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McGILL UNIVERSITY

TOURETTE'S SYNDROME FROM A SOCIAL WORK PERSPECTIVE: AN EXPLORATORY STUDY

A Thesis Submitted to

The Faculty of Social Work
Faculty of Graduate Studies and Research

In Partial Fulfillment of the Requirements

for

The Master's Degree in Social Work

by

Celina Rybak

Montreal, March 1995

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FOR STEVEN AND HIS FAMILY

Master of Social Work
McGill University School of Social Work

Abstract

Celina Rybak

TOURETTE'S SYNDROME FROM A SOCIAL WORK PERSPECTIVE: AN EXPLORATORY STUDY

Tourette's syndrome (TS) is a chronic movement disorder characterized by motor and vocal tics. This report looks at TS through the eyes of three families and two adults diagnosed with the syndrome. The social and psychological reactions and adjustment to the disorder are examined. Three approaches were used to explore the issues: a literature review; field notes and unstructured biographical interviews. Social and psychological reactions include: depression, withdrawal and suicidal ideation. Unresponsiveness on the part of the health care and social service systems contributed to feelings of anger, powerlessness, guilt and shame. The families' and individuals' ability to lobby for services was an important factor in enhancing adjustment. TS is a multi-faceted disorder; it serves as a paradigm for issues and problems that are best served by a multi-disciplinary approach. Services must be coordinated; a case management approach would facilitate efficient coordination and delivery of services.

RÉSUMÉ

Le syndrome de Gilles de la Tourette (SGT) est un désordre chronique du mouvement, caractérisé par des tics moteurs et vocaux. Ce rapport examine le SGT par le vécu de trois familles et deux adultes affectés par le SGT. Les réactions sociales et psychologiques, les effets sur la famille et les ajustements requis seront examinés. Pour l'exploration des sujets, trois approches furent utilisées: revue de la littérature, notes de terrain et entrevues biographiques non-structurées. Les réactions sociales et psychologiques incluent: la dépression, le retrait et idées de suicide. La lenteur des services de santé et sociaux provoque des sentiments de colère, impuissance, honte et culpabilité. La capacité des parents et individus à exiger ou soutirer des services est un facteur important afin d'améliorer l'ajustement. Le SGT est un désordre à plusieurs facettes; les problèmes et aspects qui en émanent suggèrent un profil-type pour une solution multidisciplinaire. Une gestion des cas faciliterait la co-ordination des services.

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PART 1 - TOURETTE'S SYNDROME - AN OVERVIEW

CHAPTER I - INTRODUCTION

(a) What is Tourette's syndrome?

Tourette's syndrome (TS) is a movement disorder. The observable manifestations of the disorder are characterized as "tics". Tics are involuntary movements such as sudden twitches of the head, shoulders, legs or even the entire body. Common tics reported are squinting, eye rolling, grimacing as well as touching behaviours such as constant tugging at clothing. Another feature of TS is vocalizations. Among the constellation of possible symptoms are sniffing, throat clearing and spitting. Other less common vocalizations include coprolalia (uttering obscene words) and echolalia (repeating what was just said).

Many of the symptoms exhibited by people with TS resemble "bad habits". Some distinguishing features of "tics" versus mannerisms are: symptoms change over time; symptoms wax and wane; tics are often exacerbated by stress; tics can be suppressed to some extent and the amount of time that they can be suppressed varies from person to person; tics may disappear completely during times of intense concentration. Along with tics, there are numerous reports of associated disorders such as behavioral problems, attention-deficit hyperactivity disorder (ADHD) and obsessive compulsive disorder (OCD). Some common OCD symptoms are counting, touching and repeated checking (A Handbook for Tourette Families).

(b) Why study Tourette's syndrome?

The last decade has been witness to a dramatic increase in the literature on Tourette's syndrome (TS). This proliferation of data has not however translated into a greater understanding of how individuals and families cope and adapt to the syndrome on a day to day basis. Little research has been carried on the effects of TS on individuals and the family. Researchers have been, and remain, fascinated by the mechanics of the disorder. As a result of this preoccupation with the technical aspects of TS, research has concentrated heavily on the neurological and genetic aspects, leaving the study of the emotional and psychosocial repercussions of the disorder lagging far behind.

The family is a self-regulating micro-system whereby difficulties in one part of the system can cause the entire system to reverberate (Minuchin, 1974). Chronic disorders are stressors that affect the entire family (Edell & Motta, 1988) and TS is no exception. These stressors can cause marital discord, financial burdens, educational problems, work related problems and more.

(c) Purpose of the study:

Tourette's syndrome sits on the cusp of several disciplines, in particular, psychiatry and neurology (Bruun, R.D. & Bruun, B., 1994). The purpose of this study is twofold. The first goal is to demystify TS, the second is to put a human face on TS through the education of both professionals and lay persons.

Through people's experiences, stories and insights I tried to build an understanding of TS and what life with TS means. The research participants represent a cross section of people from all walks of life and at various transition points in their lives. The experiences they share with us provide insight into the process leading up to diagnosis of the disorder and its resulting psychological and social implications. Their experiences provide insight into the process of coming to terms with a relatively unknown, chronic disorder.

(d) Organization of report:

The topics covered in this report are the history of TS, symptoms and diagnosis of the disorder and the resulting response and feelings they generate.

This report is divided into two parts. Part 1 describes the methodology employed in carrying out this study and recounts the history, prevalence and symptoms associated with TS. Part 2 is largely based on my analysis of the data which evolved out of the interviews. As such, discussion centers around the themes that emerged which are: powerlessness, shame and guilt, and the effects of diagnosis. Finally, the question of "Who am I?" - how TS weaves itself into the person's personality and sense of self is considered. In the conclusion, I discuss the findings that emerged in the course of this study and make some recommendations for future research and discuss the implications for practice.

Although the second part of this report is largely based on analysis of the interviews, literature from various sources was introduced in order to clarify and/or reinforce the participants' experiences. In the first part of the study, while for the most part a literature review, a few of the participants' comments were also included where appropriate.

This report looks at TS through a wide angle lens. It examines the far reaching effects of the syndrome looking not only at individual and family factors, but also at society's response to a little known, and largely misunderstood disorder.

CHAPTER II - METHODOLOGY

> For the greater part of his information the investigator, must find his own witnesses, induce them to talk and embody the gist of this oral testimony on his sheets of notes. This is the Method of the Interview, or "conversation with a purpose", a unique instrument of the social investigator.
>
> (Webb and Webb, 1932 p.130)

This report is concerned with the following questions: what does it mean to live with TS? how does TS affect the person and the family concerned? how does society respond to people dealing with this disorder? how do individuals and families react to society in view of the disorder? To answer these questions, I interviewed individuals and families living with TS in order to develop some insight into the nature and effects of the syndrome. I used people's own experiences to explore a number of broad issues that were drawn out in the process of an unstructured interview. The issues examined are as follows:

1. Factors that led the participants to seek help;
2. The participants' search for answers;
3. The meaning and consequences of diagnosis;
4. How they cope on a day to day basis;
5. The emotional and social impact of the disorder.

Three main approaches were used to study the issues as follows:

1. A literature review.
2. Field notes;
3. In-depth unstructured biographical interviews of:
    a) adults diagnosed with TS;
    b) parents whose children have the disorder;

To the best of my knowledge this is one of the first theses in social work on Tourette's syndrome. There is a paucity of literature on TS in the discipline of social work. I have read widely, drawing on literature from medicine, nursing, psychology, disability, personal accounts and social work studies in the areas of: crisis intervention, family dynamics and effects of chronic illness on individuals and families.

The process of the in-depth unstructured interview and subsequent content analysis used in this study follows closely the methodologies developed by Bogdan & Biklen (1982), Burgess (1982) and Lofland (1984). This process has been described as an "interview as a conversation". The unstructured interview approach provided me with the opportunity to probe deeply in order to try and open up new dimensions of the problem and to acquire vivid, accurate, inclusive accounts from informants that are based on their personal experiences. A standard set of questions would have been too narrow, thereby influencing perspective. The unstructured interview is nonetheless a conversation with a purpose and, while the unstructured interview may appear to be little more than an interesting conversation "...to the proficient interviewer it is always a controlled conversation which he guides and bends to the service of his research interest" (Palmer, 1928, p.171).

All of the interviews took place at the participants' homes. An interview guide was developed in order to maintain the focus of the research issues (see Appendixes A and A.1). Each of the participants were provided with an explanation regarding the nature and purpose of the study. As well, I explained to them that I was primarily interested in their story and that, in particular, I was interested in the five broad issues outlined above. They were also told that I would welcome any additional concepts, ideas or thoughts that they wished to share. The interview schedule provided some limits without blocking spontaneity and left considerable room for free flowing conversation. To reduce bias, the participants were encouraged to direct the discussion so that I might learn from them.

The interviews lasted an average of 2 hours. Where the participants represented a couple or a family, the interviews tended to be a little longer, approximately 2.5 hours, in order to allow all members to participate. Where the interviews represented an individual the interviews lasted approximately 1.5 hours.

All of the participants are French-Canadian and the interviews were carried out in French. All of the participants were selected through the "Quebec Association for Tourette Syndrome" (TSA) in Montreal, Canada. I chose to draw my sample through the TSA because the group attracts a large number of individuals living with the disorder. As such one could look upon this sample as a convenience sample. As well, the TSA is a self help group, committed to research and I felt that at least some of the members of the group would be willing to participate in the study. Because I used unstructured biographical interviews, I also required subjects that were ready, willing and able to discuss their often painful experiences with this disorder.

Subsequent to my attendance at a number of meetings at the TSA as an observer, the Association agreed to announce that the present study was to take place and called for volunteers. Three adults, one single parent family and two intact families originally volunteered to participate in the study. I was unable to reach one of the participants, and after numerous attempts, I consider that he dropped out of the study.

The final sample consists of a single parent, Christine who is in her early 40s. Christine is a high school graduate and is employed as an office clerk. She has two children, a girl and a boy. The girl, Nathalie was 19 and the boy, Eric was 13 years old at the time of the interview. Eric was diagnosed as having TS at the age of 11. According to Christine, although Eric's tics are mild, his behavioral problems are severe.

Two intact families participated in the study. The first family has three children, all boys; Daniel 4, Frederic 7 and Vincent 9. Daniel and Vincent are both diagnosed as having the disorder. Daniel was diagnosed at age 3 and Vincent was diagnosed at the age of 8. The parents, Sebastien and Catherine are in their early 40s.

Both Sebastien and Catherine are university graduates and are employed in professional capacities. The interview centered around Vincent because the younger one has not yet started school and his symptoms are still mild. According to the parents, while Vincent's TS is considered mild, he suffers from obsessions and compulsions that are interfering with Vincent's functioning.

The second family, consists of the parents, Julie and Olivier, both in their late 30s who also have three children. Olivier is a university graduate and Julie graduated from college. They both work in the family business and live outside of Montreal in a rural setting. They have two boys Stéphane, 12, and Patrick, 9, as well as a girl, Mélanie, aged 5. Both boys are considered to have the syndrome, although only Patrick, the 9 year old, was diagnosed officially by a neurologist. He was diagnosed at the age of 8. Both boys are considered to have a mild form of the disorder.

Two adults, a man and a woman diagnosed with the syndrome participated in the study. Etienne is 28 years old and was diagnosed at the age of 21 with onset of symptoms at around age 9. He is single and lives alone. He is a university graduate and is employed in a professional capacity. According to his report, he has a moderate form of the syndrome, but is presently in remission. Sylvie is 30 years old and was diagnosed at the age of 29 and reports that her symptoms started at around age 5. Sylvie states that she has a moderate form of the syndrome, however she was taking medication at the time of the interview and her symptoms had diminished dramatically as a result. Sylvie is a high school graduate and works in administration. She is a single parent to a 3 year old child.

