as a business planning technique. It has also been used for program planning in the social services (Mannes, 1989; Trochim, 1989a; Trochim 1989b), program evaluation (Galvin, 1989) and for psychological research (Daughtry & Kunkel, 1993; Phillips, 1993 Kunkel & Newsom, 1996). The technique encourages the generation and exploration of a wide variety of ideas on a given topic and minimizes the introduction of bias by the researcher in the search for relationships between the ideas.

Method

The Usenet newsgroup alt.support.tourette and the mailing list POV-Twitch were monitored from March 1996 to July 1996 and every message was recorded. Messages that were relevant to the research question (“what is the experience of living with TS?”) were put on a master list for analysis and edited so that each statement expressed only one idea, was grammatically correct, and was grammatically consistent with other items on the list. As much of the original wording as possible was retained in the editing process. Items that were redundant were removed from the master list, so that the remaining items were unique. The resulting list had 91 statements. Once a final list of statements had been compiled, a group of voluntary raters ($N = 19$) was recruited. The raters were primarily students who had little knowledge about TS. Following a standard set of instructions, they were asked to group statements that expressed a similar theme or concept into piles. The resulting sorts were analyzed with the Concept System computer software by Trochim (1993), using nonmetric multidimensional scaling (MDS). As part of this process, a point map was generated, where each statement was represented by a point. Points that are spatially close to one another are judged to be thematically similar; points that are spatially far from one another are judged to be thematically different.

Results

Ninety-one unique statements made by persons with TS were collected (Table 1). After the statements were sorted into themes by 19 volunteers, they were analyzed using MDS. The result of the MDS analysis is a map of points. These points, each of which represents a different experience, are then divided into clusters through a cluster analysis algorithm. The map had a final stress value of .29; a stress value of under .31 represents a reasonably stable solution (Trochim, 1993). A cluster solution in which the points on the point map were divided into 5 clusters was chosen as representing the optimum trade-off between homogeneity of cluster content, which is more likely to be achieved with small clusters, and parsimony of description, which is more likely to be achieved with a small number of clusters. The arrival at a five-cluster solution was facilitated by referring to the bridging index for each statement. This index, which ranges from 0 to 1, is an indication of how well a particular statement “fits” within a given cluster. The higher the number, the more likely it is that a given statement could have just as easily been included in another cluster. The lower the number, the more likely a statement is to relate to the central theme of a given cluster. The most parsimonious concept map seemed to be one with 5 clusters.

Insert Figure 1 about here

Discussion of Concept Map

Cluster 1 for the most part, was concerned with the issue of managing TS symptoms. both in interactions with other members of the public and in private. Examples of “public” symptom management included “I use humor as a diversion” (no. 9) and “I disguise my tics as mannerisms” (no. 3). Examples of “private” symptom management included “I try to distract myself from obsessive thoughts” (no. 15) and “I try to channel my compulsive tendencies into positive ends” (no. 72). Cluster 1 also contained a number of statements about maintaining vigilance toward the reactions of others in social situations: “I often ask people if my tics bother them” (no. 35) and “I don’t feel out of place playing baseball, where it’s considered normal to have weird habits” (no. 42). The descriptor “Symptom Management” was chosen to describe this cluster.

Cluster 2 was largely comprised of statements that were about what respondents reported as being the positive aspects of the disorder. such as the opportunity to help others (e.g., through support groups) and the perception that as well as imposing liabilities, the disorder also provided assets. Examples included “Tourettes makes me more exuberant about life” (no. 74) , “I think I am a better person because of Tourettes” (no. 57), and “Tourette’s Syndrome is an important part of who I am” (no. 70). The descriptor “Positive Aspects” was chosen for this cluster.

Cluster 3 was comprised of statements mainly about rejection and lack of support—from employers, educational institutions, the religious community, and the family. Examples of statements in the cluster included “I was mistreated in school because of my

Tourette” (no. 27) and “I found another job because of my boss’s attitudes toward my Tourettes” (p. 32). The descriptor “Social Rejection” was chosen to describe this cluster.

Cluster 4 was comprised largely of statements about ignorance of the symptoms of TS, both among individuals with TS and medical professionals, as well as misdiagnosis of TS and its consequences. Examples include “I was diagnosed with Tourette’s Syndrome years after I first had symptoms” (no. 5) and “I wasted a lot of years being treated for ‘anxiety’” (no. 78). The descriptor “Misdiagnosis” was chosen for this cluster.

As indicated by their relatively high bridging indices, the statements in Cluster 5 were not as homogenous in content as statements in other clusters. This made identifying a central theme for this cluster more difficult than for the others. Several of the statements in this cluster, however, were about awareness of the symptoms (e.g., no. 36, “I am amazed when I see videos of myself.”), their impact on the self (no. 39, “It would be nice to know how much is “me” and how much is Tourettes.”), and the realization that the individual with TS was different (no. 44, “I thought that tics were something that everyone did.”). Cluster 5 seems to be centered around the theme of self-consciousness of the awareness of being different. Accordingly, the descriptor “Self-Consciousness” was chosen for this cluster.

Overall, the themes are consistent with the published literature on TS. Social rejection, as reflected by peer problems in school for children (Champion, Fulton, & Shady, 1993; Cohen, Friedhoff, Leckman, & Chase, 1992; Friedrich, Morgan, & Devine, 1996; Jagger et al., 1982; Stokes et al., 1991) and social and occupational difficulties as adults (Champion, Fulton, & Shady, 1993; Keiper, 1976; Stefl, 1984) are frequently-cited

consequences of TS. Misdiagnosis--as well as missed diagnosis--of TS has also been reported by several researchers over several years (Bruun, 1984; Goggin & Erickson, 1979; Stefl, 1984; Wand et al., 1992), in spite of an increase in public awareness of TS.

The data gathered in this study diverges from the published literature in a number of ways. For example, although much of the literature on TS focuses on the control of TS symptoms, very little has been written about strategies used by persons with TS to manage their symptoms or the social consequences of those symptoms, the theme of Symptom Management. Among the strategies used by respondents to manage symptoms were: substituting less noticeable tics for more noticeable ones, disguising tics as mannerisms, avoiding public situations where tics might be noticed, and allowing "socially acceptable" tics to happen (perhaps in favor of concentrating on controlling more unacceptable tics). Respondents also reported redirecting their symptoms into other areas where they could be assets, such as focusing the energy from tics into work, or by applying obsessive tendencies on the job. On a related note, that respondents could view some of their symptoms as being potential assets is one of the more intriguing findings of this study. A number of statements in the cluster Positive Aspects reflect the fact that some respondents felt that TS could confer abilities, as well as disabilities, a position that has some support from Sacks (1992). Statements such as "Tourette's Syndrome is an important part of who I am." (no. 70) suggest that, at the very least, the disorder can become integrated as part of the self, although questions about how much of the self is due to the disorder may remain (e.g., no. 39, "It would be nice to know how much is "me" and how much is Tourettes.").

The statements collected in this study also present something that is fairly rare in the literature, a portrait of the persons with TS as a living human being. They also show a group of people who, because of the overt nature of their disorder, have had to become extremely vigilant in social situations. A vivid example of this is statement no. 42 (“I don’t feel out of place playing baseball, where it’s considered normal to have weird habits”). The rarity of such a situation, where everyone else has “weird habits,” underscores how out of place the individual who made the statement must feel most of the time. The statements also depict individuals presented with social disapproval and discrimination in every possible way, and yet struggling to overcome in ways that, at times, are very creative. A determination to overcome limitations imposed by the disorder comes through (e.g., no. 49, “I made people like me in spite of my often “strange” behavior”), even in statements suggesting that the disorder has had minimal impact on the person’s life circumstances (e.g., no. 19, “I probably have had to strive harder to achieve what I have”).

As a technique of unobtrusive social research, the monitoring of communications among individuals participating in Internet discussion groups is relatively new; the ethical issues it raises, however, are not. Webb, Campbell, Schwartz, Sechrest, and Grove (1981) noted that any research methodology in which the person’s awareness of being measured is avoided raises the issues of privacy and informed consent. They took the position that neither the right to privacy nor the right to informed consent were inviolate, but that both placed limitations on what a researcher could ethically do in the name of unobtrusive social research. Webb et al. (1981) suggested using the personal dignity of

the subject as a yardstick: no study should be performed that reduced the dignity of the subject “in any important way” (p. 152).

