THE RELATIONSHIP OF FATHERS WITH SONS WHO HAVE TOURETTE SYNDROME AND THE IMPACT ON THE FAMILY

by

Calvert F. Cazier

A dissertation submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

Department of Health Promotion and Education

The University of Utah

August 2012

The University of Utah Graduate School

STATEMENT OF DISSERTATION APPROVAL

The dissertation of **Calvert F. Cazier**

has been approved by the following supervisory committee members:

Glenn E. Richardson	, Chair	**5/7/2012** Date Approved
Sue Morrow	, Member	**5/7/2012** Date Approved
Patrick Panos	, Member	**5/7/2012** Date Approved
Richard Ferre	, Member	**5/7/2012** Date Approved
Julia Franklin Summerhays	, Member	**5/7/2012** Date Approved

and by **Les Chatelain** , Chair of

the Department of **Health Promotion and Education**

and by Charles A. Wight, Dean of The Graduate School.

ABSTRACT

Tourette syndrome (TS) is a misunderstood complex, chronic, neuropsychiatric disorder known for both involuntary muscle and vocal tics which manifests itself in childhood and usually has a lifelong duration.

Little research has been done on how families are impacted by having a child with (TS) and even less has been done on how fathers in particular are affected. Dealing with a child who has TS can be stressful to the parents as well as to the dynamics of and the family. While children with TS have many obvious challenges, their families face similar problems which may not be so readily apparent.

This study used qualitative research methods to study the relationships of fathers and their sons with TS. Qualitative research is useful for examining aspects of social life that are not easily accessed through quantitative data collection techniques.

The overarching finding which emerged in this study was that the fathers experienced a waxing and waning pattern of response in the face of an uncertain future which seemed to be influenced by the intrinsic nature of TS. They reported experiences along a continuum of success, ranging from effective responses which seemed to lead to personal growth and resilience and stronger relationships with their sons and families, to ineffective responses, difficulty developing personally, and relationship strain or deterioration. The waxing and waning pattern of responses occurred along five major themes: 1) the question of normalcy, 2) pride in son, 3) hope in the future, 4) acceptance, and 5) role satisfaction.

Each father had his own unique challenges to his son with TS which impacted his relationships with this son, his other children, and his wife. As a whole these fathers appeared to find effective ways over time to develop strong family relationships. Factors which seemed to propel these fathers forward included a clear understanding of and commitment to their roles as a father and husband and the successful development of a strong husband and wife team.

TABLE OF CONTENTS

Chapters

LIST OF FIGURES

ACKNOWLEDGEMENTS

There have been many supporters in the course of this project. Some, like my first wife, Carol Sorensen Cazier, and my mother, Lois Call Cazier, are no longer with me but had such a tremendous impact on me that I would be remiss not to acknowledge their influence. Carol supported me through my undergraduate and master’s degrees and a 30 year career in public health. My mother believed in me when others discouraged me from going to college, and she gave me the hope and determination to accomplish what I so desperately wanted.

I have been blessed with a father who, when my Tourette syndrome first manifested itself while I was in second grade, was able to love me, accept me, teach me, guide me, help me believe in myself, and most importantly be patient with me. He believed my Tourettic tics were a nervous disorder, and at first he asked me to stop a few times, and then he ignored them and encouraged me to live my life to the fullest. It wasn’t until I was 50 years old that my mom and dad learned that I had Tourette syndrome.

The members of my committee were exceptional, principled, encouraging, and willing to share their time and energy to help me complete this task. To Dr. Glenn Richardson, my committee chair, I express my appreciation for his encouragement to think outside the box and his guidance and advice when I really needed his expertise. His influence and friendship have impacted me for more than 30 years. I respect Dr. Sue Morrow as one of the best qualitative researchers in the University system, and her participation was such a blessing and welcome confidence builder for me. She graciously shared her expertise by providing input no one else could have provided. Dr. Patrick Panos first influenced me with his non-traditional approach in a research design class I took from him. His honest and open feedback has always been very helpful. Dr. Rich Ferre shared his expertise as a child and adolescent psychiatrist and published author on Tourette syndrome. He did so much to help me understand more about the difficulties that families with children with TS face and about myself as an adult with TS as well. Dr. Julia Summerhays always made me feel welcome to knock on her office door and seek advice about problems or bounce ideas off her. She also stepped up and provided important help and guidance at a time when it was especially needed.

I appreciate the time and effort given to me by my peer reviewers Carol Romagosa and Lester Keller. Their ability to read the raw data and offer suggestions was an integral part of completing this dissertation.

I would be very remiss if I forgot the most supportive and influential person responsible for me reaching my goal of a PhD, Anne Evans-Cazier, my wife, confidante, and best friend. Anne spent many hours with me conducting interviews of the fathers and even more hours editing this dissertation. Anne is an exceptional editor and without her help I could not have accomplished this task. She was always available to help me and as a result she sacrificed her time, including time when she could and should have been working on her own business. She was my rock and I love her and appreciate her for everything she did.

CHAPTER 1

INTRODUCTION AND REVIEW OF THE LITERATURE

Introduction to the Problem

> *"…some days I really want to give up…I suffer from depression…I don't handle it well…TS is hereditary…then I get angry at my bloodline."*
> *Reflections of a mother with a child with Tourette syndrome (TS)*
> *DeLange and Olivier, 2004, p. 71*

Tourette syndrome (TS) is a misunderstood complex, chronic, neuropsychiatric disorder known for both involuntary muscle and vocal tics (Abelson et al., 2005) which manifests itself in childhood and usually has a lifelong duration (Kurlan et al., 2002; Wilkinson, 2001). It is recognized as a developmental disorder involving structural abnormalities in the brain with genetic and environmental factors interacting in its expression (Leckman, Vaccarino, Kalanithi & Rothenberger, 2006; Stillman et al., 2009).

TS is considered the most severe as well as most common of the continuum of disorders with tics as their common feature (Kenney, Kuo & Jimenez-Shahed, 2008; Raffaele et al., 2004). Tic disorders can range from a mild transient tic (unrelated to TS and lasting less than 12 months) to the more blatant, debilitating tics found in TS (Hendren, 2002; Singer, 2005). The tics associated with TS last longer than 12 months and may impact the child (or adult) in many ways, including social, family, and academic. According to Leckman (2003) the degree to which the child with TS is impaired by his tics can depend on such factors as their frequency, intensity, number, and complexity along with any comorbidity the child may have.

While motor and vocal tics are obvious symptoms of TS, coprolalia is perhaps the most recognizable as well as distressing of all the symptoms experienced by those with TS (Blacher, downloaded 3/18/07; Shapiro, 2002; Singer, 2005). Coprolalia is a tic in which uncontrollable obscene words or loud, unintelligible sounds come out of the individual's mouth. This condition is somewhat rare and found in approximately 10% of those with TS (Singer).

Since de la Tourette first described this condition in 1885 (MedlinePlus, 2012), tics have been considered the hallmark of TS and the most visible symptom of this disorder (Jankovic, 2001; Leckman, 2003). A tic is a sudden, repetitive movement, gesture, or utterance that typically mimics some fragment of normal behavior. Tics are brief in duration and often occur in periodic bouts, with a frequency that may range from minimal occurrences only during times of anxiety or fatigue to uncountable bursts occurring as more than 100 times per minute (Hendren, 2002; Shavitt, Hounie, Campos, & Miguel 2006).

Very little research has been done on how families are impacted by having a child with Tourette syndrome (TS) and even less has been done on how fathers in particular are affected (Wilkinson et al. 2001; Woods, Himle, & Osmon, 2005). In the limited studies that have been conducted, parents of children with TS frequently report frustration, show a poor parent-child relationship and have marital difficulties (Wilkinson et al.; Woods et al.). Ylvén, Björck-Åkesson and Granlund (2006) found that families with children who have a variety of disabilities and chronic illnesses face daily stressors that can influence family functioning in negative ways. Although TS was not included in this study, it seems likely that families with children with TS face many similar challenges and outcomes.

People with TS report more problems than others with personal and social functioning, such as aggressiveness, mood swings, temper tantrums, and friendship and dating relationship struggles (Champion, Fulton, Shady, 1988), executive function difficulties (Jankovic, Kwak & Frankoff, 2006), being teased, ridiculed, embarrassed (Bruun, Cohen, & Leckman, 2009) and bullied (Chowdhury, 2004). It is not unusual for children with TS to come home from school or other activities devastated and demoralized and defeated because they do not know how to deal with the teasing, bullying, and harassment they experience (Chowdhury; HBO Documentary, 2005). Their self-esteem often suffers as they try to deal with social pressures from the outside as well as tics and other internal experiences such as difficulty focusing their attention, controlling their impulsivity, etc. By the time they come home they are frequently exhausted from trying to cope with internal as well as external forces that go beyond the normal developmental challenges (Carter et al., 2000). These challenges can provide an opportunity for personal growth and development but they can also lead to frustration, a miserable social life, academic problems and much heartache (Hendren, 2002; Woods & Marcks, 2005).

Dealing with a child who has TS can be stressful (Wilkinson et al., 2001) and greatly impact the parents as well as the dynamics of the family as a whole (Schapiro, 2002; Singer, 2005; Woods et al., 2005). While children with TS have many obvious challenges, their families face similarly challenging problems which may not be so readily apparent (Rosen 2002).

One particularly significant factor identified by Rosen (2002) is how well parents are able to accept things over which they have no control. Can they accept, for example, the social, emotional, and physical stresses that may result from having a child with TS? Can they deal with the stigmas, impulsivity, obsessions, and learning disabilities associated with their child’s Tourette's and comorbidities? Can they help their family accept, cope, function, and live with all the other challenges that may arise as a result of having a child with TS as a family member?

Dickstein (2002) emphasizes that a family is a complex system and that healthy interactions between the members are important to the optimal development of each member. Little is known about how fathers interact with their children with TS, whether they interact with their children with TS differently than how they interact with their other children, or, if they do, how this affects the family as a whole.

Overview of Tourette Syndrome

> *Nearly 125 years ago Georges Albert Eduard Gilles de la Tourette, a French neurologist, published his ground breaking paper Study of a Nervous Affliction (Delange & Olivier, 2004) in which he reported on nine patients who all had child-onset tics. During the course of his research he noticed that this group manifested other common symptoms as well. These other symptoms included uncontrollable noises and inappropriate and often times vulgar and insensitive utterances. In addition many of these patients had problems which today are being diagnosed as ADHD, OCD, and poor impulse control along with other coexisting problems of a behavioral nature (Jankovic, 2001; Tourette Syndrome Fact Sheet: National Institute of Neurological Disorders and Stroke, National Institutes of Health.)*

Background

History of TS

While de la Tourette defined this condition he did not know its precise etiology. He believed it to be hereditary, but for nearly a century thereafter the etiology of TS was attributed to psychogenic causes (Baylor College of Medicine, Patient Education; Jankovic, 2001; Robertson, 2010) and it was treated with psychoanalysis until the late 1960s, even early 1970s. In his proposal of a hereditary foundation, de la Tourette claimed that it was a degenerative problem that the patients inherited due to a nervous system caused by the immoral behavior of their parents, grandparents, etc. (Kushner, 2008). Today medicine recognizes de la Tourette's contribution of describing the symptoms and the course of illness, but refutes his attribution of it being a degenerative problem with a progressive deteriorating outcome (Kushner, 2008). TS is now recognized as a developmental disorder involving structural abnormalities in the brain with genetic and environmental factors interacting in its expression (Leckman et al. 2006; Stillman et al., 2009).

During the 1960s Dr. Arthur Shapiro, MD and his wife Dr. Elaine Shapiro, PhD. began pioneering research on the effect of using haloperidol (Haldol) to control Tourettic tics in a 24 year old woman (Shapiro & Shapiro, 1968).When this patient was first examined by a doctor at age 10 she had many tics and was described as an emotional child; later her doctors diagnosed her with "Habit tic[s] with hysterical background" (Shapiro & Shapiro, p. 345). Several years later when Dr. Arthur Shapiro examined this same woman, he diagnosed her with TS and started her on a treatment regimen using pharmaceuticals. Over the course of several months he treated her with various drugs and combinations of drugs in order to find something that would help her (Shapiro & Shapiro). Finally she was given haloperidol and responded favorably. This was a major breakthrough and led Shapiro and Shapiro to conclude that TS has an organic pathology in refutation of the prevailing belief that TS was psychological in origin.

In the 1980, 1987 and 1994 publications of the Diagnostic and Statistical Manuals of the American Psychiatric Association defined the clinical phenomenology of TS as simple and straight forward (Robertson, 2000) but current research has shown that it is far from simple. Robertson explains that there are now no doubts about TS having a genetic component but its pattern of inheritance is not clear.

Leckman, Vaccarina, Kalanithi, and Rothenberger, (2006) contend that the study of TS with all its sensorimotor urges, its motor and vocal tics, its comorbidities, etc. has been a nexus between the fields of psychiatry, neurology, and psychology. In other words, studying the interaction of genetic and environmental factors in TS has led to significant contributions in understanding developmental psychopathology in general and the results of these studies could be very relevant to other child onset chronic disorders and the development of greater understanding of normal development as well (Leckman, 2002).

Prevalence

Males are more likely to have TS than females, with estimates ranging from three to four times more likely (Dornbush & Pruitt, 2002) up to nine times more likely (Meidinger et al., 2005). At the 5th International Scientific Symposium on Tourette syndrome held in June of 2009, Dr. Rebecca Bitsko, PhD. of the Center for Disease Control presented the findings of the largest scale prevalence study completed to date. As part of the National Survey of Children's Health, 91,642 parents of children ages 6 – 17 were interviewed by phone and approximately 148,000 children were identified by their parents as having been diagnosed with TS, for a prevalence rate of about 3/1,000. Boys were three times more likely to have been diagnosed with TS than girls. The majority of cases were characterized as mild, while 27% were considered moderate to severe.

