

**UNRAVELING A LIFE OF TOURETTE'S SYNDROME: A NARRATIVE
INQUIRY**

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Fulfillment of the Requirements for the Degree of Master of Education in the Department
of Educational Psychology and Special Education
University of Saskatchewan
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ABSTRACT

Tourette's Syndrome is a rare, psychiatric condition that has the potential to negatively impact one's social, emotional, and academic domains (American Psychiatric Association, 2000). Those individuals most at risk from suffering from harmful effects are children and young adolescents, who are at a particularly vulnerable point in their lives as they progress through the stages of maturation and development in a variety of realms. Recent research has been conducted examining Tourette's Syndrome's neurological pathways, etiology, characteristics, and limitations of the disease (Freeman, Fast, Burd, Kerbeshian, Robertson & Sandor, 2000). However, limited research exists focusing on the lived, personal experiences of individuals living with this rare and unique syndrome. This study focused on the lives of three participants living with Tourette's Syndrome.

Conducted from a narrative inquiry approach, each participant shared their private and unique stories living with Tourette's. Stories were shared through a semi-structured interview design, where each interview was audio recorded and fully transcribed. Each individual's transcript was then analyzed and compared to each participant in efforts to identify common patterns and themes which emerged or notable differences which set each apart. The resulting findings identify an understanding of lives lived with Tourette's Syndrome, and the ultimate strength and courage that is required to overcome obstacles that the syndrome and society have placed on each individual. The findings also provide valuable information for educators and counsellors to assist in their professional practices.

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DEDICATION

I wish to dedicate this thesis to all the individuals in society who are living with Tourette's Syndrome. Each and every one of you are all truly unique and special people.

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CHAPTER ONE: INTRODUCTION

Rationale of the Study

Tourette's Syndrome is often characterized as the "foul mouth disease" (De Lange, Olivier & Meyer, p. 613, 2003). Society is greatly influenced by the media which promotes the view and belief that Tourette's Syndrome is a disease that produces involuntary obscene language and gestures. However, less than 10% of individuals will develop this as a symptom (Freeman et al., 2000). As Marsh (2007) indicated, there is a substantial amount of erroneous pieces of information that exist in society regarding the characteristics of Tourette's Syndrome.

As a result of these gross media and societal misconceptions, individuals with Tourette's Syndrome often experience feelings of reduced self-worth or the belief of feeling different (Kaplan, 2007). Therefore, it is essential that supportive understanding and awareness is promoted in order to decrease this misrepresentation of Tourette's Syndrome being a condition plagued with socially inappropriate and obscene language and gestures. By achieving understanding and awareness, this will ideally lead towards the development of a more accurate representation of Tourette's Syndrome.

The current literature pertaining to Tourette's Syndrome is generally confined and narrowed to the etiology, characteristics, and limitations of the disease. There is limited research from a qualitative methodology approach. Research focusing on in-depth experiences of individuals living with Tourette's Syndrome would prove to be a beneficial addition to the existing literature. More research is therefore essential in order to comprehend the experiences of individuals living with Tourette's Syndrome, as well as distinguish society's misconceptions of the disease.

Study Development: A Personal Context

Through my limited and modest experiences as an educator, there have been opportunities to interact, instruct, and form relationships with a variety of students. Several of these teaching opportunities have permitted me to experience all types of students ranging in ages, abilities, inabilities, and exceptionalities. It was through one of my most rewarding teaching experiences that I encountered a young student who had been recently diagnosed with Tourette's Syndrome. Throughout my experiences with

this student, I was continuously fascinated with the condition itself, and how the student was able to successfully overcome and manage life on a daily basis.

When first introduced to the student and provided with an explanation of their condition, I will admit that I too, as the majority of society typically does, fell victim to the negatively misconceptualized disease. I initially assumed it was a condition in which individuals use involuntary obscene language. My misconceptions were developed and plagued by misrepresented media portrayals of the syndrome depicting Tourette's Syndrome as the cursing and vulgar language syndrome. Entering the classroom with this frame of mind, I quickly discovered that my current views were utterly and completely incorrect. The student with Tourette's Syndrome did not possess any of the characteristics portrayed by society and media. As expected, tics were present at times but not to the degree that one would notice immediately. Uncontrollable bursts of humming, forced eye blinking and body twitches emerged as tics, but genuinely only noticeable to trained eyes. As I began to inform others on the subject of teaching a student with Tourette's Syndrome, I soon discovered I was presented with repeated similar responses about the condition. Questions revolved around issues pertaining to the degree and frequency of the student swearing and how difficult it was for me to ignore the occurrence of such tics. I was perhaps the most bothered and astonished when the response from others was laughing after it was explained I had student with Tourette's.

Over the next few months as work continued with the student, I was constantly amazed and perplexed with understanding their life experiences. Hesitant to discuss the condition on a personal level, I opted to conduct research focusing on lived experiences about individuals with Tourette's Syndrome. My search through literature revealed an abundance of information regarding the etiology, characteristics, and difficulties encountered by individuals diagnosed with Tourette's Syndrome. However, I was only able to locate minimal literature which provided me with a vague degree of insight into the life experienced by individuals with Tourette's Syndrome. I needed a deeper and richer account of personal experiences in order to truly understand the impact Tourette's Syndrome presents in one's life.

As a result of this experience, I discovered that I have cultivated a desire to develop insight and understanding of the experiences of individuals with Tourette's

Syndrome. Further, I want to use these shared experiences to develop an understanding of the lived experiences of individuals with Tourette's Syndrome have encountered. These experiences helped me to decide I needed to pursue a qualitative narrative inquiry research method to explore the experiences of individuals living with Tourette's Syndrome. This simultaneously will ultimately add a much needed qualitative narrative methodology focus to the existing literature.

Purpose of the Study

In order for individuals to develop an accurate understanding regarding Tourette's Syndrome and life experienced by those who have been diagnosed with the disorder, it would be beneficial for individuals with Tourette's Syndrome to share their personal lived experiences. This information will present educators, counsellors, families, and friends stories of experiences that have the potential to provide them a connection with individuals who have been diagnosed with Tourette's Syndrome. These stories may assist them in finding similarities and comforts in their own lived experiences. For this purpose, I have chosen to focus on and examine the lived experiences of individuals diagnosed with Tourette's Syndrome, specifically examining and understanding their educational, social, and emotional experiences. These three specific areas warrant in-depth narrative research as each of these domains have a profound impact on the individual; each in their own singular nature as well as each being interwoven and impacted simultaneously (Bawden, Stokes, Camfield, Camfield & Salisbury, 1998; Leckman, Bloch, Scahill & King, 2006; Schapiro, 2002). These subtopics merit research as Tourette's Syndrome is often a socially disabling disease which has potential to have great influence on these three particular areas.

For students with Tourette's Syndrome, 50% of students have the potential to experience academic challenges in the educational environment (Burd, 2007). Although the IQ level of students with Tourette's Syndrome is not directly affected by the disorder, students are apt to experience difficulties in regards to their organizational, fine and visumotor, and reading and writing skills. Unfortunately, due to the 90% comorbidity rate of additional exceptionalities (Robertson, 2006), it is often the comorbid conditions which prove to be the biggest challenge to students. In addition to students facing academic challenges within the academic setting, the educational environment can also

prove to be to be a disparaging and stressful event due to social ramifications which may occur. Due to the fact Tourette's Syndrome has the potential to be socially stigmatizing, 75% of students are teased or bullied during their academic years (Marcks, Berlin, Woods & Davies, 2007). These negative occurrences continue out of the academic setting as well, as 68% of individuals have reported feeling socially ostracized at various points throughout the course of their lives (Shady, Fulton & Champion, 1988). Thus, students with Tourette's Syndrome are at an increased risk of experiencing social rejection during a crucial developmental point of their lives. This social rejection increases for the depletion of self esteem, self confidence, and overall self concept to materialize (Pristia, 2003). As a result, students face an increased risk for their emotional realms to be directly negatively affected. Research indicates that depressive symptoms occur in 13%-76% of individuals living with Tourette's Syndrome and carries a lifetime risk of 10% (Robertson, 2006). As indicated above, the educational, social and emotional realms play a significant role in the developmental of young individual's lives. In order to develop an understanding of how each of these areas is experienced by individuals living with Tourette's Syndrome, research in the stories of experiences needs to be pursued. The educational, social, and emotional realms thus warrant research as Tourette's Syndrome is often identified a socially disabling and stigmatizing disease which has the potential to have a profound impact on these three particular areas.

By providing these individuals with an opportunity to openly share their experiences and express their thoughts, feelings, and emotions, I hope to achieve a sense of better understanding of the lives lived by those diagnosed with the disorder. I want to take these shared experiences and construct them into narratives, which will serve as "a communication format to organize interpretive representations and explanations of personal and social experience" (Borg, Gall, & Gall, 2007, p. 519).

Research Question

What are the experiences of individuals living with Tourette's Syndrome in regards to how the disease impacts their daily lives? By addressing this question, three specific subtopics will be of central focus. The educational experiences, social relationships, and emotional realms will be the core elements pursued and examined.

CHAPTER TWO: LITERATURE REVIEW

Introduction

The study investigated the educational, social, and emotional experiences of individuals with a diagnosis of Tourette's Syndrome. The literature corresponding to Tourette's Syndrome tends to be ignored. It is, therefore, critical and essential to pursue research with a focus on individual lived experiences constructed through narratives. In order to understand Tourette's Syndrome in its complexity and entirety, it is significant and essential to conduct a thorough review and critical analysis of the existing literature. Literature reviewed on Tourette's Syndrome reflects effects on the psychological, social, emotional, and educational areas experienced by individuals. Developing an understanding surrounding the areas directly impacted by Tourette's Syndrome will help cultivate an awareness, comprehension, and a realization of the participant's experience.

Etiology

The initial documentation of Tourette's Syndrome occurred more than a century ago by a French physician George Gilles de la Tourette (De Lange et al., 2003). During 1885, Gilles de la Tourette became the first researcher to formulate a concentration in the area of Tourette's, after observing nine patients who displayed involuntary sounds and movements (De Lange et al., 2003). This study led to several significant factors towards understanding of the syndrome (Edell-Fisher & Motta, 1990). Since then, literature pertaining to Tourette's Syndrome has been brought forwards. This is due to new research, scientific literature and media attention, with the majority of the latter frequently unjustly misrepresenting Tourette's Syndrome (De Lange et al., 2003). It is because of this misrepresentation that more inquiries need to occur from the view point of individuals with Tourette's Syndrome. Only then will a better understanding and awareness of this condition develop from their perspectives and life experiences in order to extinguish these current false beliefs.

Tourette's Syndrome is a complex, chronic, neuropsychiatric developmental disorder characterized by involuntary multiple motor tics and one or more phonic tics lasting for at least one year (APA, 2000). The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision (DSM-IV-TR), lists the following diagnostic criteria:

- A. Both multiple motor and one or more vocal tics have been present at some time during the illness, although not necessarily concurrently;
- B. The tics occur many times a day (usually in bouts) nearly every day or intermittently throughout a period of more than 1 year, and during this period there was never a tic-free period of more than 3 consecutive months;
- C. The onset is before age 18 years;
- D. The disturbance is not due to the direct physiological effects of a substance (e.g., stimulants) or a general medical condition (e.g., Huntington's disease or postviral encephalitis). (APA, 2000, p. 111-114)

Motor and phonic tics can be categorized as either simple or complex. Simple motor tics are meaningless, recurring, and rapid movements incorporating the use of one main muscle group, such as facial grimacing, eye blinking, and twitching, while simple phonic tics are repetitive and meaningless sounds, such as grunting, coughing, and humming. Simple tics have the potential to develop into complex tics. Complex motor tics utilize two or more muscle groups to generate involuntary movements such as jumping and spinning, while complex phonic tics produce repetitive utterances and expressions such as stuttering (Packer, 1998). Simple and complex motor and phonic tics are the most prevalent and common as a result of Tourette's Syndrome. However, it is often coprolalia and copropraxia that society and the media attribute to Tourette's Syndrome.

Coprolalia involves the involuntary uttering of socially unacceptable or obscene words, phrases or sentences. Copropraxia involves the involuntary production of socially obscene gestures and movements (Zinner, 2004). Unfortunately, society has stigmatized that all individuals inflicted with Tourette's Syndrome have coprolalia and copropraxia, when in reality less than 10% of individuals will develop this as a symptom (Freeman, et al., 2000). It is also critical to note that although socially unacceptable phrases or movements may occur, it is not reflective of the individual's genuine thoughts and feelings (Packer, 1998). Motor and phonic tics are substantially unpredictable and unique to each individual, with tics varying day to day (Zinner, 2006).

The majority of individuals describe their tics as a sensory effect; a building up of an unpleasant and tense sensation in a specific part of the body which is temporarily relieved by completing the urge. This feeling is often identified as pre-monitory sensory

urges, similar to an itch requiring a scratch for temporary relief (De Lange et al., 2003). The occurrence of pre-motory sensory urges typically increases as the individual ages with 11 years being the average age when these urges transpire (Leckman, 2006). It is possible for individuals to contain the ability to attempt to suppress tics, and are relatively successful for varying amounts of time. However, in order to temporarily suppress a tic, this requires a great amount of mental and physical energy which often results in loss of concentration and greater distractibility. Due to the high degree of mental and physical efforts required to suppress tics, it is not recommended that individuals, specifically children, attempt to suppress tics. By attempting to do so, the tics that may have been temporarily suppressed will eventually transpire, only to manifest themselves in more explosive forms (Packer, 1998).

A survey of Tourette's Syndrome suggests 5-30 children per 10,000 have a diagnosis (APA, 2000). The typical onset for Tourette's Syndrome begins during early childhood between the ages of 2 to 7 years, with a mean age of 7 years (APA, 2000) and males four times more likely than females to develop Tourette's Syndrome (Zinner, 2006). The frequency and severity of tics appear to be the greatest during early adolescence, between the ages of 8 and 12 years (Bloch, Sukhodolsky, Leckman & Schultz, 2006), while the gradual delineation of tic frequency and severity occurs during early adulthood (APA, 2000). Less than 20% (Bloch et al., 2006) of tics may continue through adulthood with the possibility of developing worse symptoms.

During the course of Tourette's Syndrome, individuals will experience their tics varying in frequency and intensity, known as waxing and waning. Waxing and waning occur throughout the course of Tourette's, and are characterized by fluctuating in occurrence from hour to hour, day to day, and year to year. It is not uncommon to see a period of time with many tics, and then periods where no tics occur (Hansen, 2007). Although Tourette's Syndrome is considered a chronic condition, tics can go into remission for lengthy periods of time; weeks, months, or even years (APA, 2000).

From a neurophysiological perspective, growing evidence suggests that Tourette's Syndrome develops as a result of malfunctions with the basal ganglia, a collection of interrelated brain structures situated below the cerebral cortex portion of the brain (Olson, 2004). According to Olson:

Neural circuits run from the cerebrum through the basal ganglia and then back to the cerebral cortex, providing a feedback loop that helps integrate brain functioning....One function of the basal ganglia is to learn and regulate the expression of discrete chunks of behavior, such as particular movements or thoughts....In Tourette's Syndrome, groups of neurons in the basal ganglia fail to inhibit particular movements or unwanted behaviors. As a result, these behaviors surface as tics. (p. 1391)

There is recent speculation that the specific neurotransmitter of the basal ganglia, dopamine, is likely additionally involved in the occurring malfunction (Olson).

Research has focused on the probability that genes play an active and integral role in the genetic transmission of Tourette's Syndrome, however controversy exists surrounding the validity of this issue. The majority of research indicates Tourette's Syndrome is apt to be transmitted within families, although the exact method of transmission is unknown (APA, 2000). McMahon, Carter, Fredine and Paul's (2003) genetic study examined and compared 34 children with one or both parents who had a diagnosis of Tourette's Syndrome to a control group of 13 children with parents without a diagnosis. Their results indicated that 29% of children with one or both parents with Tourette's Syndrome were diagnosed with the syndrome during the ages of 3 to 7 years, while no diagnosis existed within the children from the control group. The genetic transmission of comorbid conditions were additionally reported with high rates of occurrence (McMahon et al., 2003). Contradictory research also exists surrounding the validity of genetic transmission, however, the majority of researchers and scientists do agree that genes have the potential to play an integral role in transmission but the exact method has not yet been established.

Psychopathology

Psychopathology is the presence of multiple diagnoses of conditions, as compared to the single diagnosis of a condition (Cohen, Leckman, Peterson & Towbin, 1999). Psychopathology occurs in 90% of individuals with Tourette's Syndrome, with Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (OCD) being the most prevalent (Robertson, 2006). Kurlan, Como, Miller, Palumbo, Deely, and Andresen, et al. (2002) study indicated that in addition to ADHD and OCD, behavioral

conditions such as anxiety disorders, mood disorders, aggression, internalizing and externalizing symptoms were elevated in individuals with Tourette's Syndrome. Comorbid conditions are often identified as a risk factor of being equal to or more detrimental than Tourette's Syndrome in its singular, purest form. To experience Tourette's Syndrome in its singular purest format is generally considered the exception rather than the norm (Leckman, 2006). In Freeman et al.'s (2000) study examining 3500 individuals with Tourette's Syndrome, only 12% experienced the syndrome with no accompanying comorbid conditions. They also noted that on average, individuals are inflicted with two comorbid conditions. As research has indicated, it is often these comorbid conditions that cause the greatest amounts of impairments and difficulties in numerous areas affecting the daily lives of individuals with Tourette's.

Kurlan et al. (2002) reported studies that demonstrated ADHD being the most common comorbid condition with a prevalence rate of 50% – 75%. The combination of Tourette's Syndrome and ADHD causes individuals to display disruptive behaviors, impulsivity, and social immaturity (APA, 2000). Individuals are also apt to experience disruptive behavioral and functional deficits (Leung, Liu, Su, Zhou & Zhu, 2006). The comorbidity that occurs between Tourette's Syndrome and ADHD contains a high probability for greater overall impairment as a result of how the two disorders interact with one another (Gaze, Kepley & Walkup, 2006). A calm, focused, and relaxed state of mind contains the potential to reduce tic severity and frequency, generally the opposite characteristics of ADHD symptoms. Due to ADHD's symptoms of impairments in concentration and focus, the possibility of an increase in tics can arise (Gaze et al., 2006). The combination of Tourette's Syndrome with ADHD places individuals at increased risks of irritability, rage attacks, antisocial behavior, depression, low self-esteem, few peers, and drug abuse (Leckman et al., 2006).

Approximately 50% of individuals with Tourette's Syndrome experience OCD as a comorbid condition (Swain, Scahill, Lombroso, King & Leckman, 2007). Individuals with Tourette's plus OCD experience obsessions and compulsions. Obsessions manifest in forms of repetitive, intrusive, and unwanted thoughts while compulsions occur in the form of repetitive, intrusive, and wanted types of behaviors (Gaze et al., 2006).

According to the APA (2000), the specific subtype of comorbid OCD is characterized by

male predominance, early age onset, and an increase in the frequency of specific obsessions and compulsions (i.e. heightened aggression and reduction in contamination). Overall, the daily obsessions and compulsions experienced cause disruption to an individual's daily life. As a result of the addition of OCD, individuals with Tourette's are at a greater risk of displaying behavioral and emotional problems (Zhu et al., 2006).

Social-Emotional Implications

According to Robertson (2006), since Tourette's Syndrome is likely to be a socially immobilizing and stigmatizing disease, individuals with Tourette's Syndrome have a high probability of their social domains to be frequently negatively affected. Research has suggested that the core of the problem is largely due to society's negative perceptions and treatment of individuals affected by a psychological or behavioral disorder (Marcks et al., 2007). Studies have shown that individuals view those with Tourette's Syndrome as less popular, as opposed to those who are Tourette's Syndrome free (Marcks et al., 2007). Marcks et al. documented that children and adolescents are more susceptible to experiencing an amplified risk of social rejection and isolation there is a likelihood of these risks continuing to proceed into adulthood. In Shady, Fulton and Champion's (1988) study of 210 individuals with Tourette's Syndrome, 68% reported experiencing feelings of ostracization and social embarrassment during particular moments in the course of their lives. As a result, individuals with Tourette's Syndrome face social struggles, complications, and obstacles meeting, making, and maintaining friendships and relationships throughout the course of their lives.

It is during childhood and adolescence that social difficulties and ramifications originate and begin to surface frequently, ultimately resulting in these young individuals being subjected to harsh criticisms from their peers during a highly crucial developmental point in their lives. In Marcks et al.'s (2007) study of examining the social realm of children with Tourette's Syndrome, 75% of children reported being teased by peers as a result of their tics. These children are at a greater risk for being socially rejected by their peers (less popular) and thus becoming more withdrawn. The normal development of functional and positive peer social interaction is crucial in order for the child to develop the necessary social skills to progress through life.

Research has suggested that negative social interactions do not always occur as a direct result of Tourette's Syndrome itself, but rather due to other significant comorbid conditions, such as ADHD (Bawden et al., 1998). Comorbidity with Tourette's Syndrome and ADHD, and/or OCD places all individuals, both children and adults, at greater risk for developing poor social modifications, increased psychosocial failures, and a reduced quality of life (Lin et al., 2007). Regardless of comorbidity, individuals with Tourette's Syndrome still have a greater risk of developing social impairments. A strong relationship exists between social ostracization and a decrease in self-esteem. Individuals with Tourette's Syndrome often experience feelings of embarrassment, anxiety, and withdrawal resulting from society's tormenting, bullying, and negative views. These strong feelings habitually evolve into depleted self-esteem, self-confidence, and self-concept (Pristia, 2003) resulting in the likely probability for feelings of depression to materialize and progress.

Depression and accompanying depressive symptoms occur in 13%-76% of individuals with Tourette's Syndrome (Robertson, 2006). Depression carries a lifetime risk of 10%, with rates doubling amongst women (Robertson, 2006), and a lifetime suicidal risk of 2% (Goodman, 2006). The high rates of depression are believed to have a direct correlation to the severity of tics experienced by individuals with Tourette's Syndrome. Moderate to severe tics contain a high probability of being detrimental to one's self-esteem, due to the syndrome's chronic socially disabling and stigmatizing views. An additional factor relating to an increased risk of depression occurs with Tourette's Syndrome plus other comorbid conditions, such as ADHD and OCD. ADHD places individuals at increased rates of depression. OCD's greatest complication is depression, ranging from 13% - 75% (Robertson, 2006).

Behavioral Implications

Oppositional Defiant Disorder (ODD) is a common characteristic of adolescents with Tourette's Syndrome. Individuals with ODD are apt to display forms of noncompliance with rules, causing arguments with members of authority, and outbursts of anger and frustration (King, Scahill & Sukhodolsky, 2007). Research has indicated that ODD affects majority of individuals who have comorbid ADHD, rather than individuals with only pure Tourette's. In Freeman et al.'s (2000) study of 3500

individuals with Tourette's Syndrome, individuals who were diagnosed with comorbid ADHD displayed a positive relationship between ADHD and ODD, and thus were four times more likely to engage in anger control problems. According to Freeman et. al (2000), "the degree of comorbidity may indicate the degree of pathology in terms of brain function, which in turn leads to more numerous and increasingly more severe behavior disturbances" (p. 442). As a result of the studies, it is critical to develop an awareness and understanding that is generally the comorbid conditions that ultimately cause behavior disturbances as opposed to the Tourette's Syndrome itself.

Twenty five percent of individuals with Tourette's Syndrome experience rage attacks which are abrupt onsets of uncontrollable and unintentional displays of physical and/or verbal behaviors caused by an obvious non-provoking stimulus (Budman, Bruun, Park, Lesser & Olson, 2000). Budman et al.'s (2000) found the occurrence of rage attacks indicated that the incidence rate for rage attacks was strongly related to the presence of comorbid conditions, such as ADHD and OCD. Furthermore, the results also indicated that the combination of two or more concurrent comorbid conditions increased the probability for individuals with Tourette's Syndrome to experience episodes of rage attacks. Episodes of rage attacks are of concern to individuals who experience them. Not only can the attacks contain the potential to cause physical harm to others, but they are of great concern of causing physical harm to the individual themselves. Due to the sudden onset and uncontrollable nature of the attack, rage attacks contain the likelihood of social demoralization.

Academics

Children who are diagnosed with Tourette's Syndrome typically have the same IQ levels as their normally achieving peers. Although their IQ level may not be directly affected by the disorder, students with Tourette's Syndrome require educational supports, individualized educational programs (IEP's), or for severe cases of Tourette's, possibly special education (Tourette's Syndrome Association, 2007) as these students contain a high probability for experiencing some form of learning disability. The most common learning disabilities experienced by students with Tourette's Syndrome include impairments in organization, fine and visuomotor, reading comprehension, written representation, and mathematical computation (Packer, 1995). Not only may students

encounter difficulties in academic disciplines, but they are also prone to face social repercussions throughout the school environment as well.

Organizational impairments are likely to occur in students with Tourette's Syndrome as their executive cognitive functioning skills are affected. This impairment directly affects their abilities to stay organized. Students will experience difficulties in various organizational tasks such as initiating and completing homework, submitting completed pieces of work, breaking down long assignments into small, meaningful chunks of information, and maintaining their personal possessions (Packer, 1995).

Students with Tourette's also experience difficulties with fine motor, dexterity, and visuomotor tasks. The most significant incidence of difficulty for students with Tourette's Syndrome manifests with the task of handwriting. Handwriting requires the stillness of an arm and proper motor speed in order to produce effective handwriting, and motor tics are often problematic for this particular area. Other tasks such as copying notes from the blackboard and manipulating various objects (i.e. scissors) also prove to be difficult for students due to their fine motor and visuomotor impairments (Packer, 1995).