It is argued that the present study did not violate the privacy of the subjects as they were exchanging messages in Internet forums that were accessible to anyone who had the desire to do so; the messages were essentially public. Even so, the confidentiality of those whose messages were used in the study has been preserved. None of the items in the statement list were attributed to the person who made them; indeed, the question of who made what statement was irrelevant to the purposes of the study. Consent to use individual statements in the study was not thought to be necessary, as the statements were made in public forums, were edited before being used in the statement list, and were not attributed to the individuals who made them. It is unlikely that the dignity of any of the individuals who participated in the forums has been violated, nor is it likely that the principle of respect for persons has been violated. The potential good coming from this research, in terms of making the experience of persons with TS clearer to those who interact with them, professionally or personally, outweighs the relatively small likelihood that any of the individuals studied would come to harm.

The findings of this study were obtained from self-reports of individuals claiming to have TS and are not inconsistent with literature based on other kinds of self-reports, such as surveys. As they were made by individuals who had no identifiable gains by claiming to have TS and who were monitored without their awareness, it can also be assumed that the statements were made in “good faith.” As such, they can be considered a source of

convergent validation for information gathered from surveys and clinical experience.

They also give a new depth to the portrait of an individual coping with TS.

Conclusions

Electronic forums on the Internet on which persons with TS exchanged information, experiences, and support were monitored and a list of unique statements reflecting the experiences of persons with TS participating in the forums was generated. Analysis of these statements using concept mapping (Trochim 1993) revealed 5 major themes: symptom management, positive aspects, social rejection, misdiagnosis, and self-consciousness. Although these themes are consistent with published literature on the social sequelae of TS, statements comprising several themes reveal aspects of the disorder not frequently discussed. Among these are strategies used by persons with TS to control or manage the social consequences of their symptoms, and the perception among some persons with TS that the disorder may confer benefits as well as disadvantages.

This study represents a new method of unobtrusively gathering data on the experiences of individuals in certain groups: the monitoring of electronic discussion groups on the Internet. It is a method that has proven useful in generating a “live” picture of individuals coping with TS. It adds to the previous somewhat sterile clinical descriptions of persons with TS. It is also a method of research that appears to have proven to be successful and could be used to look at how individuals cope with other disorders.

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Table 1

Statement number, statement, and bridging index for experiences of persons with Tourette's syndrome.

Cluster 1: Symptom Management

9	I use humor as a diversion.	.00
30	I try to substitute "quiet" tics for noticeable ones.	.01
15	I try to distract myself from obsessive thoughts.	.03
3	I disguise my tics as mannerisms.	.05
34	I don't try to suppress tics that are socially acceptable.	.07
40	I can focus the energy from my tics into work.	.09
87	I use my obsessive tendencies in my job.	.09
1	I had to learn to "act" in social situations.	.10
72	I try to channel my compulsive tendencies into positive ends.	.11
21	I've become so good at "managing" my symptoms that people are shocked to learn I have Tourette's Syndrome.	.13
49	I made people like me in spite of my often "strange" behavior.	.16
42	I don't feel out of place playing baseball, where it's considered normal to have weird habits.	.20
77	I rarely tic when I'm concentrating on work.	.20
90	Ticcing makes my muscles strong.	.26

(table continues)

31	I've modified my diet and my lifestyle.	.27
66	I work better when I'm tired and the ticcing sensations get dulled along with everything else.	.28
19	I probably have had to strive harder to achieve what I have.	.31
51	I have only recently learned not to be ashamed of my tics.	.31
35	I often ask people if my tics bother them.	.32
45	I concentrate better when I can let my tics happen.	.32
20	I find myself imitating the accents and language of people I'm talking to.	.33
41	I avoid activities where I can't have time to myself.	.37
4	I am far more "myself" on medication than I have ever been.	.38
67	I try to sit where I can tic without being seen.	.43
84	I only really feel I "belong" when I am with other people with Tourettes.	.43
63	The people I work with are very supportive.	.48
62	I found the first "coming out" about my Tourettes to be the hardest.	.49
91	I use street drugs to control my tics.	.71

Cluster 2: Positive Aspects

46	I think that Tourettes has given me abilities as well as disabilities.	.04
57	I think I am a better person because of Tourettes.	.04
74	Tourettes makes me more exuberant about life.	.07
85	I have had the opportunity to help others.	.14
88	While I'm ticcing, my imagination is very vivid.	.21

(table continues)

47	I try to educate anyone who's interested about Tourettes.	.26
70	Tourette's Syndrome is an important part of who I am.	.27
12	When under stress, my tics get worse.	.41
73	It feels good to talk to people who understand what I'm going through.	.62
58	When I see strangers who have Tourettes, I want to talk to them.	.73

Cluster 3: Rejection

32	I was mistreated in school because of my Tourettes.	.01
27	I found another job because of my boss's attitudes toward my Tourettes.	.06
61	I was rejected from the educational program of my choice because of my Tourettes.	.06
55	My family members often say things that show they don't understand.	.10
8	People told me I couldn't pursue the career I wanted.	.14
37	Members of my family sometimes say insensitive things.	.17
80	My high school did not know what to do with me.	.17
14	I did not receive any support from my religious community.	.18
28	I have been thrown out of every place imaginable.	.19
48	My parents were very concerned about my ability to find a wife.	.27
56	Some of my family members taunted me about my Tourettes.	.27
64	Many people are very uncomfortable with my level of intensity.	.33
10	I was punished for doing things I couldn't help.	.34

(table continues)

2	I am overwhelmed when I am accepted by others.	.35
16	I decided to not have children.	.37
33	I am shocked when someone asks me out on a date.	.39
18	I have my guard up after years of being shunned by society.	.41
29	I quit my job because my tics interfered with my ability to do it.	.41
11	I couldn't get into the career I wanted because of Tourettes.	.42
7	I spend a lot of time by myself because of my tics.	.45
17	I'm embarrassed to talk about my symptoms even with people close to me.	.48
59	I think the media have presented us in a grossly exaggerated fashion.	.48
25	I took medication so that my family members wouldn't be embarrassed.	.50
38	I'm frightened about passing on my Tourette's Syndrome to my children.	.50
43	I've spent most of my life proving myself to others.	.50
6	I don't go to church any more, because I tend to say stuff like "shit" at times when it is not appreciated.	.52
76	I don't go to high school reunions.	.55
60	I don't let people support me, because they don't know what I am going through.	.56
50	When I met other people with Tourettes at work, we never discussed our condition.	.82

(table continues)

Cluster 4: Misdiagnosis

26	My Tourette's Syndrome was misdiagnosed.	.29
69	When I was referred to a psychiatrist, I knew more than he did.	.32
5	I was diagnosed with Tourette's Syndrome years after I first had symptoms.	.39
78	I wasted a lot of years being treated for "anxiety."	.39
24	I thought I was crazy before I found out I had Tourettes.	.40
68	The labels I carried from being misdiagnosed affected my whole life.	.43
65	My parents sent me to many specialists.	.59
53	When I was a child, I just wanted to know that someone sympathized.	.89