Clinical

Etiology

While the etiology of TS is still not fully understood, Bagheri, Kerbeshian, and Burd (1999) reaffirmed the role of genetics while also concluding that environmental factors can influence the severity, risk and course of TS. Most researchers do not believe that TS is caused by a single gene, but rather they believe that many genes have a role in its etiology (Leckman et al. 2006). Promising work by Stillman et al. (2009) and others is being done to identify the gene or genes responsible for TS. Speculation is ongoing that mutations on basal ganglia in the brain may be the cause of TS. Much about the function of the basal ganglia remains unknown at this time, however researchers believe that it may play a role in the planning and coordination of specific movement sequences and in the selection of which of the actions being considered by the cortex actually gets executed (http://www.biology.emory.edu/research/Jaeger/BasalGanglia/BG_page.html).

Some environmental factors showing a possible correlation with increased risk for TS include: low birth weight children (Leckman, 2002; Mathews et al., 2006); prematurity (Robertson, 2000); perinatal hypoxia (Leckman et al., 2006); higher incidence of maternal and obstetric complications, older parents, health problems manifesting in newborns as measured by lower Apgar score (Mathews et al., 2006);

delivery with forceps, maternal stress, nausea smoking and use of alcohol and coffee (Mathews et al., 2006; Robertson, 2000).

Presentation and Manifestation of TS

The DSM-IV TR (2000) establishes the following criteria for diagnosing TS: (a) both multiple motor and one or more vocal tics 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 post viral encephalitis).

Normally a child will present to the doctor with chronic motor and vocal tics which usually start as simple tics affecting the eyes, head, and face as well as the shoulders and extremities (Shavitt et al., 2006). Typical onset is during childhood or adolescence with manifestation generally somewhere between 3 to 8 years of age, most frequently around 7 years (Raffaele et al., 2004; Shavitt et al.). Jankovic (2001) reports that this disorder is manifested by age of 11 in 96% of patients. Tics generally peak just before adolescence and tend to decline as the child moves into adulthood (Kenney et al., 2008).

More than 80% of those diagnosed with TS as children have symptoms that diminish as they go through adolescence and into adulthood (Bagheri et al., 1999). Some researchers believe that a full remission of symptoms occurs in as many one-third of those with TS after they enter adulthood (Munson, 2005) while others believe the symptoms only diminish (Bagheri et al.). Five to ten percent of patients experience a course of intensifying symptoms with little or no improvement (Bagheri et al.). Figure 1 outlines in detail the clinical course of TS over a lifetime.

Tourettic Tics

Tics are part of a sensory urge that people with TS feel and to which they must respond (Kenney et al., 2008; Shavitt et al., 2006). While tics are real, people with TS can suppress them for short periods of time, during which the pressure to release the tics mounts (Woods et al., 2008). Eventually, however, the pressure becomes too much and the tics must be released.

Premonitory urges or sensations often precede and prompt Tourettic tics (Leckman, 2003; Singer, 2005). These sensations are frequently activated by an inner tension which is temporarily relieved after the tic is performed (Jankovic, 2001; Jimenez-Shahed, 2009). Some people with TS feel the need to repeat tics until they feel that the tics have been done correctly and then the premonitory sensation is satisfied (Jankovic, 2001; Jimenez-Shahed, 2009; Kenney et al., 2008).

Zinner (2002) compares the premonitory urge to an itch such as we have all experienced. When we first notice the itch it may be small and innocuous and not need immediate scratching so we may choose to ignore it. Over time the itch becomes more uncomfortable and it really starts to bother us and we begin focusing more and more on it. Eventually we give in and scratch it and the relief we feel is immediate.

These premonitory urges are sensory events that can be localized to various anatomical regions of the body and include such things as inner pressure, itches, urges, tension, etc. (Leckman, 2003; Singer, 2005). Examples of premonitory sensations or urges are a burning sensation in the eye before an eye tic such as blinking occurs; a tightness in the arm or leg that can be relieved only by rotating or stretching these extremities, or an urge to clear the throat (Jankovic, 2001). Premonitory urges can be found in 37% of children and more than 90% of adults with TS (Singer, 2005).

Tourettic tics follow a fluctuating course, which can be exacerbated by things such as stress, anxiety, or fatigue (Bagheri, 1999). Unless others are educated about the nature of Tourettic tics, they may be understandably frustrated with a child who at times tics so uncontrollably yet at other times does not tic as much. This can be especially difficult to accept if a child has loud vocal tics which may be distracting or severe physical tics which interfere with activities of daily life, such as a jumping or hopping tic which interferes with normal walking.

Another potentially confusing feature of Tourettic tics is that they can be voluntarily suppressed for a short period of time. People who are uninformed may tell children with TS to hold in their tics and not let them manifest themselves; these children are able to do so but for only a brief period of time. People with TS actually do not have real full control over their tics (Chowdhury, 2004) and the pressure or tension builds up until they can no longer be held in. When this happens the tics express themselves in a more forceful manner than if they were released when the urge first occurred (Chowdhury, 2004; Jimenez-Shahed, 2009; Leckman, 2003; Singer, 2005). Additionally, as the pressure to tic builds, it takes so much effort to try to suppress them that it can become extremely difficult to focus on anything other than suppressing the tics.

Comorbidities

The manifestation of tics may be the first sign of TS that families or friends notice but they may not actually be the first symptoms to present. The majority of children with TS have one or more comorbid disorders (Fernandez-Alvarez, 2002; Ozonoff, Strayer, McMahon & Filloux, 1998; Shapiro, 2002; Singer, 2005) which may manifest two or three years ahead of the tics (Jankovic, 2001;). According to a report released by the CDC in 2009, 80% of children diagnosed with TS were also diagnosed with a comorbidity, and 67% of those were diagnosed with ADHD (Bitsko, 2009). An estimated 50% to 70% of patients with TS are diagnosed with ADHD and OCD, which are the most common comorbidities (Stephens & Sandor, 1999). In addition, Stephens and Sandor believe that ADHD and OCD combined with TS can be associated with aggressive behavior such as rage in perhaps 23% to 40% of these patients.

Obsessive-Compulsive Disorder (OCD) is an anxiety disorder characterized by recurring, unreasonable, excessive, and time consuming obsessions or compulsions that cause significant distress or impair the person's ability to function in normal routines of life such as work, school, social activities or relationships (DSM IV-TR, 2000). Obsessions are not just excessive worries about real-life problems but are intrusive, inappropriate thoughts, impulses, or images that the person recognizes come from his or her own mind and tries to ignore, suppress or neutralize them, yet they recur and persist and cause significant anxiety or distress (DSM IV-TR, 2000). Compulsions are clearly excessive behaviors or mental acts the person feels strongly driven to do with the intention of preventing or reducing distress or feared negative outcomes even though these behaviors or mental acts do not have a realistic connection with the intended effect (DSM IV-TR, 2000).

Attention-Deficit/Hyperactivity Disorder (ADHD) is a disorder that is usually diagnosed in childhood (DSM IV-TR, 2000). Symptoms include inattention and/or hyperactivity-impulsivity, are present before age 7 years and cause impairment in at least two or more settings, such as school and home (DSM IV-TR, 2000).

Although tics can be embarrassing and physically uncomfortable (Carter et al, 2000; Jankovic, 2001; Wilkinson et al., 2001), they are generally not as devastating to the person with TS as the comorbidities or coexisting medical conditions that make TS so difficult to manage (Bagheri et al.,1999; Fernandez-Alvarez, 2002; Ozonoff, Strayer, McMahon & Filloux, 1998; Schapiro, 2002; Singer, 2005). Many of the educational, emotional, social, and even occupational difficulties problems experienced by those who have TS are frequently more of an artifact of the comorbidities than of TS itself (Raffaelea et al., 2004; Sukhodolsky et al., 2003). This is particularly true for those comorbidities which can lead to learning disabilities and behavioral disorders (Dykens et al., 1990; Woods et al., 2005).

While ADHD and OCD are the most common comorbidities associated with TS (Bagheri et al., 1999; Bitsko, 2009) there are many others. The other more common comorbid conditions are listed in Table 1.

Several studies conclude that children who have TS along with a comorbid condition have greater difficulty learning and adapting than children with TS only. A study conducted by Brand et al. (2002) shows that those with comorbid ADHD performed much poorer in their psychosocial functioning, while a study by Valderhaug

Table 1. Comorbid Conditions Associated with Tourette Syndrome

- Learning differences or disabilities (LD)
- Anxiety disorders
- Mood disorders
- Sleep disorders
- Executive dysfunctions
- Self-injurious behaviors
- Personality disorders
- Oppositional defiant disorder (ODD)
- Behavioral comorbidities
- Impulse control difficulties
- Depression
- Rage attacks

(Bagheri et al., 1999; Budman, Bruun, Park, Lesser & Olson, 2000; Fernandez-Alvarez, 2002; Jankovic et al., 2006; Shapiro, 2002; Zinner, 2004, Part 1; Zinner, 2004, Part 2).

and Ivarsson (2005) suggests a similar relationship when OCD is a comorbid factor. When children with TS alone were tested they performed much better in psychosocial functioning, intelligence as measured by verbal and performance measures, and word fluency than those with comorbid ADHD (Brand et al.).

Comorbid ADHD and OCD in addition to TS are highly correlated with functional impairment and disruptive behavior, creating additional problems for children with TS and these comorbidities in both social and family settings (Budman, 1998; Stephens & Sandor, 1999; Sukhodolsky et al., 2003). The risk for potential criminal behavior is increased in those with TS who also have ADHD (Jankovic et al., 2006). Research by Robertson, Banerjee, Eapen, and Fox-Hiley (2002) indicates that children with TS and comorbid obsessive compulsive symptomatology along with symptoms of depression experience a variety of complex and challenging psychological difficulties. They also observe that the children's caregivers experience complex problems as well.

Many studies demonstrate a correlation between psychosocial stress and the progression of many different disease states such as headaches, HIV, multiple sclerosis, and diabetes (Findley et al., 2003). Similar evidence suggests that both TS and OCD are sensitive to stress caused by psychosocial interactions and that children and adolescents with these disorders experience more stressful events and life stressors on a daily basis than the controls who were unaffected (Findley et al.).

Behavior Disorders

Besides the many comorbid conditions associated with TS, there are also a number of associated behavior disorders that can impact the social skills, learning ability, and personality of children with TS. Cath et al. (2000), Jankovic et al. (2006), and Dornbush and Pruitt (2002) have identified a few of these disorders as listed in Table 2.

A child with TS without any comorbid conditions may still experience TS-related behavior problems. Some of the behavioral disorders that are most difficult to deal with include: rage, anger outbursts, physical aggression, argumentativeness, and so forth. Children with TS only and no comorbidities may manifest symptoms of TS related behavior problems but they generally do so only minimally and without too much effect on their daily functioning (De Lange & Olivier, 2004). Research done by Zhu, Leung, Liu, Zhou and Su (2006) also documents that children with no comorbidities have the potential for some behavioral problems, but that such problems appear to be most closely associated with the severity of the child’s TS.

Disruptive behaviors such as explosive anger and rage, defined by Budman and Kompoliti (2006) as abrupt, unpredictable episodes of severe physical and/or verbal aggression which are grossly out of proportion to any provocation, experienced as

Table 2. Behavior Disorders

- Echophenomena (repeating back what others say)
- Echopraxia (repeating actions of others)
- Impulsive behavior
- Explosive outbursts
- Rage attacks
- Obscene language/gestures

uncontrollable and distressing, and accompanied by physiological activation, are more common in TS children. In fact, Budman, Rockmore, Stokes and Sossin, (2003) estimate that 25 – 70% of children with TS seen in their clinic have experienced behavioral problems manifesting themselves as lack of control of anger and episodic outburst. Families with children with TS often identify rage as the symptom which impairs their child the most (Budman et al.; Chowdhury, 2004).

Children with TS who also have a comorbid condition such as OCD and ADHD are more likely to have explosive outbursts (Budman, Bruun, Parks, Lesser & Olson, 2000; De Lange & Olivier, 2004; Gaze, Kepley & Walkup, 2006). Approximately 23% to 40% of patients with TS display this type of behavior (Stephens & Sandor, 1999). It is not known whether these outbursts of aggression can be controlled or whether they are involuntary in the child with TS but it is clear that is they can lead to social as well as familial problems (De Lange & Olivier, 2004). Children with TS but without the comorbidities of ADHD or OCD are unlikely to have problems associated with rage (Chowdhury, 2004).

Implications

Impact on Families

Because of the limited amount of research done specifically on the impact of TS on fathers, I looked at literature that included both mothers and fathers and also other chronic illnesses as well as TS I did this as a jumping off point in the hope that this current work as well as future studies will document similarities and differences between the impact of TS and other chronic disorders on parents as well as the similarities and differences between the impact on mothers and fathers. My review of the literature shows that parents face many challenges when they have a child diagnosed with a chronic illness, and I have gained a greater appreciation and respect for parents who have children with TS as well as parents who have children with other chronic illnesses. I recognize that having a child with a chronic illness can create many problems for the parents, the family, and the child himself.

Those studies that have been done on the family impact of having a child with TS reveal increased stress and frustrations as well as a negative effects on family dynamics (Carter et al., 2000; Zinner, Topolski, Freeman, Edwards & Patrick, 2007a). It is not uncommon for parents to feel frustrated, ashamed and confused and for them to have generally poor relationships with their child, marital difficulties, and substance abuse problems (Wilkinson et al., 2001; Zinner, Topolski, Freeman, Edwards & Patrick, 2007b). The level of impact on the family is correlated to symptom severity along with the presence of comorbidities frequently associated with TS (Wilkinson et al.; Zinner et al., 2007b).