The reading and writing abilities of students diagnosed with Tourette's Syndrome, in its purest form with no comorbid conditions, generally do not experience any significant reading comprehension impairments, aside from the occurrence of simple head or eye motor tics. Due to the rarity of pure Tourette's, it is therefore relatively unlikely students with pure Tourette's Syndrome will not encounter any reading and/or writing impairments. For students identified with an accompanying disorder such as ADHD and OCD, a reading comprehension deficit may be present but difficult to properly diagnose. Students with ADHD may experience impairments in reading as a result of their high rate of impulsivity, while students with OCD may experience impairments due to involuntary, unwanted thoughts or compulsive rituals. As stated above, students with Tourette's experience impairments with written tasks, such as handwriting, which involve fine motor, dexterity, and visuomotor skills. Writing frequently proves to be a continuing challenge for students (Packer, 1995).

Although students possess the ability to comprehend and understand mathematical concepts, impairments in mathematics tend to occur for students on an

individual basis. Some students may be able to construct mathematical calculations and computations mentally with ease, but experience difficulties when assigned to produce written work. Other students may also experience difficulties in computing mental mathematics as they become distracted by motor and/or phonic tics (Packer, 1995).

Due to the nature of symptoms manifested with Tourette's Syndrome, a high percentage of individuals experience social repercussions. As indicated in Shady, Fulton and Champion's (2005) study of 210 individuals diagnosed with Tourette's Syndrome, 68% reported experiencing feelings of ostracization and social embarrassment during the course of their lives. For students with Tourette's Syndrome, the school and its accompanying social environment can be a disparaging and stressful event. In Zhu et al.'s (2006) study examining 69 students with Tourette's Syndrome compared against a control group of 69 students who were Tourette's Syndrome free, results indicated that student's with Tourette's Syndrome experienced increased levels of emotional, and behavioral difficulties, and significantly decreased levels of social competence.

According to Zhu et al., (2006):

With their tic symptoms often drawing attentions from parents, teachers and other school children, [Tourette's Syndrome] children were often ridiculed and rebuked both in the family and at school. Initially, [Tourette's Syndrome] children may be rebuked in the family because parents may think that tics were a habit disturbance and failed to understand that it is an illness. In school, when teachers

failed to understand the disease, symptoms such as vocalization, action and coprolomania may be regarded as intentional violation of school discipline and

the children may be criticized in class. Other school children may ridicule their tic symptoms and they may feel lonely and bullied. (p. 69)

Unfortunately, the social repercussions students face throughout their academic years do not subside as they progress into adulthood. An adult with Tourette's Syndrome is more apt to experience negative social experiences and outcomes with friends and relationships. Fifty percent of adults with Tourette's Syndrome

have reported experiencing difficulties initiating and maintaining romantic relationships (Marcks et al., 2007).

Family Functioning

Just as any chronic disease can be stressful and upset the family and their surrounding environment, having a family member with Tourette's Syndrome contains the likelihood for similar feelings. When a child is diagnosed with Tourette's Syndrome, it is quite possible the syndrome will affect the family as a whole, most specifically the parents. In Hubka, Fulton, Shady, Chamption and Wand's (1988) study examining Tourette's Syndrome within the family, 58% of respondents indicated that the condition interfered to some degree with their daily lives.

It is important to draw attention to the parents of children with Tourette's Syndrome, since it is not only the children who are negatively affected by this condition. Just as individuals who are diagnosed with Tourette's find their syndrome to be socially disabling and stigmatizing often carrying negative societal perceptions, parents also experience similar feelings to their child. Minimal research has been conducted on the area of parental burden, but a few studies have discovered the devastating effects their child's condition has on their emotional, mental, and physical well being.

Caregiver burden can be "defined as the adverse consequences of a patient's illness for his or her caregiver" (Cooper, Robertson, & Livingston, 2003, p. 1370). According to Cooper et al.'s study examining psychological morbidity in parents with children with Tourette's Syndrome, they discovered parents were at an increased risk of being psychologically ill and experiencing greater amounts of burden in relationships, overall well-being, and activities. Mothers demonstrated greater amounts of psychiatric morbidity than fathers due to the hypothesis that mothers were at an increased risk as a result of experiencing and carrying a greater portion of caregiver burden. Parents may also experience the fear of reproduction, since research has indicated the role of genetics may play an integral role in transmission (Hubka et al., 1988; APA, 2000). Furthermore, parents often reported difficulties distinguishing between what their child's personality is and how much their Tourette's Syndrome consumes their personality (Hubka et al., 1988).

Siblings are also affected by the impact of having a kin with Tourette's Syndrome. As a result, they may experience feelings of guilt due to the fact they are healthy and their sibling is not. On the opposite spectrum, they may also feel a sense of overbearing responsibility to assist their kin affected by the syndrome. In varying situations, they may also experience negative feelings towards protecting the sibling in social situations (Hubka et al., 1988).

Prevention and Intervention

The majority of individuals are not aware of various prevention and intervention strategies that are available to treat Tourette's Syndrome. This is often due to the negative societal views, common misunderstanding, and relatively low incidence rates. It is crucial that interventions are initiated and implemented as soon as possible in order to entirely benefit the individual with Tourette's Syndrome. The Tourette Syndrome Foundation of Canada (2007) stated that it is important to provide treatment for those inflicted with Tourette's Syndrome as early as possible, as symptoms may materialize to be disruptive or frightening.

The symptoms displayed by individuals with Tourette's Syndrome contain the potential to cause ridicule and rejection by peers, teachers, and the general public. Parents with a child living with Tourette's Syndrome may be overwhelmed by the peculiar symptoms displayed. As an unfortunate result, the child may be threatened or excluded from various social activities and prevented from pursuing and maintaining regular interpersonal relationships. This is apparent during adolescence, a period of time which proves to be an especially difficult period for youth and even more trying for an adolescent dealing with a neurobiological impairment. Therefore, it is highly recommended to seek early treatment and diagnosis in order to prevent any psychological harm (Tourette Syndrome Foundation of Canada, 2007).

Interventions *need* to be included in educational settings. This area is necessary to explore as general educators, special educators, and speech-language pathologists are generally unaware of Tourette's Syndrome and its accompanying symptoms, effects on academics, and necessary adaptations (Legg, Temlett, & Sonnenberg, 2005).

Interventions should also continue out of the academic setting as well in order to best

serve the individual. The following list of subtopics will outline the various protective factors identified as beneficial for individuals with Tourette's Syndrome.

Academics

Since 50% of students with Tourette's Syndrome will encounter academic impairments (Burd, 2007), it is imperative these students receive the necessary educational supports and adaptations. Educational adaptations will vary from student to student, ranging from minor adaptations to more major accommodations depending on the severity of Tourette's Syndrome's. For approximately 60% of students, marked educational impairments are likely to occur between the ages of 8 to 13 years, where tic severity reaches its peak (Burd). Fortunately, following this period the difficulties gradually decrease. In order to ensure students with Tourette's Syndrome receive the most successful and positive school experiences possible, it is imperative that the general educator works with the student, parents, and other professional to achieve this standard.

Educational accommodations should be the initial strategy utilized to assist the student with Tourette's in the regular classroom. Educational accommodations are strategies which are implemented inside of the classroom in order to provide students with a disability to overcome difficulties and receive regular classroom instruction (Packer, 2005). The most beneficial accommodation that teachers and students can accomplish is to simply ignore the tics when they occur, allowing the student to feel comfortable, relaxed, and similar to their surrounding peers. However, even if the entire class has learned to successfully ignore tics when they occur, the student with Tourette's Syndrome may feel obligated to attempt to suppress tics as a result of being self-conscious or causing classroom disruption. It is possible for students to attempt to suppress tics and they can be successful for a varying amount of time. Nonetheless, temporarily suppressing a tic requires great amounts of mental and physical energy which often results in loss of academic concentration and great distractibility. Therefore, teachers should not be encouraged to ask students to suppress tics due to the loss of academic concentration ultimately causing school work to be negatively affected. In

addition, there is the likelihood that the tics will eventually transpire but display themselves in more explosive forms (Packer, 1998).

If establishing a stress free atmosphere is achieved, the severity and frequency of tics will decrease (Burd, 2007). When a student's tics become frequent and severe, teachers need to provide students a safe room. This accommodation provides the student with an opportunity to exit the room and enter a more personal area where the student can release bouts of tics that may cause personal embarrassment or classroom disruption. Preferential seating would assure an easy, accessible, and relatively discreet exit from the classroom (Packer, 2005).

Research has shown mixed results regarding the effectiveness of peer education, but there is evidence that peer education may be beneficial for the student with Tourette's, the classmates, and the teacher (Packer, 2005). Woods and Marcks (2005) study on the effectiveness of peer education concluded that brief amounts of educating peers about Tourette's does improve attitudes and acceptance towards individuals with Tourette's Syndrome. However, no study to date is able to provide objective data concluding the true advantage of peer education intervention (Connors & Kepley, 2007). Regardless, the decision to implement a peer education program should be thoroughly and openly discussed with the student, parents, and the teacher prior to the program being conducted. If the idea of implementing a peer education program receives acceptance, then it should be conducted.

Since students with Tourette's Syndrome may experience impairments in their organizational, fine motor, and visuomotor domains, general academic strategies are available to assist students to overcome challenges in these areas. Strategies such as providing the student with a scribe during large amounts of writing, the use of a computer to complete assignments as opposed to handwriting, and granting the student extra time to complete assignments and examinations will all prove to be effective (Packer, 2005). These minor adaptations reduce the amount of stress students may experience during the academic setting which ultimately assist in the reduction of tics (Burd, 2007).

Due to the complex nature of Tourette's Syndrome, it can be challenging for educators and classmates to contend with the student with Tourette's. However, the most beneficial academic intervention strategy which can be implemented is developing a

sensitive understanding and knowledge base about the syndrome (Burd). Due to the substantial amount of time students spend in an academic setting, it is thus imperative that accommodations such as ignoring tics, creating a stress free environment, peer education, and general instructional and learning strategies are implemented in order to allow the student with Tourette's Syndrome to achieve success. However, if such academic accommodations are proving to be relatively unsuccessful, the need for pharmacological management and behavioral training may prove to be a beneficial and necessary treatment addition.

Pharmacological Management

Currently, there are several medication options for treating symptoms of Tourette's Syndrome, although there is no cure to completely resolve the disorder. Drugs are used as a means of tic reduction in order to improve the domains of academics, psychosocial, and overall positive family functioning (Zinner, 2004). The most common medication(s) prescribed to treat individuals with Tourette's Syndrome include clonidine, risperidone, and haloperidol.

Clonidine should be the initial drug treatment of choice due to the fact it appears to have the least risk of side effects. Studies have indicated that approximately 25% of patients respond satisfactorily to clonidine treatment (Kerbeshian, 2007). The additional benefit to the use of clonidine is the apparent reduction of ADHD hyperactivity characteristics. However, although treatment with clonidine appears promising, it is not the most effective treatment option for Tourette's Syndrome.

Antipsychotic medication has been demonstrated to be the most effective pharmacological treatment for tic reduction in Tourette's Syndrome (Kerbeshian, 2007). Although Tourette's Syndrome is not considered a psychotic disorder, researchers have discovered that in small doses, antipsychotic medication is an effective means to treat movement disorders. Antipsychotic medications are relatively strong drugs, and therefore will not likely be prescribed unless tics are in the moderate to severe category.

Risperidone and haloperidol are two of the most commonly prescribed neuroleptic medications. Risperidone's success rate in treating Tourette's Syndrome varies from 21-61%, while haloperidol is believed to be the most effective drug treatment currently available (Kerbeshian, 2007). However, although both of these drugs appear to be

extremely effective in treating moderate to severe tics, due to their powerful natures they contain the possibility for adverse side effects. Detrimental side effects include tiredness, depression, weight gain and irritability (Kereshian, 2007).

When deciding to pursue pharmacological treatment, individuals must consider treatment of the comorbid conditions. Due to the high prevalence rate of ADHD and OCD, the effects of medications play a relatively large role in the impact on comorbid conditions. In previous years, there was concern over the use of stimulant medication, as it appeared to exacerbate tics. However, in current research this issue is up for debate. For some children, taking stimulant medication appears to have no direct effect on the increase of tic production, while for others, they report a noticeable increase in tic production and the appearance of new tics as well. The recommended practice is to try the stimulant medication and evaluate its effects, as they should be present and obvious within a week of treatment. If tic exacerbation is evident, treatment should be stopped immediately.

Before deciding to use medications as a form of treatment for Tourette's Syndrome Gilbert (2006) discusses five key points that need to be considered:

1. Majority of children generally do not require medication for their tics;
2. Physicians need to have realistic expectations of the overall effects of medication;
3. Initially prescribe milder medications before stronger medications;
4. Medication used during childhood does not appear to affect adult outcomes;
5. Develop an ultimate goal of providing the child with the necessary support and encouragement to develop into a resilient individual.

By following Gilbert's recommended considerations, the appropriateness of pharmacological treatment can be determined.

Behavioral Training

Various forms of behavioral treatment options for managing Tourette's Syndrome have been introduced and practiced as a method of treatment for the syndrome.

However, the effectiveness of behavioral treatment has shown mixed results.

Researchers have experienced difficulties in evaluating the effectiveness of the various behavioral treatment methods due to small sample size, the effects of comorbid conditions, the natural waxing and waning of tics, and the lack of longitudinal studies

(Cohen, Findley, King, & Scahill, 1999). The most common forms of psychosocial and behavioral treatment therapies include massed practice, contingency management, self-monitoring, relaxation therapy, and habit-reversal training.

Massed practice training involves the patient deliberately performing a single tic repetitively for a specified time, generally fifteen to twenty minutes with a two minute rest period. Initial results concluded that massed practice was a semi-effective treatment with more than half of patients reporting a decrease in tics (Cohen et al., 1999). However, long term studies have indicated that massed practice actually increases tic production and severity, and is therefore currently not a recommended treatment practice.

Contingency management involves the use of operant conditioning in the form of reward and punishment. During treatment, patients are rewarded for suppressing a tic for a designated amount of time, and punished for not suppressing a tic for a designated amount of time. The theory of contingency management involved the premise that if a behavior was reinforced, it would be maintained; when a behavior was punished, it would be suppressed. Although the goal was to ultimately condition patients, results have been inconclusive regarding the effectiveness of treatment. (Cohen et al.). In addition to the effectiveness of treatment, the notion of ethics is also of concern, specifically when children are involved.

Self-monitoring involves the patient observing and recording the type and occurrence of tics over a specific time frame. The goal of self-monitoring is to provide the patient with a log of tic occurrence and draw conclusions of how frequently and when tics were likely to occur. The effectiveness of self-monitoring is believed to be the most effective when used in conjunction with an additional treatment option, such as habit reversal training (Peterson, 2007).

Stress and anxiety are known to cause an increase in the severity and the occurrence of tics. Therefore, stress free environments and situations are ideal. In order to reduce the risk of stress and anxiety, the practice of relaxation training has been proven a temporary effective treatment method (Peterson, 2007). In relaxation training, patients are taught by a trained therapist the proper steps to engage in a state of relaxation. Once the therapist is convinced the patient has successfully achieved the proper understanding

and procedural steps, the patient is then encouraged and expected to use the relaxation training independently as required.

Habit reversal training is the most common and researched behavioral treatment method to date to treat Tourette's Syndrome. Habit reversal training is a comprehensive treatment method which consists of five components: awareness training (consists of 5 additional components), relaxation therapy, competing response, contingency management, and generalization. In awareness training, 5 additional components exist: response description, response detection, early warning, self-monitoring and situation awareness. Response description's purpose is for the individual to note and describe each tic that they produce. The assistance from a therapist is usually recommended. In response detection, both the patient and the therapist note the occurrence of each tic. Early warning is a procedure where the patient pays close attention to early symptoms and warning signs prior to a tic occurring independently. The use of pre-monitory urges during this stage is also effective. In the stage of self-monitoring, the patient keeps a daily log to mark the type and occurrence of tic occurrences. The final step in awareness training involves situation awareness, in which the patient identifies external cues which cause an increase or decrease in tics. The second component of habit reversal training is relaxation therapy. Patients are taught general relaxation training as a procedure to reduce areas of muscular tension and tic frequency and severity. A recommended 3-4 training sessions with a trained therapist is ideal, with daily practice treatments.

The goal of competing response therapy is to "identify a competing behavior or response that, when performed, will prevent the tic from occurring" (Peterson, 2007, p. 171). The general technique for competing response when dealing with motor tics is to involve the isometric contraction or tensing of the opposite muscle groups that are involved in the identified motor tic (i.e. shoulder shrug – strengthen the muscles in a downwards contraction to counteract the upwards tic movement). When using competing response, tics that are the most frequent and distracting should be treated first.

The fourth component involves contingency management. Unlike the previously used contingency management treatment which focused on reward and punishment, contingency management in this behavioral method focuses on outside individuals encouraging the patient to use competing response. Contingency management is

especially effective for children, who often need to be reminded and encouraged to use competing response. The final stage of habit reversal training is generalization. The ultimate goal of generalization is to provide the patient with encouragement and motivation to continually use and practice all the techniques involved in habit reversal training in public settings. By achieving this goal, patients will hopefully possess the ability to create social approval from others.

The overall effectiveness of habit reversal training appears to significantly cause a reduction in tics, but research is still relatively inconclusive regarding its long term effectiveness (Peterson, 2007). The APA has created guidelines regarding the effectiveness of psychosocial treatment, and classifies treatments as either *well-established* or *probably efficacious*. Based on the various studies and research conducted on the effectiveness of habit reversal training, the APA (2000) stated habit reversal training as *probably efficacious*. Nonetheless, habit reversal training should be considered an option as a treatment for Tourette's Syndrome.

Lifestyle

Individuals living with Tourette's Syndrome should attempt to engage in the most productive and normal lifestyle as possible. Social interaction, participation in extracurricular activities, regular doctor appointments, and a healthy lifestyle are the recommended practices for individuals with Tourette's Syndrome (Swain et al., 2007). Since stress and anxiety have shown to exacerbate the frequency and severity of tics, individuals should be placed in environments which contain minimal stress and anxiety (Swain et al, 2007). Currently, no particular diet exists which will ameliorate tics. However, a decrease in caffeinate beverages may prove beneficial due to caffeinate acting as a stimulant, which has been linked to an increase in frequency in tics (Peterson, 2007).

One can consider age itself as a possible intervention method. The frequency and severity of tics appears to be the greatest during early adolescence, between the ages of 8 and 12 years (Bloch et al., 2006), research has indicated that the gradual delineation of tic frequency and severity begins to occur during early adulthood (APA, 2000). Epidemiologic data has indicated a lower prevalence rate occurs among adults as compared to children (Bloch et al., 2006). Findings have indicated that phonic tics

become quite rare or may even disappear altogether as the individual ages. In a majority of cases, longitudinal studies have reported tics can persist into adulthood, but with tics significantly decreasing in frequency and severity. In less than 20% of cases, however, severe and persistent tics may continue through adulthood with the possibility of developing into worse symptoms (Bloch et al.).

As previously indicated, parents are at an increased risk of psychological impairments when caring for a child with Tourette's Syndrome. In order to decrease the caregiver burden, parental training and support groups are essential (Cooper et al., 2003). Support groups provide parents with opportunities to express any emotional feelings that occur with having a child with Tourette's Syndrome. Parents should be encouraged to express their feelings in order to release buried feelings. Parental training offers parents suggestions on behavior modification to reduce parent stress. Support groups can offer parents a place of comfort, empathy, understanding, and serve as a crutch during especially difficult times.

Summary

Tourette's Syndrome is a multifaceted and chronic neuropsychiatric developmental disorder which is characterized by simple and complex motor and phonic tics (APA, 2000). As a result of the occurring tics, individuals often experience feelings of social ostracization. Although individuals with Tourette's Syndrome are already plagued with a challenging disorder, substantial research has indicated an accompanying comorbid condition, such as ADHD and OCD, is highly probable (Robertson, 2006). Furthermore, it is considered rare for an individual to experience Tourette's Syndrome in its purest, singular form (Freeman et al., 2000). As a result of comorbid conditions, individuals living with Tourette's Syndrome encounter numerous social emotional, behavioural, and academic difficulties throughout the course of their lives (Bawden et al., 1998; Leckman, Bloch, Scahill & King, 2006; Schapiro, 2002). In order to assist individuals with Tourette's Syndrome to lead happy, successful, and fulfilling lives, it is crucial that interventions such as academic interventions, pharmacological management, and behavioral training strategies are implemented that are best suited to the individual (Olson, Singer, Goodman & Maria, 2006). Interventions not only have a fundamental role of providing accommodations and assistance to individuals with Tourette's

Syndrome, but interventions also play a vital role in the modification of society's misconceptualized understanding of Tourette's Syndrome. In order for a more positive and accurate understanding of the disorder, the promotion of awareness and understanding needs to continually occur.

In conclusion, a considerable amount of literature exists surrounding the neurophysiological etiology and the emotional, social, and academic implications as a result of Tourette's Syndrome. However, minimal research has been conducted focusing from a lived experience perspective. Therefore, there is a need for research that explores the stories of individuals diagnosed and living with Tourette's Syndrome in order to develop an understanding of what they confront on a daily basis throughout the course of their lives. This in turn will provide key information in efforts to dispel a syndrome that is highly misunderstood and negatively conceptualized by our present society. By conducting this type of research, it will ultimately make a unique and valuable contribution to understanding a life lived with Tourette's Syndrome.

CHAPTER THREE: RESEARCH METHODOLOGY AND DESIGN

Introduction

The purpose of this study was to develop an awareness, understanding, and knowledge base on the personal experiences of individuals with Tourette's Syndrome, and how living with the disease has affected their daily lives. In order for the participants lived experiences to be understood, it was essential to apply a qualitative narrative research approach which would ultimately allow for an in- depth and personal exploration of the participant's lived experiences with Tourette's Syndrome. Presented in this chapter is a synopsis of the qualitative narrative research methodology, participant recruitment and selection practices and procedures, and the data methods that were utilized to gather, interpret, and analyze the resulting information. Due to the societal stigma, social ostracization, and low prevalence rate of Tourette's Syndrome in Saskatchewan, ethical considerations and limitations of the study will be discussed throughout the chapter.

Narrative: An Apposite Qualitative Paradigm

The use of qualitative research as an exploration methodology has continually grown and expanded in use and popularity over recent years. Derived from a social science theoretical model, qualitative research declares to illustrate lives from the inside out (Flick, von Kardorff, & Steinke, 2000, 2004). Qualitative research "makes use of the unusual or the deviant and unexpected as a source of insight and a mirror whose reflection makes the known perceptible in the unknown" (Flick et al., 2000, 2004, p. 3). It is truly difficult for researchers to entirely agree on a single definition to explicate qualitative research. However, Denzin and Lincoln (1998) appear to capture the true essence of qualitative research by stating it is:

Multimethod in focus, involving an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. Qualitative research involves the studies use and collection of a variety of empirical materials – case study, personal experience, introspective, life story, interview, observational, historical,

interactional, and visual texts – that describe routine and problematic moments and meaning in individuals' lives. (p. 3)

The use of a qualitative research design will be most effective as the research question fits the fundamental goals of qualitative research; describing lived experiences from the inner to the outside worlds. Qualitative research is not limited to a small minority of methodological practices, but rather contains a vast and broad spectrum of methods and procedures (von Kardorff, 2000, 2004).

Narratives contain the unique and valuable opportunity for researchers to delve in the stories people live and share. Their stories are simultaneously influenced by their social, environmental, inner, and historical experiences and realms (Clandinin & Connelly, 2000). Narratives are stories, lived and told, that contain the ability to educate, inspire, and transform the self and others (Clandinin & Connelly, 2000). A myriad of definitions exists in qualitative literature describing narratives, therefore no single or simple definition exists. Throughout all narrative definitions, however, the core element of storied, personal lived experiences is prominent. Daynes and Pinnegar (2007) state it most effectively by capturing all essential elements fundamental to narrative by articulating:

Narrative inquiry embraces narrative as both the method and phenomena of study. Through the attention to methods for analyzing and understanding stories lived and told, it can be connected and placed under the label of qualitative research methodology. Narrative inquiry begins in experience as lived and told stories. (p. 5)

In addition to Daynes and Pinnegar's explanation of narrative, the discussion of the joint process of reconstructing narratives through the researcher and participant is also an important element in narrative worth noting. A narrated experience is a fitting vehicle for sharing one's personal experiences with others in the conjoined form of a result and a process. Therefore, the researcher and participant can ultimately reconstruct the experiences and collaboratively seek to understand and interpret (Fischer-Rosenthal & Rosenthal, 2000, 2004).

Underlying the basis of narrative research, Moen (2006) stated three principal claims exist. First, human beings contain the ability to arrange their life experiences into

a narrative format. Second, the stories that are expressed by the participant are ultimately shaped by his or her temporal experiences, values, the environment in which the stories are being described, and the addressee. Third, the use of multiple voices, specifically the researcher and participant, continually occurs throughout narratives.

Since childhood, individuals are accustomed to storytelling. As young children, we are constantly learning how to narrate our experiences into stories, varying between short and long versions. It is through our continual social interactions and existence that we contain the ability to create order of our stories and through narration retell our experiences. According to Clandinin and Connelly (1998), “people live stories, and in the telling of them reaffirm them, modify them, and create new one” (p. 155). It is through constant life experiences that our storytelling is an ever existing life long process. As Moen (2006) stated, “human experience is always narrated” (p. 5).