Cluster 5: Self-Consciousness

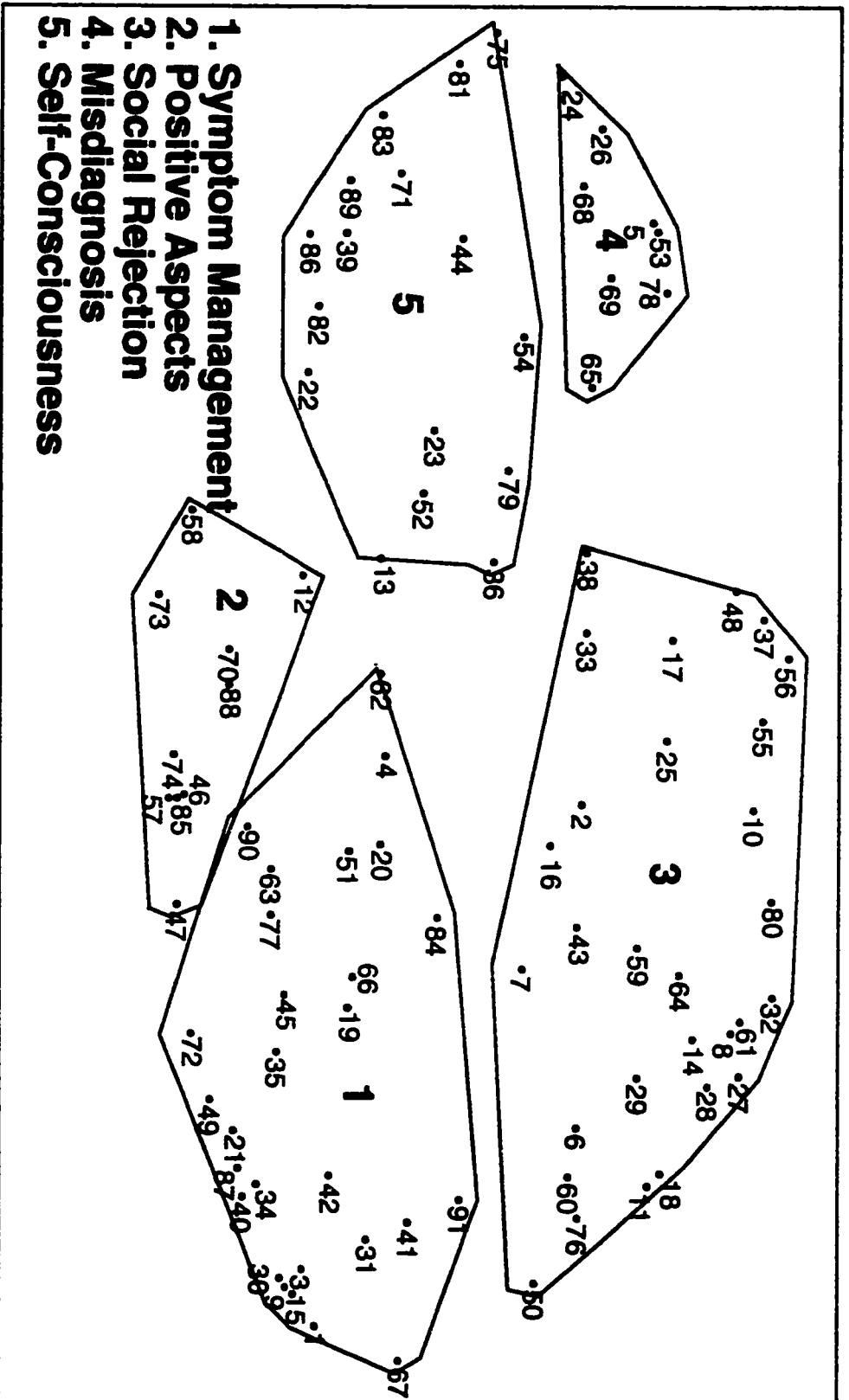
75	I was relieved when I was diagnosed.	.36
52	I often jump from topic to topic in my conversations.	.39
36	I am amazed when I see videos of myself.	.40
79	I don't know what's "safe" to talk about in casual conversation.	.50
81	I was embarrassed, confused, and afraid before my parents explained my Tourettes to me.	.51
23	My tics interfere with common daily tasks.	.54
54	I've had to have surgery because of physical damage from my tics.	.56
13	I'm tense from suppressing my tics.	.59
44	I thought that tics were something that everyone did.	.63
83	Sometimes my muscles get sore from twitching.	.69

(table continues)

86	My obsessive compulsive symptoms can immobilize me.	.71
39	It would be nice to know how much is “me” and how much is Tourettes.	.73
82	I thought I was just weird until I was diagnosed with Tourettes.	.76
89	I have often wondered what it would be like to not be concerned about tics.	.80
22	I’ve had to live with unpleasant side effects of medications.	.84
71	I’ve stopped taking medication because the side effects.	1.00

Figure Caption

Figure 1. Concept map for persons with Tourette's syndrome.



Chapter 3. The Experience of Living With A Family Member with Tourette's Syndrome, As Garnered From The Internet.

Introduction

Tourette's Syndrome (TS) is a neuropsychiatric disorder of childhood and adolescence, characterized by unwanted movements and vocalizations, known as tics (American Psychiatric Association, 1994). These movements and vocalizations appear with great variation in their intensity and presentation, and often result in social embarrassment and rejection.

Tourette's Syndrome is a familial disorder in several senses. The propensity to develop the tics that are the disorder's defining characteristic appears to be inherited. The onset of symptoms occurs in childhood or adolescence, at a time when their impact is felt not only by the individual with the disorder, but by parents, siblings, and other relatives. Yet relatively little has been published on the impact of TS on the family. The information that is available comes largely from two sources: clinicians distilling and describing their experiences in working with affected families and individuals (e.g. Cohen, Detlor, Shaywitz, & Leckman, 1982; Cohen, Ort, Leckman, Riddle, & Hardin, 1988; Harper, 1992) and surveys (e.g., Hubka, Fulton, Shady, Champion, & Wand, 1993; Jagger et al., 1982; Nomura, Kita, & Segawa, 1992). Even in surveys specifically designed to gauge the disorder's impact on the family, the respondents were largely persons with TS, and not their family members.

The presence of electronic forums in which persons with TS and their family members can share knowledge, experiences, and emotional support has created an

opportunity to gather data on the impact of TS on family members. Existing on the world-wide computer network commonly known as “the Internet,” these forums were monitored as part of another study on the experiences of persons with TS (see chapter 2). A large proportion of the messages exchanged were from family members of persons who had the disorder—usually parents, but also spouses and children. The content of these messages was analyzed using a technique, based on multidimensional scaling and cluster analysis, known as “concept mapping” (Trochim, 1989a, 1989b, 1993). The purpose of the analysis, and this study, was to determine what major themes existed in the reported experiences of family member of persons who had TS.

Tourette's Syndrome

Tourette's Syndrome is characterized by sudden, rapid, recurrent, nonrhythmic, and stereotyped movements and vocalizations, known as tics (American Psychiatric Association, 1994). The range and variety of tics is almost unlimited. Simple motor tics involve only individual muscle groups, causing a brief, isolated, jerk-like movement. Examples include an eye blink, a shoulder shrug, a head jerk, a dart of the eyes, or a twitch of the nose. Complex motor tics consist of coordinated, sequenced movements involving several muscle groups. Examples of complex motor tics include touching objects, other people, or one's self; throwing, hitting, kicking, doing knee bends, and jumping. Additional examples include the making of obscene gestures, such as “giving the finger” (copropraxia), or the imitation of gestures (echopraxia). The movements in complex motor tics may seem nonpurposeful, as in the case of head shaking; or purposeful, as in the case of touching, hitting, or the making of gestures. They may

resemble mannerisms or habits peculiar to an individual, for example, the rituals a baseball pitcher engages in before throwing the ball. A cluster of simple tics produced in rapid succession may produce complex movements resembling a complex motor tic (Jankovic, 1992; Singer & Walkup, 1991).

Simple vocal tics result in the production of a simple, meaningless sound. Examples include throat clearing, sniffing, grunting, squeaking, coughing, blowing, making sucking sounds, and barking. Complex vocal tics consist of vocalizations which may include syllables, words, phrases, or full sentences. These vocalizations may consist of words or phrases that are inappropriate or non-sequiturs, such as “no, no” or “Oh, boy.” They may involve the repetition of someone else’s words (echolalia), the repetition of one’s own utterances (palilalia), or the uttering of obscenities and profanities (coprolalia) (Jankovic, 1992; Singer & Walkup, 1991).

Tics are often preceded by premonitory experiences, uncomfortable feelings or sensations that are relieved by performing the movement (Lang, 1993). Shapiro, Shapiro, Young, and Feinberg (1982) coined the term sensory tics to describe these sensations. Bliss (1980), writing after a lifetime of having the disorder, likened these sensations to a “compelling, though subtle and fleeting itch” (p. 1344) that could only be relieved by performing a motor or vocal tic.

Tourette’s Syndrome has been diagnosed in children as young as 1 year (Shapiro et al., 1988); the median age of onset is 7 years (American Psychiatric Association). Over 90% of patients develop Tourette’s Syndrome by age 10 (Shapiro et al., 1988). By

definition, onset of symptoms must be before age 18 (American Psychiatric Association, 1994).

Facial tics are the first symptoms in two out of three cases (Bruun & Budman, 1992); vocal tics tend to have a later mean age of onset than motor tics (Bruun, 1988). In 50 to 70 percent, the initial symptom is a single tic, usually an eye blink (Nomura & Segawa, 1982; Golden, 1977; Lees, Robertson, & Trimble, 1984; Shapiro et al., 1988). The symptoms wax and wane, and, as the syndrome progresses, new symptoms appear while old ones disappear. Singer and Walkup (1991) reviewed the literature on the progression of the syndrome and concluded that 30 to 40 percent of cases will experience a remission of tic symptoms by late adolescence, with an additional 30 percent showing significant reductions in the frequency and severity of tics, with the balance remaining symptomatic in adulthood.

In spite of an increase in the awareness of TS among health care personnel and the general public over the last 3 decades, there is still likely to be a lag of several years between the onset of symptoms and a proper diagnosis. Shapiro, Shapiro, Bruun, and Sweet (1978) reported an average of 13.8 years between the onset of symptoms and diagnosis of TS in a sample of 145 patients they had seen from 1965 to 1974. Comings and Comings (1985) reported a delay of 11.2 years between onset and diagnosis in their sample of 250 patients. Wand, Shady, Broder, Furer, and Staley (1992) reported an average of 7.4 years between the onset of symptoms and diagnosis in their survey of 462 TS patients. Both Comings and Comings (1985) and Wand et al. (1992) reported that the

majority of their respondents had received their first information on TS from someone other than a physician.