All of the adult participants were employed at the time of the study and all of the children were attending school. One of the children, Eric (Christine's son), was living in a Centre d'accueil and was in a "special" class for children with learning disabilities and behavior problems. He had been living in the Centre d'accueil for eight months at the time of the interview.

Olivier and Julie allowed their children to meet with me for about half an hour. Christine also permitted her son Eric to meet with me for about half an hour. The parents were present with the children at these times.

I also attended five meetings of the TSA and was invited to observe a youth discussion group run by an adult diagnosed with TS and a doctoral student in psychology.

All of the interviews were taped and transcribed verbatim and supplemented by field notes. The data was carefully analyzed using line by line coding. The interviews were disassembled and split up into various general categories. Through the process of filing, coding, cutting and pasting a picture began to emerge. The inflow of data produced a "sparking" of ideas (Glaser, 1967). These ideas were catalogued, filed and organized along with the data to form the basis of my analysis which was then developed into a report.

The process of in-depth interviews was extremely interesting and informative. Most of the participants were very open and seemed eager to tell their stories. Still, some of the participants initially found it difficult to talk about their experiences.

As a researcher I saw myself as a part of the process and was touched by the willingness of the participants to allow me into their homes and into their lives. As I listened, I sensed the hopes, fears and struggles of the participants as they try to come to terms with this unique and largely misunderstood disorder.

CHAPTER III - HISTORY OF TOURETTE'S SYNDROME

Bouteille (1818) in his "Traité de la Chorée" states in the Preface:

> Tout est extraordinaire dans cette maladie: son nom est ridicule, ses symptômes singuliers, son caractère équivoque, sa cause inconnue, son traitement problématique. De graves auteurs ont douté de son existence, d'autres l'ont crue simulée, quelques-uns l'ont réputée surnaturelle.

As far as people with TS are concerned, the above statement holds as true today as it did in 1818. The symptoms exhibited by people with TS are odd, its cause still speculative and its very existence is still questioned by many.

The generic term "chorea" was adopted for various disorders where the predominant symptoms are motor incoordination. The word comes from the Greek and literally means "dance" in an effort to describe the movements associated with tics.

Since the time of Bouteille, various neurologists and researchers sought to differentiate choreas into specific disorders. The first clear description of TS was delivered by Itard (1825) in the now famous case of the Marquise de Dampierre. The Marquise was a French noblewoman who suffered from motor and vocal tics. Her symptoms evolved slowly, starting at the age of 7. The first symptoms to appear were involuntary convulsive spasms in the arms and hands. This was followed by movements in the muscles of the shoulder and neck, contortions and grimaces of the face and finally vocalizations. She was reported to utter bizarre sounds that made no sense and were also obscene in nature (coprolalia).

Itard (1825) provides us with an excellent description of how difficult the syndrome can be for those so afflicted when he described the Marquise de Dampierre with these words:

> ...au milieu d'une conversation qui l'intéresse vivement, tout à coup, sans pouvoir s'empêcher, elle interrompt ce qu'elle dit ou ce qu'elle écoute par des cris bizarres et par des mots encore plus extraordinaires...qui font un contraste déplorable avec son aspect et ses manières distingués; les mots sont pour la plupart des jurements grossiers, des épithètes obscènes et, qui n'est pas moins embarrassant pour elle et pour les auditeurs...(p.403).

She enjoyed a period of remission in her late teens lasting approximately two years. Her symptoms diminished considerably leaving her with only a slight twitching of the face and neck. Unfortunately this remission was just a reprieve and the symptoms reappeared with a vengeance, becoming progressively worse. As a result of the disorder, in particular the coprolalia, she became a social recluse. The Marquise suffered from the disorder all of her life and died at the age of 86.

It was seventy years later, in 1885 that Gilles de la Tourette coined the term coprolalia to characterize this uncontrollable uttering of obscenities. Sylvie, now 30 years old, has suffered from coprolalia at various times in the course of her battle with TS. She told me that one could not imagine her humilation when, as a 13 year old girl, she would walk down the street swearing and waving her arms. Sylvie felt humiliated but was simply unable to control herself. At work she is often told that she is too "exuberant" and to tone herself down. She reported that many "touretters" have problems at work and often lose their jobs due to their "exuberance".

In 1885, Gilles de la Tourette published an article entitled "Étude sur une affection nerveuse caractérisée par l'incoordination motrice accompagnée d'écholalie et de coprolalie" in which he described nine patients suffering from the disorder. He delineated the development of the symptoms. Motor symptoms of the face and then the upper limbs are often the first to appear. These symptoms are followed by vocalizations such as "hm," "ouah", "ou," and "ah".

Gilles de la Tourette held that coprolalia was an integral part of the syndrome even though only five of the patients he described exhibited such symptoms. He believed that at some point during the evolution of the disorder coprolalia would appear. It is unclear why or how he reached this conclusion but it may explain why even today, many people, including medical professionals, believe that coprolalia must be present in order affix a diagnosis of TS. He also described the waxing and waning of symptoms so common in TS. Gilles de la Tourette's major contribution to the understanding of the syndrome that now bears his name was to classify Tourette's syndrome as separate from other movement disorders.

Initially, Gilles de la Tourette held that those "afflicted" with TS were perfectly sane in terms of their ability to reason and that they were entirely conscious of their states. However, in 1899 he revised this opinion. In this, he was heavily influenced by Guinon (1886) who observed that the movements exhibited by patients were systematized and coordinated. Guinon held that there was some ritual or conscious control over the behaviour. As a result, Gilles de la Tourette began to focus on the patient's mental instability. In his 1899 paper, Gilles de la Tourette observed numerous "nervous disorders" such as anxieties, fantasies and fears in the patients and their families. This suggested to him that the patients were mentally unstable and, as a result, he termed them "degenerates". In this too, he was greatly influenced by Guinon's observation that "tiqueurs" almost always exhibited a state of instability characterized by phobias, arithomania and agoraphobia.

Because of the fact that many of Gilles de la Tourette's patients were very intelligent and enjoyed high social status, rather than label them as "degenerates", he labelled them "higher degenerates". This was an unfortunate decision historically as it set the stage for the characterization of touretters as suffering from "hysteria" (Guinon, 1886) and "mental disease" (Meige and Feindel, 1902).

Through the 1920s to the 1960s psychoanalytic theory dominated and it was believed that tics represented intrapsychic conflicts. "Cures" were few and far between and the psychiatric community lost interest in TS. In view of what we now know about the waxing and waning of tics and spontaneous remissions, it is not surprising to learn that for the most part, psychodynamic treatments were ineffective. For about 20 years, it seemed as though TS had virtually disappeared (Bruun R.D. & Bruun B. 1994). The discovery that tics could be treated with various drugs, in particular, haloperidol (Haldol) revitalized interest in the disorder (Bruun, B. & Bruun R.D., 1994, Sacks, 1990).

In 1961, it was demonstrated that the experimental medication haloperidol led to a dramatic decrease in tics in most patients. This discovery led to the downfall of the psychoanalytic model and a return to the emphasis on biological explanations of the disorder (Wand, Matazow, Shady, Furer & Staley 1993). The medical community moved away from psychodynamic explanations and a return to Gilles de la Tourette's (1885) original position wherein he states:

> Quant à l'état mental, il est parfaitement régulier: les sujets raisonnent très bien; en aucune façon leurs actes ne rappellent ceux des aliénés; ils ont parfaitement conscience de leur état; la plupart fort intelligents (p.173).

Nonetheless, the view that touretters suffer from anxieties, phobias and other problems still permeates the literature. Theories come and go. What remains is the people and their stories - their joys and their sorrows.

CHAPTER IV - PREVALENCE AND DESCRIPTION OF SYMPTOMS

(a) Prevalence:

TS was considered a rare and exotic disorder until quite recently. Its incidence was believed to be approximately 1 in 10,000 people. Epidemiological studies are inconclusive and often rely on clinical samples for their data. Thus when looking at concomitant disorders such as obsessive-compulsive disorder (OCD), learning disabilities and behavioral problems, it remains unclear whether people suffering from both TS and another disability are more likely to seek out professional help or whether it is in fact an alternate expression of TS. Furthermore, are people with a more serious manifestation of the disorder more likely to seek help? It seems sensible that people who are suffering from a more severe form of the disorder or who are contending with not only TS, but OCD as well are more likely to seek help. This is a reasonable assumption. However, science and reason do not always meet. The issue remains murky.

Research in the past decade has identified a male to female ratio of 3:1 and TS appears to affect about 1 in 2,500 individuals although actual prevalence rates are difficult to determine due to the variability of manifestations (Rea, 1991).

To address the question of prevalence in the population Apter, Pauls, Bleich, Zohar, Kron, Ratzoni et al., 1993 conducted an epidemiologic study of TS in the general population of Israel. The sample consisted of 18,364 males and 9,673 females, aged 16 to 17, that were being screened for induction into the Israeli Armed Forces.

The researchers wanted to estimate the prevalence of TS and the role of OCD and Attention-Deficit Hyperactivity Disorder (ADHD) in TS among individuals from a large unselected population based sample. Apter et al., found that of the 28,037 individuals screened, 12 met the criteria for the diagnosis of TS. The rate of OCD was significantly higher (41.7%) among subjects with TS when compared to population prevalence rates of 3.4%. They found only one individual that satisfied the criteria for both TS and ADHD. According to the researchers, this person also had OCD and a wide range of behavioral problems. What is significant about this study is that the overall prevalence estimates of 4.2 per 10,000 is consistent with prior estimates. This is surprising because all previous studies relied, at least in part, on clinical samples. This suggests that TS is a troubling disorder and that people faced with the symptoms of TS are likely to seek help.

Based on the population of Canada and Quebec (Quarterly Demographic Statistics, October 1994), if current population estimates of prevalence of TS are accurate, we can infer that approximately 12,900 people across Canada and 2,500 people in Quebec have the disorder. If such is the case, TS is not nearly as rare as once thought.

(b) Description of symptoms:

Symptoms of TS are fluid and vary over time. The major symptoms are motor and vocal tics. However, numerous studies and reports suggest that TS is not simply the discharge of tics but rather represents a constellation of potential symptoms. Dr. Dion, 1994, summarizes the myriad ways in which TS can express itself:

> Le syndrome de Gilles de la Tourette (SGT) est un désordre neuro-comportemental dont les symptômes sont variables dans le temps et aussi selon les personnes atteintes. Les symptômes principaux, liés à la maladie en tant que telle, sont les tics moteurs et vocaux de même que les obsessions et les compulsions. L'on rencontre aussi des symptômes d'anxiété ou de dépression de même que des migraines et ce d'une façon plus importante qu'on ne pourrait s'y attendre dans la population en général.
>
> (Conference, 1994, October)

The essential features of Tourette's syndrome are multiple motor and one or more vocal tics. These may appear simultaneously, or at different periods over the course of the illness. The tics occur many times a day, nearly every day or intermittently throughout a period of more than one year. Tourette's syndrome is a chronic disorder. The median age of onset is 7 years. The disorder may appear as early as one year of age. To be diagnosed with TS, age of onset of symptoms must occur before the age of 18 (DSM-IV, 1994). Other symptoms associated with TS include learning disabilities, behavioral problems, attention deficit disorder and obsessive-compulsive disorder (OCD) (Rea, 1991). It is unclear at this time whether these symptoms are varying expressions of TS or whether they constitute a series of separate disorders.