As individuals share their narration of experiences, it is an ever changing process revolving around the environment in which we are situated and the addressee of the story. As individuals age and grow in experience, their perspectives will undergo constant transformations. As a result, “human knowledge and personal identities are therefore continually constructed and revised” (Moen, 2006, p. 5).

When data has been collected from various methodological practices, it is the researcher’s responsibility to create and shape the resulting data into a narrative form. When this occurs, the researcher’s voice is heard through the text. However, voice should not be considered singular, but rather multi-voiced as it is the participant’s and researcher’s voice together that definitively creates the narratives. The resulting narratives are a combination of conjoined voices, as the participant and the researcher shape the stories through their own experiences, knowledge, values, beliefs, and feelings (Moen, 2006).

Narrative: A Theoretical Foundation

Although there are numerous definitions that exist which capture the essence of what narrative seeks to reveal, the theoretical foundation needs to be examined. Prior to fully engaging in the narrative inquiry process, one must develop a theoretical understanding of narrative inquiry and analysis in order to help bring clarity to the research methodology. Bruner (1996) indicated that narratives are sequences of events

which convey meaning. Narratives are essentially derived from the basis of stories, which are shared by the participants involved in research studies. According to Bruner (1996), “a story, then, has two sides to it: a sequence of events, and an implied evaluation of the events recounted” (p. 121). By following this philosophy, a story is only the base of narrative, as narratives are constructed text of recounted stories. “You cannot explain a story; all you can do is give it variant interpretations” (Bruner, 1996, p. 122). Bruner (1996) further indicated that narratives follow a *hermeneutic circle*, as the stories produced by participants are therefore subject to interpretation, not explanation, by the researcher.

The hermeneutics approach is centrally focused on the issue of interpretation, as the definition is historically derived from the Greek word *hermeneuein*, denoting understanding and interpreting (Patton, 2002). According to Patton (2002):

Hermeneutic theory argues that one can only interpret the meaning of something from some perspective, a certain standpoint, a praxis, or a situational context, whether one is reporting on one’s own findings or reporting the perspectives of people being studied (and thus reporting their standpoint or perspective). (p. 115)

The influence of a hermeneutic approach is widely used throughout qualitative inquiry methods. In various research methods, hermeneutics is able to approach to interpret various written text formats, such as narratives. Hermeneutics are thus intertwined in narratives, as narrative methodology seeks to analysis and thus interpret the nature of the stories in order to transform them into narrative text. According to Patton (2002), “how to interpret stories, and more specifically, the texts that tell the stories, is at the heart of narrative analysis” (p. 118).

Ethical Considerations

Due to the use of human subjects in order to conduct research pertaining to the area of Tourette’s Syndrome, the utmost ethical and confidentiality considerations were utilized. In order to assure these considerations, an official application was sent to the University of Saskatchewan’s Behavioral Research Ethics Board. Once approval was made (i.e. Beh #08-158), all guidelines were strictly adhered to throughout the course of the study.

Informed Consent

The participants included in this study were all informed both verbally as well as through a written letter outlining the purpose and practices involved in the study. Participants were asked to sign a consent form indicating their understanding and approval of participating in the study.

Confidentiality

Ensuring participant confidentiality and anonymity was of regard and all attempts to secure any identifying information were conducted. Pseudonyms selected by participants and/or the researcher were utilized to conceal all personally identifying names and places. Participants were informed that all audio recordings, field notes, and transcriptions would be destroyed following a minimum of five years after the completion of the study, in accordance to the University of Saskatchewan regulations. In addition, participants were permitted access to all collected data for the purpose of verifying accuracy and omission of information.

Moreover, participants were asked to read over interview transcripts used in the final draft of the thesis. Once the material had been read and no material that the participants disagreed with was included in the final draft, the participants were requested to sign a transcript release form. This form indicated their consent to the accuracy and interpretations conducted.

Vulnerability

Since the subject matter *could* contain the tendency to be vulnerable during certain points of the study, the emotional domains of all participants were continually monitored. In the occurrence any concern pertaining to the participant during the interview process was witnessed, suitable services (i.e. professional support such as counseling) were made available. Due to the voluntary nature of the study, participants were made aware that their participation in the study could be withdrawn at any time.

Participant Recruitment and Selection Criteria

Prior to recruiting participants for the study, it was hypothesized that difficulties would be encountered recruiting and locating participants who would be willing to partake and contribute in the study. The low incidence of individuals with Tourette's Syndrome in the surrounding population of Saskatchewan, the negative social stigma

which exists in our society stigmatizing Tourette's Syndrome, and the delicate nature of the syndrome contained the potential to create a rather small sample selection.

Participants were recruited and selected through convenience sampling; a method of sampling utilized in order to correspond to the purpose of the study as well as provide a convenient geographic location (Borg et al., 2007). Although a more random sampling procedure is desirable, the convenience type of sampling procedure needs to be pursued in order for the study to occur. As Borg et al. (2007) stated, it is generally better to conduct a study using convenience sampling rather than not conducting the study at all.

The eligibility criteria for this study included any individual, between the ages of 8 to 30 years of age, who (a) were diagnosed with Tourette's Syndrome, (b) able to communicate orally in English, (c) willing to participate, and (d) reside in Saskatchewan, and (e) signed consent or in the event of a child participating, had parental permission/consent to participate in the study.

Advertisements describing the nature of the study were posted on various Saskatchewan websites concerning disabilities (i.e. Idas.org, University of Saskatchewan Disability Services for Students blog). By pursuing online advertisements it was hoped they would reach a larger population of participants who would positively respond. In addition to posting online advertisements, contact had been conducted with the Tourette's Syndrome Foundation of Canada. This foundation was willing to advertise descriptions of the study via their website to attract members in Saskatchewan in hopes that potential participants would be recruited.

As well as advertising the study in an effort to recruit participants, other methods for locating individuals with Tourette's Syndrome were also conducted. These included contacting the Tourette's Syndrome of Canada Saskatchewan Chapter located in Regina, Universities and post-secondary colleges in Saskatoon and Regina, Regina and Saskatoon public and catholic school systems, various psychiatric wards and psychiatric doctors. Although these attempts were made, they resulted in no additional participants.

The Narrative Gathering Process

Data Collection

A narrative inquiry approach was selected as a result of the research question being designed to investigate the storied experiences of the participants. In order to

gather as much detailed and in-depth information as possible, the use of interviews was employed as the primary data collection instrument in addition to field notes.

Interviews

The utilization of interviews as a method for collecting data was deemed to be the most suitable, as it is one of the most frequent and powerful communication methods used to delve into and understand experiences of individuals (Fontana & Frey, 2003). The interviews itself was semi-structured in its design, ranging from open ended discussions to directed prompting questions to facilitate further discussions. The semi-structured interview questions (see Appendix C) were reviewed for content by an external member who has had professional experiences working with individuals with Tourette's Syndrome. The partial use of unstructured interviewing contains the ability to provide a greater amount of depth of data as opposed to other types of interview designs, such as fully structured with direct questioning (Fontana & Frey, 2003). This interview format additionally provides the participant with an opportunity to share experiences in their own format, further allowing the researcher to probe deeply into varying topic initiated by the participant (Biklen & Bogdan, 2003). Thus, participants are able to share their personal stories from their own perspectives. However, due to the unstructured nature of the questioning, Borg et al. (2007) consider this format to be moderately subjective and time consuming, but also state that this format is best applied to situations in which the participant is responding to potentially sensitive material.

According to Hopf (2000, 2004), narrative interviews occur in four distinctive phases:

1. The invitation to narrate, which must be formulated in such a way that the conversation partners are not subject to too much spoon-feeding and, at the same time, are helped to mobilize their memories and to narrate freely;
2. The independently produced main narrative;
3. Narrative-generating enquiries; and
4. Interview conclusion. (p. 206)

Throughout the narrative interview, it is imperative that the participant produces their narrative independently. The researcher needs to adopt the role of an active listener and only contribute to the continuance of the narrative through indirect questioning and

supportive gestures (Hopf, 2000, 2004, p. 206). By establishing this format, it will increase the probability of the participant will continue to share in-depth narratives.

Interviews occurred in a setting on the University of Saskatchewan campus suggested by the researcher and agreed upon by the participant in order to assure the participant felt comfortable, safe and secure. However, if the participants disagreed to the suggested setting, the location of the setting selected by the participant needed to meet the following criteria: (a) a location which the participant feels safe, comfortable and secure, (b) the location must be quiet and free of distractions, and (c) the location must be accessible to the participant and researcher. By providing the participant the opportunity to select a location meeting the stated criteria, this environment will hopefully encourage the participant to become open and contain the willingness to share personal experiences. The interview length ranged from 60 to 90 minutes. The initial interviews began with the use of a relaxed conversation, in efforts to assure that the participant was comfortable and to lead to the development of a positive relational rapport. Participants were informed of the purpose of the interview as well as to confirm the confidentiality practices implemented and followed. Upon the first interview being conducted, it was deemed essential to conduct a final follow up interview with each participant order to assist in further clarification of experiences or topics requiring further discussion. Throughout all conducted interviews, all participants were constantly monitored for any adverse effects as a result of the previous or current interviews.

After each interview, time was allotted for reviewing the interview and producing detailed notes reflecting on the interview. By allocating a period of time following each interview to reflect, it provided a time to assure quality control in order to assure that the data collected will be valuable, reliable, and dependable in efforts to reduce subjectivity and maintain a state of neutrality (Patton, 2002). The use of a reflective time period provided an opportunity to express feelings, impressions, and ideas. Furthermore, the reflective notes provided an opportunity to investigate any possible bias or prejudice which would ultimately affect the data collection and analysis.

An audio recording device was utilized to capture all verbal data throughout the entire interview, as well as allowing for complete concentration on the participant's interview. Prior to the interview, participants were informed of the use of audio

recording technology and explained the purpose for the device. Following each interview, the resulting data was transcribed into written documentation. All important data related to the research question was transcribed. Data not pertaining directly to the research content (i.e. small talk), was not transcribed. All audio recordings and transcribed data are secured, adhering to the regulations by the University of Saskatchewan.

Field Notes

The use of descriptive field notes occurred throughout the interview process; prior, during, and following. The use of field notes added necessary descriptive elements which could not otherwise be captured through the use of audio recordings. The recorded field notes provided an opportunity to describe and provide “verbal portraits of the research participants, reconstruction of dialogue, description of the physical setting, accounts of particular events, and descriptions of the observer’s behavior” (Borg et al., 2007). Following Borg et al.’s statement, the field notes that were generated in this study served as an additional source of rich information allowing visual details to be captured and created in the resulting written narratives. As Silverman (2005) stated, field notes themselves can never contain the degree of reliability that quality tapes and transcripts produces, but rather can add and provide momentum to the advancement of data analysis.

Researcher-Participant Relationship

As a narrative researcher, one must acknowledge and understand the role one plays during the data collection and analyzing process and constantly be aware of the relationship occurring between them and the participant. The researcher-participant relationship is fundamental to the data collection and analyzing process. It is this relationship that essentially shapes the entire interview and narrative process as “what is told, as well as the meaning of what is told, is shaped by the relationship” (Clandinin & Connelly, 1998, p. 162).

It is crucial that the researcher first establish and gain the trust of their participant in order for the respondent to possess the willingness to share personal in-depth experiences. Once trust is gained it must be recognized that it is not permanent, but that the trust itself can be fragile (Fontana & Frey, 2003). The researcher is in a constant position of maintaining a positive and collegial relationship with the participant, and must always gauge the effects the conducted interviews has on the overall researcher participant

relationship. Just as it is imperative that researchers establish a positive, safe, and trusting relationship between them and the participant, this is also true of establishing a positive rapport. The paramount goal of unstructured interviewing is to establish understanding, and therefore “the researcher must be able to take the role of the respondents and attempt to see the situation from their viewpoint” (Fontana & Frey, 2003, p. 78). The stronger the relationship, the more willing the participant will be in divulging and providing a wealth of pertinent information. The establishment of a secure rapport however, walks a thin line; developing too close of a relationship with the participant can cause the researcher to lose his or her objectivity, while developing a distant, unattentive, and unempathetic relationship contains the possibility that the participant may be reluctant to divulge a wealth of personal and potentially valuable personal information which may be key to the study.

Researcher’s Role – The Internal Voice

In qualitative data, the role of the researcher is complex due to the understanding the researcher is considered the primary measurement instrument (Patton, 2002). The researcher is responsible for concurrent data collection, interpretation, and analysis. Thus, the issue of credibility and trustworthiness is the heavily relied upon the researcher. In narrative data analysis however, the matter of the degree of the researcher’s voice can be of some concern.

As a researcher composes field data into written text, the notion of the inner voice must be acknowledged. It is the researcher’s sense of voice that allows for the generation of interest to captivate an audience. Adopting Moen’s (2006) views on voice, it is important to recognize that voice must be considered in the pluralized form as the mutual voice of the participant and the researcher. However, as Clandinin and Connelly (1998) state, it is not an uncomplicated approach:

This struggle for research voice is captured by the analogy of living on a knife edge as one struggles to express one’s own voice in the midst of an inquiry designed to capture the participants’ experience and represent their voices, all the while attempting to create a research text that will speak to, and reflect upon, the audience’s voices. (p. 172)

Consequently, the researcher needs to be constantly aware of representing the voice of the participant while simultaneously capturing their own personal voice as they construct the written narrative. By being aware of this matter, the degree of credibility and trustworthiness thus increases.

Evaluating Narrative Research: A Paradigm Debate

Throughout history, qualitative research has constantly been scrutinized regarding its subjectivity, authenticity, and rigor. This controversy is rooted in the long standing scientific debate regarding the most effective methods utilized to study and understand the world. The debate is stemmed in the philosophical discrepancies pertaining to the apparent nature of reality on what precisely composes knowledge and its creation (Patton, 2002). Consequently, qualitative researchers must be able to justify and defend the significance of their methodological approach and findings. By being able to verify that objectivity, bias, authenticity, and rigor were constantly being evaluated throughout the study, the value of qualitative research will then justly be recognized and understood by external sources.

Due to the interpreted nature of narratives and the close relational distance with participants, the issue of subjectivity is of constant concern. Critics have constantly considered the area of qualitative research being too subjective due to the fact that the researcher is considered the primary instrument used to collect and interpret data (Patton, 2002). A researcher's main priority is to remain objective, and in order for this to be achieved, researchers must consistently confront and evaluate their personal opinions and prejudices (Biklen & Bogdan, 2003). The issue then, is for the researcher to achieve a state of *neutrality* regarding the phenomenon being studied (Patton, 2002). According to Patton (2002):

The neutral investigator enters the research arena with no ax to grind, no theory to prove...and no predetermined results to support. Rather, the investigator's commitment is to understand the world as it unfolds, be true to complexities and multiple perspectives as they emerge, and be balanced in reporting both confirmatory and disconfirming evidence with regard to any conclusions offered.
(p. 51)

One strategy used to attain neutrality is for the researcher to utilize reflective field notes. Reflective field notes provide the researcher with an opportunity to reflect upon any subjectivity which may occur in the research. External members, such as supervisors and committee members, can also assist the possibility of bias by reviewing the recorded reflective field notes. This in turn, will support the researcher in maintaining a neutral stance.

Patton (2002) argued that the issues of subjectivity and objectivity are so consumed with negative connotations that there needs to be a movement towards terms such as *trustworthiness* and *authenticity*. In order for the study to remain objective while pursuing trustworthiness and authenticity, qualitative researchers must make continual efforts to place emphasis on being conscientious throughout the study. This can be achieved through employing balance and fairness, by taking into account multiple perspectives and realities (Patton, 2002).

In order to reduce the occurrence of bias and enhance the credibility, trustworthiness, and authenticity of qualitative research, a triangulation approach contains the potential to assist in the validation of qualitative research data and analysis. The primary purpose of triangulation is to test for consistency within the results, which will then lead to the understanding of possible inconsistencies. One should not view a decline in the credibility of results, rather view it as inviting opportunities to search for deeper insights between the narrative inquiry approach and the occurrence being studied (Patton, 2002).

Borg et al. (2007) offered various types of pursuing triangulation through the use of data sources, analysts, and perspectives. Data source triangulation offers to evaluate data authenticity and consistency through utilizing a variety of qualitative methods. In addition to verifying consistency, data source triangulation can also be utilized to “illuminate various aspects of a phenomenon” (Patton, 2002, p. 560). Data analysis triangulation involves the application of multiple external sources individually examine the resulting data and compare their findings. The use of multiple sources provides an evaluation of the effectiveness of data findings and interpretations. An additional approach to triangulation concerns the research participants reviewing the conclusions of

the study. Through using this approach, researchers are able to learn a great deal regarding the truthfulness, fairness, and authenticity of the data analysis and conclusions.

Triangulation was utilized throughout the study as a means of reducing researcher bias and enhancing the credibility of the resulting data. The study employed triangulation in the following manners; interviews and field notes as varying data sources, external reviews to assure for data effectiveness, and the participants perspectives to increase authenticity. Triangulation's primary purpose is to strengthen the credibility and quality of the research study while simultaneously defying the possibility of bias. Thus, it is essential to the qualitative research design for triangulation to be implemented throughout.

Narrative Data Analysis

As a narrative research inquirer, one must spend countless hours reading and re-reading transcribed interviews and documented field notes in order to possess the ability to produce a synoptic account of textual data (Clandinin & Connelly, 2000). In the present study, the two main data collection methods utilized were interviews and field notes. Adopting Clandinin and Connelly's (2000) narrative analytic framework, the resulting data from these two methods were analyzed by identifying: characters; places and actions where events transpired; interwoven and connected storylines; and noticeable gaps, silences and tensions. In addition, general common patterns, narrative themes, and threads were also analyzed and identified, as this is "the heart and soul of whole text analysis" (Ryan & Bernard, 2000, p. 780).

The purpose of adopting a method of analysis is to compel the researcher to make decisions regarding the interpretation and meaning making from textual data. It is important to recognize that this specific type of data analysis does not occur in a series of steps, but rather that it is continual and negotiated with constant revisions made throughout the process. The analysis that occurred in the present study resulted from careful transcription of the recorded interviews. Once the transcriptions were completed, meticulous review of the transcripts was conducted. This process included searching for constructing meaning and discovering relationships and patterns in the data. This method occurred for each narrative independently as well as jointly in efforts to search and identify commonalities shared and differences which occurred between all participants.

As Riessman (1993) explained, “close and repeated listening, coupled with methodic transcribing, often leads to insights that in turn shape how we choose to represent an interview narrative in our texts” (p. 60). Following Riessman’s philosophy, narratives were composed.

With the final construction of the narratives, participants were encouraged to read through their narratives in efforts to refine or edit any element of the narrative analysis they felt needed further adjustment. This in turn provided the participants with an opportunity to offer their personal perspectives on the accuracy of their resulting narrative. As Moen (2006) explained, “creating a narrative implies a process whereby an accurate story that occurs in collaboration between the researcher and the research subject” (p. 6). As a result of this process, the narrative is one that “organizes human experiences into meaningful episodes. The ‘raw material’ for the narratives comes from intermental life experiences and intermental images that are not accessible to direct observation” (Moen, 2006, p. 6). Thus, the individual stories that have transpired in written text are the direct creation of narratives.

CHAPTER FOUR: RESULTS

Overview

Society has been ill informed with the belief that Tourette's Syndrome is the involuntary shouting, blurting, and yelling of obscene language and gestures (Schapiro, 2002). However, only 10% or less of Tourette's Syndrome cases report coprolalia and copropraxia (Freeman et al., 2000). In efforts to dispel this belief, it is imperative that valuable and accurate information is made available to society. Although a very minute percentage of individuals may experience the drastic coprolalia and copropraxia, the remaining individuals who have Tourette's Syndrome still experience numerous challenges, frustrations and difficulties throughout the course of their lives that must not be forgotten nor neglected. Tourette's Syndrome in itself requires a more thorough and accurate understanding. Those that are faced with living with this syndrome must be understood as well. In order for society to comprehend the daily and lifelong experiences individuals with Tourette's Syndrome encounter, they must be able to access information as described through the perspective of an individual living with Tourette's. The narratives will provide a sense of awareness, understanding and empathy for those individuals who live their lives with Tourette's.

This chapter will present the stories of three individuals who are living with Tourette's Syndrome – Brad, Hannah and Kyle (pseudonyms). Each of these individuals has experienced a variety of similar and diverse events living with Tourette's Syndrome. The following will reveal each of their stories of experiences, as they reflect and progress throughout the course of their lives living with Tourette's Syndrome.

Brad

Brad is a twenty four year old male University student. He is a committed student who not only focuses on his post secondary education, but is also a proud member of the University's athletic team. Preparing to convocate from his college in the spring, Brad is currently dedicated to pursuing a career and beginning a new phase of life. In addition to his academic involvement, Brad also devotes a large percentage of his time actively training and competing in athletic events as part of the University athletic team.

Brad was recruited for this study due to his diagnosis of Tourette's Syndrome, which transpired at an early age. His recruiting occurred through a method of snowball

sampling; a sampling procedure where subjects recruit future subjects through their personal acquaintances (Borg et al., 2007). When approached to participate in this study, Brad was eager and pleased to be part of this research and graciously provided his story and time to assist in sharing his life experiences with Tourette's Syndrome. Brad was able to openly and freely share his life experiences with Tourette's through two separate interviews. These interviews took place on the University campus, an area which Brad was familiar and comfortable with.

As Brad enters the interview, it becomes immediately observable that his personality is engaging. His sociable and welcoming temperament sets the relaxed and carefree atmosphere as the conversations ensue. Intelligent, charismatic and a career driven adult, Brad's sense of humour and enthusiasm engulfs the environment and ultimately shapes each conversation that occurs by setting a light tone. As he reflects upon his life experiences with Tourette's Syndrome, it is apparent he has embraced his syndrome with a sense of acceptance and understanding. He has not let his Tourette's triumph. He is not reserved to talk about his experiences, both the positive and the negative, but rather pleased to have the opportunity to share his personal experiences living with Tourette's in efforts to help others understand and relate to him.

Brad's history of Tourette's Syndrome initially began during his early elementary school years. For young children, kindergarten acts as a step towards their development. It is in this stage, where young minds are shaped and created, and personalities are developed and enhanced (King & Boardman, 2006). For Brad, kindergarten was a place for him to explore and expand his emerging self. Like all typical young children, kindergarten serves as a place to the development of character. However, for Brad kindergarten not only served as a place for development, but also as a point in his life where his unusual actions and mannerisms characteristic of Tourette's, began to materialize and become noticeable. It was during this time where Brad's parents first began to notice unique characteristics and behaviours emerging. He had an obsession touching silky objects, moving and shaking his head, and producing verbal noises. Assuming these behaviours would cease, Brad and his parents continued on with life. These distinctive actions continued and progressed through Brad's early elementary school years.

I can remember in grade one or two the teacher would come around and I used to shake my head around; my head tics, and she would hold my head in place, try to stop me and always correct me and say 'no, you don't do that', kind of like it was a bad habit or something. I remember doing that, so all the time I was trying to keep still the whole time. I remember getting mad at the teacher going like 'Oh I can't stop'. I was confused. I'd say probably mostly confused at why she is stopping me, like it isn't helping me. I knew that of course right?

At such a young age, Brad was aware of the motor symptoms which were occurring and internally knew that they were uncontrollable, yet was not able to explain how or why they were taking place. In addition, he also felt he was not able to truly express to others the degree of how uncontrollable the occurring tics were.

With his actions continuing and progressing, Brad and his parents began to realize there was much more to these behaviours than they were able to fully understand and explain. Searching for answers, Brad's parents sought help from a special education specialist located at his elementary school. After performing psychological testing, no intellectual deficits were found. The educational specialist was not able to understand what was transpiring, nor had any knowledge about the specific symptoms either and thus recommended that Brad see a doctor in a larger city.

It was not until grade two, however, that an official diagnosis of Tourette's Syndrome occurred. Brad recalls that after meeting the new doctor in the city, he suggested exploring a potential diagnosis of Tourette's Syndrome. Brad was referred to yet another specialist located out of province who had experience understanding and diagnosing Tourette's. Brad and his family left to meet the latest specialized doctor who was successfully able to confirm the Tourette's Syndrome diagnosis. In addition to Tourette's, the specialist also identified a comorbid Obsessive Compulsive Disorder (OCD) diagnosis, common in 50% of Tourette's Syndrome diagnosis (Swain et al., 2007). When questioned to how he responded to this diagnosis at a young age, Brad is able to recall how he felt.

I remember my first reaction was when the doc told us in front of the parents. Like I was like 'See mom and dad! I told you there was some reason for it!' My parents had a little coping mechanism or kind of game to play with me saying that

I get a dollar at the beginning of the day and every time they catch me doing a Tourette or something at the time they would catch me doing whatever I was doing I had to give them the ten cents back right? So they ended up feeling SO bad after because they thought it was controllable hey? So then I was like ‘See! There you go mom and dad I had a reason for what I’m doing’. So it gave me a feeling of being normal, a sense of explaining it. If you can explain it, you feel more human.

Feeling understood, Brad was now able to find closure by being diagnosed with Tourette’s Syndrome as it provided him with a reasonable explanation for his actions.

As Brad explains his complex phase of finally being diagnosed, he articulates his experiences in an unguarded manner. Brad’s response to his diagnosis is expressed in neither anger nor sadness, but rather feeling a sense of relief. Brad felt more at ease that there was an explanation to what was occurring. He finally felt as there was a clarification to the reasons for his constant companion of tics. In order for his parents to fully understand his Tourette’s, Brad’s mother deemed it necessary to act as an advocate for her son. She became connected with Tourette’s Syndrome support groups and national foundations. His mother was then able to educate herself as well as Brad regarding his new syndrome. She was constantly attempting to discover, locate, and understand any information she could grasp in efforts to discover and learn more about her son’s syndrome.