Lack of familiarity with TS among health care personnel has been identified major reason for missed diagnosis (Comings & Comings, 1985; Wand et al, 1992), as has the mistaken belief that coprolalia must be present for a diagnosis to be made (Comings & Comings, 1985; Shapiro et al., 1988). The ability of many persons with TS to suppress their symptoms for up to several hours at a time also often leads to missed diagnosis (Comings & Comings, 1985; Bruun, 1984; Golden, 1977); a parent bringing a child with TS to the doctor may face a disbelieving physician after the child, who had been ticcing at home and all the way to the doctor's office, suppresses the tics at the doctor's office (Comings & Comings, 1985).

The few empirical studies which examined the impact of TS on the family suggest that the disorder can, but not necessarily does, lead to disruption of family life. Forty percent of the 75 persons with TS surveyed by Jagger et al. (1982) responded that they felt their relationships with siblings had been adversely affected by the disorder; fifty percent stated that their relationships with their parents or guardians had suffered. Nearly 60 percent of the 210 persons with TS or family members surveyed by Hubka et al. (1993) indicated that the disorder had interfered with the day-to-day activities of the family. Sixteen percent of family members other than the person with TS had sought counseling for issues related to the disorder. Respondents were also asked to indicate the presence of certain family problems since diagnosis was made: 21 percent indicated there had been marital problems, 6 percent indicated problems with alcohol abuse, 4 percent

indicated problems with drug abuse, and 13 percent indicated that other, undefined problems had been present since diagnosis.

That a disorder which can cause socially embarrassing behaviour might lead to restrictions in family activities seems self-evident. Similarly, it is not surprising that associated disorders involving impulsive, disruptive, or obsessive symptoms could lead to restrictions in a family's day-to-day routine. Tourette's Syndrome, however, also imposes a number of stresses on the family because of the way in which its symptoms develop, their suppressibility, the lack of public information about the disorder, and the treatment options available (Cohen et al., 1982).

The initial symptoms of TS can be innocuous and ambiguous enough that they may not be noticed, or may be interpreted as a sign of something else. In 50 to 70 percent of new cases, the first symptom is a single tic—usually an eye blink (Nomura & Segawa, 1982; Golden, 1977; Lees, Robertson, and Trimble, 1984; Shapiro et al., 1988). Tics may resemble symptoms of allergies, respiratory problems, or other disorders, and be interpreted as such by parents and health care workers (Comings & Comings, 1985; Golden, 1977; Shapiro et al., 1988). By the time a diagnosis is made, several years have often elapsed—years in which relationships between parent and child may have been marked by guilt and resentment over efforts on the part of parents to control behavior in their children that was not completely voluntary (Cohen et al., 1988).

The suppressibility of TS symptoms also poses a problem to parents, who are put in the position of having to decide which undesirable behaviors are voluntary and deserving of punishment, and whether the child is exploiting the symptoms (Bruun, 1984; Cohen et

al., 1988; Hubka et al., 1988). The tendency of a child to tic more at home, may be mistaken for a sign of problems in the home by school officials, when it is really an indication of the child's greater comfort in showing the symptoms at home (Comings, 1990).

The fact that the initial symptoms of TS are frequently ambiguous and can lead to misdiagnosis can also lead to skepticism about the medical profession (Cohen et al., 1988). Parents may do a certain amount of "doctor shopping" in an effort to find a diagnosis that is acceptable (Harper, 1980). The lack of public information about the disorder means that, when a diagnosis of TS is given, parents will likely only know about the more extreme possibilities as portrayed in the mass media, leading to anxiety over what symptoms could develop next (Cohen et al., 1988). If the symptoms of the disorder are severe enough to warrant medication, the decision to medicate can bring its own anxieties, particularly if initial trials are not successful or result in side effects that create new problems.

The Internet

The worldwide computer network commonly known as the Internet has, in recent years, been the object of increasing interest among members of the general public. This has resulted in explosive growth in the number of persons using the Internet, and a shift away from its focus as a means of disseminating academic research to a method of popular communication (Badgett & Sandler, 1993). Among the services provided over the Internet is a large collection of discussion groups, known as Usenet newsgroups, each devoted to its own particular topic. Once a message has been posted to a newsgroup, that

message, and any responses to it, are sent to all other Internet sites carrying that newsgroup. There are a number of newsgroups devoted to the exchange of information and support for persons with various medical and psychiatric conditions. Among them is the newsgroup alt.support.tourette. Internet mailing lists also provide forums for discussion of particular topics, but only to those subscribing to a given list. Any piece of electronic mail sent to a mailing list is sent to all the other subscribers. POV-Twitch is a mailing list for persons with TS and their family members. Both of these forums were monitored in this study to gather data on the experience of living with TS.

Concept Mapping

The data from monitoring the Internet discussion groups and mailing lists was analyzed using concept mapping (Trochim, 1993). As described by Trochim (1989b), the technique entails asking a group of participants to generate as many ideas as possible about a given topic. A list of unique statements about the topic is generated from the participants' contributions. Participants are then asked to sort the resulting list of unique statements into logical, homogeneous groups, with each group representing a particular aspect or theme of the topic. The sorts are then analysed using multidimensional scaling (MDS) and cluster analysis. Multidimensional scaling results in a graphic on which is each statement is represented by a point. Points that are close to each other represent statements that are similar along a given dimension; points that are distant from each other represent statements that are dissimilar. Cluster analysis results in a determination of which statements are sorted together frequently and are therefore conceptually similar.

Concept mapping has been used as a business planning technique (Trochim, 1993), for program planning in the social services (Trochim, 1989a; Trochim 1989b) and for psychological research (Daughtry & Kunkel, 1993; Phillips, 1993; Kunkel & Newsom, 1996). It encourages the generation and exploration of a wide variety of ideas on a given topic and minimizes the introduction of bias by the researcher in the search for relationships between the ideas.

Method

The Usenet newsgroup alt.support.tourette and the mailing list POV-Twitch were monitored from March 1996 to July 1996 and every message was recorded. Messages that were relevant to the research question (“what is the experience of being a family member of someone with TS?”) were put on a master list and edited so that they expressed only one idea, were grammatically correct, and were grammatically consistent with other items on the list. As much of the original wording as possible was retained in the editing process. Items that were redundant were removed from the master list, so that the remaining items were unique. The resulting list had 95 statements.

Once a final list of statements had been compiled, a group of voluntary raters (N = 19) was recruited. Following a standard set of instructions, they were asked to group statements that expressed a similar theme or concept into piles. The resulting sorts were analyzed with the Concept System computer software by Trochim (1993), using multidimensional scaling (MDS). A point map was generated, where each statement was represented by a point. Points that are spatially close to one another are judged to be

thematically similar; points that are spatially far from one another are judged to be thematically different.

Results

Ninety-five unique statements made by family members of a person with TS were collected (Table 1). Most of these statements were made by parents of children with TS. After the statements were sorted into themes by 19 volunteers, they were analyzed using MDS and cluster analysis to produce a concept map (Figure 1). The MDS analysis resulted in a final stress value of 0.29; a stress value of under 0.31 represents a reasonably stable solution (Trochim, 1993).

Insert Figure 1 about here

A solution in which the points on the point map were divided into 9 clusters was chosen as representing the optimum trade-off between homogeneity of cluster content and parsimony of description (Table 1). Homogeneity is more likely to be achieved with small clusters, while parsimony is more likely to be achieved with a small number of clusters. Referring to the bridging index for each statement facilitated the arrival at a nine cluster solution. This index, which ranges from 0 to 1, indicates how well a particular statement “fits” within a given cluster. The higher the number, the more likely it is that a given statement could have just as easily been included in another cluster. The lower the number, the more likely a statement is to fit in only one given cluster (Table 1).

Cluster 1 was comprised largely of expressions of denial or guilt over the existence of TS in a family member. Examples of statements of denial included “When our son was diagnosed with Tourettes, my husband was furious and in big time denial” (no. 63) and “I tried to explain away my son’s differentness” (no. 1). Statements involving guilt included “We feel guilty because we punished our child for behaviour she couldn’t control” (no. 19) and “We were relieved that genetics, and not something we had done, was responsible for our child’s tics” (no. 38). Accordingly, the descriptor chosen for this cluster was “Denial/Guilt.”