Tics are involuntary, rapid, repetitive, and stereotyped movements of individual muscle groups. They are more easily recognized than precisely defined (Bruun, Cohen, & Leckman, 1984). This description, leaves us in a quandary and somewhat confused as to what TS really is. I believe that Sacks (1990) paints a clearer picture of the syndrome when he states that Tourette's syndrome "is characterized by an excess of nervous energy and a great production and extravagance of strange motions and notions: tics, motions and mannerisms, grimaces, noises, curses, involuntary imitations and compulsions of all sorts, with an odd elfin humour and a tendency to antic and outlandish kinds of play" (p.92).

As I was leaving one of the TSA meetings, three of the members, all in their 20s and all "touretters" were joking and laughing. When I looked over, one of the group said "c'est pas de la tourette ça." I wonder what Dr. Sacks would have surmised if he had been the onlooker. Two members of this group participated in the present study. During the interview process, Sylvie stated "je ne sais pas jusqu'à quel point mon caractère a été affecté par le syndrome." To the people involved, their sense of humour was a part of their personality, not a part of some elusive "syndrome".

PART 2 - ANALYSIS OF DATA

CHAPTER V - POWERLESSNESS

> Even as a young child, I know that when I do something it is I who am doing it, that I cause things to happen in the world...if I didn't know these things, life would be next to impossible...imagine that it isn't you who is moving your arms and legs...but it is "somebody else".
>
> (McAdams, 1993, p.44).

The impact of TS is felt in the development of the emerging self. As children grow and learn to walk, they take pride in their accomplishments and in their ability to control their environment. The first bit of control they enjoy is their bodies. They play with their toes, they manipulate objects and then the crowning achievement, walking! As their confidence grows, they can face the great expanse beyond the safety of their home. For people with TS, this control is often achieved at great cost. Their bodies let them down - doing and saying that which they would they would prefer to keep to themselves.

Socially, touretters are often ostracized. When children are viewed by peers and adults with disdain, their self image takes a beating. As a result, people contending with TS may suffer from depression. They can become withdrawn and even suicidal (Jensen, 1988). Sebastien spoke of his son Vincent who at the age of 8 had entertained thoughts of suicide:

> Vincent, pour un petit gars de 8 ans, vouloir se suicider. Il nous en parlait...c'est une réponse à tout le stress qu'il vit...c'est difficile pour lui, le contact social. Il craint toujours de faire rire de lui, ou d'être mis à part à cause de ça, à cause du syndrome.

According to Sebastien, Vincent's suicidal thoughts were a response to the daily stress of living with a chronic, socially ostracizing impairment over which he had little control. His parents had resisted putting him on medication to control his tics. Finally they saw it as a last resort and as their only real available option. They had tried other interventions and, while helpful, the positive effects were short lived. As Sebastien said:

> Il a eu des traitement en ostéopathie. Ça été un bien qui durait comme 24 heures. Il a eu comme une belle période mais après...ça revient au grand galop. On a eu aussi une psychologue qui a suivi Vincent.

Vincent also contends with compulsions and rituals such as touching doorknobs in a certain way and for a fixed number of times. When asked how much time Vincent spent carrying out rituals, Sebastien reported that from the time he awoke until the time he went to sleep, Vincent was in action, straightening papers, touching things, counting and more. The child cried: "quand est-ce que ça va arrêter, ça!?" He had never said that of the motor tics.

Various studies report that 30 to 50% of patients with TS also suffer from OCD. Recent studies present a convincing argument that TS and OCD are concomitant disorders with OCD making up part of the spectrum of possible symptoms (Apter et al. 1993; Carter, 1991; Robertson & Gourdie, 1990).

Vincent's rituals and obsessions were interfering more and more with his daily life. One particular ritual that Vincent has to carry out is related to getting in and out of the car. Before getting out of the car, he has to touch all the windows, all the doors and all the door knobs a certain number of times and in a certain order. The family had grown used to this behaviour and when going shopping or on other outings they simply starting walking slowly, allowing Vincent to carry out his ritual. One time, his mother, thinking she was being helpful, tried to hurry the child. Vincent became extremely agitated. The pain on his face was heart wrenching. He finally exclaimed "laisse moi faire!" She never again interfered.

In her book, <u>The Boy Who Couldn't Stop Washing</u>, Rapoport (1989) recounts the story of a man who had suffered from obsessive-compulsive disorder (OCD) for many years. His son also started exhibiting symptoms of the disorder at the age of 2. This is what he had to say:

> ...it's the pain - the deep, searing, never-ending pain that makes this illness so unbearable...you begin to understand Obsessive-Compulsive Disorder in terms of the pain it causes its victims...your child has absolutely

> no control over what he or she is doing ...NONE...Your child's rituals may be totally aimless...normal human reasoning and logic does not exist with this disease. The only logic is your child's relentless pain, his enormous need to stop this pain and his involuntary behaviour geared to this end (p.28).

The rituals must be carried out, there is no stopping them. Rapoport (1989) suggests that obsessive compulsive symptoms are "tics of the mind" and that OCD and TS are really "two sides of the same neurological coin" (p.102). She observed that many patients with OCD also exhibit motor and vocal tics. Like motor and vocal tics, rituals and/or obsessions can be temporarily postponed. People try to hide their symptoms because they are ashamed and many are very good at it. For this reason, people who have OCD can hold down responsible jobs, study and look after their families.

Vincent's mother told me that Vincent is an "A" student, but due to his obsessions and tics, homework that should take ten minutes often takes one and a half hours to complete! This is extremely frustrating for both the parents and the child.

A tremendous amount of energy is expended either suppressing the symptoms or carrying out the requirements set by the OCD sufferer who is a law unto himself. He sets the rules; he sets the sentence for breaking the rules. In short, he is his own lawmaker, policeman and judge. He knows there is no sense to it, but he simply cannot stop. He may try but, sooner or later, the anxiety becomes intolerable, reaching a crescendo and finally, the rituals must be carried out in order to exorcise the demon! People may have minor rituals such as checking the front door over and over again to ensure that it is locked. Others have more debilitating symptoms that may oblige them to check the stove, the oven, the furnace and so forth, over and over again before they can leave their home. Sometimes this ritual may take hours upon hours, causing the person to become virtually housebound.

Like tics, OCD can manifest itself in a myriad of ways although some common symptoms are counting, washing and checking. In Vincent's case, the symptoms were becoming more and more debilitating. Sebastien and Catherine were bewildered in the face of this senseless disorder. Finally, having exhausted all other avenues, they decided to try medication: "alors on a décidé qu'il soit médicamenté. Là il a arrêté de vouloir se suicider, il a commencé à vivre parce que les derniers temps il ne vivait plus. Il était vraiment malheureux ".

Despite the crisis faced by this family, getting help was no simple matter. It is a sad day when an 8 year old child is so unhappy that he begins to consider ending his life. Parents want to still the hurt their child is feeling, but they need help. When Vincent expressed his feelings of despair, his father rushed to the telephone to make an appointment with the only doctor Sebastien knew who specialized in the treatment of TS in children. He was told that he would have to wait six months for an appointment! The doctor had met Vincent only once, two years prior when the diagnosis had been pronounced:

> Attendez au mois de novembre! Tabarouette! On était au mois de mai. Au mois de novembre! Vincent veut mourrir, il a un problème, son école, la rentrée, l'été. Au mois de novembre...le médecin a déjà rencontré Vincent une fois, une fois il y a deux ans.

A problem expressed by all of the participants in the study is that access to health care is difficult. Many doctors are not well versed in TS and as mentioned earlier, more often than not it is years before a diagnosis is made. Those who are knowledgeable in the field are overworked and patients are subject to long waiting lists. This can create enormous difficulties and often only the most severe cases are treated. For example, only when Eric's behavior turned violent and he was in danger of being placed were his (and his family's) problems addressed. Parents and children feel abandoned. They zig zag about, trying to wend their way through a complex health care and social service system. Sebastien, in speaking about parents and children looking for help stated: "...sont tout seul, sont perdus sur des listes d'attentes. Ils vivent avec ça...jusqu'à ce que l'enfant...devienne problématique puis là il va passer comme en urgence...mais encore là...".

All of the people interviewed, parents of children coping with TS as well as adult touretters resisted taking medication because of the potential side effects. As we know, symptoms of TS wax and wane. When a person is going through an exacerbation of symptoms, they might require medication and need to see a physician quickly. If the problem is not attended to, a crisis may ensue. It was very clear that Vincent could not wait six months for help. Sebastien, through persistence and some contacts, managed to get a prescription for his son. However, Sebastien never saw that doctor. His parents received the prescription by telephone! In Catherine's words: "on a eu la prescription par téléphone. Rien, j'ai même pas eu un médecin. Moi, je suis juste la mère! Mais...je suis juste la mère".

Needless to say, the parents are angry. They feel powerless in the face of the medical system. They want to help their child, but there is no help to be found. They feel lost, frustrated and let down. We expect doctors and other health care professionals to be empathic. At minimum, we expect them to provide counselling concerning medication and potential side effects. Even this was not provided: "il nous a pas donné conseil au niveau des médicaments. Va chercher les médicaments au coin! Ça c'est fait parce que, sinon, je suis sur un liste d'attente". The prescription was simply telephoned into the pharmacy - no advice, no counselling. The parents accepted this arrangement because their only other alternative was to put their name on a waiting list, an option that was clearly unacceptable.

Sebastien and Catherine are educated, have financial resources, and an understanding of the health care and social service systems. Yet, in the face of of their child's crisis they were lost, stumbling in the dark. Medication relieved many of their child's symptoms but there were side effects. Again they called the doctor, and were told to reduce the dosage. They never actually saw the physician except for the one time mentioned, two years earlier. The unresponsiveness on the part of the health care system not only makes parents angry, but can produce in them a sense of powerlessness. Their child is in pain and they are frantic. The child expects them to find the answers and when they cannot, parents often feel guilt and shame. Guilt because they cannot still their child's pain, and shame because in not being able to "fix" their child's problem, they may feel that they are "bad" parents.

When children are young, they often look upon their parents as being infallible. Even in adolescence, if a problem exceeds their parents, children may feel completely overwhelmed. When parents cannot "fix" the problem, children can become confused and parents may feel guilty. After all, if the problem is so big that even the parents cannot do battle with it, how is a small child to feel powerful enough to wage war against not only this strange and unpredictable syndrome, but the system as well?

Sebastien and Catherine were reluctant to put their child on medication, but with Vincent expressing thoughts of death, they felt they had no choice. When Vincent was told that there was medication that could help him, a smile alighted his face:

> Quand il a su qu'il pouvait prendre des médicaments, ça a transformé sa vie. Un sourire qui est arrivé dans son visage. Les compulsions étaient là autant, les tics étaient là autant mais ça le dérangeait plus du tout...c'est nouveau, ça fait trois semaines. C'est merveilleux pour les compulsions. Les

> compulsions ont diminué en 24 heures presque de 80%, les tics ont diminué beaucoup aussi.

As his parents started taking control, Vincent became more secure that his was a problem that could, if not be "fixed", at least be made bearable. Furthermore, I could sense that the parents also seemed more hopeful. As Vincent started to take more pleasure in life, their sense of guilt and shame diminished. By taking control, they felt that they were fulfilling their responsibility as parents.

Christine's son, Eric, went one step further than Vincent, he attempted suicide by taking an overdose of pills - he was 11 years old at the time:

> Une fois il avait fait une tentative de suicide. On revenait d'une rencontre à la DPJ (Département de Protection de la Jeunesse) pour son placement et en revenant il a tout gobé. Il ne dit pas toujours ce qu'il ressent.