When dealing with TS, parents and families must deal with myths and misperceptions, as well as the obvious and often socially inappropriate tics of their child. The following are examples of some of the common myths surrounding TS and their refutation (a) TS is an extremely rare condition, but the fact is that it is estimated to be found in 1% of children; (b) the general population often believe that coprolalia (involuntary use of obscene language) is the characteristic that defines TS, but in reality it is found in less than 15% of people with TS; (c) people with TS can be recognized easily due to their tics, however the fact is that tics can be suppressed for short periods of time which can let people with TS temporarily escape notice; and (d) the diagnosis of TS is catastrophic, but the reality is most people with TS suffer from mild cases and can successfully live with this condition (Munson, 2005; Zinner, 2004 pt. 1).

A major problem reported by parents of children with TS is the challenge they face trying to manage and cope with their children's behavioral problems, particularly aggressive behavior (Cooper, Robertson & Livingston, 2003; De Lange & Olivier, 2004; Jankovic et al., 2006). Behavioral problems were identified by parents as the aspect of their child's TS which had the greatest impact on their lives (Cooper et al., 2003). Mothers reported to De Lange and Olivier that they feel irritation, anger, and frustration, combined with fear for their children's future, for the social and societal consequences of potential impulsive behaviors, even fear for their own safety from verbal abuse and physical assault as their children become larger and stronger. DeLange and Olivier conclude that

> Verbal abuse (swearing and insulting), physical assault (with a weapon, throttling, kicking, hitting with the fist), economic abuse (stealing parents' money and belongings) and emotional harassment (manipulating and extortion) do occur and mothers have reason to be concerned. (p. 74)

In addition to aggressive behaviors which may hurt others, children with TS may engage in self-injurious behaviors which are difficult for others to understand and deal with. Reporting on children with TS seen in clinical settings, Budman and Kompoliti (2006) find that between 17-22% of patients with TS engage in self-injurious behaviors, such as head banging, slapping, self-biting, hitting, punching, orifice digging, pinching, or picking.

Research shows increased problems in children who do not have TS but who do have the two most common TS-related comorbidities, OCD and ADHD (Sukhodolsky et al., 2005). Children with OCD are found to have increased problems adapting and functioning emotionally (Sukhodolsky et al.). When children with OCD also have ADHD the impact is even greater (Sukhodolsky et al.). While this research was not conducted on children with TS, it does implicate the two most common comorbidities associated with TS, and it seems reasonable to wonder if the results could overlap into the Tourettic population, especially with the many studies that demonstrate the comorbidities rather than the Tourette's itself cause most of the problems for these children (Bagheri, Kerbeshian & Burd 1999; Brand et al., 2002; Carter et al., 2000; Coffey, 2006; Cooper et al., 2003; Schapiro, 2002; Stephens & Sandor, 1999).

Mothers and fathers of children with TS experience a significant burden of caregiving and negative impact on their general health, although fathers generally have less burden and health impact than mothers (Cooper et al., 2003). Compared to the parents of children with asthma, another chronic medical condition, mothers and fathers of children with TS have more burden and impact (Cooper et al.). The social stigma and lack of social acceptance associated with TS is believed to be correlated with the greater caregiver burden experienced by parents of children with TS (Cooper et al.).

When a child is diagnosed with a chronic illness, parents face a variety of challenges, including: fear of the enormity of the diagnosis and their powerlessness to change it (Lowes, Gregory, & Lyne, 2005); anxiety (Bowes, Lowes, Warner, & Gregory, 2009; Lowes et al.); guilt, frustration, and sadness (Bowes et al.); a changing social, emotional and personal world (Bendrix, Nordstrom, & Sivberg, 2006; Coffey, 2006; Lowes et al.); fear, isolation, and depression especially around the time of diagnosis (Coffey, 2006). Although little research has been completed specifically on how parents respond when their children receive a diagnosis of TS (Rivera-Navarro, Cubo, & Almazan, 2009), looking at how parents react to their children receiving a diagnosis of other chronic illnesses may provide a good starting place for developing an understanding.

Parents whose children are diagnosed with type 1 diabetes often experience a grief reaction similar to bereavement (Bowes et al., 2009). The diagnosis is a life changing event for the parents as well as for the children with many short- and long-term ramifications and potential losses (Lowes et al., 2005). These parents frequently lose confidence in their ability to protect their children and keep them safe, and this loss of confidence tends to continue long term even after parents become more knowledgeable about their child’s disease (Lowes et al., 2005).

The parents of children diagnosed with autism also experience grief, but the most devastating part of their grief is the despair they feel when they compare their child’s functionality to that of a healthy child (Bendrix et al., 2006). They mourn the loss of having a child who can have a typical normal life and the loss of a future in which they can interact with their child as a normal adult (Bendrix et al.). Parents of children with impaired cognitive abilities often feel chronic and episodic sadness and guilt through their child's adolescence and into adulthood, many never reaching an endpoint where they are free from intermittent grief or sorrow (Bowes et al., 2009). Lower parental expectations about the health and well-being of children with autism and childhood dementia leads to lower parental motivation and involvement in treatment and poorer outcomes for the children (Wong & Heriot, 2008).

It is known that parents of children with TS report feeling a range of negative emotions about their child's condition, including anger, hopelessness and powerlessness (Rosen, 2002). One mother described her sense of helplessness and futility over the future of her 11-year-old daughter with TS whose vocal tics included barking noises which disrupted her classroom and prompted the other students to laugh and become impatient with her (Rosen). This mother could not separate herself from the anger she felt even though she was well informed about TS and intellectually understood that it was a neurological disorder which her daughter could not control.

Understanding the impact of TS on both mothers and fathers is a vital underpinning to helping families with children with TS. I will close this section with excerpts from statements made by the mothers of children with TS who participated in De Lange and Olivier's 2004 study and suggest that the results of this study are an important step forward which may set the stage for more fully understanding how fathers in particular are impacted. The power of De Lange and Olivier's study can best be expressed using the mother's direct quotes to share their experiences, as follows.

One mother described some of the problems she faces after her child has behaved aggressively, “[when] he apologizes … I find it irritating … he hangs around me like a wet shirt … I want to say ‘Get the hell out of my face … hate your guts!’”

Some of these mothers expressed fears of what may happen in the future in comments such as, “I don’t want him to do anything that he’s sorry about later” and “he’s older and bigger and … I think if he gets the chance … he will take on … [his father].”

Another mother expressed her concern for her child’s future like this, “Where is this child going … in this society? I want to book him straight to prison … he has that kind of impulsive behavior.”

Others expressed concerns like, “the future is terribly worrying, the aggression part, wife, children, physical abuse, substance abuse … they’re high risk ... what is he going to do when he leaves school? How is he going to cope for the rest of his life?”

Some of the mothers feared for their own safety. They were afraid that aggressive, unacceptable behavior could escalate from “kicking me in the shins …” to “I’m concerned … that I’ll turn into an abused old person …” and that “he’s getting bigger, taller, stronger. I’m not sure whether I’m physically safe …” and “if there’s a weapon in the house, I’m sure he’ll use it.”

Future

The reality is that TS can be a devastating condition that alone, or in combination with other closely associated psychopathology, causes considerable suffering for those with TS and for their families. De Lange and Olivier’s study of mothers (2004), the work of Ylvén et al. (2006) and other research point to potential areas of study to learn more specifically about how fathers may be impacted. Families with children who have TS are likely similar in many ways to those with other chronic illnesses, but, here again, the similarities and differences are only beginning to be understood. While the challenges of living with TS are real, we need to understand more about how they impact fathers and families.

Family Systems Theory and Resiliency

Family Systems Theory

A family is a complex system and consistent and healthy interactions between family members results in healthy family functionality as well as the development of individual members of the family (Dickstein, 2002). Dickstein explains that the family unit is comprised of multiple levels operating on an individual basis while interacting with each other. Each member has a separate and distinct role which when combined with the other family members creates the whole. She also believes that families want meaningful stability and functionality.

Seligman and Darling (1997) believe a family system functions much like a mobile found in the crib of an infant. In a hanging mobile the objects are independent of each other, and yet, by themselves they do not provide any activity. However, if one of the objects is touched, then the motion created by that touch will impact the others and cause movement among them. A family unit is very similar. Each individual member can and does affect the other members.

This description provides us with a simplistic visualization of Family Systems Theory. A clearer picture of this theory evolves as we look at Minuchin's definition (1974, p. 9).

> The individual influences his context and is influenced by it in constantly recurring sequences of interaction. The individual who lives within a family is a member of a social system to which he must adapt. His actions are governed by the characteristics of the system and these characteristics include the effects of his own past actions. The individual responds to stresses in other parts of the system to which he adapts; and he may contribute significantly to stressing other members of the system. The individual can be approached as a subsystem, or part of the system, but the whole must be taken into account.

Family Systems Theory and Resilience

In the book *"Strengthening Family Resilience"* Walsh (1998) advocates the "systems theory" for examining family resiliency. Combining the principles of Family Systems Theory with resiliency creates a powerful framework from which to consider families who have a child with TS. As Walsh explains, the family is a social system that consists of members with similar core values and beliefs which are paramount to effective family functionality and these beliefs strongly impact how the family deals with adversity.

According to Luthar, Cicchetti, and Becker (2000) resilience is:

> … a dynamic process encompassing positive adaptation within the context of significant adversity. Implicit within this notion are two critical conditions: (1) exposure to significant threat or severe adversity; and (2) the achievement of positive adaptation despite major assault on the developmental process (p. 543).

Edith Grotberg (1995) defines resiliency as "… a universal capacity which allows a person, group, or community to prevent, minimize, or overcome damaging effects of adversity" (foreword).

Lazarus (1991) emphasizes the importance of managing response to both internal and external conflicts. This concept might be particularly important to consider as children with TS face both internal stressors such as the mounting pressure to release tics and external stressors such as pressure to conform to expectations of family members, peers, the education system, etc. According to Carter et al. (200P0) children diagnosed with TS and comorbid ADHD experience even more internal and external behavioral and social adaptation problems than children who have TS without ADHD. A child with TS may challenge the family system, but a child with TS and comorbid ADHD is even more likely to tax and possibly exceed the family's ability to respond resiliently. As individual family members are impacted, the components of the family "mobile" impact each other. This may interfere with daily family activities and result in family dysfunctionality if the family as a system cannot respond effectively

The following list outlines key concepts regarding family resiliency and the family as a system as explicated by Walsh (1998):

1) A healthy family is fluid and consequently changeable.
2) Crisis events and lingering stress affect the family and unless dealt with can create dysfunctionality in the family.
3) The impact of stress can be mediated by learning how to buffer stress and promote recovery.
4) Maladaptive responses can heighten relationship stress as well as individual and family vulnerability.
5) Crisis events can be impacted by the family processes that are implemented to deal with the crisis.
6) The family unit can be strengthened through the development of effective family resiliency in response to adversity.

Skinner and Zimmer-Gembeck (2007) suggest that researchers seek to understand the stress that children feel in their lives and how their development is shaped by their reactions to adversity. They also recommend that research on children focus on how they handle their response to emotional, cognitive, and behavioral stimuli. More specifically, it should focus on how they respond in real life situations and how these episodes affect children as they accumulate over time. Understanding how children and adolescents respond to stress provides a depiction of how they deal with life's adversity and how this adversity shapes their development. The development of children with TS can quickly be shaped by the difficulties they have responding to the social, emotional, and academic stressors to which they are exposed on a daily basis.

A Resiliency Mapping Model described by Richardson and Summerhays (2011) provides a graphical representation of the resiliency process. As shown in Figure 1.1, individuals or families move from the comfort zone in which they are in a familiar, relatively stable state of existence to a disruption, an event which causes a break in the normal cycle of daily life. The next step is resonation, a period during, which virtues or qualities are developed. These virtues or qualities enhance personal capability and empower individuals or families to move through a trough. The development of personal strengths occurs to the extent to which individuals or families take control of disruptions and accept responsibility for moving forward to resilient reintegration. Loss of personal strength leads to coming out of a trough with a lower level of resiliency than before disruption. When little or no growth occurs there will be an approximate return to the previous level of functioning. Resilient reintegration involves moving forward with the growth or gain obtained during the process of going through disruptions.

The challenges facing children with TS and their families can be better appreciated using the perspective of both family systems theory and resiliency. These children and their families face the multiple stressors related to TS itself and possibly those related to the common comorbidities as well, each of which has its own attendant problems. When personal resources are exceeded it is difficult to respond effectively to challenging situations (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). As stresses accumulate they may eventually exceed the capacity of both the children and their families to respond resiliently.

Purpose of the Study

The purpose of this qualitative study is to better understand: 1) the relationships of fathers with their sons who have TS; 2) the changes in father/son relationships which occur over time as fathers accompany their sons along their journey with TS; and 3) the impact of this journey on the father's relationship with his wife and other children. It also highlights how limited the research is to date and the critical need for further efforts to understand the impact of TS on families. I used grounded theory as the research design and the constructionist-interpretivist paradigm to help view reality through the lived experiences of these fathers.

Research Questions

Two research questions guided this study: 1) How do fathers cope with sons who have TS; and 2) how does this impact the family dynamics?