Cluster 2 was composed mainly of statements of the negative feelings parents felt toward their children with TS. Examples included “Sometimes I don’t feel very loving toward my offspring” (no. 22), “I feel resentment, stress, anger, fatigue, love, and hopelessness—all at the same time” (no. 74), and “By day’s end, I feel closer to a drill sergeant than loving parent” (no. 8.). The mixture of emotions expressed in the statements is complex, involving anger, resentment, worry, fatigue, embarrassment, and helplessness. The common denomination is that these are largely negative emotions: the descriptor chosen for this cluster was “Negative Feelings.”

Cluster 3 was comprised of statements that centered on the topic of embarrassment in social situations. Examples included “My daughter’s tic was so noticeable that in restaurants people would regard us with horror” (no. 37) and “Occasionally, my husband’s tics have been so bad we’ve had to drop plans to go out” (no. 2), and “People assume I’m a bad parent because of the way my child behaves” (no. 25). The descriptor chosen for this cluster was “Social Embarrassment.”

Cluster 4, comprised of only 3 statements, was a bit of an anomaly. Its approximately central location on the cluster map (Figure 1) suggests that its points could well have been included in other clusters. Its presence is a reflection of the fact that concept maps which did not have Cluster 4 were even more problematic in terms of parsimony and explanatory value. The statements in Cluster 4 seem to deal with the intrusiveness of the symptoms into the lives of family members; thus, the descriptor “Intrusiveness of Symptoms” was chosen.

Statements in Cluster 5 were largely concerned with the rejection of the family member with TS by the community. Examples include “The neighbors keep their children away from my son” (no. 27), “The attendant at an amusement park ride threatened to throw our son off the ride” (no. 56), and “Our community rejected our son and us” (no. 12). The descriptor “Social Rejection” was chosen for this cluster.

Statements in Cluster 6 were largely examples of families’ searches for ways to ameliorate or “cure” the disorder, or of concerns over what other effects such treatments might have. Examples include “We tried nutritional supplements and vitamins because the drugs weren’t working” (no. 14), “I have looked into “alternative medicine” to treat our son’s Tourettes” (no. 86), and “I have consulted many specialists about my child’s behaviour” (no. 95). The descriptor “Search for Solutions” was chosen for this cluster.

Cluster 7 contained a seemingly diverse set of statements with no clear theme. Closer inspection revealed that a common denominator among many of the statements was the need for information or answers, as reflected in statements such as “I’ve found it difficult to find good information on Tourettes” (no. 16) or “We spent thousands for my

husband's counseling, only to discover he had had Tourettes all along" (no. 76). Even seemingly unrelated statements such as "The doctor seemed to discount what we told him about our son's behaviour" (no. 58) or "My daughter had known about her tics for much longer than we did, and long before she had been diagnosed" (no. 78) are suggestive of an inadequate exchange of information. The descriptor "Need for Answers" was therefore chosen for this cluster.

Cluster 8 was composed largely of examples of positive, concrete steps that parents had taken to help their child with TS. Examples included "We gave an inservice to our school about Tourettes" (no. 10), "I am very active in our local Tourette's Syndrome Association" (no. 15), and "We bought our son a laptop computer to help him in school" (no. 8). The descriptor chosen for this cluster was "Positive Concrete Adaptation."

In contrast to the Positive Concrete Adaptation cluster, Cluster 9 was composed largely of statements reflecting a more passive approach to dealing with the family member's TS. Statements such as "I only discuss my son's tics when they are socially unacceptable" (no. 61) and "If my son can't control his vocal tics, I ask him to leave the room so he is not able to get the shock effect from any of us" (no. 91) indicate a less proactive, more reactive approach to dealing with the symptoms of TS than many of the measures taken by parents in Cluster 8. Statements such as "It's comforting to know that tics come and go" (no. 26), "When I'm overwhelmed I turn to God" (no. 23), and "Because of my son's Tourettes, I have met some wonderful people" (no. 92) suggest a change of attitude within the parent toward the child's TS symptoms and the task of coping with those symptoms. The common denominator of these statements is that they

do not involve actions as much as they do an increase flexibility in living with the family member's TS. Their more passive nature lead to the decision to use the descriptor "Passive Acceptance" for this cluster.

Discussion

The number and variety of clusters is a reflection of the emotional complexity of being a family member of someone with TS. A person with TS lives with the symptoms of the disorder, the reactions of others to those symptoms, and his or her emotions in regard to both. A family member also lives with all of that and the emotions resulting from empathic identification with the family member. If the family member is a parent or guardian, the responsibility for helping the family member cope also enters into the role. In this sense, it is not surprising that the concept map for family members is more complex than that for persons with TS (see Chapter 2).

The themes represented by the clusters seem to split fairly even between attitudes or emotions brought on by the symptoms or their consequences (clusters 1 through 5) and actions taken as a result of the symptoms or their consequences (clusters 6 through 9). The themes of the concept map reflect a logical progression of attitudes, emotions, and actions over time as families cope with TS. The onset of symptoms and diagnosis leads to denial of their meaning and guilt over the transmission of the disorder and the treatment of the child. As symptoms progress and become more numerous, the family has to cope with embarrassment and social rejection as a result of the child's behavior. The need for information about the disorder and the search for solutions to managing the symptoms leads to positive, often proactive measures to help the child cope better.

The themes of the concept map and the statements that comprise the themes are consistent with descriptions by Cohen et al. (1982, 1988) and Harper (1992) of how the family comes to adapt to a family member's TS. The concept map goes beyond the published literature in providing different angles on issues that have been raised in the literature. Guilt over the genetic origins of TS has been cited as a source of parental concern and family stress (Cohen et al., 1982, 1988; Harper, 1992; Hubka et al, 1988); none of the published literature has indicated that knowledge of the disorder's genetic origins could also be a source of consolation and relief, as reflected by statement no. 38 ("We were relieved that genetics, and not something we had done, was responsible for our child's tics.") in the Denial and Guilt cluster. Similarly, although the waxing and waning nature of tics has been identified as a stressor for parents (Cohen et al, 1982), the published literature to date has not suggested that a parent's mood can be closely tied to those fluctuations in the tics (e.g. no. 49, "The waxing and waning of my son's symptoms causes my mood to go up and down also."), or that the changing nature of tics can also be a source of comfort (e.g., no. 26, "It's comforting to know that tics come and go.").

Many of the statements reflect a perception that information on TS is still difficult to come by (e.g., no. 16, "I've found it difficult to find good information on Tourettes."), while others suggest that presumably knowledgeable sources are not always forthcoming with information (e.g., no. 68, "When I talk to my doctor about medications, I ask a lot of questions." and no. 57, "I told the doctors treating my son I was tired of being sent home with 'no instructions.'"). Several statements reflect parental attempts to inform others about TS as a proactive method of avoiding conflict and embarrassment in school

and in the community (e.g., no. 10, "We gave an inservice in our school about Tourettes." and no. 24 "Explaining our child's behavior has made the neighbors less judgemental.").

The range and variety of measures parents took to help their children cope with TS, as reflected in the clusters Positive Concrete Adaptation and Passive Adaptation, show a high degree of motivation and creativity that is not adequately portrayed in the published literature. Acting as the child's advocate, purchasing aids such as laptop computers to make doing schoolwork easier, attempting to educate others in the school or the community, setting up behavior modification programs, and preparing the child for self-employment are examples of the breadth of activities parents engaged in to help their child with TS. Some parents attempted to employ aspects of the disorder that are normally perceived as negative in situations in which they could be assets (e.g., no. 32, "I try to channel my child's compulsion into positive ends."). This strategy has been employed by persons with TS and deserves further exploration. Some of the statements reflect the willingness of parents to go much farther than the normally-asked for participation in the child's school progress (e.g. no. 47, "We tried hard to work with our son's school in bringing in outside consultants and doctors."), perhaps reflecting inadequate efforts on the part of the school board to accommodate the child's needs (e.g., no. 83, "When I was asked to come along on school trips, it was to 'supervise' my son."), or even inappropriate efforts to accommodate the child's needs (e.g., no. 46, "When the school told us to put our child in a school for emotionally disturbed kids, we started home schooling him.") Statements such as "I'm trying to prepare my son for self-employment, because I don't think he'll fit into a mainstream job." (no. 52) reflect a

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forward-thinking pragmatism about life after formal schooling that, ideally, would not be necessary. It is not surprising that the amount of effort required to promote the child's interests can seem like an all-consuming task (e.g., no. 69, "It seems we could spend all of our time getting help for our son.").