It becomes apparent that Brad feels strongly that it was his mother who was responsible for initiating and facilitating conferences within the school as well as with teachers, providing and supplying them with as much information as she was able to in order to provide Brad with a safe, nurturing and supportive educational environment. As Brad speaks of her involvement, he speaks with an honest, sincere and heartfelt quality to his words. It was Brad’s mother acting as an advocate and strong base of support for her son, it would be this continual familial support that would provide Brad with a positive foundation for him to develop and discover himself throughout the course of his life.

During his elementary school experiences, the students Brad went to school with were all aware of his Tourette’s Syndrome. This was due in part to advocates like his mother who was able to provide information of his syndrome to the staff and students at

his school. Upon reflection, Brad felt that his peer group ultimately accepted him for who he was, the person that he was. For any individual living with Tourette's Syndrome, it can be extremely tiring, frustrating and redundant explaining to people why unusual and peculiar noises, and physical actions emanate from them without cause. Brad experienced this as well. Brad felt fortunate, however, that he had a supportive group of friends who would stand by him and provide the reinforcement he needed when encountering a new social group to explain his condition for him.

Usually if it was someone, like if my friends were around there we'd just say 'Oh he just has Tourette's'. It's easier for my friends to explain. Otherwise if it was somebody I didn't know, I would just say I have Tourette's Syndrome or else I'd just say it was hiccups. A lot of people just thought it was hiccups.

Positive social interactions serve as a major supportive outlet for individuals living with Tourette's Syndrome, as it provides them with a sense of belonging and acceptance (Carter, O'Donnell, Schultz, Scahill, Leckman & Pauls, 2000). This proved to be accurate for Brad.

Although Brad generally felt supported in the educational environment by his peers, there were certain times in school where his friends would capitalize on his Tourette's in efforts to make a game out of his condition.

Grade four we would always treat it as a game, like for example one of my obsessive compulsive tics was every time someone would point at something I would have to point at it too. So they thought of it as a game, this is fun you know? So they had to point at it and I had to point at it too. So they thought of it as a game you know they didn't really realize it was something I couldn't really control so like pointing was fun and stuff. It definitely bothered me just cause every time I did that it got my Tourette's going more and more.

Although Brad now finds humour in the situation, one must consider the negative impact it must have had on Brad during that specific period in grade four.

During the course of their lives, children experience situations where they become bullied, teased, or intimidated by others. For a child with Tourette's, occurrences with bullying become more amplified, as 75% of children reported being teased by peers because of their tics (Marcks et al., 2007). Although Brad's peers did not associate the

pointing game with bullying or tormenting Brad, it can still be viewed as a form of distress for him. As his variety of his tics would manifest, there were particular tics, which would be more embarrassing than others.

I also had Tourette's where I cried actually for a long time. Random times I would break out in tears, it was kinda a Tourette too. That was kind a weird one it was probably the most embarrassing one growing up too hey.

As a result of tics being manifested uncontrollably, Brad had no control over his crying tic. With the lack of control Brad experienced as a result of this particular crying tic, it is entirely understandable the degree of embarrassment he would encounter in social situations. For a child with Tourette's, the random appearance of tics can cause social discomfort and unease (Pristia, 2003).

The majority of individuals with Tourette's often experience forms of social ostracization, discomfort, which can negatively impact their self-concept (Pristia, 2003). This proved to be true for Brad as well during his elementary school years. For Brad, he found comfort and solace in confiding in his mother.

Usually I came home and whined a lot. She was there to listen to me kind of just whine a bit. Rant off a bit. I don't know. Now that I think back a bit it definitely was a rant. And whining was the best way to kinda describe it. I had tons of ideas in my head cause my mind was racing all the time so someone to talk to helped a lot. It really helped and then the next day you can go to sleep a little easier and wake up.

The rant and whining that Brad expressed to his mother provided him with a sense of relief by being able to discharge the varying emotions he carried with him. It served as a method to release built up emotions as opposed to hold these feelings internally.

Depression carries a lifetime risk of 10% for Tourette's Syndrome individuals, with rates of 13%-76% (Robertson, 2006). As a direct result of his exceptionally supportive family and his positive outlook on life, Brad feels depression was never an issue for him.

No definitely not depressed no. I definitely had times where you come home after work and you've had a hard day you feel as though wow I feel pooped right? I had days like that where basically I felt exhausted. So if you feel stress you feel

low. But I'd say never depressed. I had an optimistic view of thinking. I was lucky that way. I had good support so basically I just felt tired a lot of the times. Fortunately, for Brad it was his positive attitude that allowed him to persevere through potentially trying situations, such as those that occurred during his school experiences. Although he knew that these situations caused him an increase in stress and would thus exacerbate his tics, he utilized an effective coping strategy.

The more they did that the more they kept doing stuff so I kinda played along. My coping at the time was just to go along with it. Lots of them didn't understand really. They thought it was fun for me to play along, but I didn't let them lead on to that it was kind of annoying for me. You kind of eventually ignore it too. Like well what do you do get mad? Like the kids are just going to keep going so you kind of just laugh it off. If you treat it with humour it usually went well.

It is common for individuals living with Tourette's Syndrome to utilize a variety of coping mechanisms and strategies in order to counteract social ramifications that result from tics (Carter et al., 2000). Engaging in positive social interactions with family, and encouraging individuals with Tourette's to maintain a normal lifestyle are recommended coping mechanisms (Carter et. al., 2000; Olson, Singer, Goodman & Maria, 2006).

It was Brad's strong sense of humour that allowed him to persevere through a variety of situations he encountered growing up with Tourette's Syndrome. For Brad, his humour served as a method of resilience from facing social obstacles. Brad's attitude about his Tourette's also allowed him to recall an incident that he still finds humorous to this day. Brad explains an episode which occurred during elementary school.

A substitute teacher would come in for the day and so we all would kinda get together and say okay, Brad, we're going to flare your Tourette's up and we'll back you up okay? So I would start to do a Tourette and the teacher would say quit acting up you know? The kids would say 'Ugh I can't believe you did that he has Tourette's!'. It was so bad. The sub would get so bad we'd be like 'We're going to tell the principal!'. So we made it a game and like I said if you treat it with humour it usually went well.

Although Brad felt that his friends truly did not understand that their games could potentially be disadvantageous for him, others were certain that negative consequences had the potential to occur.

During grade five, a family friend discovered how the students were beginning to utilize Brad's syndrome for their own benefit and enjoyment. The family acquaintance became dismayed and thus felt the need to advocate for Brad.

She heard from her kid that kids would point at things and stuff, but I was fine with it you know I could handle it. But she heard this and got upset so she came to our class and she actually sent me downstairs saying a teacher wanted to see me or something. Then she talked to the kids in class telling them they should be ashamed of each other stuff like that. Telling the kids you know you shouldn't be doing that stuff. I think that it was a negative thing like cause then for me at that age I didn't want to draw more attention to myself.

While her intent was to act as an advocate for Brad, he viewed this experience with a combination of emotions. As a young adolescent, he was not aware of what exactly was occurring and how it would ultimately affect him in his future. Moreover, he felt it was a negative experience as it only drew more attention to him self during a particularly vulnerable age. However, presently he is able to look beyond how Tourette's affected him in the past, and realize and appreciate the actions his mother took to protect him. Though Brad's peers may not at time have truly understood the complexity of his Tourette's Syndrome, he generally felt that they were there to support him and provide him with assistance when needed, specifically during encounters with people that were new.

Like the majority of young teenagers going through puberty, the maturation stage of adolescence can prove to be a trying time. Stress, self-concept, mood temperament and interest in the opposite sex are all elements which a teenager experiences (Byrne, Davenport & Mazanov, 2006). For someone with any type of exceptionality, this stage in life will undoubtedly be much more amplified and cause more stress. For an individual living with Tourette's this is drastically different, as children and adolescents are at an increased risk of social isolation and social ostracization (Marcks et al., 2007). For Brad

with his Tourette's, it was during his middle years in school that he realized his syndrome would begin to cause the most problems and rear itself.

It got embarrassing more from grade four till grade nine, that was the most embarrassing. I started realizing that Tourette's does set me apart a little more. At that age it's the cool factor. It started playing more of a role. Basically I wanted to be normal. Probably the toughest just going through the change you want to be different but you want to be normal the same time. That's kind of where there was an emphasis on it. It was tough growing up.

As Brad explains, he was caught in an influx of trying to feel normal, while not allowing his Tourette's to set him apart from his peers.

Typical for the teenager period of life, adolescents in this phase begin to take interest in the opposite sex. This particular phase is a perplexing period for youth living without an exceptionality. For those living with an accompanying condition, co-existing feelings of confusion and complication occur.

Sometimes I don't think I really regretted Tourette's until pre-teen age. Until when I hit teenager years and you realize kids kinda talking about girls and stuff and you can only hold it for so long. That's when I kinda started regretting having it cause then you are set apart as not normal as much.

As Brad began to realize that his Tourette's was gradually beginning to become more apparent and obvious as he matured, his stress levels began to increase as a result.

I was just kinda physically fatigued having the stress all day. So it basically felt stressed out physically. Like my head's shaking all my motor tics and my vocal tics, hiding them all the time, dealing with them, worrying about them, all while doing work and stuff like that. You know, I would try to give excuses to why I did it instead of just telling them Tourette's.

The increase of added stress has shown to amplify the occurrence of tics (Olson et al., 2006). Therefore, the amount of stress that Brad began to experience had the potential to cause an increase in the manifestation of his tics. Fortunately for Brad however, this did not appear to occur.

As Brad was now beginning to feel an increase in his stress levels during specific instances as he matured, he also had occurrences of amplified stress in the educational

setting. In an academic setting, 50% of children with Tourette's experience difficulties and impairments in the academic setting (Burd, 2007). Although Brad was able to be extremely successful and excel in the academic setting by usually being at the top of his class, there were specific instances where academic work became taxing because of his Tourette's and comorbid OCD.

I didn't like taking notes. That's what it was. I just hated writing notes. I couldn't write fast enough. Every time I write a note my Tourette needed to fix that little letter.

Brad's Tourette's plus OCD mind would have mental obsessions and urges requiring him to hook and loop each letter to an adequate standard. In efforts to maintain this standard, it ultimately caused him to experience frustrations as he took written notes, as each written letter had to look and feel perfect. Brad also experienced classroom adaptations in efforts to assist him during writing exams and tests.

They would usually give me five or ten more minutes at the very end of the test. Knowing that, well they knew that I knew the stuff they always wondered why I was the last one. They thought, well do you understand? I just told them that ya, I just can't write fast enough you know?

Due to his OCD mental compulsions with his written work, the extra time he was provided allowed him to complete examinations to his full potential. It simultaneously lessened the stress he experienced to finish examinations on time and experience success in demonstrating what he truly was academically capable of achieving. With adaptations which lessened stress, Brad gradually began to realize he could gain control over his Tourette's.

As Brad continued to mature into adolescence and began the stage of becoming a young adult, managing his Tourette's fortunately became easier as life progressed. It was the specific periods between grades eight to twelve in which Brad was able to establish and use a variety of control, coping and substitution strategies in efforts to help manage his Tourette's. He felt that by using such substitution or coping strategies that he was able to better manage his Tourette's to a degree that allowed him to feel normal and more in control of his Tourette's and its accompanying tics.

I got more and more control and better at it. More understanding what it was and how to deal with it. There were a couple things. You get little tricks of the trade. So like let's say a motor tic. So when you are moving – let's say walking down the hallways, I wouldn't do a Tourette around people but as soon as I turned around the corner and there was a pillar blocking. I got good at doing it around and behind a pillar and no one would see. Stuff like that. Things you can control. When you can hold them in and let them out at certain times. Something less painful, less observant, less dramatic right? Coping strategies. Substitutions.

Tics are one of the main characteristics of Tourette's Syndrome (APA, 2000). For Brad, he has experienced numerous tics that have come, gone, and continued to stay with him throughout the course of his life. This waxing and waning of tics is extremely common among individuals who are living with Tourette's (Hansen, 2007).

The way my Tourette's worked you get cycles. Or when you're getting a tic it would last for anywhere between a day all the way up to a year or a lifetime right? A typical tic was about a couple week cycle. So Kindergarten a lot of touching ones, I would touch things. A lot more obsessive compulsive that I could not really control that well. So touching ones. Noises, shaking the head a lot that was up until grade three I couldn't stop shaking my head. Crying. I had a crying tic. That one sucked.

Not having any control over which tic would wax and wane, Brad has thus experienced a medley of different motor and phonic tics.

Throughout the two interviews, one of Brad's tics that he feels will stay with him forever became evident. As conversations were occurring, a sniffing tic would emerge and present itself every so often. The presence of this tic would only become quite evident to others who were aware of tic characteristics that transpire with Tourette's Syndrome. When asked to reflect upon his Tourette's Syndrome and his tics that were past and present, Brad was able to identify numerous tics with ease.

I had hundreds of tics. My most elaborate one would be...oh I wish I could still do it! I'd kind of go like that do that with my chin, make sure it would feel right or else I'd keep doing it till it felt right. Multiples of three and five. I knew what a prime number was before what it was, those numbers just felt right. I'd do that

chin thing, then I'd do a head thing and then go 'Doh', like Homer Simpson. I don't want to do it now cause then I'd do it again. Then I'd do some weird head thing so it was a big elaborate sequence. That was the most complicated one. Another one is biting my shirt, oh I hated that one. This one here has probably been with me my whole life. The nose thing. It's probably the one that's going to stay I think for the rest of my life. My eyes. My eyes twitch. Those are the two I still have. I've had those my whole life. Oh shaking my head was a big one. Most of my early childhood I shook my head. Oh jumping, like sometimes jump you know the old crack story. The cracks didn't bug me as much it's just that I can't hop and make sure my legs kind of flexed a certain way. A lot of abdominal ones you can't see lots of time inner muscles that kind of flex a certain way to make it feel weird to make it feel a certain way.

As Brad discusses the variety of tics his Tourette's has, he additionally discusses how his comorbid condition affected him as well.

Due to the fact Brad had a comorbid diagnosis of OCD, his OCD combined with his Tourette's Syndrome proved to be a challenging combination. Not only was Brad now living, managing and experiencing one difficult exceptionality, but he was now faced with two concurrently in combination. For a vast majority of individuals diagnosed with Tourette's Syndrome, 90% of the Tourette's population is diagnosed with a comorbid condition (Robertson, 2006). Not only does living with Tourette's become a trying time, but when faced with an additional exceptionality it can make both conditions much more complex. Brad views his Tourette's and his OCD as a *grey line* that is difficult for him to distinguish what is due to his Tourette's and what is due to his OCD.

It tough to...sometimes I know its OCD just cause it's not a tic it's just a feeling I get. But then your tics are satisfied by a feeling as well.

This became apparent as Brad recalls many mental rituals that he needed to complete in order for him to satisfy his feelings. For Brad, the most difficult part of living with Tourette's Syndrome was during the night when it was time for his body to relax and go to sleep.

Going to bed was the worst. The Tourette's mind would just race. Okay so I had this little line. Imagine a straight line that's curved. It has a hook going outside.

So it's kind of, I don't know...line and kinda hooked outside. So that one hook cannot be unhooked but for my Tourette's to feel good I'd have to...in my mind...I don't know like I'm doing it now. I would have to flip it back. And once it flipped back then I kinda unhooked it and make the complete circle and loop it up a certain way. It's so weird to explain!

It is difficult to entirely envision the mental processes Brad encountered as a result of his Tourette's combined with his OCD. As Brad thoroughly describes one of his mental procedural fixtures he needed to accomplish in order to satisfy his OCD, it becomes apparent the degree of complexity that occurred in his mind. The degree of mental effort and eventual mental exhaustion would be taxing on one's mind. Thus, one can understand why sleep presented to be an irritating obstacle Brad encountered on a nightly basis.

In combination with his OCD traits, Brad has experienced his Tourette's Syndrome tics for the past twenty years. He has experienced his tics in numerous behaviours, appearances, and manners. A variety of tics have emerged, ceased, and continued; those to which he believes will be present with him forever. This distinctive history of his tic acts as a means to create a unique part of his Tourette's Syndrome. As an outsider viewing external motor and phonic tics, it is difficult to comprehend and grasp what a tic exactly feels like, prior to its emergence and immediately following its appearance.

The way I've explained it was always like kinda like a habit. So let's say biting nails, you get that urge you always got to bite your nail. Sometimes you don't think about it but as soon as you see it you got to do it again. So Tourette's is the exact same way. It's just a scale, so say that's a one out of a ten, Tourette's feels more like say...that one there? That's like a three I just have to do it or else it just bugs me you know? I can only hold off for so long. So the thing is you actually can hide it and go away but that one there it's a lot tougher too; it's more amplified.

As Brad expresses his feelings just prior to a tic emerging, he is describing a premonitory urge; the sensation patients with Tourette's experience just before a tic manifests (De Lange et al., 2003).

As Brad speaks, the one tic that he believes will remain with him forever is his sniffing tic. He has accepted the fact it will persist with him throughout the course of his life, and is able to look past it and view it as a minute inconvenience. Brad's comparison with biting nails as a habit, and the feeling that he gets before, during, and following a tic provides others without Tourette's to grasp at a comprehension and awareness of what having Tourette's entails. Accompanying tics feel and act as a regular, everyday experience. Although Brad is as descriptive as possible, one can never truly understand the feeling of having a complex array of motor and phonic tics.

It is also important to not only understand how individual's with Tourette's, such as Brad, must cope with the continual and uncontrollable occurrence of motor and phonic tics, but it is also imperative to examine the physical side effects that occur as a direct result. Brad's tics presented with unpleasant side effects as a direct result of his tics being manifested. Not only were social situations at times difficult, but he encountered arduous moments as an outcome.

It was tough. For example, I couldn't go to sleep a lot of the time with Tourette's. It would affect my sleep so it was tough growing up. I'd get like headaches every time like every time I shook my head I'd get headaches more and more. Side effects of the Tourette's.

Yet as Brad speaks about the negative side effects that clearly affected him throughout his life growing up with Tourette's, he is able to quickly turn his humorous side on adding to other negative aspects about living with Tourette's in the same breath. *Hide and go seek sucked! You had to hold your breath for a long time hoping you wouldn't be found. It was childhood games like that.*

Brad and his family tried a variety of methods in order to help stabilize his Tourette's. However, most of the methods that Brad experimented with did not come with positive benefits, rather negative experiences. Brad remembers when he was sent out of province to a specialist.

Basically he took me aside without my parents one time to ask me, 'Brad, does Tourette's go away?'. I was like yeah, pretty much you know. 'So okay, the first step is just don't do it anymore. You're going to stop doing them'. So I was like okay?! Like it's just hard on your body you can't stop it.

Brad was fully aware that he was unable to cease his tics caused by his Tourette's and relayed the information the specialist provided him to his parents. Naturally, his parents were upset and appalled by the advice that was given to Brad. His parents sent Brad to another doctor located near his hometown in efforts to see what else could be done to assist Brad with his Tourette's. The new advice was to try three various medications.

The first one didn't do anything. The second one I gained a lot of weight, oh I was a chubby kid! I don't know why but I was chubby and slept all the time. Maybe they did it to slow me down? Like I still did Tourette's but...and the third one was Zoloft. And that one there it was a tough one that was right when my Tourette's started going away.

He found it difficult to attribute whether or not it was his third medication, Zoloft, that caused a reduction in his tics, or rather that it was a combination of him maturing into adolescence. Whatever the reason, Brad independently decided to cease all medication feeling that he would be able to manage his Tourette's by himself. By adjusting his lifestyle and attempting to manage his Tourette's independently, Brad began to rely on sports as a means of relief and support.

A major outlet for Brad throughout the course of his life was athletics. Excelling at sports at an early age allowed Brad to shine. It allowed him to not only be known as an individual with Tourette's Syndrome, but rather allowed him to shine for who he was and the athletic skills that he was able to demonstrate. A majority of extracurricular activities that children are exposed to not only provide them with an increase in self-esteem, but children also learn to enhance and develop their social interactions providing them with the opportunity to make lasting friendships. For Brad, both his athletic and social skills were positively enhanced.

One, it allowed me to excel at something I was good at. So since I had Tourette's people acknowledge okay well he's great at sports. Kind of gives me that angle. It gave me friends. You can kind of hide your Tourette's in sports. It just looks like part of the game and stuff so it felt normal. I felt more normal in sports.

While in elementary and high school, sports such as volleyball provided Brad with an opportunity to create positive relationships with friends and develop respect. Athletic activities allowed him to play while managing his tics simultaneously.

Playing volleyball is a sport where there are breaks; there is a thirty second rally or a ten second rally. So for that ten seconds, I could hide my Tourette's or in between volleys I could do a tic and get back to it. A release of energy.

However, not all sports proved to be as simple for Brad with his tics present. As a result, of his sniffing tic, swimming was not practical as it would cause difficulties with breathing underwater. However, clearly born an athlete with inherent physical skills, Brad was able to excel at most of his athletic endeavours. Now part of a sport team, Brad identifies his life experiences with sports as playing a crucial and positive role.

I was an extrovert definitely growing up and the sports helped a lot. Being on teams and being good at sports people respect you a little more you know? So with Tourette's now, sports were a good release. It definitely releases a lot of stress and stuff too. I think it's therapeutic in a way.

Brad also found support through other venues as well. As Brad began to learn more about his Tourette's, and how his life would be directly affected by the syndrome, he found comfort and hope by watching informational videos about Tourette's Syndrome. The video's featured everyday citizens who had grown up living with Tourette's. Individuals such as chefs, professional athletes, and community citizens were featured. For Brad, seeing that there were other people in the world who had grown up with Tourette's, and were able to live successful, happy, and normal lives proved to be a sense of relief, reassurance and solace.

It helped me. Younger actually it did help me. Actually it helped me to know there were people older than me that had Tourette's. I told you about the video? That did help me knowing that people can do sports and lead a successful life. A normal life. It helped me.

As a result of his mother playing such an active role as an advocate and educator for her son, she was able to inform and fill Brad with a vast amount of information pertaining to his Tourette's. Brad became more informed about his condition and began to develop an understanding and acceptance towards his Tourette's. Further, he was able to identify and recognize his condition at a more personal and in depth method.

Knowledge was key. The more I learned about stuff how the body works too gives me reasoning. Why is the sun bright? When you learn it's a star and it's bright.

So that helped me out there. Other ways were dealing with tricks of the trade learning how to mask things. Practice perfect right? Also I think the fact that my body chemically changed as well right.

As Brad matured, so did his attitude towards his Tourette's Syndrome. In addition to his new feelings regarding his Tourette's, Brad also identifies the knowledge he learned about Tourette's Syndrome, and his body chemically altering as a result of puberty as key components to his new enlightened attitude towards his syndrome. With these key components, Brad now contained the ability to understand his Tourette's.

Tourette's Syndrome is a potentially stigmatizing disease that can prove to be difficult for all individuals living with the condition. This was no different for Brad. Throughout the course of his life, Brad can identify the most stressful circumstances in which his Tourette's became evident. Times became especially difficult and taxing in public situations.

Let's say a quiet hall, like say a church. So going to mass is quiet so you're made aware of how, as soon as you think about Tourette's it gets worse. Situations in the public where it's obvious I'm not distracted and stuff my Tourette's came more on a roll. Movie theatres were a tough one. Very tough one. Cause especially before they had big theatres like the high seats you could always see your head so I always asked to sit in the back or something. Or else in the front I would always keep my head still so basically I would always come out of the theatre with a tight, tight neck.

Situations as Brad described above proved to be the most challenging growing up while attending public events. As Brad describes his most trying times in public situations coping with his Tourette's, it is clear that he speaks with an honest, sincere, and heartfelt tonality.

Through difficult public and social events he relied on the strength and the support of his family to pull him through even the most trying times.

With being able to have a supportive family, a very supportive family. Supportive parents. Without that it would have been a much difference picture. But everyone was for me the whole way. Teacher's too. It helped. Having a brother and sister two years apart you know my family, they're at school all the time with me too

they would always back me up after in a good way. It was always in a positive way.

Due to the support that Brad received throughout the course of his life, he strongly believes this acted as a catalyst that lead him to the positive, optimistic and care free attitude that he holds with him as an adult. His encouraging outlook on life has allowed him to not feel pity, remorse, or anger for his life living with Tourette's. Although Brad lives with an extraordinary exceptionality, he chooses not view himself in this light. He has learned to accept that Tourette's has been a part of his life in the past and will continue to be as he progresses in to the future. With Brad's positive outlook, he is able to offer advice to others who encounter a life with Tourette's.

I'd tell them at a young age it really helped me knowing that there are people out there with Tourette's living normal life styles, they get married too they can do that. I remember at adolescence I had a big concern whether I could find someone to date as well too. So once you get the confidence enough to go through adolescence and stuff you overcome that and you get the confidence. Showing that look, you're normal pretty much. That it helps at a young age growing up through life and through the middle age. Really leading by example. Just showing that you can be normal. I could claim myself as being disabled, but I choose not to. I don't feel it as being a disability.

Brad is able to reflect upon his past experiences growing up with a potentially stigmatizing syndrome and can identify how he feels fortunate about numerous aspects of his life. He speaks with sincerity as he explains how he feels that living with Tourette's has not been a disservice to his life, but rather as a positive appreciation. It has made him ultimately grow stronger as a human being. However, it took cumulative life experiences for him to arrive at his current positive and optimistic state of mind.