Christine, went in search of help for her son. Not having all the resources available to her that Sebastien and Catherine could muster (education, money) her efforts were thwarted. She felt powerless and inadequate in the face of her son's needs. She was denied help at every turn. A sense of helplessness took over, leading to depression. Learned helplessness, is the belief that we cannot alter our situations through our actions or behaviours. Learned helplessness is a common side effect of long periods of sustained powerlessness and often leads to depression.[1] Christine, having tried everything she knew how to find help for her son and herself, finally gave up. Exhausted, she slipped into depression:

> Au printemps l'année passée, j'ai arrêté de travailler. J'étais épuisée, même à la maison, je n'avais plus la force de faire quoi que ce soit. L'école passait leur temps à m'appeler. Les gens disaient que du négatif de lui, et je n'étais pas capable d'avoir de l'aide nul part...j'ai bien déploré le système parce qu'il n'y avait pas de services.

Christine felt powerless, guilty and ashamed. She felt that she was not patient enough, not understanding enough; in short, she believed that she was a bad parent.

> J'ai commencé à aller au réunions pour les parents à l'Association (TSA). Je me rappelle la première réunion, j'avais passé la nuit à pleurer. Tu écoutes autour et tu te poses des questions. J'avais l'impression que les autres étaient patients avec les leurs et moi non. Je me culpabilisais. Je me posais des questions sur son avenir. Je voyais tout noir.

Christine had just resumed her work two months prior to our interview. With the help of Youth Protection, a psychiatrist, an educator and a social worker, Christine was trying to put her life back together. The initial lack of response on the part of the health care and social service systems contributed to her sense of helplessness and ultimate depression. Instead of

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[1] Seligman, M.E. defines helplessness as "the psychological state that frequently results when events are uncontrollable." See Seligman, M.E. (1975). <u>Helplessness: On depression, development and death</u>, San Francisco: W.H. Freeman and Company, p.9.

providing her with a little service at the outset, she and her son are now major consumers of these systems. While I sensed that she was still depressed, she seemed to be looking towards the future with some hope. She has started taking courses and going out with friends. With the help of an educator and a psychiatrist, Eric is developing better social skills and is learning to manage his anger. As both Eric and his mother start taking control of their lives, their self-esteem is improving. This feeling of empowerment has translated into improved functioning for both Eric and Christine.

CHAPTER VI - SHAME AND GUILT

> Shame is singularly powerful among negative emotions in its power to shrivel the self. The shamed self shrinks, constricts, compresses, and attempts to absorb itself into nothingness...Shame overpowers with suddenness. Experienced as a surge of awfulness that quickly rises from the abdomen to heat the back of the neck and further humiliate the self by blushing the face, there seems to be no escape and no way to hide one's humiliation from the observing eyes of others.
>
> (Berez, 1992, p.75)

(a) Shame

Children who are different or seem to behave in an odd manner will often become the object of ridicule by peers. Tics arouse curiosity, usually leading to teasing by peers and feelings of shame on the part of the child (Berez, 1992). We have all at one time or another felt the emotion of shame. We have all heard the statement "I was so ashamed, I just wanted to crawl into a hole and die!". Normally we do not mean these words to be taken literally. However, imagine, for just a moment, being assaulted constantly, every few minutes, by this overwhelming feeling of shame. The assault on the self is excruciating, at times unbearable.

Faced with ridicule and shame, constantly being barraged with feelings of shame, life can become a burden. Patrick, 9 years old, tells us, as only a child can, what it means to be different in a child's world: "ben, à l'école...tu fais rire de toi pis tout ça. Y'en a qui me demande: 'c'est quoi ton problème?' pis tout ça...surtout ce qui me dérange à l'école, c'est mes tics".

When Patrick started experiencing loud vocal tics the situation became more and more intolerable. It was clear that his self-esteem was deteriorating and that the situation was becoming serious. As a result, his parents started sending him to a psychologist to provide him with some additional support. Julie, his mother, put it this way (in English):

> When his big vocal tics happened he said "I don't like my body...I wish I was on a desert island and I could do all my tics...I don't like myself". We were losing him...his self-esteem was very affected and we thought that this is in between medication and doing nothing. We try the psychologist and if that doesn't work, we go with medication. Then the tics went down and we kept going on with the psychologist because he likes it.

Shame makes people want to hide. The simplest events become risky ventures. Events that should be enjoyable such as going to the cinema or out shopping can become an enterprise fraught with danger as Julie explains:

> On est allé au cinéma puis pendant le film, ça dérangeait. Le monde se virait. Puis là, on est sorti. Il a dit "tu vois, tout le monde me regarde!"...au magasin, les gens se penchaient dans l'allée en voulant dire qu'est-ce que c'est ça! Quand on dit "accepte-toi, Patrick" on ne sait pas qu'est-ce que qu'on lui demande.

> On était à côté de lui. On voyait la perception qu'il avait, les gens se moquaient de lui. (Au cinéma) il y a le gardien qui est venu nous voir. Quand la présentation était finie, il allumait les lumières, tout le monde est sorti. Tout le monde nous a regardé en voulant dire "quel sorte de monde vous êtes?!".

The moment Patrick leaves the safety of his home, his life is a series of dangers. Instead of the outside world being a place of joy and discovery, it is riddled with potential land mines.

A constant assault on the self can lead to what Middelton-Moz (1990) refers to as debilitating shame. Debilitating shame makes a person want to run away and hide. It is not punishment that the person fears, it is rejection and abandonment. Middleton-Moz describes it in this way:

> Debilitating shame is an isolating experience that makes us think we are completely alone and unique in our unlovability...(it) is a state of self-hate and self-devaluation...it makes us feel that life is happening to us and that we are helpless in the wake of that happening... reality perspective is lost...all of our vulnerabilities become exposed and magnified. We believe that others in our world view us with disdain...we no longer feel the temporary shame of having made a mistake in public or failed an expectation we set for ourselves ...we are mistakes and failures (pp. 16 & 17).

Middleton-Moz was not speaking of TS when she wrote the above words, but they express so eloquently the potential damage to the self that a such a barrage of shame can exact.

Tourette's syndrome is often unpredictable and while a person may have some temporary control over symptoms, ultimately, the tics must come and the person is embarrassed. This experience is repeated over and over and thus becomes the perfect recipe for debilitating shame which can lead to self-hatred and, in extreme cases, to suicidal ideation. It is no longer the tic that is an embarrassment, it is the "I", the self. When people, and in particular children, feel shame on this scale and have no means to express their feelings, they can become more and more disconnected from their world. In Middleton-Moz's words "A sense of internal isolation and uniqueness is the fabric out of which debilitating shame is created" (pp. 19 & 20).

School often becomes the playing field for the game of shame. In school, if children are laughed at or isolated, the shame response in the child increases. Parents entrust their children to teachers. As children head off to their first day of school, one can observe parents looking wistfully and fearfully on. They want school to be a positive experience for them. They hope that their child will forge new friendships and delight in the process of learning. When a child has TS these hopes and desires may be thwarted by misunderstanding. Hubka, Fulton, Shady, Champion & Wand (1988) describe a case where a teacher invited a child to hop in front of the class since he liked hopping so much! When children are shamed by other children, it hurts; when a teacher humiliates a child in front of his or her classmates it can be devastating. Stéphane, 12, spoke of an incident in class similar to the one recounted by Hubka et al.. Stéphane had a tic that caused him to make snorting sounds. One of his teachers asked him to leave the class when he made these sounds. However, another teacher went one step further. In front of the other children, he would pinch Stéphane's nose: "mon professeur, quand je faisais mes tics, il me faisait sortir de la classe ben souvent parce que je dérangeais le monde. Y'en avait un qui m'a pincé le nez à cause que je dérangeait".

Hubka et al. state that at their clinic in Winnipeg, when a child is diagnosed with TS, the members of the multi-disciplinary team attempt to go to each child's school and meet with the child's teachers and classmates as a means of reducing stress and to promote understanding. They consider that meeting with school personnel is vitally important so that teachers may receive information, support and concrete suggestions regarding the handling of behavioral and academic problems (Hubka et al, 1988). An intervention of this nature could have avoided the incidents recounted by Stéphane. Stéphane's parents have since spoken to the principal and the teachers about both their childrens' problems and they have become extremely supportive. Patrick, their 9 year old, has difficulty writing because of his tics. He was missing recess, lunch breaks and had a great deal of homework at night because he could not keep up with the class. In order to facilitate learning and allow Patrick to keep up with his classmates, they have provided him with a computer. Now he can keep up with the other children. His eyes sparkled as he told me about the computer and how he can now be like the other children and play at recess. Stéphane now speaks openly about TS and did an presentation on the subject, profiling his brother Patrick. According to the parents, the presentation was well received.

All of the interventions described above have served to foster understanding and many school problems have been mitigated. It is of paramount importance that parents and professionals liaise with the educational system in order to explain to teachers and school directors that the behaviors exhibited by the child related to symptoms of TS are not intentional. It is essential that they be made to understand that the child is not intentionally trying to make the teacher appear foolish or that he or she is not simply being contrary. The problem is that parents have been obliged to do all of the liaising on their own, without benefit of professional support. The constant need to intervene on behalf of their children can burnout already exhausted parents. Furthermore, mothers often carry too much of the burden. They become the contact person for the school and the doctor, the chauffeur to psychotherapy sessions and the family spokesperson (Hubka et al, 1988).

Children often find it difficult to speak of their problems and are usually ashamed of having TS. When a child feels the need to hide a part of himself such as an illness the shame response increases. The consequences can be disastrous. Christine in speaking of her son Eric stated: "il était gêné et mal à l'aise de prendre ses médicaments à l'école. Il me téléphonait constamment puis il disait que ça fonctionne pas".

Because Eric was so ashamed of his "problem" and so feared being ostracized, he ceased taking his medication and his behavior problems became intolerable. He could not cope with school, the children rejected him and Christine was unable to continue working under these conditions. As mentioned earlier, Eric was ultimately placed in a Centre d'accueil and Christine had to take a leave of absence from her job.

For other children and their caregivers the effects are not always quite so dramatic. Still, each day is fraught with shame and potential disaster. Sebastien's son Vincent is not ready or able to explain to his classmates why he "tics" and is not willing at this point to have his parents do it for him. Sebastien put it this way: "c'est dur...les enfants entre eux, quand un enfant fait ça (les tics, les rituels) passent des remarques. Puis lui, il n'a pas encore la capacité d'expliquer ce qu'il a comme problème".

Finally, Vincent did speak to one schoolmate and explained his problem to him. He came home and excitedly recounted this event to his mother:

> Mais là, il en a parlé pour la première fois à quelqu'un...il est arrivé puis il était tout fier de me dire ça "maman, je l'ai dit à quelqu'un!"...je l'avais dit "le jour où tu va le dire à quelqu'un, tu va sentir une boule de moins, ça va te soulager". Mais, il a 9 ans, tu sais. On n'est pas pour lui demander l'impossible.

While an important milestone, as Vincent's mother Catherine pointed out, he is only 9 years old and the potential need to explain arises countless times a day. It is a heavy burden for a child to constantly explain to everyone he meets that he has TS and what that means. As a result, most of the time Vincent simply does not explain. His father Sebastien puts it succinctly:

> ...c'est une situation qui se répète autant de fois par jour qu'il a l'occasion de le dire mais il le dit pas...il faut le stimuler...puis y dire "si tu fais ça tu vas te sentir mieux" puis là, il le fait, puis il sent mieux. Mais la fois suivante, il faut qu'il refasse encore toute la démarche.

Society's reaction to people who display bizarre or out of context behaviour can be unforgiving. This lack of understanding can lead people with TS, and their families to avoid social gatherings. Catherine and Sebastien, and Julie and Olivier, had both refused invitations to family gatherings. Julie and Olivier did not want to put pressure on Patrick at a time when he was experiencing an exacerbation of symptoms and Catherine and Sebastien avoided a family party because they felt that their extended family was not accepting of the syndrome and were insinuating that Sebastien and Catherine were somehow the "cause" of their childrens' problems.