Conclusions

The results of this study indicate that family members of a person with TS face a more varied set of issues due to the more complex roles played by family members. The amount of commitment and energy required to help a child with TS cope in school and in the community can easily make this task a full time job, causing other aspects of family life to suffer, such as the relationship between the parents or the relationship among siblings. Parents, grandparents, and other relatives may have to come to terms with the fact that they have they also have the disorder. The genetic etiology of TS can lead to finger-pointing and blaming among in-laws and other relatives (e.g., no. 70, "My mother denied that her side of the family could have passed down the Tourettes gene"; no. 72, "My husband's family blamed our son's symptoms on medication I took while pregnant."). Psychological intervention can help family members accept the presence of TS in the family, educate them about the disorder and its course and assist them in developing effective coping strategies, for both the person with TS as well as other family members.

The themes derived from the statements in this study suggest a clear progression in coming to terms with the disorder's existence in a family member: denial and guilt over the disorder's presence in a family member, as well as social embarrassment and

rejection lead to need for answers and a search for solutions. This in turn leads to the taking of positive concrete actions to help the child, as well as acceptance of the disorder and incorporation of the disorder into the family's lifestyle by reacting only to those symptoms that could lead to negative social consequences. Family members of a person with TS can be very creative in the ways they find to help that person cope with the disorder. It is likely that, the more ways in which a family can help the family member with TS cope, the less passive and more in control the family feels. Again, psychological intervention can help family members feel more in control over the disorder, through the development of concrete measures to help the person with TS in school and in the community.

This study also shows that the Internet can be a useful source of subjects for the researcher. The thousands of newsgroups, mailing lists, and other electronic discussion forums provide a largely untapped source of data, not only on persons with medical or psychological disorders, but on individuals with particular sexual preferences, occupations, lifestyles, or interests. As these are public forums in which anyone can participate, unobtrusively monitoring statements made on a given forum poses few ethical problems. Although many participants in these make very intimate revelations without concealing their identities, it is still recommended that the identity of individuals making statements be concealed.

On a related note, Internet support groups can be a useful adjunct to "live" support groups and psychological therapy or counseling. Surprisingly little misinformation was exchanged among participants in the forums monitored for this study. Participants were

supportive of one another, and frequently very useful information was exchanged. Many of the statements gathered in this study came from participants comparing notes on what they had done to help a family member, and whether it had been effective for them. For a disorders with a relatively low prevalence, such as TS, Internet discussion forums give interested individuals a much larger pool of potential people to share their ideas with than might be found in even a large city.

Concept Mapping proved to be a useful method of categorizing the content of statements made on Internet discussion forums. It has the advantage of providing a graphical representation of where individual statements lie in relation to each other on a given dimension, and of which statements are thematically similar. It provides few opportunities for a researcher's bias to affect the results, and it is faster and easier to do than other forms of qualitative research.

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Table 1

Statement number, statement, and bridging index for experiences of family members of persons with Tourette's syndrome.

Cluster 1. Denial/Guilt

19	We feel guilty because we punished our child for behavior she couldn't control.	.32
17	When my child was diagnosed, I wanted to believe it was just a temporary thing.	.38
67	Family members who are in denial about my son's diagnosis also seem to have Tourettes themselves.	.39
70	My mother denied that her side of the family could have passed down the Tourettes gene.	.41
63	When our son was diagnosed with Tourettes, my husband was furious and in big time denial.	.48
13	When my son was diagnosed with Tourettes I decided not to have any more children.	.50
72	My husband's family blamed our son's symptoms on medication I took while pregnant.	.51
9	My teen-aged daughter told me she never wants to have children.	.59

(table continues)

38	We were relieved that genetics, and not something we had done, was responsible for our child's tics.	.67
41	I know many parents who use their children's diagnosis as an excuse for their behavior.	.67
80	I have trouble knowing when my son's bad language is due to his Tourettes.	.71
85	My wife and I disagree on how to deal with our son's rage attacks.	0.75
36	Even though our husband and I both carry the Tourettes gene, we haven't let that stop us from having children.	0.80
73	I don't know when to punish my son because I don't know when his behavior is intentional.	0.80
1	I tried to explain away my son's differentness.	1.00
Cluster 2. Negative Feelings		
22	Sometimes I don't feel very loving toward my offspring.	.00
8	By day's end, I feel closer to a drill sergeant than loving parent.	.01
74	I feel resentment, stress, anger, fatigue, love, and hopelessness-- all at the same time.	.01
66	Some of my daughter's symptoms have caused me to panic.	.04
21	I feel like I got a defective version of the kid I "ordered."	.05
4	We are always on edge as we do not know how our son will react to situations.	.10

(table continues)

45	It's so devastating when you can't seem to do anything to help your child.	.15
65	My son's compulsive worrying bothers me more than his tics.	.15
28	I get embarrassed by my son's behavior on a semi-constant basis.	.16
3	I have sleepless nights worrying about my son's future.	.21
20	Sometimes I can't keep up with the waxing and waning of my son's tics.	.23
29	I am worried about my son committing suicide.	.24
49	The waxing and waning of my son's symptoms causes my mood to go up and down also.	.24
30	When my husband is under stress, his tics will keep both of us awake at night.	.25
53	My relationship with my husband has suffered because of our son's Tourettes.	.33
93	I feel guilty about having passed Tourettes on to my son.	.34
Cluster 3. Social Embarrassment		
55	Sometimes our son's vocal tics were loud enough that our family could not watch television.	.25
37	My daughter's tic was so noticeable that in restaurants people would regard us with horror.	.27
39	My husband has painful memories about the abuse he took for his tics.	.29
2	Occasionally, my husband's tics have been so bad we've had to drop plans to go out.	.32

(table continues)

87	Both my parents had Tourettes and life was frantic and chaotic.	.38
25	People assume I'm a bad parent because of the way my child behaves.	.41
42	Our daughter feels socially isolated.	.60
Cluster 4. Intrusiveness of Symptoms		
7	We have canceled plans to go out because of fear of leaving our children alone together.	.40
6	I discovered my son was using his diagnoses as a way of getting out of things at school.	.57
69	It seems we could spend all of our time getting help for our son.	.57
Cluster 5. Social Rejection		
27	The neighbors keep their children away from my son.	.20
59	The neighbors called the cops on my son.	.22
56	The attendant at an amusement park ride threatened to throw our son off the ride.	.23
12	Our community rejected our son and us.	.27
88	One of our son's tics resulted in an accusation of sexual harassment.	.31
31	Other children made fun of our child's tics, causing him to not want to go to school.	.37
83	When I was asked to come along on school trips, it was to "supervise" my son.	.42
5	My son was ridiculed by some of his teachers.	.52

(table continues)

51	I've been frustrated trying to educate people in our school system about Tourettes.	.55
48	I can't count the number of times we met with our school because of our son.	.56
Cluster 6. Search for Solutions		
14	We tried nutritional supplements and vitamins because the drugs weren't working.	.12
68	When talking to my doctor about medications, I ask a lot of questions.	.17
89	After starting medication, my daughter became more like other girls her age.	.17
44	When we tried to take our son off his medication, he asked to be put back on.	.18
86	I have looked into "alternative medicine" to treat our son's Tourettes.	.19
50	If my son goes a day without his medication, I see a big difference.	.20
95	I have consulted many specialists about my child's behaviour.	.20
34	We have taken our child to several specialists.	.21
40	My son was hospitalized to better manage his Tourettes.	.24
43	It takes a lot of trial and error to find the best medication or combination of medications.	.25
57	I told the doctors treating my son I was tired of being sent home with "no instructions."	.30
64	I'm afraid that medicating my daughter will dull her.	.36

(table continues)

Cluster 7. Need for Answers

58	The doctor seemed to discount what we told him about our son's behaviour.	.30
54	We sent our daughter to an ear, nose and throat specialist for what turned out to be a tic.	.36
84	The school accused me of over-medicating my son.	.41
76	We spent thousands for my husband's counseling, only to discover he had had Tourettes all along.	.42
16	I've found it difficult to find good information on Tourettes.	.45
35	We have found some of the side effects to our daughter's medication very difficult to deal with.	.50
78	My daughter had known about her tics for much longer than we did, and long before she had been diagnosed.	.52

Cluster 8. Positive Concrete Adaptation

52	I'm trying to prepare my son for self-employment, because I don't think he'll fit into a mainstream job.	.07
75	We've set up our own behaviour modification program for our son.	.08
79	We bought our son a laptop computer to help him in school.	.10
32	I try to channel my child's compulsions into positive ends.	.13
81	I've kept my son in a regular classroom--I want him to learn the same things as everyone else.	.15
10	We gave an inservice in our school about Tourettes.	.17

(table continues)