I think Tourette's makes you stronger as a person, having any kind of difficulties or hurdles to overcome in life makes you stronger hey? You know even if people point and laugh at you, you just learn how to deal with that cause even if being normal as a person they'll have someone make fun of them as well and being able to deal with that at a young age helps you get on with life I think too. It really helped me out. Another good thing with the Tourette's too, the positive side of

things, you could identify and could relate with people who have disabilities. I feel very lucky and privileged, put it that way. Being able to do all the stuff I can do. I saw somebody in a wheelchair for example. I would rather take Tourette's any day. It gives you an appreciation I think. For myself at least, it really gives me an appreciation.

It is this positive outlook that Brad developed throughout the course of his life that has played an integral role in allowing him to not let his exceptionality define the limits he can achieve.

In reviewing Brad's narrative, he has delivered a detailed explanation of the life experiences he has encountered throughout the course of his life, and how he views his future. For a young male to be diagnosed with two comorbid conditions which prove individually and jointly to be taxing, Brad has demonstrated acceptance, understanding, and confidence. He has developed a positive and optimistic outlook on his life. Brad has never viewed his Tourette's Syndrome as a negative occurrence, but rather has viewed it as a unique characteristic that has added to his overall personal composition. He has never regretted having Tourette's and does not view it as a disability, adding that there are many more unpleasant situations that occur to other individuals in society. Brad's narrative provides a comprehensive explanation on a life lived with Tourette's Syndrome; for which individuals with Tourette's can empathize and relate to, and for individuals without Tourette's Syndrome to understand and value.

Mother and Daughter (Hannah)

Hannah is a fun spirited eight year old female. She entered the study with anticipation to learn more information regarding Tourette's Syndrome, as well as to share her experiences thus far with Tourette's Syndrome. Hannah's diagnosis with Tourette's Syndrome occurred fairly recently. She underwent a long, tiresome, and frustrating process to finally achieve an accurate diagnosis. Hannah's mother volunteered herself and Hannah to participate in this study subsequent to discovering advertisements for participants.

Hannah's interviews occurred at the University campus. Two interviews took place, both with Hannah and her mother present at all times. At such a young age, Hannah's experiences may not be as robust and eloquently spoken as desired, yet consideration must be taken into account regarding her age and the complexity of her Tourette's Syndrome. Hannah's narrative provides valuable insight to what life is like for a young child living with Tourette's Syndrome.

In addition to Hannah being interviewed, Hannah's mother was interviewed as well in an effort to provide a comprehensive background context of the history of Hannah and her diagnosis. Hannah's mother's narrative will appear prior to Hannah's to present her own story with Hannah's diagnosis and history with Tourette's.

I knew from an early age that something was not right with our daughter. She'd have very violent temper tantrums, like very just awful and bizarre kind of fits of rage. When you have two kids beside each other you go like 'Oh my god that is so weird'. There were always excuses made for why that happened whenever I would consult a doctor. As a mother, you just know when something is not right. Getting people to listen was the hardest thing saying no, something is not right. We kind of got bounced around and then as things got older the violence and the aggression kind of grew. The first counsellor we saw said I think Hannah has some anxiety problems. That seemed like such a weird diagnosis for me because we're very social people. There was a good psychologist named "Dr. Horton". After some testing and stuff we kind of thought initially it was Asperger's. We knew it was kind of Autism spectrum but we didn't know really where the fit was. And she said I think I finally got what your daughter has, it is Tourette's. So we

were kind of thankful because you're searching, searching, searching right, you don't know?

We tried different therapies first. After that didn't seem to be getting anywhere and again the increase in symptoms we were referred to a child psychiatrist. Once we got in we were told they thought Hannah had some real neurological issues and they thought she had a brain tumour. He said she does have neurological symptoms and signs but there is no tumour so we don't think there is anything other than Tourette's, but she definitely does have Tourette's. This was eight. We started at seven by the time we got in it was age eight. So this has been kind of a two year process of getting diagnosed. A diagnosis is sometimes a blessing and a curse, while grateful to actually know what you are dealing with it is hard to come to the realization what life will look like now. Once we actually had the final diagnosis I didn't want to say to her 'Oh you have this, oh you have this, you have the flavour of the month'. I kind of just told her we finally discovered what it is. And then I kind of talked to her a little bit and explained what it is and we don't really know how to treat it. It's not curable but it will get better. I didn't know myself at that time what really to expect.

I am a proud and humble person so when my daughter acts out in a public place it is extremely embarrassing and humiliating. You know you always have that judging part even with people in public because they don't have that sign around her neck by the way I have...you know what I mean? So that is kind of the hardest. Tourette's is not an easy diagnosis to have as when people see kids in a wheelchair they have certain expectations, but when your child looks normal people can be awfully cruel due to their ignorance. This is the reality we as a family struggle with. I refuse to be shut in because my daughter has Tourette's and hope that going into the future society may have a better appreciation to not always judge a book by its cover. Maybe someday there will be a cure. That is what I hope for and that one day my daughter can have a 'normal life'.

Hannah's mother has encountered a complicated experience trying desperately to seek answers to her daughter's abnormal behaviours. When an accurate diagnosis was finally identified, it provided her with a sense of relief, as there was now a plausible

explanation to her daughter's peculiar behaviours. One of the most difficult tasks she encountered throughout the process was explaining to her daughter about her Tourette's; the fact no cure currently exists and it would be a lifelong condition posed with difficult and frustrating moments. However, she also articulated that it is important for Hannah to recognize her Tourette's will eventually improve. Although Hannah now presently understands she has Tourette's Syndrome, it was important to discover the events leading up to the official diagnosis, and the difficulties Hannah and her family has encountered thus far. Hannah's mother's narrative provides a background context to fill in gaps of information that Hannah herself may not be able to articulate nor understand at such a young age. This in turn provides more depth and understanding just prior to Hannah's narrative.

A bright, young, and vivacious child enters the room with a smile. She sits down, perhaps a bit timid at first, but filled with wonder and curiosity as to what will occur in our meetings and what role she will play. Excited about her upcoming classroom assembly, she eagerly speaks about her new, fancy and exciting wardrobe options for her performance.

I have two shirts that are fancy, like one of them has diamonds on it like sorta like reflections they reflect and one of them has like a belt thing on it. I'm not sure what it's called. The part I like about it is it has my favourite color on it. Well one of them doesn't but black and white are my favourite colors, my semi favourite colors.

Hannah is in grade four and loves school. Her favourite activities are horseback riding, coloring and scrapbooking. Hannah is like every typical child at age eight – she loves exploring, playing, interacting with friends, and has favourite and not so favourite subjects in elementary school. However, in one manner Hannah is unlike her peers in many ways. Hannah has Tourette's Syndrome, a condition that she only became familiar with two years ago after her conclusive diagnosis. Since the span of the last two years, Hannah has begun to develop a basic understanding of her Tourette's. At times Hannah struggles to truly describe what her Tourette's is and how it makes her feel inside. However, at her young age she expresses her thoughts and feelings with the best of her abilities in an effort to make it make sense to outsiders attempting to view and

understand. *A tic is where you sort of like have a problem with your brain. I make noises. Get angry. And I cough. When I cough, it sort've hurts. On my throat. I get sore throats.*

Hannah's tics are manifested into two main forms, noises and coughing. In regards to her coughing tics, she often finds that people misconstrue it as a sneeze, when in reality it is truly a cough she cannot control. In addition to her coughing tics, Hannah also presents other vocal tics which she indicates are difficult to control. *I have Tourette's, and that I have the kind that I have is where you say um and stuff. Mostly it's um.*

Individuals living with Tourette's Syndrome often describe a premonitory urge they experience just prior to a tic manifesting (De Lange et al., 2003). When questioned as to how she feels just before one of her tics emerging, she experiences difficulties in pinpointing the exact feeling she encounters. In her best efforts, she is able to offer insight. *It feels...like pressure's going to come out of your mouth. Explode!* As Hannah experiences this particular feeling just prior to the emergence of a tic, she also experiences a sense of relief after the tic has occurred.

In efforts to control Hannah's Tourette's, her family has experimented with a combination of drug treatment therapy. Hannah discusses her experiences with taking medication.

When I take my pills...well when like last year I think it was when I took my pills it sorta gone away for about a month or so. Well when I took two whole white pills and three blue pills it sorta made me sleepy in the morning so if I had to go to the babysitters then I would be sorta sleepy to get up. I usually go back to sleep cause both my pills. But that was only a month that happened.

Although there is no drug available that completely resolves Tourette's, there are combinations of pharmacological treatments that are currently available and continually experimented with (Robertson and Stern, 2000). These drugs include haloperidol, clonidine and risperidone. As Hannah describes how her medications directly affect her tics, she additionally describes the unwanted side effects that her pharmacological treatment has on her. Common side effects of medications include anxiety, sedation, depression, and weight gain (Gilbert, 2006). Hannah is able to realize that although her

medication may be ceasing her tics to stop there are unpleasant side effects which occur. Through experimenting with different dosages, Hannah feels that she is finally on a correct drug treatment path as she explains her tics do not manifest as much as prior years.

In addition to drug treatment options, Hannah is also attempting to restrain her tics through means of suppression, common for individuals with Tourette's Syndrome (Packer, 1998).

Well I can hold them for a long time. When my throat's dry it helps more better to stop cause then when you swallow it just feels dry and it stops it. I try to hide them for a couple hours. Like say school starts at 9:00 a.m. so then I can probably hold it till lunch. And then I'll probably do it for a couple minutes in the afternoon and then I'll stop for the rest of the afternoon at school.

Individuals who attempt to suppress tics have reported it takes mental energy and effort in order to control the emergence of tics (Packer, 1998). For children at a young age, this can be extremely tiring and taxing on their mental, physical, and emotional well being. Hannah feels that what appears to work for her is when she is readily occupied with school work or other extracurricular activities that provide her with opportunities to become ultimately distracted from attempting to control the emergence of her tics.

When we go riding on quads. Like I don't really do it cause we're going fast. I don't really cough cause when I'm horseback riding or writing about something I usually don't cough. It keeps me busy so then I don't have to like swallow that much and then it just makes me cough when I swallow.

For Hannah, it is these activities that provide her with a sense of engagement and a relief period from the manifestation of her tics.

Elementary school experiences for any child regardless of race, gender, sex or exceptionality, can at times prove to be difficult during specific situations (Lehman & Repetti, 2007). Issues revolving around friendships, games and activities, and bullying are at the heart of elementary school negative experiences. For Hannah, her risk of experiencing social ostracization during her elementary school years are amplified as a result of her Tourette's Syndrome (Shady, Fulton & Champion, 1988). Fortunately, for Hannah Tourette's has thus far not been a major issue with her peers during her school

experience. She believes that this is due to her classroom teacher providing education amongst her classmates regarding her Tourette's Syndrome and how it directly affects her on a daily basis; a process which has mixed reviews regarding its effectiveness (Packer, 2005).

In grade three my teacher told the other grade three class and my class. That I have Tourette's. Like she described how hard it is to not blink your eyes. Cause then probably some of the kids would tease me if they didn't tell.

Hannah, however, feels that by informing her classmates about her Tourette's has prevented potential issues of bullying; an issue of concern that is reported in 68% of Tourette's cases (Shady, Fulton & Champion, 1988). Thus far, it appears that by Hannah's classroom teacher and Hannah educating the students about Tourette's Syndrome, it has made a positive impact on their awareness, acceptance, and understanding of what Hannah struggles with on a daily basis. Hannah is not reserved about sharing her experiences living with Tourette's to individuals, both young and old, who are receptive to her comments. Hannah explains that as her teacher was educating both grade three classes regarding her Tourette's, Hannah herself spoke to the class. This task required courage, bravery and valour.

I just said it's hard to do it hard to do it; keep my noises. That I make noises. Mostly it's um. And I cough. I don't have that moving Tourette's. I only do the talking Tourette's.

Hannah indicates that it was not easy speaking to the class about her Tourette's as one can imagine. As she discusses this moment, it becomes apparent that an obvious feeling of pride is evident.

At a young age, Hannah demonstrates maturity and knowledge as she lives with her Tourette's Syndrome. She already contains the ability to distinguish the similarities and differences between the various forms of tics that occur with Tourette's. Hannah is able to demonstrate this aptitude of knowledge as she discusses the various forms of information she has read and viewed about individuals with Tourette's. Hannah discussed a recent book she borrowed from the library.

My dad got one from the library about Tourette's. I read two pages. She was running and she was sorta moving weird. And she started...when she put her

hand up she started struggling like moving it around. She has the moves, she has the talking one.

Drawing similarities and differences between her and the main characteristics of Tourette's, Hannah articulates these differences by describing how the character displays motor tics and she does not.

The information that Hannah receives from books and video sources helps her develop an understanding of Tourette's, as well as presents her with an opportunity to connect with other individuals who have Tourette's and provides comfort, reassurance, and support as she progresses through life. Hannah reflects upon a video she watched, and the information she was able to obtain.

When this guy had Tourette's and he teached about it. Watched that one in grade three. You can try and stop it. And that you can feel the way...you can feel worried sometimes about it. He tries to help him and other kids not worry about it.

As Hannah is exposed to various forms of media available to assist her life with Tourette's, it is clearly evident that she possesses an innate desire to assist other individuals who have Tourette's. She would actively encourage them to learn about the syndrome, or act as an advocate to inform society about Tourette's. Her inspiration has come from one particular video.

They were talking about Tourette's and the guy who taught people how to learn that would help others if they had Tourette's. Like say it was a baby that had Tourette's I could go over there and help it stop and teach it how to stop it and stuff.

In summation, it is apparent that each of the multimedia forms Hannah has been exposed to has already impacted her life thus far with Tourette's. As she continues to view media regarding Tourette's, her knowledge surrounding her syndrome will only expand.

Although Hannah and her teacher have spoken to each of the grade three classrooms in her school about her condition, Hannah still encounters numerous questions from friends. For some children living with an exceptionality this could be a negative experience, causing them to want to ignore the questioning regarding their condition and hide from their peers. For Hannah however, this is not the case. She

embraces the questions she receives and in turn feels like she is able to teach others and spread positive information about Tourette's Syndrome.

But just say like I wanted to learn about it so my friends could teach like my friends to be nice to me and kind. And so they would know about it so I could like...If I was a teacher I would teach them about it and see if they...if one of them in my class had it then I would just...like when I was an adult I would try and help them with it and with their work and stuff and to learn more about it.

In addition to wanting to help others learn about Tourette's, Hannah also offers advice on her own personal experiences and methods she utilizes to reduce her coughing tics.

...just so that if they have it that they want to learn how to get rid of it and stuff like make your throat dry. Then I would tell them more about it and why do you get it and stuff if I knew the answer. Well usually every year more people come in our school like new people and just say they had it then I would help them out.

As Hannah speaks regarding how she feels responding to questions about her Tourette's, she goes further on to discuss how she would embrace others who are newly diagnosed to Tourette's Syndrome or to those individuals who are not aware of the syndrome itself. Through these discussions it is apparent she is willing to graciously extend her caring, generous, and warm heart in offering advice on her own personal experiences to those individuals who may be new to Tourette's.

It is evident that friendship is a main centre of Hannah's source of happiness. As Hannah speaks of gregarious moments she spends with her beloved friends, she speaks with passion, excitement, and sentimentality. Hannah's friends have played an important role in her life as a positive outlet of light in her life when difficult situations arise as a result of her Tourette's.

I feel happy that I have friends and they treat me the way that I want to be treated. It feels happy that you have friends. It feels good for your teachers to tell the other kids about it and that's really it. It feels good that you have good, nice friends and that they treat you the way they want to be treated.

Hannah indicates how crucial it is that she is treated with respect, and how happy she feels as a result of being treated fairly and equally. She additionally recognizes the importance of treating others with the same respect and dignity that she amiably

appreciates. Friendship is an extremely important area of Hannah's life. As she discusses her experiences with her friends, her face shines with enthusiasm and pride. For a child with Tourette's Syndrome, friendship is a crucial and vital support system in effort to prevent issues of social ostracization and avoid experiencing feelings of not being able to belong to a social network (Robertson, 2006).

Hannah's statements indicate that she has had positive role models and advocates throughout the past few years of learning about living with her Tourette's, in efforts to help her live a normal life. She has learned to be accepted and treated for who she is, not as a result of her Tourette's. Hannah speaks fondly of her educational experiences thus far, and feels like her teachers will always be there to support her as she continues on her path of life.

I have teachers that talk about it and to learn to help me to help other people learn more about Tourette's and see what they do for Tourette's and stuff. They ask me how I feel about it. They let me watch some videos about Tourette's and they let me learn more about it and when we have substitutes they tell them. And they help me learn about it more and to help me have good friends and so they can know about it so they won't worry about it.

Fortunately, the school environment has thus far been a positive experience for Hannah. As she articulates that her teachers and friends have been a reliable and supportive system for her, it is now apparent where her passion for school arises.

For Hannah, living and managing Tourette's is complex. Not only does she work at understanding and controlling her tics, she also experiences a much more difficult side to her Tourette's. Hannah is a child with Tourette's Syndrome who experiences rage attacks; a condition which 25% of Tourette's individuals encounter (Budman et al., 2000). Although mixed conclusions have resulted in the exact link between Tourette's and rage attacks, current research links a connection between these two exceptionalities (Budman et al., 2000). When questioned about which part of her Tourette's annoys her, Hannah indicates it is when her anger begins to consume her pleasant and vibrant personality.

Hannah has a basic understating of her anger problems. *I get in fights. I get very mad. I usually threaten people [and it is usually caused by] something that someone's*

done. The majority of Hannah's anger confrontations occur in the family home. Hannah is quick to blame her siblings as the initial cause of her anger to transpire. Her reaction to her feelings of frustration generally results in fighting and threatening individuals who surround her.

In efforts to assist Hannah in controlling her bursts of rage, she utilizes calming strategies.

My mom prints off a saying where you should walk away and go to a quiet place, stuff like that. If you need to talk about it you can talk about it, or you can just walk to a quiet place. Or just go in your room and do something fun. Well go in my room and call a friend. Mostly coloring I do.

Hannah is aware of what specific activities will assist her in reducing the anger and frustration she experiences, and how to transfer her emotions to a calm state. These activities provide her with an opportunity to engage in interests that delight her.

Hannah admits that although she is able to remind herself of calming strategies that are of assistance, she does at times require some helpful reminders or cues from her mother to take the necessary steps to place herself in a calming state of mind. Once calm, Hannah is able to reflect upon the situation usually feeling a sense of remorse or feeling *awful*. She indicates that her main sense of remorse focuses on how she experiences anger towards different individuals for no apparent reason, but that it just happens.

As Hannah continues to mature, cope and control her Tourette's, she will also have to simultaneously learn to manage her anger and utilize effective calming strategies in efforts to keep her in a positive state of mind, as well as ensure her physical safety and the safety of others that surround her. For the 25% of Tourette's cases where individuals experience rage attacks, it is a comorbid condition that adds to the complexity of an already multidimensional syndrome (Budman et al., 2000).

At a young age, experiencing any form of struggle or conflict in one's life can be extremely challenging and discouraging. For a young individual learning that they will be living with any exceptionality for the rest of their lives can be an extremely difficult, frustrating, depressing and a challenging time. As Hannah will always live with Tourette's, she reflects upon her Tourette's in many aspects. She considers the knowledge she has gained and wants to further explore, her frustration and anger that

comes as a result of the syndrome, and her willingness to accept her Tourette's and kind hearted nature to help others. And yet, through all the difficulties, she still manages to have a positive outlook on life.

But that makes me more special because you have something special and you're thankful for what you have.

Kyle

Kyle is a twenty four year old male. He maintains an active and eventful life, as he is a full time University student, a member of the University athletic team, a member of the athletic council and yet maintains an occupation when time permits. Each commitment that Kyle undertakes, he demonstrates dedication, consistent effort, and gratification. For these reasons, Kyle was content on serving as a participant in the study. Kyle's interviews were conducted on the University campus. Two separate interviews occurred in an effort to delve in Kyle's life experiences living with Tourette's Syndrome. Through the interviews, Kyle was able to articulate both his positive and negative experiences with Tourette's, and how he has matured into the adult he has become.

The educational experience for all students can deliver a mix of positive and distressing occurrences. Students encounter emotions of happiness, excitement, frustration and distress throughout various aspects through the educational domain. These areas include friendships and social circles, curricular demands, and puberty. As students develop and progress through their academic experiences, each of these areas is apt to change. Students gain new friends, while losing old friends. Academic pressure increases as grades become more critical towards their future endeavours and sense of self-worth. Puberty further adds pressure as children enter adolescence and experience a medley of physical and emotional transformations. Although these areas can prove to be challenging enough for the average student, these areas can increasingly be amplified for any student who faces a type of exceptionality. For Kyle, growing up with Tourette's Syndrome proved to be challenging through these areas throughout the course of his elementary school experiences. He continually had the pressure of maintaining a normal status while attempting to cope and live with his Tourette's Syndrome, a condition which has immense potential to be socially stigmatizing (Marcks et al., 2007). Each day possessed the potential to be a struggle, specifically socially and emotionally.

Well I guess like regular daily things that affect me in elementary school with Tourette's would be putting dishes away from breakfast and supper. Having to put them on a certain side in the dishwasher. Whenever I was walking around whether it was to school or around the block with the dog or something, the line game that I would play. Trying to hide the tics just throughout the day in

elementary school. In elementary I'd usually, well not usually, but I don't have this anymore, usually get really, really frustrated with something. Maybe a couple times a week I'd have to kind of release anger in some weird way. Like screaming into a pillow or just going into my room.

Kyle's diagnosis occurred during his early elementary school years between grades two and three. For Kyle's parents, it did not come as a surprise when their son began to exhibit signs and symptoms of Tourette's Syndrome, as Kyle's father and uncle also live with Tourette's Syndrome. Kyle's genetic background may appear to be unique; however growing amounts of research in the area of genetics have supported the results that Tourette's Syndrome has a genetic link between parent and child (APA, 2000). Aware that genetics may play an important factor in the transmission of Tourette's, Kyle's parents took him to see a specialist where he was officially diagnosed with Tourette's Syndrome.

I think I was kinda semi clinically diagnosed like early elementary school, maybe grade two, grade threeish. My dad has it and also probably his brother so they kind of suspected it.

As Kyle states, his family was not surprised by the official diagnosis because of the role genetics had played in his family. Having experience with one family member living with Tourette's Syndrome, Kyle denotes his family was previously aware of Tourette's Syndrome and fortunately already contained knowledge about the syndrome and its characteristics.

Most children would be disheartened by the news of being diagnosed with a lifelong challenging condition; however, Kyle initially did not seem to be affected by his condition. *I guess in elementary school it was kind of when I first found out I had it I was like oh cool, I'm neat, I'm different.*

Although Kyle indicates to not initially be distressed by his Tourette's Syndrome, Kyle believes at such a tender age he was not fully able to truly understand exactly what Tourette's Syndrome was and how it was going to affect him for the rest of his life. He was aware he had a condition and chose to view it as positive occurrence as opposed to a negative. However, as Kyle matured and progressed on to grades four and five, he began

to develop the knowledge and understanding of precisely what his exceptionality entailed and began to notice how his Tourette's would begin to affect him on a daily basis.

Probably grade four, grade fivish I kinda started to understand what it was I guess. Mainly that it was involuntary tics. That was the main thing. Stuff that I couldn't really control that I did. Kinda weird behaviours.

Kyle's tics began to emerge during this time. He exhibited uncontrollable motor tics in a variety of behaviors; unique inhaling and exhaling breathing tics, forced blinking, and licking of his lips.

I guess one of the big ones actually that I had especially before taking medication for it was licking my lips. I would get absolutely massive scabs from about there to there, like not just the lips but all the skin around it, basically for the entire winter. So when it got cold out I started licking my lips and I would just get huge, huge scabs around my mouth. Another thing like weird, forced blinking. I used to do weird forced blinking things. That was actually another thing I picked up from someone who was on my hockey team. He used to blink really hard. I don't know if he had Tourette's or not but I picked that up from him. That was not a nice one to have. And always lots of different kind of breathing tics. All different kinds of breathing ones like breathing out. I had that one pretty bad. Also breathing in ones like (inhale). Did that one pretty much all of elementary school.

As Kyle describes the variety of tics he has encountered with his Tourette's, he focuses on his breathing tics as being the most dominant. While describing his breathing tics, Kyle demonstrates how these tics would manifest. His inhale occurs deeply, as his chest rises with each inhale.

Kyle identified the licking of his lips as being the most embarrassing tic his Tourette's presented him with, as there was no infallible method he could utilize to try and entirely disguise or hide the uncontrollable tic that was occurring. However, being surrounded by a classroom full of peers unaware of his condition, Kyle nonetheless attempted a disguising technique to attempt to mask this self-conscious tic.

Yeah well I guess the thing is that I especially disguised was licking my lips. So a lot of times I would wear turtle necks or especially in class I would pull my shirt up over my nose like this and just go through a class like that and just lick it

under my shirt so people couldn't see or whatever. So yeah, I was embarrassed about what it looked like cause it was really, really obvious.

As Kyle speaks about his most discomfoting tic and his foremost efforts taken to conceal it, it becomes apparent that he is able to place himself back in a grade four classroom. Here, he is unable to control the emergence of his lip licking tic and feeling uncomfortable by the physical marks it left as his peers surround him. While he recalls his method of concealing his mouth under exaggerated collars, he is able to demonstrate the precise method he utilized on a frequent basis throughout his elementary school experiences. As Kyle speaks, his voice flows with ease as he presents how Tourette's Syndrome affected him as a young child. He is not distant in sharing his experiences, but rather states his case through a factual, calm, and straightforward manner.