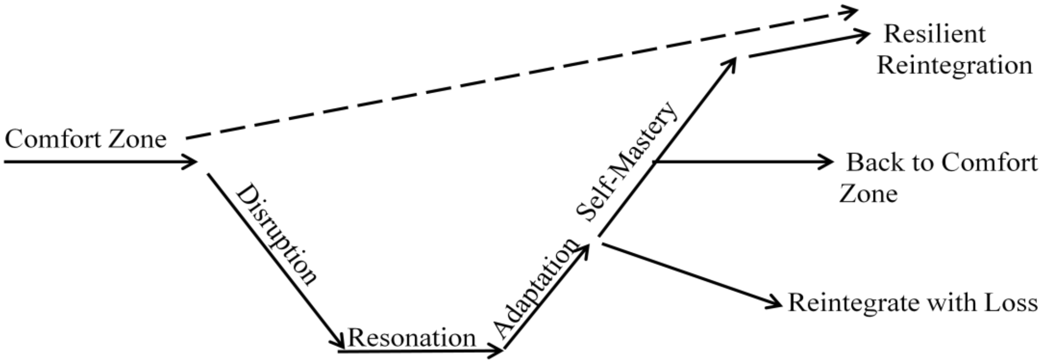

Figure 1.1 Richardson's Resiliency Mapping Model 2002

Research Questions

Two research questions guided this study: 1) How do fathers cope with sons who have TS; and 2) how does this impact the family dynamics?

Rationale for Qualitative Methods

This study was conducted using qualitative research methods. This approach was appropriate in the study of fathers and their relationships with their sons with TS because qualitative research is useful for examining aspects of social life that are not easily accessed through quantitative data collection techniques (Glaser & Strauss, 1967) and when dealing with questions involving "subjective experience and situational meaning" (Davies, et al., 2004 p. 116). It is also recommended for research in fields in which there is limited knowledge (Davies, et al., 2004). There is a gap in the research in the area of interest of this dissertation and using qualitative methods allowed me to gather data, draw conclusions, and generate new ideas about the interactions between fathers and their sons with TS. During the interviews with the fathers I was able to listen to their experiences as they described their life with their son with TS. This helped me gain a better understanding of their world, their perceptions, their frustrations, their happiness (Ulin, Robinson, & Tolley, 2005). I was able get a glimpse of their lives, their thoughts, their hopes, their fears, their interactions, and their resiliency. This allowed me to interpret meaning from their lived experiences.

Researcher as Instrument/Horizons of Understanding

Reflexivity

As a researcher, I owed it to myself as well as to the participants of this project and those who read the final results to reflect upon those values that have shaped my life and could possibly impact my research. I looked at such things as my own TS and related struggles, my moral, ethical and social values, my beliefs about marriage and families, in particular about fathers and the way they related to their children, especially their children with TS.

Charmaz (2006), in her definition of reflexivity, explains that by scrutinizing his or her research, the researcher allows “the reader to assess how and to what extent the researcher’s interests, positions, and assumptions influenced inquiry” (pp. 188-189). She highlights the importance of taking a reflexive stance to inform others how the research was conducted, how it is connected to the participants, and how the written reports present the participants.

Morrow (2005) emphasizes that reflexivity provides researchers with the opportunity to examine how their research is impacted by their own personal experiences and world views. As a qualitative researcher I worked to be open and accepting of the idea that reflexivity was a vital part of my research and that my writing was shaped by what emerged (Creswell, 2007). As part of this study, I acknowledge that my writing can impact not only myself as the researcher, but also the participants and those who read the study (Creswell).

With this qualitative dissertation I tried to be careful with how I handled the participants' stories so they felt comfortable sharing with me openly and honestly (Gilgun, 2005). Treating participants with respect so that they did not feel marginalized, discredited or offended helped me maintain credibility with them and obtain valuable, rich information. I did my best to write an accurate interpretation and reflection of the participants' stories. Before completing this dissertation all participants were given the opportunity to read and edit their interviews and to provide additional input to ensure that I accurately reflected the story they told. No participants made changes to the transcripts I sent.

I was careful to minimize my influence or the influence of Anne Evans-Cazier, LCSW (approved by the IRB to act as my interviewer) on the meaning of the participants' stories. I was cognizant that our involvement could influence the research and that it was difficult if not impossible for me as the researcher to remain an outsider in this process. Nevertheless, I tried to be very aware of my biases and by so doing believe I was able to write an accurate representation of the data I gathered.

Biases

Strauss and Corbin (1998) discuss a concept which they call "waving the red flag" (p. 97), i.e., advice to researchers about being aware of the biases that we bring to the research arena. They explain:

> Analysts, as well as research participants, bring to the investigation biases, beliefs, and assumptions. This is not necessarily a negative trait; after all, persons are the products of their cultures, the times in which they live, their genders, their

> experiences, and their training. The important thing is to recognize when either our own or the respondents' biases, assumptions, or beliefs are intruding into the analysis. Recognizing this intrusion often is difficult because when persons share a common culture, meanings often are taken for granted. Researchers sometimes become so engrossed in their investigations that they do not even realize they have come to accept the assumptions or beliefs of their respondents. (p. 97)

I tried to be diligent in recognizing bias by learning to stand back and observe and evaluate the data in an objective manner. Because TS is such an integral part of my life and who I am, I had to do my best to avoid bias while realizing that it is impossible to be completely free from it (Strauss & Corbin, 1998).

I was officially diagnosed with TS 14 years ago at the age of 50, although my original symptoms manifested themselves within the usual time frame of onset, somewhere between the age of 7 and 8 years. I was very fortunate that I had parents who were understanding and patient with me even though I was a typical child with TS and comorbid ADD and OCD. At the time of diagnosis I had little understanding of the problems that TS frequently creates for families.

I am a father, but none of my children have TS so I do not know what it is like to be a father of a child with TS. However I do know what it is like to be the child with TS. Armed with this knowledge and experience I believe that I was able to approach this project with passion, insight, understanding, compassion, and reflexivity. As a result I felt my own horizons were expanded as I recorded and interpreted the stories of the fathers participating in this research.

My parents had their imperfections and struggles and they made their mistakes, but for me as a boy with TS they could not have been better parents. Among other things, they provided me with the two greatest constants I needed in order to survive: 1) love and 2) unconditional acceptance. I am sure this was extremely difficult for them considering they did not know what TS was or anything about ADD or OCD.

The potential bias of most concern to me is the fact that my father set such high standards for me, my TS, and my success in living with this problem. I was never put down nor do I ever remember being the recipient of a verbal attack due to any frustration he may have felt with me. I was not spanked and I do not remember him losing control of his anger when he disciplined me. I did not ever get the feeling that he was embarrassed of me but rather he always showed pride and confidence in me.

Because of my lived experiences with my father I can see how I could have been very biased against fathers who were ashamed or frustrated or embarrassed about their son with TS. But I believe that I was able to avoid comparisons and conclusions based on my lived experiences.

Subjectivity

Subjectivity helped position me as a “co-constructor of meaning” (Morrow, 2005, p. 254) as I worked to interpret the data. I tried to set aside my own preconceptions and experiences as much as possible by making my biases known and taking measures to bracket them and then be consistent with my bracketing so that I could better understand the experiences of the study participants (Creswell, 2007). In reality, bracketing was more difficult than it seemed theoretically, but I was conscientious in my awareness and realized that I was not expected to eliminate all bias (Creswell; Strauss & Corbin, 1998).

Managing Biases

Being upfront and open about my biases and the impact they could have on the development of my theory freed me to use my creativity and explore connections in the emerging theory (Cutcliffe, 2000). This process made it possible for me to interpret the data accordingly (Greenhalgh & Taylor, 1997).

Another method I used to manage bias while enhancing rigor was to create an audit trail by thorough documentation of my data in such a way that other researchers may reconstruct my process. To this end I carefully recorded and documented my interviews, including my observations and conclusions (Strauss & Corbin, 1998; Ulin et al., 2005).

Data Analysis

Data analysis was an ongoing, evolving process through which theory emerged. The theory which emerged was an ever developing process, not a perfected conclusion (Glaser & Straus, 1967). I used an iterative cycle of explicit coding and constant comparison to identify multiple categories, properties, and hypotheses along the way.

Immersion

A thorough analysis of the data required the researcher to immerse himself in the data by reading and rereading the data in order to become familiar with it. I recognized that the data generated would be voluminous and to avoid becoming overwhelmed I immediately began immersing myself in the data. This familiarity helped me become more cognizant of emerging themes (Marshall & Rossman, 2006) and, it aided in the development of meaningful codes and categories (Ulin et al., 2005). Through early immersion I was able to (a) acclimate myself to the data, (b) start coding the data, (c) identify gaps in the data which I addressed early, (d) follow-up more quickly with study participants if more detail was needed or questions arose, and (e) identify emerging themes early in the process.

I immersed myself in the stories the fathers told, made and studied field notes, wrote and reviewed memos which were included in a reflective journal, used analytic memos, and reviewed transcriptions and observations. These activities enabled me to find the core meaning embedded in the data and guided me in my interpretation of the data.

Memos

Memos were integral in the development of my theory and were used for more than just storing information. They aided me as I moved from raw data to developing concepts. They encouraged early analysis of codes and data and they facilitated creativity and imagination by stimulating ideas. These memos also served as a key transition from data collection to preparing reports of my findings (Charmaz, 2006; Strauss & Corbin, 1998). I used them to record, sort, order, retrieve, cross-reference categories and themes, and help determine which concepts should be developed and refined (Strauss & Corbin).

Continual writing encouraged creativity and new insights, which helped the data analysis to proceed to more powerful interpretations (Marshall & Rossman, 2006). During this process I wrote regularly using memos and a reflective journal. All of this was done with the intent of strengthening my writing and improving the final product.

Constant Comparative Method

As a grounded theory researcher I used constant comparative methods to make comparisons between the data gathered through observations, interviews, and other materials. These comparisons were helpful in identifying and developing emerging ideas and categories (Strauss & Corbin, 1998). This process brought insight and meaning as I transformed the data into significant findings (Marshall & Rossman, 2006). Both data analysis and the discovery of theory involved interpretation and active engagement through the use of comparative methods (Charmaz, 2006).

I employed the four stage constant comparative method as outlined by Glaser and Strauss (1967). These stages included (a) comparing incidents applicable to each category, (b) integrating categories and their properties, (c) delimiting the theory, and (d) writing the theory.

Stage One

In this stage I coded each incident into as many different categories as possible and compared it with other incidents already recorded in the same category. This process led to the clarification of the theoretical properties of the categories (Glaser & Straus, 1967).

Stage Two

In stage two I moved from comparing incidents with incidents to examining how incidents compared with the properties of the emerging categories. Analyzing data in this manner throughout the data collection process led to the development of theory as the properties of categories become integrated through a constant comparative process (Glaser & Strauss, 1967).

Stage Three

In the third stage of the constant comparative method I delimited the process in the three major ways outlined by Glaser and Strauss (1967). First, the theory tended to emerge in a natural way as new incidents and observations aligned with previous ones which prompted fewer and fewer major modifications of categories and their properties. Second, the number and variety of coding categories began to reduce. And lastly, the list of categories was further delimited as I observed fewer and fewer new incidents which added new insight to the already established patterns.

Stage Four

In stage four I experienced a growing confidence in the theory emerging from the data, categories, memos, and major themes that had evolved.

Concept Formation and Development

Concepts were developed through the use of coding to identify recurring themes, phrases, concepts, or even words that eventually led to the discovery of patterns in the data (Field, & Morse, 1985). The coding process included the three phases outlined by Strauss and Corbin (1998): open coding, axial coding, and selective coding.

Open Coding

Strauss and Corbin (1998) compared open coding to putting together a puzzle. When the pieces of a puzzle are dumped out onto a table, they are in a jumbled state of disorganization and the picture they could make is unclear. Sorting the pieces into groups by certain qualities, such as by color or whether or not a piece is an edge piece, helps to form groups, which aids in identifying patterns and fitting the pieces together to form a coherent picture. Similarly, in open coding, the initial data collected may appear to be a jumble and a coherent picture is not clear. The researcher may look at his data and wonder what he has, where he should start, and how to identify what is important. Each researcher must analyze the data, identify key categories of happenings, events, and instances, and then create his own scheme for coding the emerging categories (Creswell, 2007; Marshall & Rossman, 2006). In this study coding the data in as many ways as possible allowed the researcher to discover categories and properties that would have been difficult to find otherwise (Glaser & Strauss, 1967). My initial efforts were only tentative analyses which laid the foundation for a more critical analysis. The memos used in open coding helped in my conceptualization and thinking process (Strauss & Corbin).

Axial Coding

Continuing with the analogy of the puzzle, during the axial coding phase pieces of the data puzzle began to be put together (Strauss & Corbin, 1998). The properties and dimensions of the categories were further developed by answering questions of where, when, what, how, with whom, and with what consequences (Strauss & Corbin). Subcategories were defined and refined in relation to the broader categories as the data was reassembled. Each piece of the puzzle was put into its place and the data became clearer and the quality of conceptualization of the whole improved (Strauss & Corbin; Charmaz, 2006).

Selective Coding

During the final phase, selective coding, the categories that needed further development were filled in and the data were analyzed with increasing refinement to identify a core category around which concepts integrated (Strauss & Corbin, 1998; Creswell, 2007). The possible relationships between categories were explored and integrated into a theory (Charmaz, 2006).

Comparative Analysis

Comparative analysis has come to encompass many meanings and is used for many different purposes, however Glaser and Strauss (1967) believe that comparative analysis is a generalized method used to generate theory that can be used for any population no matter its size. For the purpose of this research I used it to: validate facts by assuring the accuracy of the evidence gathered; establish empirical generalizations of these facts so that theory had more power to explain and predict; verify the theory and the relevance of the emerging categories through continual analysis and data checking and; generate new theories from the gathered data.

Charmaz (2006) believes that the data should be analyzed from the bottom-up because the strength of grounded theory lies in how well it is grounded in the data that was gathered. This approach provided me with a method of viewing the data in a subjective manner. I was open to the unexpected that may have occurred during the data gathering process and the potential direction in which it took me (Charmaz).