24	Explaining our child's behaviour has made the neighbours less judgmental.	.17
15	I am very active in our local Tourette's Syndrome Association.	.19
60	Although I act as an advocate for my child, I try to avoid overprotecting him.	.22
33	We arranged for our son to be able to leave the classroom when his Tourettes is acting up.	0.24
82	I feel it is my duty to warn/discuss the unpleasant outcomes of some of my son's tics.	.24
94	I try to understand what it is like for my child to have Tourettes.	.24
18	Accepting our son's diagnosis has been a giant leap in deciding how to go forward.	.25
47	We tried hard to work with our son's school by bringing in outside consultants and doctors.	.30
77	When our son started assaulting people, we made it clear we would call the police.	.30
46	When the school told us to put our son in a school for emotionally disturbed kids, we started home schooling him.	.41

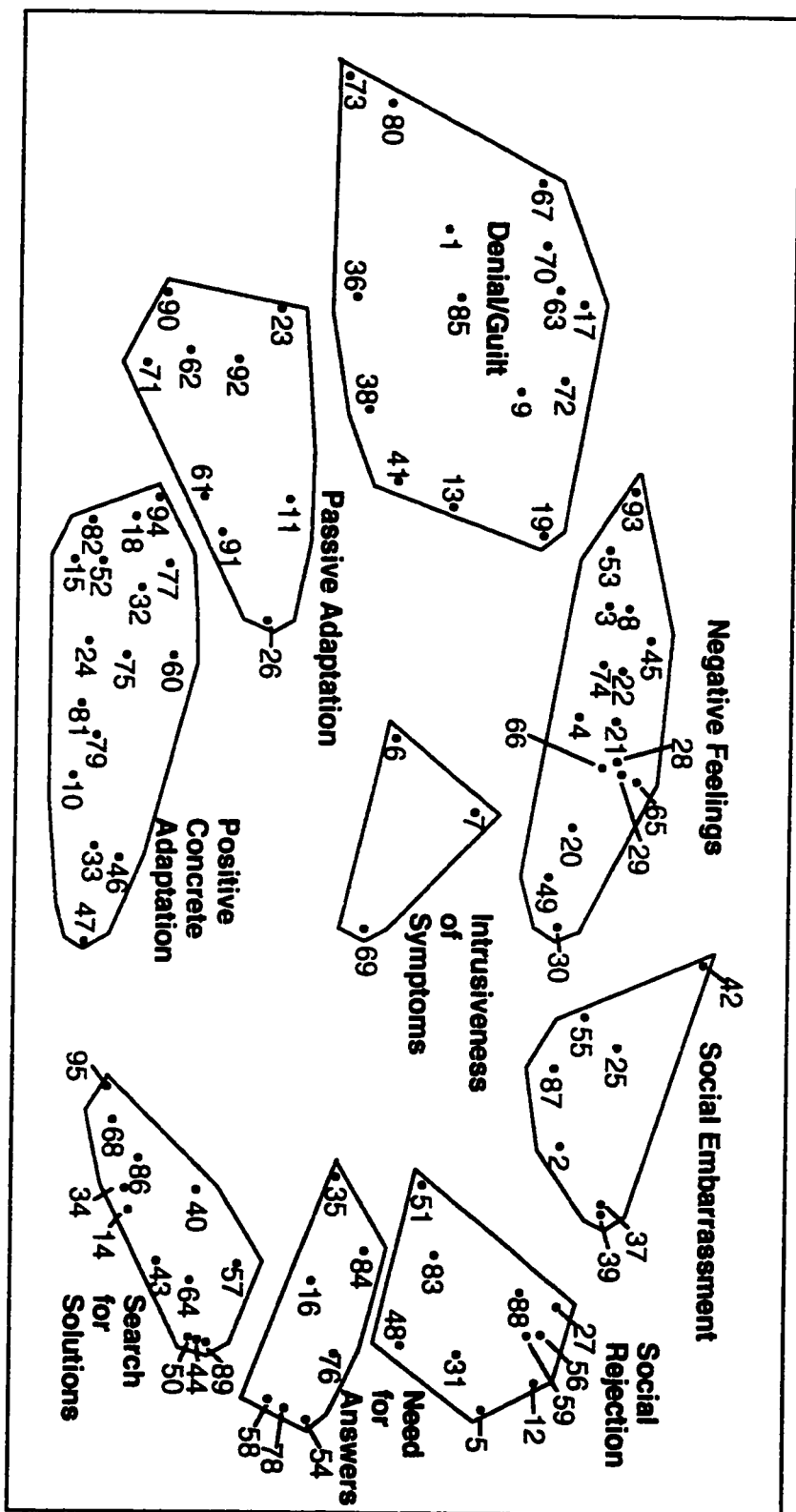
(table continues)

Cluster 9. Passive Adaptation

71	We don't let our son use his diagnosis as an excuse for his behaviour.	.20
62	If my son is doing something annoying or unpleasant, I try to find out if it is a tic or if it is something he can stop.	.32
90	I talked to my son about trust when I thought he was using his tics as an excuse for bad behavior.	.32
61	I only discuss my son's tics when they are socially unacceptable.	.35
91	If my son can't control his vocal tics, I ask him to leave the room so he is not able to get the shock effect from any of us.	.37
11	I pray for my child.	.47
26	It's comforting to know that tics come and go.	.51
23	When I'm overwhelmed I turn to God.	.59
92	Because of my son's Tourettes, I have met some wonderful people.	.76

Figure Caption

Figure 1. Concept map for persons with Tourette's syndrome.



Chapter 4. Summary and Conclusions.

The two studies in this thesis were undertaken because of the relatively little published research on the psychological and social effects of TS on those who have the disorder, and their family members. In the case of family members, this literature amounts to a few questions on questionnaires, and a small number of articles distilling the experience of clinicians who treated persons with TS and their family members. The existence on the Internet of a newsgroup, alt.support.tourette, and an electronic mailing list, POV-Twitch, for persons with TS and their family members provided a ready-made pool of potential subjects, easily and inexpensively reached. The technique of Concept Mapping provided a relatively easy and unbiased method of analyzing statements made on these two electronic forums for thematic content.

In the study on the experiences of persons with TS (Chapter 2), the Usenet newsgroup alt.support.tourette and the electronic mailing list POV-Twitch were monitored from March 1996 to July 1996 and all messages that were relevant to the research question ("What is the experience of living with TS?") were recorded. A master list of statements that reflected aspects of living with TS was created from these messages. A message could have several statements in it that were relevant to the research question. Redundant items were eliminated, so that the resulting list contained items that were unique. The items on this final list were then edited for spelling, grammatical consistency, and brevity. The final list had 91 statements.

Once the final list of statements had been compiled, a group of voluntary raters (N = 19) was recruited. Following a standard set of instructions, they were asked to group statements that expressed similar themes or concepts into piles. The resulting sorts were analyzed with the Concept System computer software by Trochim (1993), using multidimensional scaling (MDS). A point map was generated, where each statement was represented by a point. Points that are spatially close to one another are judged to be thematically similar; points that are spatially far from one another are judged to be thematically different. Through the use of a cluster analysis algorithm, statements that were frequently grouped together and that were therefore conceptually similar were identified.

For the study on the experiences of family members of persons with TS (Chapter 3) a similar series of steps was followed. Statements that were relevant to the research question ("What is the experience of being a family member of someone with TS?") were collected from the newsgroup alt.support.tourette and POV-Twitch. The resulting collection of statements was edited down into a set of 95 unique statements about the experience of being a family member of someone with TS. These statements were given to a 19 voluntary raters who then sorted them into piles of statements that were conceptually similar. The resulting sorts were analyzed with the Concept Mapping software (Trochim, 1993), resulting in a point map and a map cluster map.

For persons with TS (Chapter 2), 5 clusters or themes were identified. The cluster Symptom Management was comprised of statements on how the person with TS controlled his or her symptoms and managed the possible negative social repercussions of

the those symptoms. A distinction could be made between control of public symptoms, which could provide discomfort to onlookers, and control of private symptoms, which provided discomfort to the person with TS. A number of statements about the control of public symptoms involved redirecting or reshaping the tic into something more socially acceptable. Maintaining vigilance in social situations was a common factor for many of the statements.

The cluster Positive Aspects was comprised of statements reflecting positive events or situations that had occurred because of the disorder, such as the opportunity to help others in support groups, and statements reflecting the perception that TS actually conferred benefits as well as liabilities. This was one of the more surprising results of this study.

Statements in the cluster Social Rejection dealt with rebuffs faced by persons with TS—from peers, teachers or instructors, religious institutions, family members, and employers. Statements in the cluster Misdiagnosis were largely concerned with ignorance of the disorder, in the community, among members of health care professions, and even persons with TS. Many of the statements dealt with the consequences of that ignorance, such as spending many years being inappropriately being treated for anxiety.