Kyle continued to progress and develop through early elementary school. As he developed in age, his tics began to materialize more recurrently. Throughout this time, there were always those individuals who had no knowledge of the syndrome Kyle was living with on a daily basis. Thus, there were moments throughout his elementary school experience that were unpleasant.

Other people throughout elementary school, if they saw me doing something really weird, which I'd usually be doing, like different kinds of tics, they'd defiantly give me weird looks. I guess that's one thing that was kind of uncomfortable. People you didn't know being like what is that guy doing? Other people didn't really have a clue what I was doing I'd say. They'd just wonder what I was doing when I was doing tics probably.

Kyle is able to recall a specific incidence that occurred during grade four. For him, this moment has remained in his memory. It serves as an unpleasant reminiscence of his Tourette's and those who were unable to demonstrate a sense of understanding what Kyle could not control.

Well I guess probably a really specific one that kind of sticks in my memory was when in elementary school we did kind of library sessions where the grade four or five classes would go into the library into a Pooh's corner kind of nook and everyone would sit there in the library and read or whatever and I remember it was a bunch of older kids. I used to do this really, really violent kind of sniffing.

Inhale sniff not an exhale sniff. It was really deep and I made like a really, really weird face when I did it. Anyways, yeah, that was probably my main tic in elementary school now that I think about it. But I was doing that really big inhaling kind of snorting snuffle and I always tried to disguise it. I remember cause it was kind of embarrassing when people saw it and I remember some of the older kids who were sitting across from me seeing it and they'd be like talking to one another and pointing and that's like a really distinct memory about being embarrassed about it.

For an episode that has occurred over a decade ago, the degree to which it had its affect is apparent.

There were individuals who were unaware of Kyle's Tourette's during his school experiences. This made him feel embarrassed as his tics manifested during various moments throughout his educational experiences. However, for every individual who was unaware, there were those that surrounded him and encouraged him through difficult times. Kyle chose to make his peer group aware of his Tourette's Syndrome. He strived to explain what Tourette's truly was in efforts for them to develop an understanding. Although he made attempts to accurately and genuinely explain what life was like for him, they were only able to understand at a basal level.

My friends have always kind of understood what it is. I mean I don't know how much you can at that age but I'm sure they took it as something that...I think they understood enough that it was something that was part of me and something I couldn't control. If I did something weird they'd not bug me about it. I wouldn't say they were supportive as much understanding.

Although Kyle does not describe his friends as supportive, but rather more understanding, they still served as a support system for him. It was a positive social network that he could rely on.

In efforts to provide Kyle's classmates to develop an understanding of what Tourette's Syndrome was and how it affected Kyle on a daily basis, Kyle's grade seven teacher acted as an advocate for him. Her intent was to provide peer education revolving around Tourette's Syndrome, a method which has had mixed results in regards to its effectiveness in the educational setting (Packer, 2005).

Well I guess in elementary I can remember, I'm not sure if it was a good thing or a bad thing my teacher did, but she decided to show us this movie on Tourette's Syndrome trying to make me feel more comfortable and try to let the other student's know I had it.

Prior to Kyle's teacher presenting the video to the class, Kyle's teacher ensured that Kyle felt comfortable about the peer education that was going to occur. Kyle agreed and felt that it might *be nice and let people know what I have and what I deal*. However, although Kyle's teacher's intentions were sincere and honest, the video itself depicted a true clinical depiction of Tourette's Syndrome individuals with severe cases.

So she showed this movie to the class and it was just...like I obviously had a relatively minor case and the people in the movie were like at the completely other extreme like hospitalized T.S. patients that were really, really serious and it was just not helpful at all and just made me look like a total freak. The people in the movie were really, really severe so I can remember that in elementary school.

While Kyle shares his video experience, he presents his story with a sense of humour. As he reflects, he now finds hilarity in how obscure the video appeared when compared to him. This experience substantially lessened the degree of his Tourette's compared to the depictions in the video. Although the video may have depicted critical cases of Tourette's Syndrome and not accurately depicted the degree of Tourette's Syndrome that Kyle encountered, the video appeared to have mixed results with his classmates. Kyle indicates it did not accurately portray his specific Tourette's severity level and thus made him appear abnormal. However, he was also not treated atypically as a result of his Tourette's after his peers were exposed to the video.

That whole week people were asking me crazy questions about it. Even in elementary when it was more severe a lot of people didn't really know that I had it and it makes sense because I didn't really tell them. I'm sure they knew I had something but they didn't know it was T.S. They basically asked me about it for the next couple of days and after that I don't know if things...I mean people didn't really treat me any different cause I had it or anything.

Fortunately for Kyle, he did not experience any truly negative consequences as a result of the video being presented.

It was the continual efforts of his teachers that provided Kyle with a strong base of support and advocacy to engage and enjoy his school experiences. Demonstrating their attempts to become actively involved and understand Kyle's *different quirks and behaviours*, left a lasting positive impression on Kyle. In addition to the support he found from his teachers, Kyle also notes that his mother played an active role in providing key information to all of his teachers. Kyle's mother, a teacher as well, acted as a confidante and advocate for Kyle throughout his school experiences in order to assure he felt safe, secure, and understood in the educational setting. This was effectively initiated and carried out by his mother and compassionate educators.

My mom was always really good about talking to the teachers and communicating to them about what I had and how I might act differently I guess. So they would even talk to my mom maybe in parent interviews or maybe they'd even call her I don't know. But they'd actually talk to her and let her know if I was having a bad week with Tourette's or whatever, something related to that and they'd sometimes be like 'Hey Kyle, your Tourette's is bad this week. How are you feeling? What's going on?'

Kyle not only found support and encouragement from his mother and teacher actively advocating for him, but he also found refuge through extracurricular activities, specifically sports. For Kyle, these activities provided him with an outlet to release extra energy and become distracted by the engaging activities. It additionally allowed him to solely focus on the action occurring throughout the sporting activity and act as a distraction from his Tourette's.

I think that usually when I am focused on a certain activity like making a project like a craft or something, or taking part in some kind of sport, that would take my mind off everything and being focused on that would kind of steer me away from my tics and that really helped me a lot.

It is clear that extracurricular opportunities served as a major outlet of support and enjoyment for Kyle, as he actively pursued athletics throughout his life. Activities such as soccer, hockey, and piano and a vast majority of other leisure activities lured Kyle into the athletic life. This passion, desire, and drive have followed him to the present, where he is currently involved with a "University athletic team". As Kyle speaks about his

involvement in a variety of sports and leisure activities throughout the course of his life, it is evident through his speech how essential sports has been and continues to be the key in his life. In addition to his involvement with sports at the University level, Kyle has expanded his passion for sports by participating in valuable opportunities such as coaching, serving on a “University athletic council” and seeking employment at an athletic store. All of these endeavours have provided him with a strong base of support and delight in being able to be successful and actively involved in activities which distract him from his Tourette’s.

As Kyle used extracurricular opportunities in an attempt to de-stress and focus on events that distracted him from his tics, he also utilized tic suppressing strategies. Individuals with Tourette’s Syndrome commonly attempt to restrain their tics, frequently causing large amounts of mental and physical energy directed towards the suppression (Swain et al., 2007). For Kyle, he too strived to curb the emergence of his tics. In efforts to genuinely understand the mental and physical battle he encountered, Kyle is able to comprehensively describe the feelings that occur with suppression.

It’s just you subconsciously you’re telling yourself that you have to do this sniffle or whatever, this facial twitch and everything’s telling you, you have to do it and you should do it and its going to feel good to do it but on the other side of your brain you’re just like there’s no reason to do this its not going to change anything. So I guess in that way it took a lot of battling thoughts to suppress that.

While Kyle mentally struggled to suppress his tics, he eventually found that his tics would manifest in some way and realized that he would have to surrender.

I mean it was pretty tough but if you focused all your energy on it for a couple of minutes and try to lock yourself on it and freeze it, it kinda waned. But usually just give in and do whatever behaviour your brain is telling you to do.

For Kyle, it made more sense to eventually release his tic as opposed to exhausting energy on attempting to suppress an occurring tic.

Increased stress levels can cause an amplification and intensity in the occurrence of tics (Burd, 2007). For Kyle, when reflecting upon certain and particular emotions or events that would cause an increase in his tics, he explains it is difficult to pin point the exact cause of the rise of tics.

I'm not sure what would bring it on. I know that if I think about it, if it is just in the corner of my mind I'll think about it more and more and then I'll have a big tic outbreak or whatever. If I'm with someone who has Tourette's and I see who has tics, I'll do something the same and not be able to control that.

Although Kyle is not able to precisely identify particular incidences that would cause an increase of tics, he does indicate that his thoughts may serve as a trigger.

Kyle also feels that when he was younger and out in public he tended to notice an increase in his tic manifestation. Fortunately, he did not generally feel overwhelmingly uncomfortable or embarrassed when out in public situations. This resulted from him not being especially concerned with how people viewed him as tics emerged. Kyle felt confident with who he was and would not let Tourette's take over his life.

In terms of actually people seeing my tics, not so, so much. It wasn't that just being out in public with strangers was uncomfortable, that I didn't want them to see my tics or anything. Just for some reason being in kind of claustrophobic really busy areas with a lot of people. I know that when I was younger whenever we went to the "festival" with our class or whatever, being in really, really crowded environments would kind of bring about different tics and stuff. I'm not sure if it made me uncomfortable and brought the tics out but usually I'd have a lot more T.S. behaviours in those kind of situations, though I'm not sure why.

Although Kyle may not be able to arrive at a conclusion as to what events or emotions triggered an increase in the occurrence of tics, it is important to note that Kyle was not just facing one exceptionality. He consistently managed two exceptionalities throughout the course of his life, even to the present, which actively played a critical role in conjunction to his Tourette's Syndrome. Like a vast majority of Tourette's Syndrome individuals, the complexity of the syndrome is amplified by the addition of a comorbid condition. Kyle not only coped with living with his Tourette's and the tics that occurred as a result, but also dealt with Obsessive Compulsive Disorder (OCD), extremely common in Tourette Syndrome cases (Swain et al., 2007).

I didn't have any specific tests for OCD or ADHD or anything like that. But I guess from what I understood from the doctors I talked with was kind of

Tourette's Syndrome was very closely tied with those and if you have Tourette's you'll probably be very close to being diagnosed with those.

Kyle may not have ever officially received a diagnosis for his OCD, but he exhibited numerous symptoms and characteristics of the condition. Kyle not only faced a singular potentially trying syndrome, but OCD as well, added to the complexity of a socially stigmatizing condition. Kyle's OCD caused his Tourette's to become more multifaceted, thus confronting an additional potentially arduous exceptionality. Kyle recalls how his OCD affected him during his elementary school experiences.

Well like walking on sidewalks like to and from school. I'd play really weird intricate games with the lines. It would be a competition between my left foot and my right foot and stepping over a line counted like 100 points or something for that foot and stepping on a line with that foot count liked negative 50 points or something for that foot. Just like I played my left side is my favourite team today kinda thing. Or I'd play kinda the same left to right side game putting dishes in the dishwasher. Like I'd have to try and put all my dishes on the left hand side or whatever something like that. Because I was left handed in hockey I had to put all my dishes on the left hand side of the dishwasher.

When questioned if it was difficult to distinguish and separate his Tourette's and tics apart from his OCD behaviours, Kyle felt that it was relatively easy to discriminate each exceptionality from one another.

I consider most of my tics related to up here so either facial movements or breathing tics and OCD just to be weird habits or rituals that I do I guess.

In efforts to truly understand the difference he felt between distinguishing an OCD behaviour from the emergence of a tic, he further explains the premonitory urge he experiences prior to a tic occurring, common in a vast majority of Tourette Syndrome individuals (De Lange et al., 2003).

Probably the best way I could describe it is a kind of feeling, like an itch, that you have to get that just gets worse and worse and worse until you do that certain behaviour.

By Kyle relating his premonitory urge to the feeling of an itch, it provides individuals with an opportunity to relate to these feelings Kyle experiences on a regular basis. As a result, one can develop a sense of empathy.

As Kyle encountered two trying exceptionalities on a daily basis throughout the course of his life, he admits there were moments in his life that were frustrating, annoying, and tiresome. Although these instances did not occur on a regular basis, rather on occasion, Kyle recalls the anguish he experienced as a result of difficult times.

Like the really, really strong anger bursts probably ever few weeks I'd say. It would be anger, hate. That type of thing. And you would just want to...well when I was in elementary school I would just go to my room, close the door, scream into my pillow and at max it would take like 30 minutes to get over it. Usually I'd be fine and kind of shrug it off ten minutes later. It was nothing I'd be depressed about for a long period of time.

During the moments in his life when Kyle experienced bouts of frustration and anger, he was able to find support, comfort and solace by turning towards his mother for emotional assistance. Although Kyle knew his friends understood his Tourette's, he never discussed the intense feelings he was experiencing during trying moments. Since he was unable to find any connection towards peers his own age living with Tourette's, it was his mother who became his true confidante and most supportive individual throughout the course of his life.

I would say my mom. Especially in elementary school when Tourette's was worse. When I'd have big mood fluxes and swings I'd be like really down about something Tourette's related and I could usually talk with her in private or I remember going to the park and just going out and sitting on the swings with her and kind of just talking about that and life in general. That was really, really nice to have. It got me away from or set my mind on something that I guess took away from the tics and stuff like that. She was always a really, really nice and comforting person to talk to about that kind of stuff.

While Kyle speaks about his experiences with his mother during his stressful times, it becomes clear that she has become important person to him. Not only did she

serve as an active advocate for Kyle during his elementary school experiences, but she also simultaneously played a vital role providing emotional support to Kyle.

During the time that Kyle began to gradually come to terms with his Tourette's and how it would affect him on a daily basis, he began to experience more positivity. This occurred as a result of beginning to experiment with pharmacological treatment in efforts to reduce his tics; a method which simply has no cure, but only a cause in tic reduction (Zinner, 2004).

I remember being told by my mom that I was going to have to take medication and I kinda though it was kind being cool. I'm special; I get to take drugs or whatever. I started taking the medication at the end of that year. That was when my chapped lips and licking of the lips were at an absolute peak and it was very scarring and it was hard walking around like that all the time. Yeah like taking the drugs definitely went from there to there. I started taking the medication clonidine and it pretty much had an immediate effect there. I didn't get the big scabs on my lips. And then just gradually throughout elementary to high school it kinda just tapered off. I mean with puberty it declined and everything so.

Kyle indicates it was puberty that caused a reduction in the severity of his Tourette's. It is during the ages between eight and twelve where tic severity is at its peak (Bloch et al., 2006), it then gradually declines as one ages into young adulthood (APA, 2000). For Kyle, this proved to be accurate. Life began to become easier as he aged, leaving behind marked moments of difficulty and beginning to enter unproblematic and relaxed periods of his life.

From probably late elementary school on I didn't really feel myself or see myself as being too, too different from everyone else around me, besides the fact that yeah, I'd do something weird here and there that most people wouldn't recognize and notice. But I didn't really see other people as being normal and myself as abnormal I guess.

As Kyle matured, he began to realize that he was normal. He started to adopt a positive state of mind, and recognize and value the person that he was. He did not allow Tourette's to define him as being abnormal.

As Kyle shares his personal, private and special life experiences living with Tourette's Syndrome, he is able to develop an engaging atmosphere; one which invites the listener in to his world and mentally attempts to place themselves in particular moments throughout Kyle's life. Evidence of the importance sporting activities has provided him with in the past, is actively carried through to the present. In addition to the passion Kyle exudes for sports, he eagerly discusses his education and his future endeavours. Kyle is currently pursuing post secondary education at the University level and is graduating this year. Clearly academically and career driven, he is continuing on to further his education even after his graduation. As he reflects on his life experiences he has encountered with Tourette's and how it may affect him in the future, he is able to show growth and a sense of appreciation for his Tourette's Syndrome.

I guess to look at it kind of in a positive way. Like what I thought about it when I first found out was to look at it that way. It's a really unique quirk that very, very few people have. To look at it in that kind of unique and positive way and that well usually if it's at a really bad stage when you're younger it's usually going to get better when you get older. It's not going to progress or get any worse so it's only going to get better from there.

Although Kyle's tic outbreaks are not as severe as they were during his elementary school experiences, one of his tics still manifest themselves regularly, specifically his breathing tics.

I still at least tic wise do the breathing one. Definitely the breathing out short breaths that's something I can't even remember when I wasn't doing that.

Though his breathing tics remain, the path that Kyle's Tourette's has taken in regards to the gradual decline in severity is common with Tourette's Syndrome cases, as research indicates a delineation in the acuteness of Tourette's as one reaches adulthood (APA, 2000). He still occasionally disguises his tics by camouflaging them with strategies he has learned and perfected over several years.

I do the (exhale). I guess I kind of disguise it by covering it up with a laugh sometimes because it kind of sounds like a laugh when you're doing that.

Kyle is still continuing to treat his tic reduction through pharmacological means, which he has been since grade four. Although Kyle's tics may exhibit themselves

periodically, Kyle's OCD still remains, although not at the extreme level which occurred during his early elementary school years. As Kyle discusses his past life experiences with Tourette's and OCD, it becomes apparent how his OCD still affects him to this day. Upon viewing a piece of brightly coloured and attractive fabric during the interview, Kyle felt the incessant urge to grasp the fabric and get a sense of its texture. Kyle explains how his OCD still manifests and affects him in a similar form which he experienced growing up.

I guess it's not really tics but I still am...actually that's probably the thing that hasn't gone away whatsoever. I'm still really, really, touchy feely. Like that. It looked like a really cool fuzzy material and I have to see what it feels like. It's like oh that's what that feels like. It's like oh that's what that surface is like. I don't know. It just interests me and yeah not knowing what that texture is like will bug me I guess. Yeah that's something that I still do quite often.

Although Kyle's OCD for the sensation of being in contact with texture of materials and objects has remained, his OCD has also altered in different ways as he matured. Kyle's OCD has transformed itself from a game format to more of a particular and meticulous system.

I don't play those OCD games that I did when I was a kid. I'm pretty obsessive with some of my other stuff in my life but not in a games way. Just like let's see...even writing stuff down taking notes in class. Just being super, super picky how every one of my letters looks even if a teacher is so far ahead of me and I'm way behind taking notes. Now if I don't have my 'e' curled and attached the way I want it too, I'll go back and erase it and fall further and further behind.

This meticulous nature directly caused by his OCD, provides Kyle with frustrating moments; moments which he has little control over triumphing. For moments like these, Kyle has learned to accept the fact they will be difficult to entirely extinguish.

Throughout Kyle's life, the information he has discovered and learned about his Tourette's did not result from direct means, such as doctors, specialists, and informational print. Rather, Kyle describes his wealth of knowledge as informal and acquired through second hand experiences.

If we had internet back then I'm sure I would have Googled or Wikied it and found out more about it. But most of what I learned was basically from my parents and what they told me about it really. It wasn't like I found I had Tourette's Syndrome and my parents gave me, here read this text book about it. It was just kind of accumulated knowledge. They knew a couple of other adults that had it and of course my dad had it but they just tell me second hand from what doctor's said or what friends dad's had it. What they said about their experiences. It was kind of an informal learning of what it was I guess.

As Kyle learned more about his Tourette's through second hand experiences, he felt he was never able to truly connect with other individuals living with Tourette's that were his own age. There were adults living with Tourette's to which he could question and attempt to develop a connection, yet the age difference impeded any type of meaningful and relevant relationship to occur.

Due to the low incidence rate of Tourette's; 5-30 children per 10,000 have a diagnosis (APA, 2000), Kyle encountered difficulty locating peers who had similar experiences with Tourette's Syndrome. Throughout his life, Kyle could confide in peers and family members about his syndrome, but never truly felt they could relate to what he experienced. It was not until University, however, that Kyle was finally able to locate another individual who had Tourette's Syndrome and at last could discuss the positive and negative life experiences with Tourette's. It was this exciting yet comforting opportunity to share and reflect personal experiences has served as a key positive experience for Kyle with his Tourette's.

So 'Brad' is a good buddy of mine on my 'sports' team and everything. When I first found out that he had Tourette's Syndrome, just being able to talk to him. I remember pretty well we were in the sport meds centre and doing cold tubs after a work out and we just talked about it and our experiences about it for a long time. Like we were just sitting there in the tubs talking about it and sharing our own thoughts and feelings. And that was kinda neat just to be able to talk to him about something that we can relate to each other with. I've never really known anyone my own age with it. Like I said my parents had friends or knew of other

adults that had it but I couldn't really talk to them about T.S. 'Brad' was the first person actually my age that I could kinda relate too.

Although it may have taken over a decade for Kyle to finally connect to another individual living with Tourette's who was his own age, it was this connection that ultimately finally provided Kyle with someone to empathize with. For this, he is greatly appreciative.

Kyle has endured and encountered a medley of experiences throughout his lifetime as a result of his Tourette's Syndrome. For any individual who faces an arduous exceptionality such as Tourette's, Kyle has endured, persevered, and learned to accept his Tourette's. He has encountered wearisome, difficult and frustrating moments in his life, yet also experienced an array of positive, encouraging, and optimistic periods. It is specifically these encouraging experiences that have allowed Kyle to develop the positive and mature attitude he now carries with him when reflecting upon his past with Tourette's, and what his future holds. As Kyle is able to reflect upon his experiences as a whole, he recognizes that Tourette's has played an active role by shaping his life experiences; encountering both positive and negative occurrences and outcomes. Fortunately for Kyle, today he strongly believes and is able to view his experiences with a more positive outlook.

I mean at times it made you feel kind of different in a negative way. Just like I said when people give you really weird looks when you are having a tic outbreak or something like that or doing something weird it kinda made you feel small and different in a bad way at those times. I guess growing older the negative side of it just diminished and diminishes and I kind of accepted it more and more and kind of growing out of it and it being less and less noticeable in my life. It's kind of back to being something different and special in a good way maybe. I guess I've just grown to accept it. I mean sometimes it's frustrating, not very often, like sometimes I'll have a bad tic outbreak and it's just like ugh...I wish I could stop this from happening. But besides those one or two times a month kind of things I don't think it really affects me too, too much. Yeah in the way I got about life or anything. Just come to live with it.

This statement demonstrates how Kyle has learned to understand and recognize that his Tourette's will constantly be a part of him, just as it has in his past and will continue to be in his future. Unfortunately for Kyle, it was not until he was attending post secondary education that he finally was able to meet and develop a friendship with a peer his own age and finally develop a connection with another individual who had lived and continues to live with Tourette's Syndrome. For those newly diagnosed individuals, majority of them children, Kyle is able to offer reassuring and encouraging advice that he has developed and learned to appreciate through his own personal like experiences.

I would say accept and be happy that you are unique and a little bit different from other people out there. Also just to learn about it as well. Learn what it's all about and don't think it's a punishment or something like that.

In addition to the advice, Kyle also adds a key detail, one which as caused him to reflect upon his growth as an individual living with an exceptionality.

I think you have to learn a little bit more about yourself and how to deal with your emotions and deal with being a little bit different from everybody. So I think you learn it's a bit of a learning experience that way.

Summary

Through the use of narratives, each of the participants has offered their own private and personal perspectives on their life experiences living with Tourette's Syndrome. Insights were offered in regards to how they have lived and continue too with their Tourette's. Notable comparisons can be established by reflecting on each of the three narratives. Each encountered a comorbid condition adding to the complexity of Tourette's Syndrome. All three described encountering not one major exceptionality such as Tourette's, but their comorbid conditions as well. These comorbid conditions they face have proven to be just as trying, as indicated by the participants themselves. In addition to comorbidity, each narrative discusses each individual's positive and distressing experiences with Tourette's Syndrome in regards to how the syndrome has directly affected their social, emotional, and academic realms. Coping strategies, extracurricular activities, and strong family support were also identified throughout each narrative as critical components of assisting each of the participants during particularly stressful periods.

Although each participant's narratives draw on many parallels, each of their life experiences has their own unique distinctions. As each individual explains their life with Tourette's, the diversity in how their tics manifested are noted. Each of them has their own unique and distinct set of motor and phonic tics. Furthermore, there are distinctions in how each of their comorbid conditions impacted their lives, and how both their Tourette's and comorbid conditions still continue to impact them to the present. In addition to variation in experiences, the age of the participants is one of the broadest differences noted. Brad and Kyle have provided their life history with Tourette's being the eldest of the participants. At a more mature and adult age, they were able to reflect upon their past experiences with Tourette's, and the growth and acceptance they have gained as they aged. Hannah, at her young age, offers glimpses of what her life with Tourette's has quickly become, and how the young cope, accept, and understand how potentially trying syndromes will affect them throughout the course of their lives.

Jointly and independently, each narrative has provided a wealth of information to allow a sense of knowledge, understanding and empathy in efforts to provide insight to

their lives. As previously indicated, significant similarities and noteworthy differences have surfaced as a result of the narratives.

CHAPTER FIVE: DISCUSSION

Overview

Tourette's Syndrome is a neuropsychiatric disorder characterized by involuntary motor and phonic tics (APA, 2000). Due to the involuntary nature of occurring tics, individuals with Tourette's often encounter negative experiences with social ostracization and depleted self-esteem (Marcks et al., 2007; Robertson, 2006). The purpose of this study was to examine individuals living with Tourette's Syndrome, and how the syndrome has impacted their lives. Of particular focus were three central subtopics on their educational experiences, social interactions and relationships, and their emotional domains. Three participants were recruited and willingly participated in this study. Through the use of interviews, each participant was able to articulate their personal story, both positive and negative, of their experiences living with Tourette's Syndrome. Each narrative occurred as a result of the interviews and was based on how Tourette's has directly impacted their lives. While examining each narrative, notable parallels as well as unique distinctions became evident. Such findings occurred as a result of extensive review, summation, comparing and contrasting each narrative. These specific parallels and differences will be identified, discussed, and correlated to current research on Tourette's Syndrome.