In order to provide a thorough analysis of the data, I immersed myself in reading and rereading the data. By doing this I became familiar with it which helped me become more cognizant of emerging themes (Marshall & Rossman, 2006) and, in the long run, aided in the development of meaningful codes and labels (Ulin et al., 2005).

Immersing myself in the stories the fathers told me, studying my field notes and reviewing my observations enabled me to obtain the core meaning of what the fathers were really sharing in terms of their feelings and thoughts and even behaviors. Eventually this immersion helped guide me in my interpretation of the data.

Marshall and Rossman (2006) encourage researchers to write continually in order to generate new insights. During this research process I wrote regularly and frequently on my thoughts, ideas, attempts to be creative, questions that needed to be asked, follow-up to be done, and so forth. All of this was done with the intent of strengthening my writing and improving the final product.

Trustworthiness

Rigor was maintained by adhering to the accepted policies and procedures for qualitative research and by compiling an auditable trail of documentation throughout the process. This included keeping a reflective journal in which I recorded my thoughts, my feelings, unusual events, ideas that helped guide my research, etc. Throughout this process I maintained an awareness of my biases, bracketed them and was consistent when I discovered new ones.

I kept an auditable trail of thorough documentation of the data collected and the analysis process (Lietz, Langer & Furman, 2006; Robert Wood Johnson Foundation, retrieved 2008). Primary data for this project were gathered from interviews conducted with fathers who had sons with TS. Observational data were gathered and recorded at the time of the interviews and immediately following them. Some fathers were also observed on various other occasions that arose.

The data were reviewed after every interview and observation. This allowed me to notice new ideas and to be in a position to make any modifications that were needed, while at the same time maintaining the integrity of the study and strengthening the data I gathered (Ulin et al., 2005).

Lietz et al. (2006) suggests that it is essential to protect the rigor of qualitative inquiry by engaging "in efforts that increase our confidence that our findings represent the meanings presented by our participants" (p. 443). To do this I tried to accurately reflect the meanings and visions of the fathers' reports of their thoughts, feelings, and experiences towards their TS children over my own (Lietz et al.).

Ethical Considerations

This research was guided by the regulations and guidelines established by the University of Utah for doctoral students writing their dissertation. As part of these regulations and guidelines, I submitted relevant and required material to the Institutional Review Board (IRB) for approval including the commitment to following the established protocol for doing research with human subjects. Minor changes to the initial procedures for this study were submitted for review and given approval by the IRB prior to implementation.

Professional integrity, ethics, and confidentiality were maintained throughout this process. Participants were verbally notified of study requirements and purpose. The process for obtaining consent was followed explicitly before any interview began and each participant signed an IRB approved informed consent form prior to participating in the study. I also signed the consent form and gave one copy with both signatures to the participants and kept the second copy for my records.

Participants were advised of the confidential nature of the interview and given an explanation of how the interview data would be used. The consent form informed them that their identity would be protected and that any personal data or direct quotes used would be referenced by fictitious names (Creswell, 2007). In addition I explained that all data would be stored in a secure, locked file accessible only to me and that participants could withdraw from the project at any time and for any reason. I also informed participants before the interviews began that if they disclosed information about the abuse of children or the elderly that I was obligated to file a report with the appropriate authorities.

In order to prevent potential harm to the participants I tried to be sensitive to their vulnerabilities as they expressed their deepest thoughts, fears, emotions, frustrations, etc. I recognized that it was my responsibility to protect these participants from potential harm (Ulin et al., 2005). Bowen (2005) cautions qualitative researchers to be aware of and guard against the likelihood that they may be at greater ethical risk than quantitative researchers. He suggests potential sources of such risk include:

1) The closer contact a qualitative researcher is required to have with the participants in order to adequately gather the data requires an immersion into the life of the fathers.
2) The closer involvement with the research itself.
3) The greater latitude in how the data is interpreted.

Explanation of Reporting Format

This dissertation follows the three article format. Chapter 2 reports on the results of my qualitative research on fathers with sons with TS. The overarching finding which emerged in this study was that the fathers experienced a waxing and waning pattern of response in the face of an uncertain future which seemed to be influenced by the intrinsic nature of TS. They reported experiences along a continuum of success, ranging from effective responses which seemed to lead to personal growth and resilience and stronger relationships with their sons and families, to ineffective responses, difficulty developing personally, and relationship strain or deterioration. The waxing and waning pattern of responses occurred along five major themes: 1) the question of normalcy, 2) pride in son, 3) hope in the future, 4) acceptance, and 5) role satisfaction.

Chapter 3 is a theoretical article exploring the potential for the application of waves one and two of resiliency inquiry as described in Richardson's Metatheory of Resilience and Resiliency (2002) to FCTS. The first wave of resiliency research involves the identification of resilient qualities and how they can be utilized to optimize FCTS functioning. The second wave of resiliency research deals with the resiliency processes through which families gain access to or recognize and utilize their innate resilient qualities to grow stronger and reintegrate with gain; Richardson's Resiliency Mapping Model (2011) provides the springboard for the development of a TS-adapted graphical representation of the resiliency process.

Chapter 4 is another theoretical article and examines the application of wave three of resiliency inquiry as described in Richardson's Metatheory of Resilience and Resiliency (2002) to FCTS. This involves the identification of the energy, passion, and motivation that can lead FCTS through their trough of chaos and along their journey of living resiliently with TS (Richardson).

Chapter 5 provides a review of the research findings. In addition, this chapter also offers suggestions for future research.

Appendix A: *Interview Question Guide*

Below are the general questions that guided the interviews. The interviews began with the most general questions and the interviewers tried to encourage the fathers to tell their story in their own way. Not all questions were asked of each father as frequently the fathers covered the relevant topics without direct questioning.

Research Question #1: From the perspective of fathers who have a son with Tourette syndrome, how have they reacted to and coped with having a son with Tourette's?

1) Please tell me a bit about you and your family. How long have you been married? How many children? Names and ages. Your education and occupation. Your wife's education and occupation.
2) How has having a son with Tourette's affected your life?
3) How would you describe your son with TS?
4) How would you describe the severity of your son's Tourette's?
5) When your son with TS was born – what were your hopes, dreams, and aspirations for this son? Have they changed? If so, how?
6) After your son began to exhibit some symptoms, but before he was diagnosed, what were your thoughts/feelings?
7) When your son was first diagnosed with TS, what were your thoughts? Fears? Concerns? Have they changed? If so, how?
8) Can you talk about any struggles your son with TS has had in school, your perceptions of his educational abilities, other interests/talents he has?
9) Do you know if your son tries to suppress his tics in certain situations? Explain.
10) Do you talk with your son about TS?

11) Do you view your son with TS as being ‘disabled’ or ‘handicapped’ or ‘special’? Please share your thoughts.
12) How has having a son with TS impacted your relationship with your wife?
13) How has having a son with TS impacted your relationship with your other child/children?
14) Has having a son with TS impacted other areas of your life?
15) What are your biggest challenges with having a son with TS? And how do you cope?
16) Do your aspirations, hopes, and dreams for your son with TS differ from those you have for your children without Tourette's? If so, how?
17) Do you think your social life is impacted as a result of having a son with TS? If so, how?

Research Question #2: How do fathers of sons with Tourette syndrome understand their role in the family dynamics?

1) How do you understand your role as a father?
2) How do you think having a child with Tourette's has impacted your family?
3) How do you perceive your responsibilities as a father to your son with TS?
4) Are these perceptions and responsibilities different towards your son with TS verses your child/children without TS? How?
5) Describe the energy it takes to provide for the needs of your son with TS.
6) How do you balance the needs of your son with TS and the needs of your other child/children?
7) Is the way you cope or discipline different in the home vs. out in the public?

8) What are your thoughts about your son’s perceptions of you as a father?

9) How do you cope with having a son with TS?

References

Abelson, J. F., Kwan, K. Y., O'Roak, B. J., Baek, D. Y., Stillman, A. A., Morgan, T. M. et al. (2005). Sequence variants in SLITRK1 are associated with Tourette's syndrome. *Science,* 14(310):211.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed. text revision). Washington, DC: Author.

Bagheri, M. M., Kerbeshian, J., & Burd, L. (1999). Recognition and management of Tourette's syndrome and tic disorders. *American Family Physician,* 59(8).

Baylor College of Medicine, Department of Neurology, Patient Education. (Last Modified: November, 2007). Tourette syndrome (TS). Downloaded 3/21/09. *TS - Baylor College of Medicine - webpage.htm*

Benderix, Y., Nordstrom, B., & Sivberb, B. (2006). Parents' experience of having a child with autism and learning disabilities living a group home. *Autism* 10, 629-641.

Bitsko, R. H. (2009). *Report on epidemiologic findings from CDC. Proceedings of the 5th International Scientific Symposium on Tourette Syndrome,* USA, p. 11.

Blacher, J. The double whammy: Tourette syndrome and associated disorders as they impact families. *Exceptional Parent Magazine*. Downloaded 3/18/2007 from http://www.eparent.com/researchreflections/rsearchreflections_07_02.htm

Bowen, G. A. (2005). Preparing a qualitative research-based dissertation: lessons learned. *The Qualitative Report* 10(2):208-222.

Bowes, S., Lowes, L., Warner, J., & Gregory, J. W. (2009) Chronic sorrow in parents of children with type 1 diabetes. *Journal of Advanced Nursing* 65(5), 992–1000.

Brand, N., Geenen, R., Oudenhoven, M., van der Ree, A., Cohen-Kettenis, P., et al. (2002). Brief report: cognitive functioning in children with Tourette's syndrome with and without comorbid ADHD. *J Pediatr Psychol.* 27(2):203-8.

Bruun, R. D., Cohen, D. J., & Leckman, J. F. (2009). Guide to the diagnosis and treatment of Tourette syndrome.
Retrieved from http://www.tsa-usa.org/Medical/guidetodiagnosis.html 12/18/09.

Budman, C. L., Bruun, R. D., Park, K. S., Lesser, M., & Olson, M. (2000). Explosive outbursts in children with Tourette's disorder. *Journal of the American Academy of Child and Adolescent Psychiatry* 39(10): 1270-1276

Budman, C. L., Bruun, R. D., Park, K. S., & Olson, M. E. (1998). Rage attacks in children and adolescents with Tourette's disorder: a pilot study. *J Clin Psychiatry,* 59(11):576-80.

Budman, C. L., & Kompoliti, K. (2006). Impulse-control disorders in Tourette syndrome. Created for the Tourettes Syndrome Association.

Budman, C. L., Rockmore, L., Stokes, J., & Sossin, M. (2003). Clinical phenomenology of episodic rage in children with Tourette syndrome. *Journal of Psychosomatic Research* 55:59– 65.

Carter, A. S., O'Donnell, D. A., Schultz, R. T., Scahill, L., Leckman, J. F., & Pauls, D. L. (2000). Social and emotional adjustment in children affected with Gilles de la Tourette syndrome: associations with ADHD and family functioning. *J. Child Psychiat*. 41(2):215-223.

Cath, D. C., Spinhoven, P., van de Wetering. B. J., Hoogduin, C. A., Landman, A. D., van Woerkom, T. C., et al. (2000). The relationship between types and severity of repetitive behaviors in Gilles de la Tourette's disorder and obsessive-compulsive disorder. *J Clin Psychiatry*, 61(7):505-13.

Champion, L. M., Fulton, W. A., & Shady, G. A. (1988). Tourette syndrome and social functioning in a Canadian population. *Neurosci Biobehav Rev*. 12(3-4):255-7.

Charmaz, K. (2006). *Constructing grounded theory: a practical guide through qualitative analysis.* Thousand Oaks, CA: Sage.

Chowdhury, U. (2004). *Tics and Tourette syndrome a handbook for parents and professionals.* London: Jessica Kingsley.

Coffey J. S. (2006). Parenting a child with chronic illness: a metasynthesis. *Pediatric Nursing,* 32(1):51-59.

Cooper, C., Robertson, M. M., & Livingston, G. (2003). Psychological morbidity and caregiver burden in parents of children with Tourette's disorder and psychiatric co-morbidity. *J Am Acad Child Adolesc Psychiatry*, 42(11):1370-1375.

Creswell, J. W. (2007). *Qualitative inquiry & research design: choosing among five approaches.* Thousands Oaks, CA: Sage.

Cutcliffe, J. R. (2000). Methodological issues in grounded theory. Journal of Advanced Nursing, 31(6):1476-1484. Retrieved 5/13/2008. http://web.ebscohost.com/ehost/deliver?vid=5&hid=120&sid=c2999c32-0e39-40e9-9491-938d8

Davies, B., Gudmundsdottir, M., Worden, B., Orloff, S., Sumner, L., Brenner, P. (2004). Living in the dragon's shadow fathers' experiences of a child's life-limiting illness. *Death Studies,* 28:111-135.

De Lange, N., & Olivier M. (2004). Mothers' experiences of aggression in their Tourette's syndrome children. *International Journal for the Advancement of Counseling,* 26(1):65-77.

Dick, B. (2007). Grounded theory: a thumbnail sketch. Retrieved 10/5/2007. http://www.scu.edu.au/schools/gcm/ar/arp/grounded.html

Dickstein, S. (2002). Family routines and rituals – the importance of family functioning: components on the special section. *Journal of Family Psychology*, 16(4):441-4.

Donne, J. (1572-1631). No man is an island. http://isu.indstate.edu/ilnprof/ENG451/ISLAND/

Dornbush, M. P., Pruitt, S. K. (2002). *Teaching the tiger: a handbook for individuals involved in the education of students with attention deficit disorders, Tourette syndrome or obsessive-compulsive disorder*. Duarte, CA: Hope.

Dykens, E., Leckman, J., Riddle, M., Hardin, M., Schwartz, S., & Cohen D. (1990). Intellectual, academic, and adaptive functioning of Tourette syndrome children with and without attention deficit disorder. *J Abnorm Child Psychol*. 18(6):607-15.

Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: grounded theory in counseling psychology research. *Journal of Counseling Psychology* 52(2):156-166.

Fernandez-Alvarez, E. (2002). Comorbid disorders associated with tics. *Rev Neurol.* 34 Suppl 1:S122-9.

Field, P. A., & Morse, J. M. (1985). *Nursing research the application of qualitative approaches*. Rockville, MD. Aspen Publication.

Findley, D. B., Leckman, J. F., Katsovich, L. M. A., Lin, H., Zhang, H., Grantz, H. et al. (2003). Development of the Yale Children's Global Stress Index (YCGSI) and Its Application in Children and Adolescents with Tourette 's syndrome and Obsessive-Compulsive Disorder. *J Am Acad of Child & Adolescent Psychiatry,* 42(4)450-457.

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology,* 50(5):992-1003.

Gaze, C., Kepley, H. O., & Walkup, J. T. (2006). Co-occurring psychiatric disorders in children and adolescents with Tourette syndrome. *Journal of Child Neurology* 21(8):657-664.

Gilgun, J. F. (2005). Grab and good science: writing up the results of qualitative research. *Qualitative Health Research* 15(2):256-262.

Glaser, B. G., & Strauss A. L. (1967). The discovery of grounded theory: strategies for qualitative research. Aldine Transaction: New Brunswick.

Greenhalgh, T., & Taylor R. (1997). How to read a paper: papers that go beyond numbers (qualitative research). *BMJ 315:740-743.* Retrieved 8/9/2008. http://bmj.bmjjournals.com/cgi/content/full/315/7110/740

Grotberg, E. H. (1995). A guide to promoting resilience in children: strengthening the human spirit. – The international resilience project, from the early childhood development: practice and reflections series, #7 (Foreword). Bernard Van Leer Foundation.

Haverkamp, B. E., & Young, R. A. (2007). Paradigms, purpose, and role of the literature: rationale for qualitative investigations. *The Counseling Psychologist,* 35(2):265-294.

HBO documentary, I have Tourette's but Tourette's Doesn't Have Me! 2005. http://www.biology.emory.edu/research/Jaeger/BasalGanglia/BG_page.html

Hendren G. (2002). Tourette syndrome: a new look at an old condition. *Journal of Rehabilitation* 68(2):22-27.

Jankovic, J. (2001). Tourette’s syndrome. *N Engl J Med*, 345 (16):1184-1192.

Jankovic J., Kwak, C., & Frankoff, R. (2006). Tourette’s syndrome and the law. *J Neuropsychiatry Clin Neurosci* 18(1):86-95.

Jimenez-Shahed, J. (2009). Tourette syndrome. *Neurol Clin* 27 (2009) 737–755.

Kenney, C., Kuo, S. H., & Jimenez-Shahed, J. J. (2008). Tourette's syndrome. *American Family Physician,* 77(5):651-658.

Kurlan, R., Como, P. G., Miller, B., Palumbo, D., Deeley, C., Andresen, E. M., et al. (2002). The behavioral spectrum of tic disorders: A community-based study. *American Academy of Neurology* 59(3): 414-420.

Kushner, H. I. (2008). The art of medicine history as a medical tool. Downloaded 3/24/09. www.thelancet.com Vol 371.

Lazarus, R. S. (1991). *Emotion and adaptation*. New York. Oxford University Press, Inc.,

Leckman J. F. (2002). Tourette syndrome. *Lancet,* 360:1577–86.

Leckman, J. F. (2003). Phenomenology of tics and natural history of tic disorders. *Brain & Development* 25 Suppl. I S24-S28.

Leckman, J. F., Vaccarino, F. M., Kalanithi, P. S. A., & Rothenberger, A. (2006). Annotation: Tourette syndrome: a relentless drumbeat – driven by misguided brain oscillations. *Journal of Child Psychology and Psychiatry* 47(6):537–550.

Lietz, C. A., Langer, C. L., & Furman, R. (2006). Establishing trustworthiness in qualitative research in social work: implications form a study regarding spirituality. *Qualitative Social Work*, 5(4):441-458.

Lowes, L., Gregory, J. W., & Lyne, P. (2005). Newly diagnosed childhood diabetes: a psychosocial transition for parents. *Journal of Advanced Nursing*, 50(3), 253–261.

Luthar, S. S., Cicchetti, D., Becker, B. (2000). The construct of resilience: a critical evaluation and guidelines for future work. *Child Dev.71(3):543-562.*

Marshall, C., & Rossman G. B. (2006). Designing qualitative research, Fourth Edition. Sage Publications.

Mathews, C. A., Bimson, B., Lowe, T. L., Herrera, L. D., Budman, C. L., Erenberg, G, et al. (2006). Association between maternal smoking and increased symptom severity in Tourette's syndrome. *Am J Psychiatry* 163:1066-1073.

MedlinePlus. (updated 2/16/2012).

Meidinger, A. L., Miltenberger, R. G., Himle, M., Omvig, M., Trainor, C., & Crosby, R, (2005). An investigation of tic suppression and the rebound effect in Tourette's disorder. *Behavior Modification*, 29(5):716-745.

Minuchin, S. (1974). *Families and family therapy*. Cambridge, MA: Harvard University Press.

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52(2):250-260.*

Munson, B. L. (2005). *Myths & facts about Tourette's syndrome*. Downloaded 11/27/09 from www.nursing2005.com

Ozonoff, S., Strayer, D. L., McMahon, W. M., & Filloux, F. (1998). Inhibitory deficits in Tourette syndrome: a function of comorbidity and symptom severity. *J Child Psychol Psychiatry*. 1998 Nov;39(8):1109-18.

Raffaele, R., Vecchio, I., Alvano, A., Proto, G., Nicoletti, G., & Rampello, L. (2004). Blink reflex abnormalities in Tourette syndrome. *Clinical Neurophysiology,* 115:320–324.

Rennie, D. L. (1998). Grounded theory methodology: the pressing need for a coherent logic of justification. [Electric version]. *Theory Psychology*, 8, 101-119.

Rivera-Navarro, J., Cubo, E., & Almazan, J. (2009). The diagnosis of Tourette syndrome: communication and impact. *Clin Child Psychol Psychiatry,* 14(1):13-23.

Richardson, G. E. (2002) The metatheory of resilience and resiliency, *Journal of Clinical Psychology.,* 58 (3), pp. 307-321.

Richardson, G. E, Summerhays, J. F. (2011). Magnify your life: a progressive bombardment approach to preventing childhood obesity. http://health.utah.gov/obesity/documents/Richardson. Downloaded 3/11/2012;

Robert Wood Johnson Foundation. Retrieved 9/6/2008. http://www.qualres.org/HomeAudi-3700.html

Robertson, M. M. (2000). INVITED REVIEW Tourette syndrome associated conditions and the complexities of treatment. *Brain*, 123:425-462.

Robertson, M. M., Banerjee, S., Eapen, V., & Fox-Hiley, P. (2002). Obsessive compulsive behaviour and depressive symptoms in young people with Tourette syndrome. A controlled study. *Eur Child Adolesc Psychiatry*, 11(6):261-5.

Robertson W. C. (2010). Tourette Syndrome and other tic disorders. Downloaded 1/27/10. http://emedicine.medscape.com/article/1182258-overview

Rosen, L. (2002). Family dynamics in the treatment of Tourette syndrome. *Exceptional Parent,* December 2002.

Schapiro, N. A. (2002). Dude, you don't have Tourette's: Tourette's syndrome, beyond the tics. *Pediatric Nursing*, 22(3):243-253.

Seligman, M., & Darling, R. B. (1997). *Ordinary families, special children a systems approach to childhood disability.* The Guilford Press, New York.

Shapiro, A. K., & Shapiro, E. (1968). Treatment of Gilles de la Tourette's syndrome with haloperidol. *Bril. 3. Ps,chiat.* 114, 345-350.

Shavitt, R. G., Hounie, A. G., Campos, M. C.R., Miguel, E. C. (2006). Tourette's syndrome. *Psychiatr Clin N Am* 29:471–486.

Singer, H. S. (2005). Tourette's syndrome from behaviour to biology. *Lancet Neurol,* 4:149-159.

Skinner, E. A., & Zimmer-Gembeck. (2007). The development of coping. *Annual Review of Psychology,* 58:119-144.

Stephens, R. J., & Sandor, P. (1999). Aggressive behaviour in children with Tourette syndrome and comorbid attention-deficit hyperactivity disorder and obsessive-compulsive disorder. *Can J Psychiatry,* 44(10):1036-42.

Stillman, A. A., Krsnik, Z. E., Sun, J., Rasin, M. R., State, M. W., Sestan, N., et al. (2009). Developmentally regulated and evolutionarily conserved expression of SLITRK1 in brain circuits implicated in Tourette syndrome. *The Journal of Comparative Neurology* 513:21–37.

Strauss, A., & Corbin J. (1998). *Basics of qualitative research*. Sage Publications.

Sukhodolsky, D. G., do Rosairo-Campos, M. C., Scahill, L., Katsovic, L., Pauls, D. L., Peterson, B. S., et al. (2005). Adaptive, emotional, and family functioning of children with obsessive-compulsive disorder and comorbid attention deficit hyperactivity disorder. *Am J Psychiatry*, *162(6):1125–1132).*

Sukhodolsky, D. G., Scahill, L., Peterson, Z. H., King, R. A., Lombroso, P. J., Katsovich, L., et al. (2003). Disruptive behavior in children with Tourette's syndrome: association with ADHD co-morbidity, tic severity, and functional impairment. *J Am Acad Child Adolesc Psychiatry,* 42(1):98-105.

Ulin, P. R., Robinson, E. T., & Tolley, EE. (2005). *Qualitative methods in public health: a field guide for applied research*. San Francisco: Josey-Bass.

Valderhaug, R., & Ivarsson, T. (2005), Functional impairment in clinical samples of Norwegian and Swedish children and adolescents with obsessive-compulsive disorder. *Eur Child Adolesc Psychiatry*, 14(3):164-73.

Walsh, F. (1998). *Strengthening family resilience*. The Guilford Press, New York.

Wilkinson, B. J., Newman, M. B., Shytle, R. D., Silver, A. A., Sanberg, P. R., & Sheehan, D. (2001). Family impact of Tourette's syndrome. *Journal of Child and Family Studies,* 10(4):477-483.

Wong, M. G., & Heriot, A. S. (2008). Parents of children with cystic fibrosis: how they hope, cope and despair. *Child: Care, Health and Development*, 34(3):344-354.

Woods, D. W., Himle, M. B., Miltenberger, R. G., Carr, J. E., Osmon, D. C., Karsten, A. M., et al. (2008). Durability, negative impact, and neuropsychological predictors of tic suppression in children with chronic tic disorder. *J Abnorm Child Psychol.* 36(2):237-45.

Woods, D. W., Himle, M. B., & Osmon, D. C. (2005). Use of the impact on family scale in children with tic disorders: descriptive data, validity, and tic severity impact. *Child & Family Behavior Therapy*, 27(2):11-21.

Woods, D. W., & Marcks, B. A. (2005). Controlled evaluation of an educational intervention used to modify peer attitudes and behavior toward persons with Tourette syndrome. *Behav Modif*, 29:900-912.

Ylvén, R., Björck-Åkesson, E., & Granlund, M. (2006). Literature review of positive functioning in families with children with a disability. *Journal of Policy and Practice in Intellectual Disabilities* 3(4): 253–270.

Zinner, S. H. (2002). Ask the medical advisory board. *Tourette Association Newsletter*, Summer, p.6.

Zinner, S. H. (2004). Tourette syndrome—much more than tics—moving beyond misconceptions to a diagnosis, pt 1. *Contemporary Pediatrics* 21(8):22-36.

Zinner, S. H. (2004). Tourette syndrome—much more than tics—management tailored to the entire patient, pt 2. *Contemporary Pediatrics* 21(8):39-39.

Zinner, S. H., Topolski, T. D., Freeman, R. D., Edwards, T. C., Patrick, D. L. (2007a). Family experience of youth with Tourette syndrome. Abstract 16. *Journal of Developmental & Behavioral Pediatrics*, 28:(4)p S5. [Abstracts of Plenary Sessions and Posters Accepted for Presentation at the 2007 Annual Meeting of the Society for Development and Behavioral Pediatrics].

Zinner, S.H., Topolski, T. D., Freeman, R. D., Edwards, T. C., Patrick, D. L. (2007b). Quality of life among youth (ages 11-18) with Tourette syndrome. Abstract 17. *Journal of Developmental & Behavioral Pediatrics*, 28:(4)p S5. [Abstracts of Plenary Sessions and Posters Accepted for Presentation at the 2007 Annual Meeting of the Society for Development and Behavioral Pediatrics].

Zhu, Y., Leung, K. M. , Liu, P. Z., Zhou, M., & Su, L. Y. (2006). Comorbid behavioural problems in Tourette's syndrome are positively correlated with the severity of tic symptoms. *Aust N Z J Psychiatry,* 40(1):67-73.

CHAPTER 2

THE RELATIONSHIP OF FATHERS WITH SONS WHO HAVE TOURETTE SYNDROME AND THE IMPACT ON THE FAMILY

Abstract

This study provides an introductory understanding of some of the challenges and problems associated with having a son with Tourette syndrome (TS) and the potential impact on fathers and the family.

This qualitative study using grounded theory was conducted to better understand: 1) the relationship of fathers with their sons who have TS; 2) how father/son relationships changed over time; and 3) how this impacted the father's relationship with his wife and other children. Recruitment came from one of two sources: 1) the Neuropsychiatric Clinic Tourette Syndrome Genetic Study at the University of Utah; and 2) snowball sampling.