I was impressed by Sylvie. She is articulate, well read and extremely bright. She told me that she had always wanted to go to college and had attempted some courses. However, with all of her tics, she was uncomfortable in a classroom full of people. She could not concentrate on the lectures as well as on trying to control her tics. She failed a number of courses and ultimately quit. Her shame and embarrassment blocked her growth and potential.

Transitions are difficult for everyone, but when faced with a chronic disorder of this nature, age appropriate transitions can be delayed or blocked (Rolland, 1989). In Sylvie's case, transition from adolescence to adulthood was fraught with difficulty and pain:

> Je ne pouvais pas aller au CEGEP (collège), j'avais trop de tics. J'ai échoué plusieurs cours à la première session. Etre assise dans une classe avec plein de monde avec mes tics c'était l'enfer.
>
> La transition, ça été pénible parce que j'étais une adolescente qui passait dans un monde adulte mais avec un gros problème, c'est que je ne pouvais pas agir comme tous les autres adultes. C'était difficile dans ce sens là, mais ce n'était pas conscient.

The limitations that TS, or more precisely, that Sylvie imposed on herself because of the shame and embarrassment she felt was not conscious and it is only now as an adult that Sylvie is becoming aware of just how much TS has affected her behavior and decisions regarding her life. Sylvie's tics are now considerably diminished due to the medication she had started taking only two months prior to our interview. The experience of being almost tic free has been a major revelation for her. Still she has not changed her behavior; she avoids group activities where she might find herself exposed.

Nevertheless, she believes that without tics, she can now begin to consider more of a social life:

> Je me comporte quand même comme avant. Par exemple, au cinéma je vais m'asseoir au fond pour être sûr qu'il n'y aura personne derrière moi. Dans le métro, je prend une place où il y a personne. Je préfère rester à la maison plutôt que sortir. Les médicaments m'aident à accepter ma maladie et me permettent une tentative de vie sociale.

Sylvie recounted that she had always wanted to go back to school but was afraid because of her negative college experience. Towards the end of the interview she stated: "j'ai toujours vu ça (l'université) comme une possibilité, maintenant je la vois comme une probabilité".

(b) Guilt

What is the difference between shame and guilt? Middleton-Moz (1990) makes the distinction in this way:

> When we experience guilt, we blame our behaviour. When we experience shame, we blame our character and being...Guilt is associated with wrong-doing. When we feel guilty, we feel that we owe a debt to another. Shame is associated with wrong-being or a feeling of inferiority and worthlessness. When we are shamed, there is a wound to our being and our self-esteem (p.56).

Christine told us that when she attended her first meeting at the Tourette's Syndrome Association (TSA), she felt very guilty. It seemed to her that the other parents there were patient with their children and that she was not. She spent the night following the meeting, crying. She felt guilty because she thought that she was a worse parent than the others; she felt guilty because her child was suffering and she did not know how to help him. How to deal with TS, how to cope with a suicidal child was never in the "parenting manual".

Christine was still fighting, still searching. She felt an obligation to her son and went in search of resources so that she could respond to his needs. She wanted to help him and, as Eric improves, as the help so badly needed is provided, her guilt is diminishing and her sense of competency as a parent is being restored. By learning more about the syndrome and how to manage her child better she has been empowered.

Unlike shame, which implies that "I", the person am bad, we can observe that she felt that she was not patient enough. Intermingled with guilt, we also sense that she felt shame. Unlike Middleton-Moz, I do not believe that we can separate the feelings of guilt and shame so neatly. When we commit a wrong that can be easily addressed and restitution is relatively simple, then perhaps we are dealing with an incidence of pure guilt. For example, if I borrow a friend's car and I damage it, I can make restitution by paying for the repairs and no longer feel guilty. On the other hand, when a child has a medical problem, in this case a chronic problem that often goes undiagnosed for many years, many parents not only feel guilty because their child is unhappy but they may also feel shame that they are not "better parents". When family members reinforce this feeling of incompetence on the part of the parents, the guilt and shame is multiplied. These feelings can retard the process of actively searching for help. Julie, in discussing Stéphane's behavior problems describes it this way:

> Dans cette période là, je pensais que c'était ma faute s'il était comme ça. Puis j'avais une belle-mère qui était ben culpabilisante. Tout ça m'a empêché de faire les étapes et démarches que j'ai fait un peu plus tard parce que je me disais que c'est ma faute.

Julie explained that for a long time she had sensed that her child's behavior, his rages, were out of the ordinary - not quite "normal" but due to her self-blame, she was primed to believe that she was simply a "bad parent". Finally, the situation with Stéphane became intolerable; his behavior was out of control.

At last, after seven years of self-doubt and self-blame, Julie recounts that she stumbled onto a social worker that was able to help:

> ..j'étais allée voir un travailleur social. Là il a comme désamorcé tout ça, puis ça prit six mois pour désamorcer tout le climat, mais après six mois je commençais d'en avoir des résultats. C'était finalement par l'encadrement ...la discipline puis la constance que j'ai réussi à diminuer les symptômes que je savais pas dans ce temps là qui était le syndrome...ce monsieur m'a donné deux heures avant de commencé l'école, parce que là, j'anticipais déjà l'école. Puis c'était la meilleure ressource que j'ai eue en passant.

Julie started her foray into the health care system when Stéphane was 4 years old. She never got any clear answers. She was only too ready to hear that there was nothing wrong with her son, and that she was in fact the problem. It took 7 years before she finally stumbled onto this social worker. He did not blame her; he certainly did not know that Stéphane had TS; he simply treated Stéphane like any other child with behavior problems and provided not only suggestions on how to better manage her child, but also made Julie feel that she is competent and capable. In her own words:

> L'intervention qui était la plaque tournante, c'était cette intervention d'une après-midi avant de commencer l'école...je vivais beaucoup, beaucoup de culpabilité...c'était le comportement puis, à un moment donné, quand t'es toujours en colère, moi aussi je deviens en colère...je me suis dis, c'est ma faute, c'est moi qui le rend comme ça...ça t'oblige à te remettre en question quand tu vas rencontrer une personne comme ça. En tout cas, j'étais prête parce que là, je me suis dis, je ne peux plus aider mon fils.

Subsequent to her change in attitude towards her son, he developed motor and vocal tics. She called the social worker and he told her to simply ignore the tics which was in fact the best advice. While the social worker offered to follow Stéphane during the school year, Julie felt that she would prefer to see if she could manage on her own, with the social worker acting as a resource person. Here again, we see that she is trying to take control and fulfill her role (as she perceives it), reinforcing her belief that she is and can be a good parent. With the support of the social worker, the atmosphere at home, which at that time was tense and angry, started to improve: "puis tout, tout avait diminuer à la maison, la tension avait baissé. J'avais un veil oiseau qui ne chantait plus puis il s'est remis à chanter".

As her son's behavior problems diminished, her sense of competency as a parent increased. The family appeared happy. Julie exuded confidence, providing the children with a sense of security and well being. Furthermore, she attributed the change in the home to her change in attitude, giving her the sense that she was in control of the situation and that she had the power to bring order and happiness into her life and the life of her children:

> Ma plus belle récompense c'est de voir les enfants heureux...c'est de voir Patrick capable de rire un peu de ses tics nerveux, de voir Mélanie avoir un peu de compréhension pour son frère...il me semble que je suis en train de leurs transmettre quelque chose qui va servir plus tard dans la société, qu'ils vont être capables de se défendre avec ça quand ils vont être en difficulté.

CHAPTER VII - EFFECTS OF DIAGNOSIS

> All the labels boil down to the same thing:
> I'm in deep trouble. Doctors and other
> professionals give you textbook answers and
> truly believe it's the right advice. Yet none
> that I have met have lived, for even one day,
> with a child like mine.
>
> (Nastoff, 1986, p.75)

Tourette's syndrome was largely unheard of in the public domain until quite recently. There have been a number of television programs such as "L.A. Law" where the disorder has been profiled, demonstrating some of the difficulties that people with TS face daily. While such programs can educate the public, they usually profile extreme cases thereby providing a distorted view of the syndrome. Tourette's syndrome is a spectrum disorder. Dr. Dion (Conference, October, 1994) stated: "le SGT est un 'spectrum disorder': il y a une continuité entre les tics chroniques, simples ou multiples, jusqu'aux formes les plus graves de SGT avec mouvements constants et vocalisations incoercibles".

Most people who have TS have a mild form of the syndrome. All of the children who participated in the study are diagnosed as "mild" and the two adults are diagnosed as suffering from a moderate manifestation of the disorder. Still, the term mild is relative. Some people with mild symptoms have difficulty coping in school and work and others with moderate symptoms may manage without substantial difficulty. Some people have severe tics but do not suffer from OCD. Others have relatively mild tics but are troubled by compulsions and rituals. Whether or not the impairment (TS) will translate into a handicap and the degree to which the person's social adjustment will be hindered by the impairment will depend in large part on society's response to him or her (Oliver, 1980). Other mitigating factors include support systems and the individual's personal characteristics (personality, socio-economic status, intellectual capacity etc.).[2]

Often there is a long delay between the onset of symptoms and diagnosis of the disorder. Burd, Kerbeshian, Cook, Bornhoeft & Fisher (1988) carried out a survey of identified patients in North Dakota. They found that the mean age of onset of symptoms was 7 years with a range of 2 to 12 years. An average of 5.4 years elapsed between the onset of TS symptoms and diagnosis. In the case of the two adults interviewed, Etienne reported the onset of symptoms at age 9. He was "officially" diagnosed as having the syndrome at age 21. Sylvie reported the onset of symptoms at age 5 or 6 and

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[2] The World Health Organization provides us with a three part definition of impairment, disability and handicap. An impairment is defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function". Disability is defined as "any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being" and handicap is defined as "a disadvantage for a given individual resulting from an impairment of disability, that limits or prevents fulfillment of a role that is normal depending on age, sex, social and cultural factors". See United Nations, World Program of Action Concerning Disabled Persons, (New York: United Nations, 1983) p.3.

was "officially" diagnosed with the syndrome at the age of 21.

Children are being diagnosed earlier now that the syndrome is better known. However, even now, it is often years between the onset of symptoms and diagnosis. The reason for this is twofold. First, many pediatricians are still not knowledgeable regarding the syndrome and early symptoms such as squinting usually suggests eye problems. The optometrist is often the first person to see the child. Second, early symptoms appear to be nervous habits, not worthy of attention. Finally, as the symptoms evolve, everyone becomes more concerned and eventually, they find their way to a neurologist or psychiatrist who pronounces the diagnosis. It is unclear when the symptoms of the participants' children started. There is an evolutionary course to the illness, and it is only in retrospect that parents can say that certain behaviours that were seen as "nervous habits" probably represented early symptoms. Still, on average, for the children in this study, approximately 5 years elapsed between the onset of symptoms and diagnosis of TS.

The road to diagnosis is often fraught with frustrations and obstacles. More often than not, an article in the paper acts as a trigger and parents and adults make the connection. In essence, four of the five participants in the study made an initial diagnosis in this manner and subsequently made an appointment to see a doctor. The fifth participant, reported that she had seen a television report on the syndrome. At that time she and her mother did make the connection between her child's symptoms and the description on the program. At the time, her child was still very young and his tics minor and she simply forgot about it. When her son was finally diagnosed with the syndrome seven years later, she recalled the program. In her own words Christine stated:

> J'avais entendu parler une fois, un soir à la télé. Ma mère et moi on a fait un rapprochement à ce moment. A l'époque, il était quand même jeune et ses tics mineurs. Puis j'ai oublié ça. Quand le docteur a diagnostiqué, je me suis rappelé cette émission. Je n'ai pas paniqué parce que je croyais que avec les médicaments ça va le calmer.