Findings

Individuals living with Tourette's Syndrome encounter a combination of struggles throughout the course of their lives. These difficulties tend to occur in the social, emotional, and academic realms as a direct result of the manifestation of their tics causing humiliation and discomfort (Leckman et al., 2006). In addition to tics, due to the high comorbidity rates associated with Tourette's Syndrome, these problems are often compounded and add more difficulty to daily living as a result of the comorbid conditions. In an effort to seek in-depth understanding on how these specific areas are impacted, requests were made for participants willing to share their personal experiences living with Tourette's Syndrome. Due to the low incidence level and sensitive nature of the syndrome, only three individuals positively responded and actively engaged in the research study.

Brad, Hannah and Kyle were provided with the opportunity to share their personal experiences living with Tourette's Syndrome. Each participant was able to contribute information, and share their own individual ways and perspectives. Collectively, they discussed how they have handled the diagnosis and began to accept and almost appreciate Tourette's. They shared positive and sometimes humorous memories surrounding Tourette's, and identified encouraging influential people who ultimately shaped their lives. While discussing the positives in their life with Tourette's, they also were able to articulate the negative aspects of how the syndrome has impacted their lives. Conversations focused upon embarrassment, discomfort and frustration were also shared, as each was openly willing to reveal private thoughts and emotions centering on such experiences. Common themes emerged as a result of reviewing each of the three narratives. These collective subjects will be discussed in the following subheadings.

Psychopathology

Current research literature indicates the psychopathology of Tourette's Syndrome to be at a 90% incidence rate (Robertson, 2006). The most prevalent comorbid conditions appearing with Tourette's Syndrome are ADHD, 50% - 75% and OCD, 50% (Kurlan et al., 2002; Swain et al., 2007). Due to the expected occurrence of one or more comorbid conditions in a vast majority of Tourette's Syndrome cases, it was expected that the participants involved in the study would be included in this statistic. All three participants in this study have been diagnosed, or display indicators of diagnosable comorbid conditions. For two of the participants, Brad and Kyle, they both have experienced, and continue to experience evident and observable obsessive compulsive disorder (OCD) traits and characteristics. According to the APA (2000), OCD is found more commonly in males, thus Brad and Kyle support this finding. OCD mental obsession behaviours, with repetitive and intrusive thoughts requiring the need to perform exhausting mental tasks were evident in both participants' cases. For Brad and Kyle, they both describe the mental obsessions they became fixated on in efforts to mentally loop and hook letters and objects until this satisfied their obsession. As Leckman et al. (2006) explain, these mental obsessions can be described in research literature as "mental sensations including urge only, energy release (mental energy that builds up and needs to be discharged), incompleteness, and just-right perceptions" (p. 646).

In addition to the mental obsessions, both male participants demonstrated and experienced physical compulsions requiring them to perform repetitive and unwanted forms of behaviours. Brad and Kyle each described how they needed to complete specific physical tasks, mainly tasks requiring specific directions (e.g. left and right), in efforts to once again satisfy the compulsion. Leckman et al. (2006) describes such physical tasks as “body sensations (usually tactile, muscular skeletal/visceral, or both) occurring either before or during the patient’s performance of repetitive behaviors” (p. 646).

For Brad and Kyle, they both indicated how frequently their Tourette’s and OCD consumed a large portion of their everyday lives. For Brad, it was difficult to at time distinguish the difference between a tic and an OCD obsession or compulsion. However, Kyle indicated that he could feel and differentiate his tics from OCD characteristics. Regardless of being able to accurately distinguish between a tic and an OCD symptom, the combination of Tourette’s Syndrome and OCD can prove to be more detrimental than a sole diagnosis of Tourette’s (Dodick & Adler, 1992).

As Gaze, Kepley, and Walkup (2006) indicate, OCD characteristics contain the potential to cause significant tension and distress throughout the course of an individual’s life as they perform daily activities. This accurately reflects for Brad and Kyle’s lived experiences, as they both indicate the amount of stress their comorbid conditions have actively played throughout the course of their lives.

However, for Hannah the amount of anger that she is experiencing and expressing because of her Tourette’s, is concerning. Although Hannah herself is able to indicate her experiences with anger at a simple level, Hannah’s mother is better able to articulate her apprehensions for Hannah’s outbursts of anger. Although not officially diagnosed, Hannah could potentially be dealing with rage attacks, a condition which research has shown to be active in 25% of Tourette’s Syndrome cases (Budman et al., 2000). Rage attacks are believed to be highly associated with Oppositional Defiant Disorder (ODD) and ADHD (Budman et al., 2000). Individuals with Tourette’s Syndrome plus rage experience abrupt explosive outbursts of anger or rage (Gazy, Kepley & Walkup, 2006). As indicated by Hannah’s mother, she has witnessed Hannah have unusual, sometimes violent, anger eruptions. Aware that this type of behaviour is abnormal, she questions if

the episodes of anger are caused as a result of the Tourette's, or can be identified as a comorbid condition. When asked about her own personal experiences with her anger, Hannah is able to recognize that she does encounter incidents with rage, but has difficulty identifying specific reasons for her outbursts. She is, however, able to articulate that she has been attempting calming strategies to assist her to return to a state of normalcy. Further, Hannah admits that she is not always able to remind herself to use such relaxation strategies, and needs to be prompted by her mother in order to do so.

Regardless of the type of comorbidity each of the participants have and continue to experience as part of their lives, it is evident that their comorbid conditions are practically equal to the degree their Tourette's Syndrome affects them. In all three narratives, each participant is able to articulate the degree that their comorbid condition affects them, as well as how it acts as an integral component of their Tourette's Syndrome.

Treatment

Tourette's Syndrome has no cure, only treatment options to assist individuals with their Tourette's. The two most common methods of treating Tourette's are pharmacological and behavioural, with pharmacological treatment being the most prevalently used method (Olson, 2004). Pharmacological treatment does not entirely resolve the occurrence of tics, but rather assists the individual in the attenuation of tics. Due to the high degree of comorbidity associated with Tourette's Syndrome, the pharmacological treatment method becomes more complex when additional conditions are present (Robertson & Stern, 2000). Thus, when patients are deciding to pursue this option, they are apt to try a variety of medications in efforts to find the most suitable in treating their Tourette's and comorbid condition(s) while simultaneously minimizing displeasing side effects.

All three participants have experimented with a variety of pharmacological treatments in order to decrease their tics. Both Hannah and Kyle have treated their Tourette's with Clonidine, an Alpha₂-adrenergic agonists recommended as the first treatment option (Zinner, 2004). This drug is designed to cause a reduction in the occurrence of tics. In addition to the attenuation of tics, Alpha₂-adrenergic agonists simultaneously treat comorbid conditions such as ADHD and anxiety, with relatively

mild side effects (Zinner, 2004). Side effects of medication are one the greatest concerns when treating individuals with Tourettes's Syndrome. Brad and Hannah have both discussed their personal experiences with side effects of medication, often causing weight gain and sedation.

In regards to the effectiveness of the drug, Brad and Hannah have their own personal opinions. As Brad indicated, he is undecided if his pharmacological treatment was successful in his delineation of occurring tics, or rather it was a combination of his medication and his puberty. Hannah, however, strongly feels that her medication is the sole reason for the reduction in the manifestation of her tics. Kyle was not on the same drug as Brad and Hannah, but was treated pharmacologically as well. For Kyle, he noticed an immediate decrease in the reduction of his tics during elementary school. As a result, Kyle believes the pharmacological drug treatment was an effective therapy in the delineation of his tics.

Social Interactions

Individuals with Tourette's Syndrome are more apt to experience negative social interactions and encounter difficulty making friends because of their condition (Marcks, et al., 2007). This is often caused by society misunderstanding Tourette's and thus making negative opinions towards individuals with the syndrome. As a result, individuals with Tourette's Syndrome, more specifically children, are at an amplified risk of social rejection and isolation, tormenting and harassing (Marks et al., 2007). The participants in the study were questioned regarding their social interactions throughout the course of their lives. Brad, Hannah and Kyle all indicated that they were fortunate to have a close, supportive group of peers who were there to provide them encouragement during difficult periods. This social network was a key foundation to build and support necessary positive social interactions. Although each participant described positive social relations, they also touched upon marked moments that were discouraging and trying as a result of their uncontrollable tics manifesting during social situations. Majority of these instances occurred during their school experiences.

Brad discussed how his random outbreak of tics would cause moments of embarrassment when his classmates were present. In efforts to reduce his distress, he attempted numerous disguising techniques, which he learned to perfect over the years to

successfully help mask his occurring tics. Such disguising techniques are a commonly practiced intervention, specifically with school aged children (Wilson & Shrimpton, 2003). As a result, Brad generally felt that his Tourette's may have set him apart from his peers, but he did not encounter social isolation or ostracization. Hannah did not indicate whether her Tourette's has caused her any social difficulties. She recognizes that her Tourette's differentiates herself from other students, but believes that she has been accepted by her peer group regardless of her Tourette's. Kyle articulated how significant negative moments have remained fixed in his memory. Kyle eloquently expressed how his specific tics caused distressing moments throughout elementary school. He touched upon the embarrassment he encountered from students who did not understand his Tourette's, as well how his tics at times made him feel uncomfortable in his educational setting. Although Kyle did encounter trying moments, he also articulated how he generally had positive social interactions and an understanding peer group.

Fortunately, although research indicates individuals with Tourette's are apt to encounter distressing social interactions and possible isolation, each of the three participants have not experienced it to this degree. Although Brad and Kyle indicated they have experienced embarrassing moments, they have learned to move past these incidents and embrace a positive outlook for their future. Hopefully in Hannah's situation, her social network will continue to remain positive, supportive, and understanding.

Family

Familial support has been identified as a critical long-term goal as a means of providing individuals with Tourette's Syndrome a support system (Zinner, 2004). Supplying an encouraging familial foundation will ultimately assist the individual with Tourette's to adopt a positive self-concept and self-assurance, and eliminate detrimental sentiments as a result of the syndrome. Prior to a positive parental support system occurring, Leckman (2006) indicated that in order for a child with Tourette's to feel supported by their parents, it is necessary that parents themselves become educated about critical key facts about Tourette's Syndrome.

Familial support is clearly evident in all three participant's lives. Brad and Kyle both indicated how their mothers took active leadership roles to discover a wealth of

knowledge on Tourette's Syndrome when both were initially diagnosed. Their mothers searched through various mediums to find as much information as possible in an effort for them to develop a thorough understanding of the syndrome their sons would be living with for the rest of their lives. Once they were able to gain this vast amount of knowledge, they were able to inform their child's teachers in order to provide their sons with a supportive and understanding teacher and educational environment. Throughout both their narratives, Brad and Kyle continually articulate that it was their mothers who served as the central advocate throughout the course of their lives. In addition to acting as the main information link, both Brad and Kyle have identified their mothers as their main support system.

For a vast majority of individuals with Tourette's Syndrome, it is common for them to experience social ostracization, discomfort, embarrassment, and at particularly difficult periods, marked moments of depression (Marcks et al., 2007; Gaze, Kepley & Walkup, 2006). Brad and Kyle were able to recall general and specific moments where they relied on their mothers as an emotional support system. It was their mothers to whom they confided their distress and disheartened emotions to. In return, it was also their mothers who were able to provide them with positive encouragement and optimism for the future, while ultimately imparting on them feelings of security, safety and most importantly love. For Brad and Kyle, it was their mothers who served as a critical role model in the creation to whom they have become in the present.

Peer Education

Shprecher and Kurlan (2009) indicated that educating teachers and peers regarding Tourette's Syndrome is a critical and essential intervention that should initially be done. Teacher and peer education must centre on the involuntary nature the student has over the occurrence of tics, to ignore tics when they occur, and to stress acceptance and belonging. The recommended approach to educating teachers and peers is to be completed by a trained professional, and/or informational multimedia options that are available. Research regarding the effectiveness of peer education has resulted in mixed outcomes; however, peer education is nonetheless a recommended practice (Packer, 2005).

All three participants discussed their experiences with teacher and peer education, and expressed their own personal thoughts and feelings regarding the delivery and effectiveness of this practice. Hannah and Kyle's classroom teachers took it upon themselves to serve as peer educators to inform all three participant's classmates about Tourette's Syndrome; information regarding the syndrome, its characteristics, and how to react towards those with Tourette's. All three participants felt that by their classroom teachers educating their peers about their Tourette's that it ultimately made them feel more safe, accepted, and comfortable in their educational environment. Although the peer education did result in more students directly questioning them about their Tourette's, participants did not feel this was a negative experience, but rather a positive one as it demonstrated their curiosity and interest in their Tourette's.

The manner in which Kyle and Hannah's teachers delivered the peer education differed slightly between each individual. Kyle's teacher took it upon herself to locate a video on Tourette's Syndrome and decided to share it with Kyle's classmates. Although her intent with the video was to serve as an information tool, it unfortunately did not accurately depict Kyle's specific, less severe case of Tourette's. The video, however, did act as an informational tool in which Kyle was appreciative of his teacher advocating for him and his Tourette's Syndrome. Hannah and her classroom teacher had agreed that together they would inform her classmates about her Tourette's. For Hannah, she believes this was a good decision to allow her peers to understand her Tourette's, as well as to prevent any possible issues of social ostracization or bullying from occurring. Regardless of the method selected by the teacher to present information to the participants peers, all three participants have identified they were appreciative and grateful their classroom teacher advocated for them on their behalf. The positive impact of peer education supports the theory that peer education is a recommended intervention practice (Prestia, 2003).

Extracurricular

Individuals living with Tourette's Syndrome are encouraged to engage, participate and live a normal life. Although minimal research exists on the effects of involvement in extracurricular activities, studies have shown that participation in competitive sports and artistic activities have assisted in the improvement of their overall self-concept (Schapiro,

2002). In addition to self-concept improvement, involvement in such activities also contains positive gains in other areas as well. For children and adolescents who participate in a variety of activities, the time they dedicate to their interests acts as a proactive strategy of resilience by providing them with ample opportunities to engage in regular social interactions with peers (Schapiro, 2002). As a result, it can be argued that regular extracurricular involvement serves as a positive experience for children and adolescents with Tourette's Syndrome as it increases their overall self-concept and self-esteem, while additionally presenting them with critical positive peer relationships.

The participants involved in this study all discussed the variety of extracurricular activities they have been and continue to be involved with. All three individuals articulated the fundamental role activities have served as a positive outlet in their lives. These engagements provided them with opportunities to engage in social interactions and develop their self-esteem. As Brad reflects on how sports had an effect on his development, he realizes that this venue has provided him with peers. For Brad and Kyle, it is clear how their involvement in athletics as children has played an essential role in their overall development. Both Brad and Kyle were heavily engaged in a variety of sporting activities as children, and their passion and athletic skills have continued to be pursued at the adult level. Hannah at her young age is able to realize the importance of being involved in a variety of hobbies. Although she does not yet fully understand or identify that such involvement creates positive peer relationships, her participation undoubtedly does.

As all three participants discussed the positive developments they have perceived as a result of regularly being involved in extracurricular activities, they also articulated an additional important aspect. For Brad, Hannah and Kyle, their participation in leisure interests caused a reduction in the occurrence of their tics. These activities served as a place to hide and disguise their tics. In addition to their tics being hidden and disguised by activities, their engagement in leisure interests also served as a place where they could ultimately become distracted from their tics as well as forget about their tics entirely. Brad indicated his tics would not occur while he was engaged in a volleyball rally, but would manifest as he rested. Hannah expressed that her tics would disappear while she was quad riding. She described how activities, such as horseback riding, ultimately made

her forget about her tics as she was kept busy by the activities. Kyle's response was similar to Hannah's stating that his mind would become focused on the activity he was engaged in and help deter him from concentrating on his tics. As a culmination of how all three participants described how extracurricular events have assisted them to achieve happiness and normalcy, Brad states it best by articulating that sports provided him with an environment in which he could truly feel normal and not set apart as a result of his Tourette's.

Information

Being able to gather, learn and understand as much information as possible regarding Tourette's Syndrome is beneficial to ensure resilience to the syndrome. By individuals developing an understanding of Tourette's and how it will remain and affect them throughout the course of their lives, it provides them with supportive reassurance they can live a successful and productive life. As Robertson (2000) indicated, supportive reassurance is part of the management of Tourette's Syndrome. All three participants in this study were provided with substantial information regarding their condition, as supplied by their parents, specifically their mothers, or research conducted by them independently.

For Brad, Hannah and Kyle, they have all been provided with information about Tourette's Syndrome by their mothers. It was their mothers who served as the center of information about Tourette's, who were then able to deliver their knowledge to their child who was living with the syndrome. This information served as a key component to the understanding of their condition. In addition, the information acted as a source of reassurance as they were able to connect their Tourette's with the data made available by medical professionals or other individuals living with Tourette's. A parallel that occurred between how information was distributed between all three participants occurred in the manner it was delivered. All three individuals discussed how they had been exposed to different videos focusing on Tourette's Syndrome. In addition, all three agreed that these videos provided them with more knowledge and understanding about their Tourette's. The videos also presented them with an opportunity to find connections between their Tourette's and the Tourette's symptoms depicted in the video. Further, the videos all had a great impact on their future, as the video's demonstrated successful adults living normal

lives with their Tourette's Syndrome. As Brad indicated, it allowed him to develop an understanding that he too could live a happy and successful life. He stressed the importance viewing a video played in the positive outlook he had on his future.

Brad indicated that the knowledge he gathered about his Tourette's Syndrome was a critical component to his understanding of Tourette's. It provided him with knowledge to understand how his Tourette's Syndrome was occurring as well as how it would affect him in the future. Hannah is currently viewing different forms of media to gather information about Tourette's and is able to distinguish similarities and differences between her Tourette's and those depicted. Kyle indicated how his knowledge mainly came from second hand experiences as described by his father, but he also gained more information about his condition once he was able to connect with another peer his own age living with Tourette's Syndrome. For him, this served as the most effective and profound source of information that he was able to acquire, as he finally could find a true connection with another individual living with Tourette's. This served as the paramount informational tool.

Acceptance

There is no current literature surrounding the topic of accepting a lifelong Tourette's Syndrome diagnosis. Although no such research currently exists, each participant was able to thoroughly articulate the processes they have taken in order to arrive at a level of acceptance that Tourette's will remain a constant throughout the course of their lives. For Brad, Hannah and Kyle, each of them have developed their own path of understanding and accepting their Tourette's Syndrome. Each of the three has their own unique methods and viewpoints to how they have developed their acceptance. There are also parallels of how each participant has developed their acknowledge their Tourette's.

No research to date has been conducted examining the effects that an individual's personality plays in the treatment of Tourette's. Although no research in this area has been pursued, it was found in this study that Brad's personality played an active role in enabling him to learn to manage and accept his Tourette's Syndrome. Brad articulated the importance a sense of humour has played throughout the course of their lives in efforts to manage, cope and accept his Tourette's, especially during potentially arduous

moments. He quickly learned from an early age that his most effective tool would be a humorous personality. With this state of mind, he began to learn to treat his Tourette's with a sense of humour in order to make his life with Tourette's more positive and allowing him to persevere through life's challenges.

Hannah has only been diagnosed with her Tourette's Syndrome two years ago. As a result, she has just begun to develop an understanding of her syndrome as well as how it has and may affect her throughout the course of her life. However, her acceptance of her Tourette's mirrors Kyle's belief; together these two individuals contain the belief that their Tourette's has made them ultimately unique and distinctive. Hannah clearly articulated that her Tourette's has made her even more special, and as a result she is thankful for what she has in life.

Kyle was able to accept his Tourette's more readily from an early age as a result of his father living with Tourette's. As Kyle indicated, his family was not stunned by his diagnosis, but rather almost expected it. As a result, Kyle's acceptance perhaps came easier, as he was able to view his father living with Tourette's. His acceptance of his Tourette's also gradually developed with age as well, as Kyle stated his negative feelings towards Tourette's diminished as he matured. In addition, Kyle also believes that his Tourette's Syndrome has provided him with the outlook of being different, and perhaps even special expressed through a positive mind frame.

Study Limitations

This study was limited in regards to its sample size. Due to the low incidence of Tourette's Syndrome and interest in participating in this study, a relatively small sample size occurred. In addition to a low number of participants, the age of the participants was limited as well, as two of the three participants involved in the study were the same age. As a result, this did not provide an opportunity to explore a variety of individuals with Tourette's Syndrome at varying ages, rather only allowed for the experiences of two varying age groups in total. An additional limitation occurred by having all three participants involved in the study from the same geographical location. A more randomized locale of each participant would be more desirable to achieve greater diversity in their experiences. In efforts to reduce the identified limitations of the study

and progress forward with research in the area of Tourette's Syndrome, implications for future research will be identified and discussed.

Implications for Future Research

The objective of this study was to explore the lived experiences of individuals with Tourette's Syndrome, with a focus on how the syndrome impacted their educational, social, and emotional realms. In regards to future research being pursued in this area, there are specific segments to be focused on. Foremost, there is a need for a larger sample to further compare and contrast participant's experiences living with Tourette's Syndrome. By having more participants involved in such a study, one can examine and identify supplementary common themes and emerging differences as identified by each individual. Second, identify the severity of each participant's Tourette's Syndrome using the Yale Global Tic Severity Scale (YGTSS) (Bloch et al., 2006). By doing so, it would permit the researcher to compare and contrast the degree of how the severity of the participant's Tourette's directly impacts their life experiences. If such measures were to be taken, a trained professional with YGTSS experience must be used as a resource in the study. Third, interviewing a participant's family member (i.e. parents) would offer an external insight into how they have observed the Tourette's has affected their family member's life. These peripheral opinions would offer an additional dimension of information that may enhance or differ from the information gathered from the participant living with Tourette's Syndrome.

By implementing the suggested implications for future research, there are benefits to be made. The information gathered from more participants living with Tourette's Syndrome will provide further insight in regards to the depth of how the syndrome impacts each individual on a similar or different basis. Any research pursued on how Tourette's Syndrome impacts one's educational, social and emotional experiences will ultimately provide a much needed foundation to develop an understanding on the effects Tourette's Syndrome plays on individual lives. Other dimensions of one's life experiences can also be explored, such as the parental impacts experienced by having a child with Tourette's Syndrome, successful treatment methods and options, as well as examining the role extracurricular opportunities assists in the development of happiness and success.

This study utilized a qualitative method to explore personal experiences of individuals living with Tourette's Syndrome. The use of a quantitative research method may also prove to be beneficial. Through a quantitative approach, a larger sample size could be obtained, while also increasing the possibility for participants since anonymity could be assured. Thus, participants would possibly feel more secure to share their private personal experiences. As previously indicated, a larger sample provides researchers with more results to compare and contrast and ultimately create more valid and trustworthy results.

Educational Implications

When considering the low incidence level of Tourette's Syndrome, 5-30 children per 10,000, the probability of encountering a child with Tourette's Syndrome is quite rare (APA, 2000). Regardless of the low incidence level, due to the unique nature of Tourette's it is critical for professional educators to recognize, understand and support students with Tourette's. Educators must be knowledgeable about the facts regarding Tourette's, and demystify the common belief that Tourette's Syndrome is simply a "foul mouth disease" (De Lange et al., p. 613, 2003). Due to the fact children spend a vast majority of their lives situated in an educational environment, it is essential that all educational personal involved implement proactive strategies to assist students with Tourette's Syndrome in the academic setting.

Minimal research has been conducted focusing on the impacts peer education serves as a proactive strategy to support students with Tourette's. Despite this, research which has been pursued in this area supports the notion that peer education serves as a critical intervention tool to assist the student with Tourette's (Packer, 2005; Shprecher and Kurlan, 2009). When deciding to pursue peer education, it is vital that the parents of the child with Tourette's, as well as the child themselves are involved in the implementation of peer education. All professional educational personal should collaborate and discuss necessary interventions and strategies that will best suit the student's needs inside the educational environment. Once a team approach has been determined, it is then necessary to decide how the peer education will occur, which personnel will be involved, and what information will be shared.

In addition to educators implementing peer education, it is also imperative they provide the student with necessary adaptations and accommodations inside the classroom. Due to each Tourette's Syndrome case being unique dependant on severity, the necessary adaptations and accommodations will need to be suited to meet the individual needs of the student. As Wilson and Shrimpton (2003) indicated, the most effective strategy is one of a multi-faced nature, focusing on how the needs of the student can be met in all dimensions. Wilson and Shrimpton (2003) have designed a framework which focuses on meeting the needs in their physical, social/emotional and psychological dimensions. With this framework as the focus, the student with Tourette's will experience success in the educational environment and ultimately develop heightened self-esteem and a self-concept. As Prestia (2003) stated:

identifying challenges, developing interventions that use student's strengths, and promoting an environment that values diversity and acceptance of others are key components to unlocking the potential of students with TS. With carefully planned interventions and adaptations, the success of students with TS in the school setting can be enhanced. (p. 71)

Practical Academic Applications

The results of the study allowed for the identification of eight findings. As a result, three of the findings that emerged can directly be applied to assist educators in the academic setting. Findings that can be directly applied into the educational environment include peer education, social interactions and extracurricular involvement. By implementing these three specific opportunities, two other findings can simultaneously be implemented; information and acceptance. These two themes do not need to be specifically addressed, but can be achieved by being interwoven into the peer education, social interaction, and extracurricular applications. Rather than speaking directly to students about information and acceptance of Tourette's Syndrome, these two areas can be integrated into each of the opportunities. This can be successfully accomplished by educating students about Tourette's Syndrome (i.e. characteristics and classroom adaptations) while simultaneously encouraging acceptance of all individuals, regardless of an exceptionality, through peer education, social interaction and extracurricular experiences. This ensures that classmates are not explicitly lectured regarding

information about Tourette's Syndrome and acceptance of students with Tourette's, thus allowing for the integrated process of these two specific themes running concurrently throughout each of the three applications. Through developing an understanding and application of the findings, this can guide educators in how to best support students with Tourette's Syndrome in the educational environment.