These fathers faced the normal and expected challenges that other fathers experienced raising their children, in addition to challenges influenced by the intrinsic nature of TS. By its very nature, TS waxes and wanes and follows an unpredictable course. New Tourettic tics tend to develop spontaneously, last for an unpredictable period of time, may intensify or not, may or may not fade away or diminish. Tics vary in location, complexity, severity and frequency. New tics may follow old tics or be

superimposed on existing ones. The process of new tics developing, intensifying, and fading is referred to as waxing and waning. . Each father experienced and reacted to the waxing and waning of his son’s symptoms as well as the uncertainty about what the future would bring.

Fathers reported a range of effectiveness in responding to challenges. Some challenges were created directly by TS and its related comorbidities and are categorized as primary challenges. Others were created by the fathers’ ineffective responses to these primary challenges and are categorized as secondary challenges.

As fathers responded effectively to primary challenges they experienced personal growth which led to stronger, more positive relationships with their son and other family members. Father’s responding ineffectively experienced secondary challenges creating further difficulties and negatively impacting family relationships.

The fathers’ waxing and waning pattern of responses in the face of an uncertain future occurred along five major themes: 1) normalcy, 2) pride, 3) hope, 4) acceptance, and 5) role satisfaction.

Introduction

Although an estimated 750,000 children in the United States have Tourette Syndrome (TS) (Zinner, 2004), little research has been done on the impact of a child’s TS on parents and the family, and even less has focused specifically on how fathers in particular are impacted when a child with TS is part of the family and how this in turn impacts the family (Wilkinson et al. 2001; Woods, Himle, & Osmon, 2005). From a family systems theory perspective, it is not just the children who have TS, but it can truly be said that all members of their families have TS, in the sense that whatever affects one family member affects the entire family. In order to begin filling in that significant gap in the literature, this study concentrates on fathers and their relationships with their sons with TS and the impact on the family.

Purpose

The purpose of this study is to provide an introductory understanding of some of the challenges and problems associated with having a child with TS and the potential impact on families. It also highlights how limited the research is to date and the critical need for further efforts to understand the impact of TS on families.

This qualitative study was conducted to better understand: 1) the relationship of fathers with their sons who have TS; 2) how father/son relationships changed over time as fathers accompanied their son along his journey with TS; and 3) how this journey impacted the father's relationship with his wife and other children. I used grounded theory as the research design and the constructionist-interpretivist paradigm to help view reality through the lived experiences of these fathers.

Literature Review

The unique difficulties, frustrations, and challenges confronting children with TS can provide opportunities for personal growth and development, but they can also lead to frustration, social miseries, academic problems and much heartache (Hendren, 2002; Woods and Marcks, 2005). It is not uncommon for children with TS to be misunderstood and subjected to teasing, bullying, and even to cruel jokes (Chowdhury, 2004; HBO Documentary, 2005). These children live with challenges that most people do not even realize which can have a major impact on family dynamics and functioning and create distress and disruption in their lives.

Families with children with TS face all of the same challenges that other families face in addition to those associated with TS. The resilient family recognizes the chaos created by disruptions and works to turn these into family strengths, which can lead to changing the very nature of the family itself (Flach, 1997). Symptoms of TS can occur as early as infancy, although about 7 years of age is more typical, and even the earliest symptoms a child experiences can create disruptions in families (Hawley, 2012). Zinner (2004, pt. 1) reports that after Tourettic symptoms become more noticeable and comorbidities reveal themselves parents often experience "incredible relief" when they eventually seek medical advice and their child receives a diagnosis.

Methods

Grounded Theory

Using a grounded theory research design allowed me to be rooted in the perceptions and lived experiences of both the study participants and myself as the researcher. I did not begin with a preexisting theory, but rather developed a theory grounded in the data gathered through listening to each father tell his story, and observing his reactions and emotions during the interview. In several cases the father invited his wife and son to visit with me after the interview. This allowed me to make first hand observations of the interactions of the father with his wife and son. I also had some additional contacts with fathers, with one father at a Tourette Syndrome Association summer picnic and with another father at a community event. In both cases I was able to observe the fathers interacting with their families (Creswell, 2007; Dick, 2007; Rennie, 1998; Ulin et al., 2005). As the process unfolded, the richness of the data was incorporated into the generation of the theory (Fassinger, 2005).

Constructionist-Interpretivist Paradigm

The constructionist-interpretivist paradigm suggests that there are multiple realities, each of which is valid, (Haverkamp & Young, 2007) and that the meaning of these realities must be interpreted rather than being directly observed. This paradigm was used to view reality through the lens of the lived experiences of the fathers. It helped shape my view of the fathers' worlds through their perceptions. As such it influenced the problems that were studied, the data that were found useful, the methods used to gather the data, the way the study was conducted and myriads of other decisions and choices involved with this research (Ulin et al., 2005).

Selection Procedure

Participants were selected to create a homogeneous sample that met criteria established prior to data collection. The selection criteria was intended to: 1) generate a sample which was homogeneous in several key areas; and 2) help distinguish the stresses associated with having a son with TS as they accumulate over time from other stresses that might impact a father. Fathers dealing with multiple significant life stressors in addition to having a son with TS may react very differently to their TS son. The initial focus was on sons because TS is more prevalent in males and studying only males at this point eliminates possible gender related differences in how fathers interact with a child with TS. Studying only sons who have had TS for at least 3-5 years is important as the length of a father’s exposure to his son may have an impact on his reactions toward his son due to accumulated stress and frustration (Ferre, RC. (2008).

In order to have a valid study it is important to have enough participants to reach redundancy. However, according to Morrow (2005) the size of the sample does not necessarily determine the quality or adequacy of the evidence produced in qualitative research. From the beginning it was anticipated that the study would involve 10-12 participants, the final number to be determined by the progress of the data collection.

Recruitment

Recruitment of fathers came from one of two sources: 1) the Neuropsychiatric Clinic Tourette Syndrome Genetic Study; and 2) snowball sampling, which is obtaining a sample (father meeting the criteria) from someone who is well-situated to refer cases (Morrow, SL. 2008). Thirteen fathers were interviewed but only nine were used in this study. Four additional fathers were selected but did not meet the criteria. Pertinent data were not in two of the clinic files and the information was incorrect on two other fathers referred through snowball sampling. Due to the fact that these four fathers took time out of their busy schedules and were willing and anxious to participate, I continued with the interviews even after I ascertained that they did not conform to the selection criteria. These were nonconforming cases contained many similarities as well as differences and offered other perspectives on the impact of having a son with TS that could lead to future research. Information from these fathers was not included in the data analysis, but is mentioned in the text. These fathers and the perspective they shared are identified as non-conforming cases.

Data Gathering

Data were gathered through semistructured interviews conducted by Anne Evans-Cazier, LCSW and me. Because I have been diagnosed with ADD I received approval from the IRB at the University of Utah to use Anne to conduct the interviews with me being present to ask additional or follow-up questions as needed. Also, this freed me to observe the fathers during all interviews.

The interviews lasted 60-90 minutes and were audio-recorded and then transcribed. The interview questions are listed in Appendix B. The interviews began with open-ended questions about the father and son relationship and the family. More specific or in-depth questions were asked as needed to elicit information pertinent to all of the questions on the question guide. Many fathers addressed a number of question topics without direct questioning so not all fathers were asked all questions, however each father covered all question topics either directly or indirectly.

Data Analysis

Data analysis began with a systematic examination of the data gathered from individual interviews of the fathers. These interviews helped me identify relationship patterns between the fathers’ and their sons. All fathers had different experiences leading to their own understanding of their reality of living with the challenges of their sons TS.

Data analysis was an ongoing, evolving process through which theory emerged. The emergent theory was an ever developing process, using an iterative cycle of explicit coding and constant comparison to identify multiple categories, properties, and hypotheses along the way.

Constant comparative methods were used to make comparisons between the data gathered in the individual interviews of the fathers. These comparisons were essential in identifying emerging ideas, developing categories, bringing insight and meaning to the data, and interpreting and transforming the data into significant findings.

Comparative analysis was used to: 1) validate facts by assuring the accuracy of the evidence gathered, 2) establish empirical generalizations of these facts so that theory has more power to explain and predict, 3) verify the theory and the relevance of the emerging categories through continual analysis and data checking, and 4) generate new theories from the gathered data. The data were broken down and put together again in new and meaningful ways, leading to the identification of overarching themes.

In order to provide a thorough analysis of the data, I immersed myself in reading and rereading the data. By becoming familiar with the data I became more cognizant of emerging themes which aided me in obtaining the core meanings of the stories these fathers shared in terms of their feelings and thoughts and even behaviors. This immersion guided me in my interpretation of the data.

Rigor was maintained by adhering to the accepted policies and procedures for qualitative research which included: peer reviews to help with data analysis and interpretation, memoing, note taking, and reflective journaling to record my thoughts, feelings, interactions with the participants, new ideas, etc. Throughout this process I maintained an awareness of my biases, bracketed them, and was consistent when I discovered new biases.

Results

The overarching finding which emerged in this study was that the fathers experienced a waxing and waning pattern of response in the face of an uncertain future which seemed to be influenced by the intrinsic nature of TS. They reported experiences along a continuum of success, ranging from effective responses which seemed to lead to personal growth and resilience and stronger relationships with their sons and families, to ineffective responses, difficulty developing personally, and relationship strain or deterioration. The waxing and waning pattern of responses occurred along five major themes: 1) the question of normalcy, 2) pride in son, 3) hope in the future, 4) acceptance, and 5) role satisfaction.

The results are presented as follows: 1) the influence of the intrinsic nature of TS on fathers' response pattern, 2) the fathers' continuum of effective responses to the challenges associated with TS and related comorbidities, and 3) the unfolding of the five major themes in the lives of the fathers over time.

Response Patterns Influenced by Nature of TS

These fathers faced all of the normal and expected challenges that other fathers experience raising their children, and they also experienced additional challenges influenced by the intrinsic nature of TS. By its very nature, TS waxes and wanes and follows an unpredictable course (Bagheri, Kerbeshian, & Burd. 1999; Leckman. 2002; Chowdhury. 2004; Edell, Motta. 1989). New Tourettic tics tend to develop spontaneously, last for an unpredictable period of time, may intensify or not, may or may not eventually fade away or diminish. Tics vary in location, complexity, severity and frequency. New tics may follow old tics or be superimposed on existing ones. The process of new tics developing, intensifying, and fading is referred to as waxing and waning. The pattern of waxing and waning in TS is unpredictable (Chowdhury, U. 2004). Each father of a son with TS experienced and reacted to the waxing and waning of his son's symptoms as well as the continuing uncertainty about what the future would bring.

The fathers spoke of the many, varied challenges they faced that led to the waxing and waning response phenomena they experienced. Human thoughts and emotions are, of course, complex and do not fit easily into tidy packages, however, these phenomena can be grouped meaningfully into two categories which appeared to have an interactive waxing and waning connection to each other as seen in Figure 2.1.

Every father reported his own issues with his TS son that was part of his life and challenge of being a father. Although there were similarities between the fathers, each was uniquely challenged to develop his personal strengths in response to the waxing and waning and unpredictable course associated with his particular son's TS.

The level of personal growth and resilience appeared to lay the foundation for and give direction to the developing relationships. Fathers reported that as they became more knowledgeable about and experienced with the course of TS, they learned to recognize the waxing and waning of their son's symptoms. As they described their own responses to TS it became apparent that they experienced a waxing and waning course of thoughts and feelings as each tried to deal with his son and his struggles. For example, many of the fathers reported that sometimes they had confidence that their son could successfully adjust to the challenges of TS and that at other times they became fearful that their son would never be able to live a normal life.

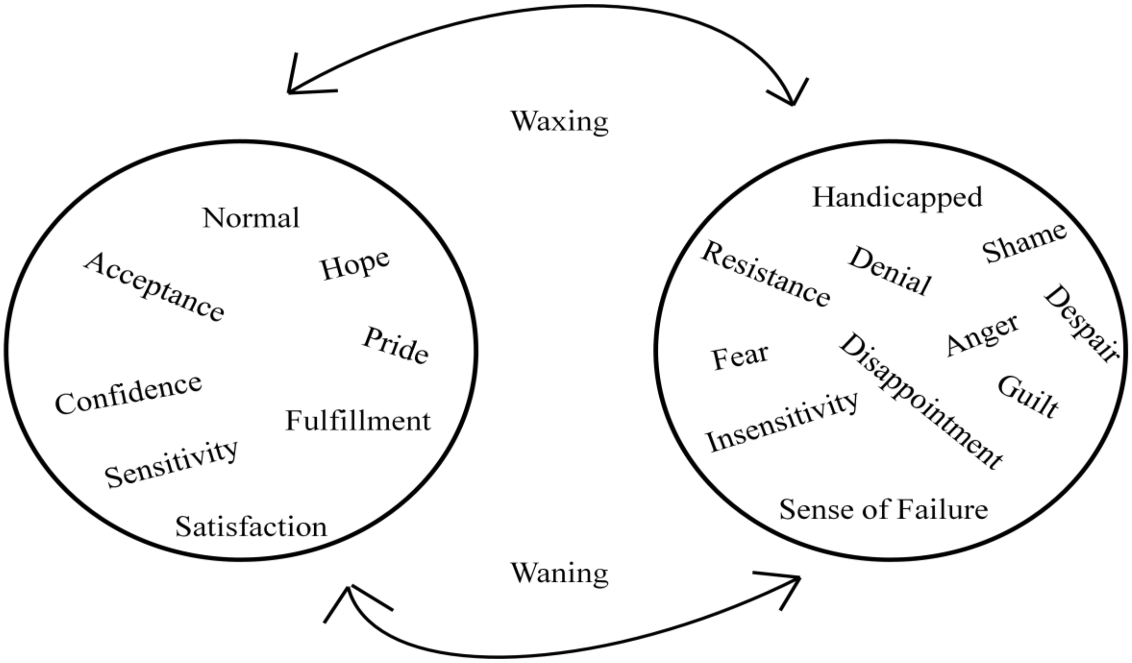

Figure 2.1 Father's Waxing and Waning

Continuum of Effectiveness in Fathers' Responses

Fathers reported a range of effectiveness in responding to challenges. Some challenges were created directly by TS and its related comorbidities and will be categorized as primary challenges. Others were created by the fathers' ineffective responses to the primary challenges and will be categorized as secondary challenges. There appeared to be a cumulative or additive dimension to the fathers' response patterns which led fathers to head down diverging paths.