The last cluster, Self-Consciousness, was comprised of statements whose common thread was the awareness of being different, and the constant vigilance required by the possibility that the symptoms of TS might present themselves at any time.

For family members of persons with TS (Chapter 3), 9 clusters or themes were identified. The cluster Denial/Guilt was comprised of statements expressing guilt over

having a child with TS, or of statements reflecting a denial that there is something wrong with the child.

The cluster Negative Feelings was comprised of statements, made largely by parents, indicating anger, frustration, resentment, fatigue, or worry over their TS children's behavior. Many of the statements reflected a dissonance between perceived "ideal" parental emotions of love and nurturing, and the real, unpleasant emotional reactions of the parents to their children's behavior.

The Social Embarrassment cluster was comprised of statements reflecting embarrassment over the expression of the family member's symptoms in public. The cluster Intrusiveness of Symptoms contained only three statements, all of which dealt with the encroachment of the TS family member's symptoms into the lives of other family members. The cluster Social Rejection was comprised of statements of how the family member with TS, or other family members, had been rebuffed by other members of society because of symptoms.

The statements in the cluster Search for Solutions had a common theme of searching for ways to help the family member with TS, either through consulting multiple medical specialists, "alternative" medicine, or modifying the TS family member's diet. Some of the statements have a desperate tone to them, as though the person making the statement felt he or she had run out of options. Statements in the cluster Need for Answers shared the theme of frustration over inadequate information. In some cases, this was due to a lack of information; in others, this was due to an inadequate exchange of information between the family member and, e.g., a health care professional.

Statements in the cluster Positive Concrete Adaptation were examples of concrete, proactive steps family members had taken to help the family member with TS cope better in school, in the community, or at work. Statements in the cluster Passive Adaptation reflected a less proactive approach. They were concerned with how to react to certain kinds of behaviors, and with steps family members without TS had taken to live with the person's disorders. Some of these steps involved attitudinal changes on the part of family members about having someone with TS in the family.

The most surprising finding from both of the studies in Chapters 3 and 4 was that some persons with TS perceived the disorder as providing benefits (see the cluster Positive Aspects). These benefits included greater exuberance about life, a more vivid imagination while ticcing, or benefits not clearly defined. Statements such as "Tourette's Syndrome is an important part of who I am." (no. 70) indicate that the individuals with TS do not necessarily feel "possessed by a force not under their own control" (Cohen, 1980, p. 395). A neurologist with several patients and friends who have TS, Sacks (1992) has argued that the disorder can be a spur to greater creativity and exuberance about life.

Closely related to the finding that, for some individuals, TS conferred benefits as well as liabilities, was the finding that both persons with TS and parents of persons with TS attempt to channel aspects of the syndrome into more constructive ends. One individual used the obsessional tendencies that are sometimes associated with TS in his occupation as a pilot, performing rigorous pre-flight checks. One parent of a child with TS channelled his obsessive tendencies into a passion for collecting antiques. In a related

vein, a number of statements referred to the substitution of “quiet” tics for socially unacceptable ones, or to turning incipient tics into movements referring to mannerisms.

Many of the themes derived from the map for persons with TS have analogous themes in the map for family members. Only in one case, however, is there a one-to-one correspondence: Social Rejection (persons with TS) and Social Rejection (family members). Symptom Management had similar counterparts in the clusters Positive Concrete Adaptation and Passive Adaptation on the family map. Misdiagnosis had content analogous to that of Need for Answers and Search for Solutions on the family map; Self-Consciousness had analogous counterparts in the clusters Social Embarrassment and Intrusiveness of Symptoms. Positive Aspects had no corresponding cluster on the map for family members.

Two clusters on the family map had no counterparts on the concept map for persons with TS, even though many persons with TS themselves become parents of children with TS: Negative Emotions, which was comprised largely of parents’ statements of negative feelings toward the child with the disorder, or toward themselves for falling short of the idealized loving nurturing parents; and Denial/Guilt, which was comprised largely of parents’ and other relatives’ statements regarding responsibility for the child’s disorder, and of statements indicating denial of the existence of TS, or a desire to minimize the importance of symptoms.

In this particular instance, monitoring of Internet discussion forums proved to be an effective method of gathering rich and descriptive data about the experiences of persons with TS. In general, the unobtrusive monitoring of Internet newsgroups and mailing lists

appears to be a highly effective way of gathering data on specific groups, provided that a forum for members of that group to exchange ideas exists. The naming conventions of Usenet newsgroups provide an indication, often highly specific, of their content. Hence, if a newsgroup exists on a topic of interest to the researcher, it can be located relatively easily. Mailing lists are more difficult to locate, as one must be a subscriber to participate. However, lists of mailing lists exist on the Internet and, if there is a newsgroups on the topic of interest, relevant mailing lists may also eventually be mentioned by newsgroup participants.

Ethically, unobtrusive monitoring of newsgroups and mailing lists poses few problems. By their very nature, these are public forums, so monitoring them does not constitute an invasion of privacy. If one is careful to quote statements without indicating who made them, omitting or changing any information that could give away the identity of the “speaker,” then it is unlikely that the person making the statement could come to harm. As a method of analyzing content, Concept Mapping has a distinct advantage in this regard, as the process of editing statements for inclusion in list to be sorted usually results in the stripping of contextual information that could be used to identify the speaker. The process of cluster analysis provides a further protection, as the theme of a given cluster is of greater interest than any given statement in the cluster.

In the present study, the themes derived from analysis of statements made by persons with TS and themes derived from analysis of statements made by family members of a person with TS were consistent with what had previously been published in the literature. This provides one indication of the validity of the data gathered, as does the

fact that all statements appeared to have been made in “good faith.” That is, they were made by individuals who did not appear to gain anything by making them, other than what these forums were created to provide their members—information and emotional support.

The quality of information available on the Internet is a potential source of concern, as there is no widely-accepted way of guaranteeing that a given individual made a statement, and no way of guaranteeing the authenticity of any statement made. In the present study, a number of factors worked to preserve trust in the attribution of statements and of the authenticity of information. Firstly, there was very little misinformation spread among the newsgroup or the mailing list. When obviously incorrect statements—or statements of dubious authenticity—were made, they were usually in the form of widely broadcast commercial messages offering a cure for something. In short, the lack of credibility was immediately obvious. Secondly, a significant proportion of the contributors to the forums were themselves members of a health care professions, usually aware of disputes in the literature, and capable of correcting misinformation when it was given. Thirdly, and perhaps most importantly, the individuals participating in the forums formed a very close-knit community and, as such, provided a number of checks and balances among themselves as well as any potential newcomer. Individuals with agendas other than the stated purpose of the forum were not accepted and tended to drop out of discussion. This last fact is also a factor that would impede the use of questionnaires e-mailed directly to participants; the effect would be similar to barging in on a group therapy session and taking an opinion poll.

The cohesiveness of the participants in the forums was striking, in view of the different age groups and occupations of the members. No formal effort was made to measure this, but participants came from widely different walks of life: students, military, health care professionals, business people, and others. This diversity of occupations, backgrounds, and ages would normally work against the creation of group cohesiveness, however, the medium of electronic mail seems to have a "levelling" effect which makes these differences no longer seem so important. Particularly striking was the ease with which different generations communicated with each other; several of the adolescent or young-adult participants were able to participate in "mentoring" relationships in which older persons with TS guided them through issues they had faced when they were younger. Outside of the medium of electronic mail, with its levelling effect, it is likely that these relationships would never have formed.

One final conclusion can be reached from having monitored the concerns of persons with TS and their family members as expressed on the Internet: there is still a role for psychologists and other mental health professionals in the treatment of the disorder. There was a time in the history of the study of TS when tics were considered to be psychogenic in origin, leading to a number of blind alleys in the treatment of the disorder (Shapiro, Shapiro, Young, & Feinberg, 1982). Although there are a number of drugs that have now been proven very effective in controlling the symptoms of TS (Cohen, Riddle, & Leckman, 1992), the concept maps for persons with TS and for family members suggest there is still a role for counselors, psychologists, and other mental health professionals in treating psychological sequelae of the disorders. This can involve

psychoeducational counseling about the disorders, its etiology, its treatment and course; it can also involve family counseling or therapy for families which have not been able to assimilate the fact of a family member's TS. Mental health workers also have a role to play in diagnosing associated conditions (e.g., learning difficulties) and initiating a plan of treatment or making the appropriate referrals. Finally, they can also act as advocates for the person with TS (Dedmon, 1986; Dedmon, 1990; King & Cohen, 1994; Ostfeld, 1988).

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