In the above statement, we can sense that Christine had faith that medicine would "cure" her son. Unfortunately, as her story unfolds, we shall see that medication alone is not a sufficient response to such a multi-faceted problem. Indeed, Christine's story is a study in "what can go wrong, does go wrong" or "how <u>not</u> to deal with individuals and families living with TS".

Christine's son Eric contends with tics, phobias and in particular violent and problematic behavior both at school and at home. Christine described her son as lacking in maturity and social skills. Eric has failed sixth grade twice and is constantly rejected at school. When there was a scheduled school camping trip, the other children and the teachers told Christine that he was not welcome on the trip primarily due to his negative and violent behavior. Finally, Eric had to be placed in a Centre d'acceuil because his mother, a single parent could no longer cope with him.

Christine had spent two years trying to get help for her son. He refused to take his medication; he was violent and abusive. She tried to get help through the social services network, they refused. The school kept sending Eric home - calling her at work. When she could no longer manage, she decided that she had no choice but to place him in a Centre d'accueil. At one point he became so distraught that she took him to the emergency room of a hospital. Finally, he calmed down and they were simply sent home without counselling - without any assistance. She was told that he would have to wait six months before he could get an appointment with a psychiatrist. In the meantime, family life had deteriorated to the point where Christine could no longer leave her home. She was afraid to leave her son alone because of his destructive behavior and past suicide attempt. She was also afraid to stay with him because most of his rage was directed at her. Life became unbearable for everyone and finally Eric was placed. He was still at the Centre d'accueil at the time of the interview. He had been there eight months and was scheduled to return home shortly. Christine tells her story in this way:

> Découragée, j'ai appelé à la DPJ (Département de la Protection de la Jeunesse). Il a fallu en arriver en placement. Puis moi, ça m'a fait du bien. Ça m'a fait de la peine aussi, c'est pas facile à accepter ça mais j'étais tellement brûlée.
>
> Ça pris six mois avant d'avoir un rendez-vous (avec un psychiatre). Là ça va mieux. Ça pris deux ans de démarches avant d'aboutir à l'hôpital. Peut-être que si j'avais eu les services toute suite à l'hôpital, peut-être

> qu'on en serait pas arriver là. De l'aide! J'en avais tellement besoin mais j'en avais pas.

Tourette's syndrome is a disorder that is difficult for both those who have the disorder and their families to manage. They need help, understanding, education and support. Scahill, Ort and Hardin (1993) remind us that underneath all the abstract issues of symptoms and behaviors is a child or adolescent who may be having difficulties across several domains: at home, in school, among peers and in the development of the self. I might add that this equally applies to adults both in work and play. Scahill et al. go on to say that TS can serve as a model for multidisciplinary treatment involving parents, teachers, school nurses, social workers, psychologists, physicians and child psychiatric nurses. While these observations are no doubt accurate and sensitive to the needs of this population, it does not reflect the experiences of the participants in this study.

Sebastien describes his experience vis-à-vis the diagnosis of his son Vincent, who was 8 years old at the time in this way: "les contacts qu'on a eu avec les hôpitaux, ça été d'apposer le diagnostic et de (se faire) dire: 'non, non tout va bien, il n'y a pas de problèmes'. On se retrouve chez nous puis on les vit les problèmes".

Even adults who have lived with the disorder for half a lifetime, unaware that their symptoms constitute some kind of neurological disorder are shocked and overwhelmed on learning that they have TS and that generally, it is a life long disorder. Sylvie diagnosed herself when she read a report published by the TSA.

After reading the report, and even though she had lived with the symptoms for over twenty years, she was shocked and overwhelmed. She describes her feelings in this way:

> Ils m'ont donné un pamphlet de 30 pages. J'ai tout lu. J'ai braillé trois heures et je me suis dit "oh wow! C'est pratiquement ma biographie ça!" La boum que ça fait dans ma tête ce serait comme un jeune de 18-20 ans qui en fouillant dans les tiroirs des ses parents découvre des papiers d'adoption. J'ai eu le même rush.

Six months after she was "officially" diagnosed, Sylvie started to go into a depression. She went in search of a psychiatrist through the social services network. The first psychiatrist she consulted knew very little about TS and she felt that she had to "teach" him the disorder. It was frustrating for both of them. Fortunately, he was able to refer her to another psychiatrist knowledgeable in the area of TS. Sylvie had just started seeing her at the time of the interview but seemed to feel that this psychiatrist could help her. Sylvie had lived with the syndrome for most of her life. There were many personal issues that she needed to confront and resolve. All of the participants who sought professional counselling stated that they did not want the social worker, psychiatrist or psychologist to treat the syndrome, but rather to help them deal with the "fallout" of the disorder.

Julie, upon learning that her son Patrick, now 9 years old has the syndrome, stated that she was shocked and upset. She went into a period of mourning. She describes her feelings as follows:

> C'était un choc! J'ai pleuré pendant trois mois de temps. Encore des fois je trouve ça dur. Je trouve ça dur parce que c'est moi qui a transmis ça à mes enfants. Ils l'ont pire que moi...je m'inquiète pour leurs avenir; je ne serais pas toujours là...
>
> Quand j'ai appris le diagnostic pour lui, j'ai appris le diagnostic pour moi. J'ai compris plein d'affaires que moi je faisais qu'est-ce que je comprenais pas. Puis Stéphane, Patrick, de voir que dans ma famille il y a avait plein de personnes bizarre que je ne comprenais pas que j'ai compris. C'est comme une personne adoptée qu'on montre ma famille, ma famille que j'ai jamais vue. Puis là, on se ressemble tous! C'était un choc! Ça change rien sauf que ça m'aide à comprendre des choses...pas de culpabilité mais pas fière.

Now that a label has been affixed to the behavior, what then? All of the participants were left on their own to manage as best as they could. As Julie puts it "c'est beau la maladie diagnostiquée, comment qu'ils sont. Là, tous les jours...j'avais personne pour m'aider." Etienne put the matter very succinctly when he said "une fois qu'il y a diagnostic, peut-être médication, il reste que la personne a une vie à vivre."

A diagnosis of a lifelong neurological disorder requires that professionals take the time to support the individual and the family as they adjust to this new state of affairs. And it is a new state of affairs.

Etienne had lived with the symptoms of the disorder for over ten years. He had functioned well, had a good social life, graduated university and was holding down a responsible position. In short he was doing very well. It is true that he often felt different. But what is rather unusual in his case is that he was not ostracized or shamed. His tics became worse when he left home to go to university. He consulted a doctor and was given medication for the tics (age 19) but was not officially diagnosed with TS until two years later subsequent to reading an article in the newspaper about the disorder.

> En fait, j'ai lu dans un journal un article qui expliquait les désordres moteurs et le syndrome de Tourette. En lisant cet article, je me suis reconnu. En quelque sorte, j'ai posé moi-même le diagnostic. Par après, j'ai pris rendez-vous avec un médecin.

In terms of his reaction to the diagnosis and the "label" of Tourette's syndrome, Etienne felt a certain loss of control and the sense that there was nothing to be done. In his own words, he states:

> Pour moi j'ai eu l'impression d'une certaine perte de contrôle, l'impression qu'il n'y a plus rien à faire...je n'étais ni content ni déçu. La seule chose qui m'est venu à la tête c'est que je ne mourrai pas comme ça! Alors j'ai décidé de faire tout ce qui est possible de faire pour contrôler ça le plus possible.

Etienne felt not only powerless and out of control, but also feared that all of the potential symptoms that make up this syndrome would befall him. He became obsessed with the disorder. On receiving the diagnosis, he was not provided with counselling nor was he told that as he had experienced a mild to moderate version of the syndrome all his life, it was highly unlikely that it would escalate. He was in fact, told very little. Even though he had lived with his symptoms all his life, the effect of being labelled was devastating, as the words below bear witness:

> J'ai vécu un névrose obsessionnelle sur le syndrome de Tourette. J'ai été hospitalisé pour cette névrose pendant un mois dans un hôpital de psychiatrie. En fait c'était cette immense crainte de devenir tout ce que j'avais vu et finalement j'ai réalisé que non. Donc, tout ça, cette histoire de Tourette n'a pas été si positive que ça, mais la façon que j'ai réagis était très positive par contre. J'ai pris le contrôle et mes distances aussi. Parce que la différence entre Etienne avant diagnostic et après...je ne sais pas si c'est pertinent de me rattacher à une maladie.

Etienne was not ostracized as a child, had many friends and was successful in school. His parents, rarely commented on his tics and his teachers and friends seemed to accept him without question. Even when he left home to attend university, Etienne did not suffer social sanctions and continued to do well in school and enjoy a full social life. What protected Etienne from ridicule and rejection? He himself posed the question and could not adequately address it. His family's acceptance certainly played a role. The children in this study also have their parents' acceptance and yet they still face ridicule and rejection outside the home. The question remains unresolved.

Sylvie on the other hand, was harassed at home, laughed at in school and made to feel that she was "crazy". In fact, she told me that at times, she had questioned her own sanity. It is interesting to note, that for Sylvie, the label of TS provided her with an explanation for her behavior and helped to restore her self-esteem and well-being. Subsequent to being diagnosed, she started seeing a psychiatrist to deal with some of the emotional issues created by a lifetime of being treated as though she was "crazy" by her family and the isolation she had experienced as a result of her experience with TS. Sylvie also found it difficult to get the services she needed through the public domain and could not afford to buy services. Through persistence and by "banging on doors" she managed to find one of the few psychiatrists in the city knowledgeable about the syndrome.

Sylvie still has the impairment (TS) but is far less handicapped than she had been. On the other hand, Etienne, who had functioned extremely well prior to diagnosis became handicapped subsequent to being labelled with the disorder, albeit temporarily. Finally, with support and education, he has been able to come to terms with himself. Happily, Etienne has been in remission, or as he sees it, has taken control of TS as opposed to having TS control him. It is unfortunate that support was not provided from the outset. Had it been, it is likely that a lot of pain and suffering could have been avoided. Education and support are essential if we are to break the cycle between impairment and handicap. Etienne has been able to learn and grow from the experience:

> La prise de conscience que j'ai fait c'est, jusqu'où je peux me rendre dans mes tics. Je peux faire n'importe quoi, il vont comprendre, ils savent. Quand j'ai réalisé ça, ça m'a placé devant un immense angoisse; j'avais des choix à faire tout simplement. Là j'ai vécu l'angoisse. Cette prise de conscience causait ça. Cela a été long pour comprendre que je vivais de l'angoisse pour d'autres raisons, pas pour le syndrome de Tourette.

In other words, Etienne believes that he was blaming the syndrome for all his problems. Furthermore, he was bothered by the idea that the syndrome "excused" him from expected norms of behaviours. This troubled him and made him fearful that his identity would become swallowed up by the syndrome. As he said, "c'est difficilement contrôlable pour certains et la personne s'identifie à ses tics". Dr. Oliver Sacks (1987) made the same observation in his case study entitled "Witty Ticcy Ray". Ray, like Etienne had lived with TS most of his life and was diagnosed subsequent to reading an article in the popular press.

In discussing the possibility of using haloperidol to reduces his tics, Ray asked Dr. Sacks "suppose you could take away the tics, what would be left? I consist of tics - there is nothing else..." (p.98). When Dr. Sacks initially tried to treat Ray with haloperidol, the results were both magnificent and disastrous. On the one hand, the tics all but disappeared; on the other hand, the side effects of the medication were intolerable. For example, Ray was a weekend musician and found that on haloperidol, he was musically dull. As well, he developed parkinsonian symptoms. Haloperidol had thrown him from one extreme to the other.