The decision to implement peer education can be a valuable experience for both the student with Tourette's and their peers. All three participants discussed their experiences with peer education, both positive and negative. Hannah articulated her strong belief in the success of her peer education program by reducing the potential for bullying from occurring. By educators and peers acknowledging student exceptionalities and diversity, this creates proactive strategies for positive student engagement and social interactions.

Directly associated with peer education is the notion of strong social supports. Students with Tourette's Syndrome are apt to experience negative social experiences throughout the course of their lives. In order to combat this occurrence, encouraging supportive social networks is of utmost importance. Implementing strategies such as circles of friends, positive student pairing, and social networking inside the classroom environment are all useful to support constructive social interactions. As indicated by all three participants, their constant support and understanding came from a consistent, encouraging, and strong social circle. It was this peer group that ultimately assisted in their development of happiness and an optimistic future.

All three participants discussed the importance that extracurricular involvement has provided them with. Not only did extracurricular activities cause a reduction in their tics, it simultaneously provided them with an opportunity to build social networks as well as develop their overall self-esteem. In the educational environment there are a variety of opportunities for students to be involved in extracurricular athletics and activities. Educators need to encourage students with Tourette's Syndrome to be actively involved in a diverse array of extracurricular endeavours. This in turn will result in their overall development of feeling a strong sense of belonging, happiness, and optimism.

Conclusion

In conclusion, the findings of this study have demonstrated how Tourette's Syndrome has a profound impact on each participant's educational, social, and emotional dimensions. Although each participant's Tourette's did not create intellectual impairments inside the educational environment, the social environment contained within the educational setting has proven to be a main element involved. The educational environment proved to be challenging for all participants during specific periods of their lives. They encountered moments of discomfort, teasing and embarrassment. However, they have each in their own unique way, found outlets of support in efforts to combat the moments of negativity they have experienced. Familial support, specifically maternal, extracurricular activities, and sustained friendship have all proven to be successful intervention strategies. The combination of their educational, social and emotional dimensions all have interplayed simultaneously throughout their development. The study has identified and discussed how Tourette's has played a central role in each participant's social and emotional developments. In addition, it has revealed how their Tourette's Syndrome has allowed them to view themselves as unique and special individuals who are not looking for pity. They have overcome potentially tremendous obstacles as a result of their Tourette's, and as a result, can be viewed as courageous individuals who have not allowed their Tourette's Syndrome to ruin their lives. The individuals who participated in this study courageously opened their intimate personal experiences for others. Their efforts allowed for valuable knowledge and information demystifying the stigma surrounding Tourette's Syndrome to be spread. Each participant recognizes that although they face a potentially arduous exceptionality, they do not want the label of being different or feelings of pity. They would rather be viewed as their own unique individual. For that, they are grateful.

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**APPENDIX A:
Ethics Proposal**

**Behavioral Research Ethics Proposal
Format for Application for Approval of Research Protocol**

1. Name of Researcher: Melanie Bilokreli

Supervisor: David Mykota

Department: College of Education, Educational Psychology and Special Education

1a. Name of Student: Melanie Bilokreli (M.Ed Candidate)

1b. Anticipated start date of research study: July 2008

Expected completion date of research study: January 2009

2. Title of Study: Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry

3. Abstract:

Tourette's Syndrome is a complex, chronic, neuropsychiatric developmental disorder characterized by involuntary motor and phonic tics (APA 2000). As Marsh (2007) indicated, there is a substantial amount of erroneous pieces of information existing in our present society regarding Tourette's Syndrome characteristics which society has cruelly and unjustly stigmatized Tourette's Syndrome. Therefore, it is essential that supportive understanding and awareness is promoted in order to cease this misrepresentation of Tourette's Syndrome being a condition plagued with socially inappropriate and obscene language and gestures. By achieving understanding and awareness, this will ideally lead towards the development of a more accurate a representation of Tourette's Syndrome. For this study, a qualitative research approach, informed by narrative inquiry, is proposed to answer the question "What are the experiences of individuals living with Tourette's Syndrome on how the disease impacts their daily lives? By addressing this question, three specific subtopics will be of central focus. The educational experiences, social interaction relationships, and emotional realms will be the core elements pursued and examined". Interviews will be the main data method used facilitated by prompting questions in efforts to encourage individuals to share their experiences, stories, thoughts,

feelings and perspectives. The results of this study will be of particular interest to educators, counselors, and other individuals living with Tourette's Syndrome.

4. Funding: No sources of funding exist for supporting this research.

5. Expertise: This section may be omitted as a result of none of the criteria involving vulnerable populations, distinct cultural groups, or in cases where the research is above minimal risk is applicable.

6. Conflict of Interest: This section may be omitted as a result of none of the criteria involving conflict of interest or financial benefits are applicable.

7. Participants:

Due to the low incidence of Tourette's Syndrome in the province of Saskatchewan, participants will be selected using a method of convenience sampling. Advertisements describing the nature of the study will be posted on various Saskatchewan websites concerning disabilities. Potentially interested participants will be able to respond to the advertisements through means of communication with myself, the researcher, via telephone, as indicated on the advertisements. The eligibility criteria for the study includes any individual, between the ages of 8-30 years of age, who (a) were diagnosed with Tourette's Syndrome, (b) able to communicate orally in English, (c) willing to participate, and (d) signed consent or in the event of a child participating, had parental permission/consent to participate in the study.

7a. Recruitment Material: Appendix A

8. Consent: Consent will be obtained directly in person upon the participants completing the consent forms. Consent forms are located in Appendix B and clearly outline the details of the study and the rights and obligations of the participant. The participant's signature on the form will therefore signify the participants' understanding of their consent, obligations, and rights. In all cases of children under the age of 18, signed consent of the parent(s), guardian(s), or caregiver(s) will be obtained prior to their participation. The child's permission will also be obtained through their own assent form.

9. Methods and Procedures:

Two to three interviews not exceeding 90 minutes in length will be the method of data collection in this study. A list of prompting questions (Appendix C) will be utilized in

efforts to facilitate conversation and inquiry. The participant may refuse to answer any questions and will be allowed to withdraw at any time without penalty. Interviewing methods will be used along with prompting questions to obtain information regarding experiences living with Tourette's Syndrome. An initial meeting will be facilitated in efforts to begin building and establishing rapport, and explaining the purpose of the study. The participants will be informed of their rights, consent, and obligations along with an explanation of the consent form.

Interviews will occur in a safe, non-threatening environment located on the University of Saskatchewan campus in the College of Education, as agreed upon by the researcher and participant. However, if the location is not possible, a similar location will be utilized as agreed upon by the researcher and participant.

Following each interview, transcripts will be created which participants will be asked to review for content and confidentiality, being able to alter or remove any kind of information they see as necessary. These revisions will be discussed with the researcher by phone or in person. Following completion of the two or three interviews and revisions of content, I will then begin to initiate the recreation of each participant's personal story. Following completion of each story, each participant will once again be asked to review the story for accuracy and confidentiality. It may be necessary for the researcher to contact the participants for clarification or for more information until no more revisions of the stories are required.

10. Storage of Data:

Following the conclusion of this study, the information which has been collected will be stored in a locked and secure file cabinet in my supervisor's, David Mykota, office. This data will be saved for a minimum of 5 years after the completion of the study.

11. Dissemination of Results:

Data collected will be used to provide written material for the thesis. The thesis will be submitted to the College of Graduate Studies and Research in partial fulfillment of the requirement for the degree of Master of Education in the Department of Educational Psychology and Special Education, University of Saskatchewan.

12. Risks, Benefits, and Deception:

This research project does not include any elements of deception. There are minimal anticipated risks associated with this study. However, certain personal experiences may at times be difficult to speak of. At all times, participants are free to decide what they will or will not disclose, and may therefore choose not to answer a question.

Furthermore, a list of professional resources (e.g. counseling services) will be made available to participants, should they feel the need to further resolve their feelings.

Participants will be debriefed in the initial meeting regarding the nature of the study.

Participants may refuse to answer any questions and are free to withdraw from the study at any time without penalty. Should the participant withdraw, all data will be promptly destroyed.

Written consent will be obtained from each participant. Audiotapes will be used with the written consent of the participants. Information will be kept confidential and be coded with no identifying information.

Pseudonyms will be used in the final written thesis to insure complete anonymity. The participants will not receive compensation, but have the opportunity to share their story regarding living with

Tourette's Syndrome in efforts to promote awareness and understanding.

The costs/inconveniences/risks of this study include:

1. The understanding that participating requires approximately two to three interviews not exceeding 90 minutes of the participant's time.
2. The understanding that the participant will be required to approve the accuracy of their interview transcript.
3. The understanding that the participant's permission must be given to use their transcript in the final written thesis of Melanie Bilokreli (Researcher).

The benefits of the study include:

1. The opportunity in sharing personal experiences of living with Tourette's Syndrome.
2. The opportunity to assist others (i.e. educators and counselors) in developing an awareness and understanding of Tourette's Syndrome.
3. The opportunity to allow others with Tourette's Syndrome to connect to the shared stories of experience described by the participant's.
4. The opportunity to contribute research of a qualitative nature that is much needed in the area of Tourette's Syndrome.

13. Confidentiality:

Confidentiality and anonymity of the participants will be insured. The participants will be informed verbally and in writing of their rights of confidentiality. They will also be provided a consent form (Appendix B) to sign which details the exact nature of the study, the right to refuse answering any questions, and the right to withdraw from the study at any time without penalty. Signature of the form will signify their understanding of their rights and will be taken as consent of the participant. All data will be coded and the participants will be given pseudonyms to protect the identity of each individual. All participants will have the opportunity to review and revise all transcribed interview data and also remove any of their responses. Participants will be requested to sign a transcript release form (Appendix D) where they will acknowledge by their signature that the transcript accurately reflects what they stated or intended to state. Signing of a sign-off release form (Appendix E) will indicate the participant’s consent to what it included in the final thesis document.

14. Data/Transcript Release:

The parent, and parent and child, will review the final interview transcript and sign the transcript release form found in Appendix D thereby acknowledging that the transcript accurately reflects what they stated or intended to state.

15. Debriefing and Feedback:

Opportunity for debriefing and feedback will take place when the data/transcript release and sign-off forms are signed by the participants. Parents will be debriefed one-on-one whereas their child may be debriefed one-on-one, or with parent(s) present, depending on the comfort level of the child and/or parent(s). The participants will have the opportunity to receive a copy of the final completed thesis.

16. Required Signatures:

Researcher Name: _____ Signature: _____

Supervisor Name: _____ Signature: _____

Department Head: _____

Signature: _____

Other (if necessary): _____

Signature: _____

Contact Name:

Melanie Bilokreli

Phone: 306-374-3776

Email: mdb833@mail.usask.ca

David Mykota

Phone: 306-966-5258

Email: david.mykota@usask.ca

**APPENDIX B:
Sample Advertisement**

“Narrative Inquiry of Individuals with Tourette’s Syndrome”

Participants diagnosed with Tourette’s Syndrome are being recruited to voluntarily participate in a research project titled *Unraveling a Life of Tourette’s Syndrome: A Narrative Inquiry*. The overall goal of this study is to develop an understanding of the experiences, thoughts, feelings, and perspectives regarding personal experiences of individuals living with Tourette’s Syndrome. The purpose of this research is to provide participants with an opportunity to share their stories of their daily experiences living with Tourette’s Syndrome. The benefits of participating in this study as a participant include an opportunity to contribute to an awareness and understanding of personal experiences living with Tourette’s Syndrome. By doing so, these experiences can also assist professionals (i.e. educators and counselors) to develop an understanding of the disorder, as well as provide other individuals living with Tourette’s Syndrome an opportunity to find connections and comforts with your experiences.

Participation in this study will involve answering guiding questions regarding participants experiences living with Tourette’s Syndrome. This will occur in approximately two to three interviews consisting of no greater than 90 minutes per interview. Interviews will be audio taped and transcribed, and will be securely stored in a locked file cabinet in my supervisor’s office for a minimum of 5 years. Confidentiality regarding the information that is provided will be assured by the researcher and my supervisor and your individuals answers will not be shared or presented in any manner that would identify the participant as the source.

If you have any questions, or are interested in participating in this study, please feel free to contact me by the following methods:

Melanie Bilokreli

Masters of Educational Psychology and Special Education Candidate

Telephone: 306-374-3776

Email: mdb833@mail.usask.ca

APPENDIX C:
Guiding Questions - Participant

1. Tell me how your Tourette's Syndrome diagnosis came about?
2. How did you feel when you were initially diagnosed?
3. How do you feel now about your Tourette's?
4. Share a positive experience with your Tourette's.
5. Share a negative experience with your Tourette's.
6. How has your Tourette's Syndrome impacted your life? In what ways?
7. What characteristics does your Tourette's present you with now? Past? Any change?
8. How does your family react/feel to your Tourette's?
9. How do your friends react/feel about your Tourette's?
10. What were your school experiences like?
11. What activities do you engage in? How have they helped you?
12. What do you know about your Tourette's?
13. What does your future look like?
14. If you could share anything to outside individuals who do not know about Tourette's Syndrome, what would it be and why?
15. How do you feel about how the media has portrayed Tourette's Syndrome?
16. Describe a typical day.
17. What does your Tourette's feel like to help others understand?
18. If you could pick one word to describe your Tourette's, what would it be and why?

Guiding Questions - Parent

1. Tell me how the Tourette's Syndrome diagnosis came about.
2. How did you tell your child about the diagnosis? What did you say?
3. What symptoms does your child display?
4. Have you shared this information with the school?
5. What medications/therapies have you tried?
6. Where have you found information about Tourette's Syndrome? Has it been helpful?

APPENDIX D:
Consent Form - Participant

Title of Study: Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry

Researcher:

Melanie Bilokreli, Master of Education candidate in the College of Educational Psychology and Special Education, University of Saskatchewan

You are being asked to voluntarily participate in a research project titled *Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry*. The overall goal of this study is to develop an understanding of your experiences, thoughts, feelings, and perspectives regarding your experiences living with Tourette's Syndrome. The purpose of such is to provide you with an opportunity to share your stories of your daily experiences living with Tourette's Syndrome. Through a narrative inquiry approach, your stories will ultimately be re-created and constructed in order to act as a communication format to organize, represent and explain your personal experiences. The benefit to you as the participant is an opportunity to contribute to an awareness and understanding of your personal experiences living with Tourette's Syndrome. By doing so, your experiences can also assist professionals (i.e. educators and counselors) to develop an understanding of the disorder, as well as provide other individuals living with Tourette's Syndrome an opportunity to find connections and comforts with your experiences.

Participation in this study will involve answering guiding questions about your experiences. This will occur in approximately two to three interviews consisting of no greater than 90 minutes per interview. Ideally, interviews will be conducted at the University of Saskatchewan's College of Education building. Interviews will be audio taped and transcribed, and will be securely stored in a locked file cabinet in my supervisor's office for a minimum of 5 years. Confidentiality regarding the information that you provide will be assured by the researcher and my supervisor and your individuals answers will not be shared or presented in any manner that would identify you as the source. However, despite being presented anonymously, the details of your stories may make you identifiable to people who already know you.

Upon beginning the study, you will be provided with a brief explanation of the study and presented with an opportunity to ask questions. You may refuse to answer any interview question and are free to withdraw from participation in this thesis study at any given time. If you choose to withdraw from the study, all information you provided will be destroyed.

You will have the opportunity to review and revise all transcribed interview data and your recreated story and remove or alter any of the information at any given time. You will be asked to sign a transcript release form, acknowledging that the transcript and recreated story accurately reflects what was said in your personal interview and also giving permission to include excerpts from the transcripts to be used in the thesis. Further contact by the researcher after the interviews will be to accommodate questions or clarification.

If you have any questions or concerns regarding the project itself or the methods utilized, please contact Melanie Bilokreli (Researcher) at 306-374-3776 or David Mykota (Supervisor) at 306-966-5258.

The proposed research project was reviewed and approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board on _____, 2008. Please feel free to contact the Ethics Office collect at 306-966-2084 if you have any questions regarding this study or the rights of a participant in any study.

I have read and understand the description provided above; I have been provided an opportunity to ask questions and my questions have been answered satisfactorily. I agree to participate in the study described above, with the understanding that I may withdraw this consent at any time. **A copy of this consent form has been given to me for my records.**

Name of Participant: _____

Signature of Participant: _____

Date: _____

Signature of Researcher: _____

Date: _____

Consent Form - Parent

Title of Study: Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry

Researcher:

Melanie Bilokreli, Master of Education candidate in the College of Educational Psychology and Special Education, University of Saskatchewan

You are being asked to voluntarily participate in a research project titled *Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry*. The overall goal of this study is to develop an understanding of your experiences, thoughts, feelings, and perspectives regarding your experiences living with a child with Tourette's Syndrome. The purpose of such is to provide you with an opportunity to share your stories of your daily experiences as a parent of a child with Tourette's Syndrome. Through a narrative inquiry approach, your stories will ultimately be re-created and constructed in order to act as a communication format to organize, represent and explain your personal experiences. The benefit to you as the participant is an opportunity to contribute to an awareness and understanding of your personal experiences with Tourette's Syndrome. By doing so, your experiences can also assist professionals (i.e. educators and counselors) to develop an understanding of the disorder, as well as provide other individuals living with Tourette's Syndrome an opportunity to find connections and comforts with your experiences.

Participation in this study will involve answering guiding questions about your experiences. This will occur in approximately two to three interviews consisting of no greater than 90 minutes per interview. Interviews will be conducted at the University of Saskatchewan's College of Education building. Interviews will be audio taped and transcribed, and will be securely stored in a locked file cabinet in my supervisor's office for a minimum of 5 years. Confidentiality regarding the information that you provide will be assured by the researcher and my supervisor and your individuals answers will not be shared or presented in any manner that would identify you as the source. However, despite being presented anonymously, the details of your stories may make you identifiable to people who already know you.

Upon beginning the study, you will be provided with a brief explanation of the study and presented with an opportunity to ask questions. You may refuse to answer any interview question and are free to withdraw from participation in this thesis study at any given time. If you choose to withdraw from the study, all information you provided will be destroyed.

You will have the opportunity to review and revise all transcribed interview data and your recreated story and remove or alter any of the information at any given time. You will be asked to sign a transcript release form, acknowledging that the transcript and recreated story accurately reflects what was said in your personal interview and also giving permission to include excerpts from the transcripts to be used in the thesis. Further contact by the researcher after the interviews will be to accommodate questions or clarification.

If you have any questions or concerns regarding the project itself or the methods utilized, please contact Melanie Bilokreli (Researcher) at 306-374-3776 or David Mykota (Supervisor) at 306-966-5258.

The proposed research project was reviewed and approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board in August, 2008. Please feel free to contact the Ethics Office collect at 306-966-2084 if you have any questions regarding this study or the rights of a participant in any study.

I have read and understand the description provided above; I have been provided an opportunity to ask questions and my questions have been answered satisfactorily. I agree to participate in the study described above, with the understanding that I may withdraw this consent at any time. **A copy of this consent form has been given to me for my records.**

Name of Participant: _____

Signature of Participant: _____

Date: _____

Signature of Researcher: _____ Date: _____

Parental Consent
(For child under 18 years of age)

Title of Study:

Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry

Researcher:

Melanie Bilokreli, Master of Education candidate in the College of Educational Psychology and Special Education, University of Saskatchewan

Your child is being asked to voluntarily participate in a research project titled *Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry*. The overall goal of this study is to develop an understanding of your child's experiences, thoughts, feelings, and perspectives regarding your experiences living with Tourette's Syndrome. The purpose of such is to provide them with an opportunity to share their stories of their daily experiences living with Tourette's Syndrome. Through a narrative inquiry approach, your child's stories will ultimately be re-created and constructed in order to act as a communication format to organize, represent and explain your child's personal experiences. The benefit to your child as the participant is an opportunity to contribute to an awareness and understanding of their personal experiences living with Tourette's Syndrome. By doing so, your child's experiences can also assist professionals (i.e. educators and counselors) to develop an understanding of the disorder, as well as provide other individuals living with Tourette's Syndrome an opportunity to find connections and comforts with their experiences.

Participation in this study will involve answering guiding questions about your child's experiences. This will occur in approximately two to three interviews consisting of no greater than 90 minutes per interview. Ideally, interviews will be conducted at the University of Saskatchewan's College of Education building. Interviews will be audio taped and transcribed, and will be securely stored in a locked file cabinet in my supervisor's office for a minimum of 5 years. Confidentiality regarding the information that you provide will be assured by the researcher and my supervisor and your child's individuals answers will not be shared or presented in any manner that would identify

you as the source. However, despite being presented anonymously, the details of your child's stories may make you/your child identifiable to people who already know you.

Upon beginning the study, you and your child will be provided with a brief explanation of the study and presented with an opportunity to ask questions. Your child may refuse to answer any interview question and is free to withdraw from participation in this thesis study at any given time. If your child chooses to withdraw from the study, all information provided will be destroyed.

Your child, in the presence of the parent(s), will have the opportunity to review and revise all transcribed interview data and their recreated story and remove or alter any of the information at any given time. You will be asked to sign a transcript release form, on behalf of your child, acknowledging that the transcript and recreated story accurately reflects what was said in their personal interview and also giving permission to include excerpts from the transcripts to be used in the thesis. Further contact by the researcher after the interviews will be to accommodate questions or clarification.

If you have any questions or concerns regarding the project itself or the methods utilized, please contact Melanie Bilokreli (Researcher) at 306-374-3776 or David Mykota (Supervisor) at 306-966-5258.

The proposed research project was reviewed and approved on ethical grounds by the University of Saskatchewan Behavioral Research Ethics Board on _____, 2008. Please feel free to contact the Ethics Office collect at 306-966-2084 if you have any questions regarding this study or the rights of a participant in any study.

I have read and understand the description provided above; I have been provided an opportunity to ask questions and my questions have been answered satisfactorily. I agree to have my child participate in the study described above, with the understanding that they may withdraw this consent at any time. **A copy of this consent form has been given to me for my records.**

Name of Participant (child): _____

Signature of Participant (child): _____ Date: _____

Signature of Participant: _____ Date: _____

Signature of Researcher: _____ Date: _____

Children's Assent

Title of Study: Unraveling a Life of Tourette's Syndrome: A Narrative Inquiry

Researcher:

Melanie Bilokreli, Master of Education candidate in the College of Educational Psychology and Special Education, University of Saskatchewan

Please put a check mark (✓) if you agree with each of the following sentences:

_____ I would like to share my stories and answers questions about my Tourette's Syndrome.

_____ I will let Melanie use some of my stories to help others, but no one will know the stories that I tell are mine.

_____ I know that I can quit this study at any time I wish.

_____ I will receive a copy of this assent from Melanie.

Children's Signature: _____

Date: _____

**APPENDIX E:
Data/Transcript Authenticity**

This transcript form is to provide acknowledgement that the interview data accurately reflects what was said during the interviews which occurred with Melanie Bilokreli (Researcher). This data may be included in the final written thesis of Melanie Bilokreli (Researcher).

I, _____, hereby give acknowledgement that the transcribed interview data accurately reflects what was said in my interview. I am comfortable with the efforts that have been taken in order to ensure that any identifying information of this material has been altered or eliminated. I have reviewed the transcripts of my interview and hereby acknowledge this in the information and consent form. **I have a copy of the Sign-Off Permission Form for my own records.**

Signature of Participant

Date

Signature of Researcher

Date

Data/Transcript Authenticity (Child)

This transcript form is to provide acknowledgement that the interview data accurately reflects what was said during the interviews which occurred with Melanie Bilokreli (Researcher). This data may be included in the final written thesis of Melanie Bilokreli (Researcher).

I, _____, on behalf of my child,
_____, hereby give acknowledgement that the transcribed interview data accurately reflects what was said in my child's interview. I am comfortable with the efforts that have been taken in order to ensure that any identifying information of this material has been altered or eliminated. My child and I have reviewed the transcripts of my child's interview and hereby acknowledge this in the information and consent form. **I have a copy of the Sign-Off Permission Form for my own records.**

Signature of Participant (Child)

Date

Signature of Parent

Date

Signature of Researcher

Date

**APPENDIX F:
Sign-Off Release Form**

I, _____, have reviewed the stories of my lived experiences written by Melanie Bilokreli, and I agree that they accurately reflect what I shared during the interviews. I hereby provide my permission to include the above material for inclusion in Melanie Bilokreli's (Researcher) final written thesis, and/or to be used in a manner as described in the information and consent form. I am satisfied with the efforts which have been taken to ensure that any identifying information in this document has been altered or eliminated. **I have a copy of the Sign-Off Permission Form for my own records.**

Signature of Participant

Date

Signature of Researcher

Date

Sign-Off Release Form (Child)

I, _____, have reviewed the stories of my child _____ experiences written by Melanie Bilokreli, and I agree that they accurately reflect what I shared during the interviews. I hereby provide my permission to include the above material for inclusion in Melanie Bilokreli’s (Researcher) final written thesis, and/or to be used in a manner as described in the information and consent form. I am satisfied with the efforts which have been taken to ensure that any identifying information in this document has been altered or eliminated. **I have a copy of the Sign-Off Permission Form for my own records.**

Signature of Participant (Child)

Date

Signature of Parent

Date

Signature of Researcher

Date