Treatment with haloperidol was suspended for three months. During this period, Ray and Dr. Sacks explored the possibilities that life could offer without tics and, as well, the tradeoffs. Ray had lived with TS since the age of 4. He had been living with it for over 20 years. He hardly knew if it was a gift or a curse and he was not sure he would care for a life without TS.

Ray was heavily dependent on his exotic disorder and needed time and counsel to explore the possibilities that life might offer him without the bizarre symptomatology of TS. He called himself "the ticcer of President's Broadway" and identified strongly with the syndrome referring to himself in the third person as "Witty Ticcy Ray" saying that he was so prone to "ticcy witticisms and witty ticcicisms" that he was not sure whether it was a gift or a curse (Sacks, 1985, p.98). Following three months of counselling, Ray once again tried haloperidol. This time, the side effects were minimal. Ray might have chosen, as do many people with TS to eschew medication, but at least it would have been a choice. Etienne also finally received counselling, although not at the outset. Counselling at the outset would have been instrumental in avoiding his crisis and ultimate hospitalization.

For most people, diagnosis is a welcome relief that is delivered after years of searching for answers. Support and education are essential tools in crisis prevention. When people are left to their own devices to educate themselves, they may become misinformed and fearful. Diagnosis without support can cause great distress because:

> ...au fur et à mesure qu'une personne est renseignée, cela peut devenir inquiétant. Quand une personne apprend ce que sont les symptômes cela peut devenir inquiétant. De savoir que c'était les symptômes de Tourette et voir toutes les possibilités de manifestations, cela était une grande inquiétude.

Fisher, Burd, Conlon, C. and Conlon R. (1986) have evaluated or provided workshops or counselling to over 130 adults and children coping with TS. In managing these children they identified three areas as being particularly relevant to children, their families and for psychologists, counsellors and educators who work with them. The first area deals with providing information about the disorder. The disorder is diverse and manifests itself differently in different children. According to Fisher et al., discussion should cover the following:

(a) circumstances that may exacerbate the disorder;
(b) differentiation of ones own behaviour from the symptoms of the syndrome;
(c) differentiation of tics and habits;
(d) symptomatic changes with age;
(e) treatment alternatives and their relative effectiveness.

The second area concerns the effects of the disorder on the individual's relationships and work experiences. The children and their families need to understand the effect the disorder may have on peer relations, discipline, dating and problems with school work. The third area deals with the need for emotional support for psychological reactions to symptoms. The authors accurately state that intrusive movements and verbalizations can lead to depression, feelings of loss of control and of being different from others. As well the disorder can cause anxiety in groups, concerns about medication and frustrations about having to explain unusual behavior.

When counselling a patient who is intelligent and functioning at a high level, we may have a tendency to forget that they too need education and support. It is not adequate, as was demonstrated by Etienne's story, to leave them to their own devices to inform themselves as best they can.

CHAPTER VIII - WHO AM I?

> ...Touretters must face a doubleness in their lives - the self and the "it", the disease, which with Tourette's takes the form of a multitude of explicit compulsions. One is driven to act against one's own will. The relationship of the self and "it" can be particularly complex, especially if the disease has been present since early childhood. The Tourette's and the self shape themselves to each other until eventually, like a long-married couple, they become a single compound being.
>
> (Sacks, 1995, p.D5)

There is a great deal of medical data about tics and associated disorders but very little on how TS is experienced by the person living with it. Etienne described it in this manner:

> A l'intérieur, j'imagine des bruits, des sons, des images. Ça peut aller très vite, sans arrêt excepté quand je parle. Quand je parle c'est plus au ralenti. A part ça, quand je suis concentré sur une chose, ça va plus au ralenti...c'est partout mais c'est pas douloureux, une espèce d'hyperactivité intérieure. Pas nécessairement mentale mais physique aussi. Les éléments fonctionnent très vite; les idées, les sons, les bruits, les images. Maintenant je me rend compte de ces périodes de grande activité cérébrale.

The above statement has nothing to do with the outward manifestations of the disorder. Clearly, to Etienne, Tourette's syndrome is an internal as well as an external experience. Given that TS is a neurological disorder, it is hardly surprising that there would be effects other than the external manifestation of tics. There is very little scientific data that speaks of the individual's internal experience of TS. The literature is rife with descriptions of the outward symptoms, as though the body functions independently of the mind.

The experience of Tourette's syndrome cannot be separated into little components such as squinting, barking, swearing and so forth. If we erase the internal experience of a person, do we not in some fundamental way erase the individual?

Most reports deal with the observable phenomena of TS. Sebastien, in discussing his son Vincent states: "...le syndrome, c'est beaucoup de tics, beaucoup moteur, un petit peu vocal...puis la maladie se transforme, là il y a beaucoup de compulsions". However, shortly after making the above statement, Sebastien made the observation that perhaps the compulsions were really an effort to control the environment because Vincent felt out of control: "parce que tous ses tics qu'il ne contrôle pas, il cherche à cacher ça. C'est pas lui qui décide les tics. Ça vient alors il les refoule puis c'est là que tout ça se transforme en compulsions pour lui". Is OCD really an integral part of TS or is it in fact a response to the symptoms; an effort to create sense and order out of senselessness and disorder?

Tics are not necessarily the main issue. It would be more accurate to say that it is peoples' reactions and the sense that you are a slave to a body that is unpredictable that is most problematic. Etienne put it this way:

> Pour moi, c'est pas les tics en tant que tel. C'est pas agréable mais, plus au niveau de se sentir différent probablement, se sentir prisonnier de son corps. Les tics c'est une manifestation. Les tics veulent rien dire. Il y a une sensation qui précède un tic et la décharge passe dans un tic."

Here we can see that Etienne is trying to separate mind and body, however, later in the interview he states:

> ...je ne veux pas que mes sentiments, émotions, angoisse, colère, ma peine ou ma joie passe en tics. Parce que j'ai réalisé qu'il y a beaucoup de ces émotions qui passent en tics...se transforment en tics sans que je me rend compte.

From Etienne's first statement we observe that there is an attempt to rationalize the tics as events that happen independent of the self. On the other hand, based on the subsequent statement, it seems that at least in Etienne's case, at times, he experiences the tics as a physical expression of thoughts and feelings.

The questions: who am I? what is me and what is TS? is a continuous battle for those dealing with the syndrome. I have often heard people with TS refer to themselves as "touretters". Sylvie stated when speaking of another individual "c'est un tourette".

When asked whether she can distinguish between herself and the disorder she stated: "...c'est un combat continuel. J'essaye de savoir ce qui est moi et ce qui est le syndrome...".

The attempt to separate the disorder from the self can create a dichotomy within the person's sense of self. Dr. Francine Lussier (1994), a psychologist, in speaking of children and adolescents states the problem in this way:

> Le syndrome Gilles de la Tourette (SGT) c'est non seulement une maladie des tics moteurs et vocaux, c'est aussi, neurologiquement, une perte des mécanismes de contrôle. A cause de cela, le SGT affecte l'émergence d'un sens du SOI, un SOI qui me fait dire que je suis une personne, avec des sentiments, des désirs, des intentions et des agissements qui ont une certaine cohérence interne et une continuité dans l'espace et dans le temps (p.5).

When these physical outbursts occur, much to the chagrin of the child, he/she feels out of control. Dr. Lussier (1994) goes on to say:

> La plupart des enfants ont une expérience de leurs tics, sans lien avec les événements, sans but, une chose qui saute au dehors de leurs corps vis-à-vis laquelle ils se sentent impuissants...plusieurs d'entre eux vont même élaborer plus ou moins consciemment un double SOI: le bon Eric, le mauvais Eric, restant toujours dans une angoisse plus ou moins prononcée que ne surgisse le mauvais SOI...

> cette "division" peut être utile pour conserver la cohérence des impulsions et les actions qui ne sont pas véritablement les siennes. Mais le maintien de cette "séparation", de cette "division" interne draine l'énergie de l'enfant et s'ajoute aux troubles de la concentration (pp. 5,6).

Sylvie found that, for her, medication has been an answer to her prayers. It has been a revelation and she now enjoys an expanse and freedom that she never dreamed possible. She does not yet trust it as her words reveal: "j'espère que ça va durer...". Tourette's syndrome has been a very unhappy experience for Sylvie and in giving up her symptoms, it does not appear as though she is giving up a fundamental sense of self. Rather, it appears as though she is giving up a part of herself that she has long ago rejected (la "mauvaise" Sylvie). This does not appear to be true in Etienne's case. When his tics got very bad, he did go on medication for a time. Eventually, he weaned himself off the medication and prefers to "take control" himself. He seemed to feel that he had lost something more than his symptoms, perhaps a sense of who Etienne is. Both Sylvie and Etienne had lived with the disorder for most of their lives. The difference is that Etienne was not ostracized or excluded in his daily life. He had learned to accommodate and integrate TS and it had become a part of him.

Sacks, 1995, describes a surgeon with TS, Dr. Carl Bennet. Dr. Bennet had tried medication but he simply could not tolerate the feeling that on medication, he was not "himself". Sacks describes it this way: "they reduce his Tourette's assuredly, but they reduce <u>him</u> as well, so that he no longer feels fully himself" (p.D5). Dr. Bennet is able to live a full and productive life with TS. Dr. Bennet he is more than a "touretter"; he is a multifaceted individual - father, husband, doctor, friend and much more. Nevertheless, he sees TS as an integral part of who he is.

Witty Ticcy Ray found that he too had to sacrifice a part of himself when he started taking haloperidol - on medication he was musically "dull". For Ray, TS is much more than tics and witticisms:

> ...having Tourette's is wild, like being drunk all the while. Being on Haldol (haloperidol) is dull, makes one square and sober, and neither state is really free...You (normals) are free, you have a natural balance: we must make the best of an artificial balance (in Sacks, 1990, p. 101).

Ray missed the wildness, but had found that without medication, he had problems at work. Finally, he decided that he would take medication "dutifully" during the week and would "let fly" on weekends (Sacks, 1990, p.101). By allowing himself weekend drug holidays, Ray found a way to accommodate, while still keeping separate, both his "tourettic" and his "solid citizen" personalities.

Through the above statements, we begin to develop an understanding that TS is much more than tics. It affects personality and the development of a fundamental sense of self as a single, integrated individual.

Four people - Sylvie, Etienne, Dr. Bennet and Ray - and four ways in which the disorder is experienced, integrated and "treated". Dr. Bennet states: "Tourette's syndrome is a funny disease - I don't think of it as a disease but just as me (in Sacks, 1990, p.D5). "Touretters" are just people; people from all walks of life; each one unique, each one integrating TS into their lives and into their sense of self in their own special way.

CHAPTER IX - CONCLUSION

(a) Summary

In this study, I set out to discover how people cope and live with Tourette's syndrome. I identified people who either have the disorder or are parenting children diagnosed with TS. Specifically, I wanted to use people's own experiences and insights to examine a number of broad issues as follows:

1. Factors that led the participants to seek help;
2. The participants's search for answers;
3. The meaning and consequences of diagnosis;
4. How they cope on a day to day basis;
5. The emotional and social impact of the disorder.

Through people's experiences, stories and insights I worked to build an understanding of TS and what life with TS represents. The research participants provided insight into the process of coming to terms with a relatively unknown, chronic disorder.

As I learned about the life experiences of the participants, a number of themes emerged which increased my understanding of TS and the difficulties faced by the individuals and families contending with the syndrome. In this concluding chapter, I briefly outline the findings that emerged in the course of analysis. I note some implications for practice, the limitations of this exploratory study and suggest future research that is needed to expand our understanding of the personal and social worlds of "touretters".

(b) Findings:

The experiences of the participants demonstrate that TS is unique to each individual and his or her context. Tourette's syndrome is a biopsychosocial disorder. It is not only a neurological disorder, nor is it simply a chemical imbalance in the brain. At the present time, TS is defined and diagnosed entirely by symptoms. There is no test that can positively identify TS. Based on the literature and observations, it would appear that TS is a neurological disorder that affects psychological and social functioning. Along with tics, many people report associated disorders such as obsessive compulsive disorder (OCD), learning disabilities and behavior problems although their relationship with TS remains unclear.

Access to professionals in the field of TS is difficult. Many doctors and other health care providers are not well versed in TS and, more often than not, it is years before a diagnosis is made. Those who are knowledgeable in the field (doctors, psychologists and social workers) are overworked. Patients are subjected to long waiting lists and only the most severe cases are treated. Even during periods of crisis, the response has been too slow to meet the needs of this population. Parents were told that their suicidal children would have to wait six months before they could get an appointment to see a psychiatrist or a neurologist. Parents are angry; they feel powerless in the face of the medical and social service systems.

The road to finding help can be long and arduous and often many years elapse before a diagnosis is made. It was difficult to determine when the symptoms of the children started and thus, the time elapsed between onset of symptoms and diagnosis is retrospective. On average, it appears that approximately 5 years elapsed between onset and diagnosis for the children in this study. Given the small sample size, it is not possible to generalize, although onset and diagnosis in this study is in keeping with Burd et al's 1988 survey where an average of 5.4 years elapsed between onset of symptoms and diagnosis. For the adults, the average delay between onset of symptoms and diagnosis was 18 years. Initial diagnosis is more often than not triggered by the reading of an article or seeing a television program and a subsequent visit to a physician. This was true for all of the participants in this study.

Most people who have TS have a mild form of the disorder. All of the children in this study have a "mild" form of TS and the adults stated that they have a "moderate" form of the disorder.

Even adults who have lived with the syndrome for over half a lifetime, unaware that their behaviors constituted some kind of neurological disorder were shocked and overwhelmed on learning that they have TS. All of the participants were left on their own to manage as best as they could. The "label" of Tourette's syndrome led to feelings of loss, despair, anger and fear. None of the participants were provided with counselling at the time of initial diagnosis. It was only when they went into crisis that they finally received services. Even then, getting services was no easy matter. TS is a distressing disorder. All of the children and both adults with TS required the services of educators, social workers, psychologists and/or psychiatrists. They did not seek these services in order to "cure" the TS. Rather, the help they required was in adjusting to the syndrome. In particular, they sought information about medication; education about the syndrome and support and counselling for the negative feelings that TS can engender. As well, one of the parents sought counselling and treatment for depression. Subsequent to finding the help they needed anxiety diminished and quality of life improved.

When a child has a medical problem, in this case a chronic problem that often goes undiagnosed for many years, parents often feel guilty and ashamed. They feel guilty because their child is unhappy and they feel ashamed because they may feel that they are somehow to blame for their child's symptoms. When family members reinforce these feelings on the part of the parents, the guilt and shame is multiplied and may retard the process of actively searching for help.

The unresponsiveness on the part of the health care system contributed to parents' and individuals' anger and produced in them a sense of powerlessness, generating feelings of guilt, shame and depression. By learning more about the syndrome parents, children and adult "touretters" were empowered thereby diminishing their sense of powerlessness, shame and guilt. Adjustment was enhanced by the parents' (on behalf of their children) and individuals' ability to lobby for the services and help they required.

The symptoms of TS are fluid and vary over time. The major symptoms are motor and vocal tics. Tourette's syndrome is unpredictable and while a person may have some temporary control over symptoms, ultimately, the tics must come and the person is usually embarrassed. When the experience is repeated over and over it can lead to self-hatred and in extreme cases to suicidal ideation. One of the children in this study considered suicide and another actually made a suicide attempt. Children find it difficult to speak about their problems and are often ashamed of having TS. Society's reaction to people who display bizarre or out of context behaviour can be unforgiving. This lack of understanding can lead "touretters" and their families to avoid social gatherings and other activities. Two families avoided family celebrations and one of the participants dropped out of college due to self-consciousness about her tics. Activities such as going to the movies or shopping are also difficult and childrens' school experiences may be fraught with shame.

Parents of children coping with TS, as well as adult "touretters" resist taking medication because of the potential side effects, usually resorting to medication only after all other avenues have been exhausted. For some medication is of great benefit, for others, the side effects and the sense of not being "themselves" may outweigh the advantages. As a result, they choose to live with their symptoms as opposed to taking medication. Counselling concerning medication and potential side effects was not always provided. In one case, a prescription was called into a pharmacy; the doctor never saw the child in question.

Tourette's syndrome is much more than tics. The impact of TS is felt in the development of the emerging self; it is an internal as well as an external experience. The experience of TS cannot be separated into little components. Some people are able to accommodate and integrate TS it into their sense of self, while others may reject the part of themselves that is "tourettic" which may in turn, lead to a dichotomy of the self.

A pattern emerged; there is a slow, progressive onset of symptoms. Years go by and, as the symptoms become more and more distressing, people begin to seek help through the health care (doctors) and social service systems (psychologists, social workers). During the time leading up to diagnosis, people go through various stages. The first is the concern that something is not "quite right". When help is not forthcoming, a sense of powerlessness and helplessness may ensue which produces feelings of shame and guilt and may lead to depression. Finally, a diagnosis is made. There are reactions: fear, denial, shock and anger. When counselling is not provided in order to resolve these feelings, families and individuals may go into crisis. Finally, help is found. Over time, people start to feel empowered and their sense of powerlessness, shame and guilt is reduced and their functioning improved.

(c) Implications for practice:

Parents and professionals need to forge links with the educational system. They must educate teachers and school administrators about TS. School officials must be made to understand that the child is not intentionally trying to annoy the teacher or disrupt the class. Training and awareness programs are needed to educate teachers, social workers and counsellors.

The constant need to intervene on behalf of their children can burnout already exhausted parents. Tourette's syndrome is a disorder that is difficult for all concerned. People need help, understanding, education and support. TS is a multi-faceted disorder and is paradigmatic of issues and problems that require a multi-disciplinary treatment approach involving parents, teachers, school nurses, social workers, psychologists, physicians and child psychiatric nurses. Services must be better coordinated. Social workers are ideally suited to act as "case managers" to facilitate efficient coordination of services.

Greater public awareness of TS is essential in order to break the cycle between impairment and handicap. Some community organization time should be deployed to assist and support existing organizations in finding the means to expand public education.

For most people, diagnosis is a welcome relief that is delivered after years of searching for answers. Support and education is essential. Diagnosis without support can cause great distress. When people are left to their own devices, to educate themselves, they may become misinformed and fearful. Professionals must provide information about the disorder regarding treatment alternatives, differentiation of tics from habits and the effects that the disorder can have on relationships, work and school experiences.

TS can cause anxiety in groups, concerns about medication and frustrations about having to explain unusual behavior. Emotional support for psychological reactions to symptoms such as depression, feelings of loss of control and of being different from others need to be provided as well.

(d) Limitations and implications for further research:

This report is of an exploratory nature and the sample is small. As such, the findings must be viewed as tentative. As well, given that the sample was drawn from a self-help organization, it may not be representative of the population at large. Further studies with larger samples are needed. As well, longitudinal studies, following children and families for many years are needed in order to determine how well this population fares over time.

The child is often the focal point of research. TS is indeed a disorder that begins in childhood but due to its chronic nature, it affects adults as well. More studies on adult functioning and TS are needed particularly as it relates to employment and educational achievement.

Little research has been carried out on the effects of TS on the individual and the family, and even less on the social adjustment of adults with TS. Researchers have concentrated heavily on the neurological and genetic aspects of TS leaving the study of the emotional and psychosocial repercussions of the disorder lagging behind. To my knowledge, this is the first or one of the first social work theses on the subject of Tourette's syndrome - more studies are needed. Further research, both qualitative and more rigorous quantitative studies with larger samples are needed.

d) A few closing words:

The shift back to the view that Tourette's syndrome is a neurological disorder maintains the dichotomy between the mind and the body seen all too often in medicine. As new theories replace old theories and old theories replace new theories, scientists are certain of the rightness of "their theory" and are equally convinced that the "others" are wrong. At the present time, there is no proven diagnostic procedure, definitely known cause or totally effective treatment for TS. We have no definitive answers - no definitive cures. Given this state of affairs, the best medicine for TS, for the moment, is to help people to better understand the dynamics of this disorder and how to live with it - and live well with it, on a day to day basis. We must look beyond the symptoms and behaviours of "touretters" and begin to see the people:

> Despite a chronic condition, it is time
> to realize that TS is only part of that
> person...(you are) not only a Touretter,
> but...above and beyond everything else,
> a unique human being, precious and
> irreplaceable.
>
> (Dion, 1995, p.1)

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APPENDIX A

INTERVIEW GUIDE

1) **FACTORS THAT LED YOU/FAMILY TO SEEK HELP**
   - behaviours, activities that appeared "odd";
   - gradual/sudden realization that something was "wrong"
   - remarks from family, friends, educators;
   - educational problems;
   - social problems;
   - behaviour problems;

2) **HELP SEEKING ACTIVITIES:**
   - looking for support (friends, family, church, support groups);
   - contacts with mainstream agencies (hospital, CLSC,school);

3) **DIAGNOSIS:**
   - process of discovery;
   - newspapers, journals, television etc.
   - professionals (doctors, psychologists, educators)
   - friends, family
   - support services, psychoeducation, clergy
   - feelings regarding the "diagnosis" (guilt, relief, fear etc.)
   - having children/more children

4) **MANAGING/COPING**
   - strategies
   - what works/what does not work
   - personality or Tourette's syndrome (TS); distinguishing
   - social life
   - education
   - work
   - managing transitions (childhood, adolescence, etc.)
   - service utilizing/utilized

5) **PRESENT FUNCTIONING**
- modified expectations
- relationships (spouse, child, siblings, extended family)
- work/school
- social activities (couple, family, individual)
- most troubling aspect of living with TS
- positive factors (family closer, more sensitive, etc.)
- services utilizing/services needed
- feelings regarding living with TS on a day to day basis

APPENDIX A.1

Guide d'Entrevue

1) **LES FACTEURS A L'ORIGINE DE VOS SOUPÇONS**
   - comportements, activités anormales
   - réalisation soudaine/graduelle que quelque chose n'allait pas
   - remarques de la famille, amis, professeurs
   - problèmes scolaires
   - problèmes sociaux
   - troubles généraux de comportements

2) **ACTIVITÉS DE RECHERCHE D'AIDE**
   - recherche de soutien - amis, parents, église, autres
   - contacts avec les institutions - hôpitaux, CLSC, écoles

3) **DIAGNOSTIC**
   - la découverte
   - journaux, revues, télévision
   - médecins, psychologues, enseignants
   - familles, amis, autres
   - services psycho-education, clergé
   - ressentiments vis-à-vis le diagnostic (culpabilité, libération, peur, inquiétudes)
   - enfants/autres enfants

4) **GESTION/ADAPTATION**
   - stratégies
   - ce qui marche, ce qui ne marche pas
   - personnalité de l'individu ou syndrome - comment distinguer
   - vie sociale
   - éducation
   - travail
   - gestion des transitions (enfance, adolescence...)
   - services utilisés

5) **FONCTIONNEMENT ACTUEL**

- attentes réduites, modifiées
- relations, interactions (famille, amis)
- milieu scolaire, professionnel
- activités sociales/familiales
- aspects les plus troublants de Syndrome Gilles de la Tourette (SGT)
- facteurs positifs (rapprochements dans la famille)
- services utilisés, souhaités
- votre opinion libre sur la vie quotidienne avec SGT