Overall it was observed that as fathers responded effectively to primary challenges they experienced personal growth and laid a foundation for building stronger, more positive relationships with their son with TS and other family members. On the other hand, as they struggled and responded ineffectively they experienced secondary challenges which created further difficulties and negatively impacted family relationships.

Primary challenges are life events/stimuli that are related to the son's TS and/or co morbidities which can impact the father either directly or indirectly. Take for example the situation of a father who has an ineffective emotional reaction to a new experience with his son with TS. The new experience is the "primary challenge" and his ineffective emotional reaction would become his "secondary challenge."

The fathers' stories suggested that when they responded effectively to primary challenges, they headed down a path in which they were strengthened by this initial response and developed personal qualities that positioned them to respond effectively to the next primary challenge they would face. In addition, their effective response did not create a secondary challenge, with its attendant disruptions and struggle.

On the other hand, when fathers had an ineffective response to a primary challenge and created a secondary challenge, they headed down a path in which the initial response not only left them without the development of new strengths, but in which they also now faced the additional secondary challenge. Further analysis of the data suggested that one ineffective response and the creation of a secondary challenge was often followed by an ineffective response to the secondary challenge and therefore the creation of yet another secondary challenge in a spiraling pattern of loss and disruption.

For example, one of the fathers in the study, Cameron, faced the primary challenge of his son's tics and spoke about how hard it can be on parents "to sit back and not make a big deal of it…. I don't think we did but there is this impulse, I mean, I see why people do. You know, because you are worried about it and you want to help them … I want to make sure he feels comfortable … I try to be sensitive to him." This father recognized his son’s TS-related difficulty and worked hard to have a sensitive and appropriately supportive, effective response resulting in personal growth and resiliency.

Another father, McKay, faced a similar situation which resulted in the creation of a secondary challenge. McKay shared his experience, “sometimes I’ll yell at him and physically move him away from the situation or tell him that he needs to go and you know, chill somewhere, and be away from his brother or be away from everyone until he can, kind of get a grip, and, and that might not necessarily be the most productive way to deal with it, nevertheless that’s what happens from time to time, and you know, that’s, that’s one segment of my poor coping strategy.” In this case, the father’s ineffective response created a secondary challenge of tension and disconnection in the father-son relationship. He still needed to find a way to deal effectively with the original tic related issues and now also faced the secondary challenge of the tension and disconnection created by his response.

The pattern these two fathers put in motion differed. The first father became stronger as he effectively coped with his son’s Tourettic tics and related comorbid behaviors. His responses helped him develop himself personally and prepare to cope effectively with future challenges. The second father experienced a similar primary challenge but dealt with it ineffectively which put him on a more difficult path along which he now had to deal with additional problems such as distancing and disconnection. As he explained, “then it comes back to … you’re not being fully engaged with family.” Ineffective responses such as this led fathers in this study to repeated ineffective responses, continuing until they could respond effectively to challenges.

Five Major Themes Unfold

The following sections examine each of the five major themes which emerged from the fathers' reports of their experiences with their son with TS over the course of time i.e. normalcy, pride, hope, acceptance, and role satisfaction.

Theme One: Normalcy

Most of the fathers in this study indicated that they were quite conflicted about whether or not their son should be considered normal or handicapped. This appeared to be a sensitive and confusing subject about which their thoughts and emotions waxed and waned, sometimes within just a few moments in the interview itself as well as by report throughout time in their everyday life. During the interviews several fathers said they did not consider their son to be handicapped at one point and then that they did consider him to be handicapped at another point. The uncertainty of the future seemed to play an important role in this waxing and waning.

The question of normalcy usually first arose when a father noticed odd sounds or behaviors that were later recognized as his son's first Tourettic tics. Many fathers reported a period of waxing and waning uncertainty and fear during which they weren't sure whether what they were observing in their son was part of normal maturation and development or something out of the ordinary.

Some fathers quickly realized that their son had TS, while others remained confused and bewildered much longer, sometimes even for years. Those in the study who were the quickest to realize that their son had TS had some previous knowledge of TS or knew someone who did. For example, some of the fathers had professional training in medicine or psychology or had extended family members who did. One of these fathers recalled noticing his son’s throat clearing and head flicking and his thought, “oh, my goodness…he’s got Tourette's.” He then used his professional skills to begin adapting. He reviewed the professional literature and talked to his colleagues who were experts in the field.

However, even those fathers who had the professional background to help them recognize what was happening still faced the emotional impact of a father confronting the fact that his child had a significant disorder. One of these fathers said, “I remember the day I diagnosed him, I mean, it was pretty painful. It was pretty, pretty emotional. He had been doing a lot of throat clearing. He was about 7.”

As mentioned, other fathers agonized for a much longer time. For example, Alex didn’t get his son Randy diagnosed until he was in junior high school and only did so then because it “got to a point where he became completely incapacitated with his tics.” This diagnosis happened 10 or 11 years after the father first recognized his son had problems at the early age of 3 or 4 years. McKay recalled that his son Gene exhibited what he called “little habits” as early as preschool and his preschool teachers tried to convince McKay and his wife that their son “was psychotic and that we should take him to get help.” By the time his son was five McKay knew that his son “wasn’t your typical, normal kid.” As the tics continued, McKay reported that he continued to be confused and didn’t know what to think of his son’s behaviors “I don’t know if that is normal but [I] didn’t know what it was.” Even with all these concerns and frustrations, Gene was not officially diagnosed until he was 11 years old and in the sixth grade.

Although many of the fathers reported feeling distressed and concerned by the early unexpected manifestations of TS and comorbid conditions, they also reported feeling relieved in a way when their son was finally diagnosed. Both Lowell and his son Gordon were relieved when Gordon was diagnosed. Through his tears Gordon expressed his relief and sense of normalization when he learned of his diagnosis, “I am not crazy, I’m so not crazy.” Lowell confirmed his own feelings following Gordon’s diagnosis, “it was a great relief to know that there was a medical model that could classify his dysfunction.” He went on to explain, “We really didn’t know what Tourette's [was]. He started making these odd noises all the time and, doing odd behavior all the time and so I didn’t really know what Tourette's [was]. But I remember thinking at that time, this is a problem, but we will deal with the problem.”

Many fathers didn’t like the label handicap because of its negative connotations. London stated that one of his big fears was that his son Chad was “going to feel like less of a person” as a result of his TS. After expressing this concern he showed his sensitivity towards this son when he said, “I don’t want him to feel less of a person.” Brian, along with several others, didn’t want the words handicapped or disabled applied to his son because he thought those labels could be used as a crutch “especially if you tell them you can’t do that or you can’t, you know it’s a crutch we don’t use those, and I don’t think they're true.”

All of the fathers interviewed recognized that TS created certain challenges and difficulties but they reported they were moving towards believing that overall it wouldn’t stop their sons from succeeding and doing what they wanted with their life. However many of them were still conflicted and waxed and waned in their thoughts and emotions about their son’s future. One father quantified his hope and belief, and perhaps addressed the uncertainty of many fathers, when he stated that his son could succeed, but only “if the tics stay down, he can go as far as he wants.”

The following are a sampling of comments fathers made about whether or not their son should be considered normal or handicapped:

I don’t “see it as a handicap the Tourette's. I see it as an obstacle that he is going to overcome.”

“I probably treated him more you know it sounds bad normal you know, this is something that you can certainly work through and it’s an obstacle that you can overcome.”

“We’re all different, what’s nor[mal], would I consider myself normal? Maybe a little goofy, a little quirky. I guess that’s a tough question to answer, I guess outside of the norm, … I guess if you’re functioning in society or in the community I would say you're, you're kind of, you know in that respect you're kind of meeting expectations, I don’t know how to answer that truthfully, I would say that Alton, you know, is normal, you know the opening his mouth, or that, or he’s not normal, I wouldn’t say that I don’t know how to answer that truthfully.”

“It is, it is disabling, you know. I mean that is the fact. … You know, we were all disabled.” “I have always considered him normal but when you use the word disabled, if I am honest about it, it was disabling.” I don’t “like the word handicap but it fits. I mean he was handicap[ped] by the tics.” “He couldn’t function … regardless of what we did.”

Theme Two: Pride

A waxing and waning sense of pride was a major theme for the fathers in this study. One father reported an illustrative experience. He mentioned the pride he has felt in his son “I saw his tremendous ability, I thought, [he] is going to be a very successful kid and, you know, I was always very proud of him and I had high expectations for him,” and he talked about his doubts and disappointment. “I am having my serious doubts that he could achieve that kind of thing (obtain a college degree) because I am wondering if he is going to be able to be focused enough.”

Then the father’s pride began to rise again as he recounted that actually in college his son “didn’t do as bad as I thought he would do,” and then wane as disappointment crept back in “but he didn’t do as well as he could have done.” As his son’s symptoms waxed and waned, the father’s pride and his disappointment waxed and waned as well. As pride waxed stronger, disappointment waned, as disappointment waxed, pride waned.

Another father described waxing and waning sense of pride in his son. First he described the obvious pride he had for his son’s willingness to serve others, “he is so sweet and loving and he will do things for people, just, just to be a good person. He doesn’t expect a reward out of it.” Then later the father expressed his frustration and disappointment in his son in family life at home because his son “doesn’t like to help here.”

The following single line comment from the father London about his son who does his homework but doesn’t turn it in captures both his waxing pride in his son’s abilities and frustration and disappointment in his performance, “I guess our biggest frustration is knowing how smart he is.”

The following are a couple of representative comments made by fathers about their growing pride in their sons:

McKay's son Gene is an artist who enjoys drawing comic strips using a little T-Rex dinosaur as his main character. McKay was visibly touched as he described the Father's Day strip Gene drew using one of their fishing trips as his inspiration. This panel showed a back view of "the dad dinosaur and the son dinosaur fishing," The son dinosaur said, "the best thing about you is, is that you're my dad." McKay described his feelings of love and pride for his son this way, "it was just so cute, and, and you know to think that your son felt that way about you enough to draw it out…"

Lowell sums up the pride he has for his son Gordon "… he might not be the perfect child as the world would call him, but he is definitely a perfect child…. I am glad he is my son." This same feeling of pride and gratitude was felt by other fathers, as well.

Theme Three: Hope

As was the case for many of the fathers, pride and disappointment in this case were closely connected to hope and fear. When this father felt rising pride in his son, he also experienced rising hope in his future; when he felt growing disappointment, he also experienced growing fear for his son's future.

This father reported feeling "saddened by the fact" that he and his son were not as close as he would like and that his son didn't want to be around him that much. He reported further that, "I try to be positive whenever I am around him. I try to my best to be positive. But somehow it always works around to, you know, something that he needs to improve on." To this point the father had not been able to come out of the troughs of disappointment and fear and reintegrate with gain to a solid sense of pride and hope. His fear and disappointment were creating secondary challenges to the father – son relationship, pushing his son away. In one telling exchange, the father told his son in frustration, “you have the capability to be a CEO at any company or you are going to be the smartest Wal-Mart cashier.”

This was not an isolated example. Fears were especially common early on when they were founded on inaccurate and misleading information and stereotypes such as thinking that his son would be shouting vulgarities for the rest of his life. Many of the fathers wanted to believe in their sons but the reality was that as they watched them struggle it taxed the father’s belief that all would be well. London paid a compliment to his son’s ability, “He could do good at everything he does,” then adds a qualifier, “but he doesn’t try hard enough.” He expressed this same struggle between hope and fear, pride and disappointment again in a more poignant and blunt way, “He is a great kid but he is a kid who sees the finish line and stops.”

The fears these fathers experienced were different for each of them, but the fears were real and they were challenged to learn how to deal with them. Most of the fathers reported gaining some level of acceptance of their son and his challenges and some ability to develop hope in their son’s future. Chase worried about kids picking on his son, and in fact kids did make fun of him. Chase admits to being very protective of this son and hypersensitive to him. As time went on the tics waned and so did Chase’s worry. The question remained, would his fear return if his son’s TS waxed again?

When Michael’s son Dale turned 12 Michael lacked almost any hope at all and was extremely fearful for his son’s future. At that time, in Michael’s words, “all hell broke loose.” He recalled how his son’s TS “went crazy. I mean hitting himself, [using] the F-word constantly. He couldn’t function in school, couldn’t make it through first period. Literally [he] missed a year and one-half of school.”

This dad went on to describe how through the 7th and 8th grade years Dale’s tics got so bad that he had to go to the counselor’s office to tic.

> He would call [his mom]. He couldn’t even speak when he would call from school. He would be crying. He would be ticking. He would be screaming. He would be yelping. He would be twitching. He would be, ‘come get me, Mom. I’ve got to come home’ …. There was no relief. I mean, there was no relief. … I mean, there was no real break even between the tics. [It was] life changing.

Two years later, Dale’s tics waned and with that waning Michael’s hope for his son began to wax. He knew that Dale would always have some tics but he also began to have hope that they wouldn’t always be “life changing” or “debilitating” and he could “function in society” and not have to become a “recluse and stay in the house all day.” He began to hope even in the face of an uncertain future.

While this was an extreme example, most of the fathers came to believe to some degree that their son had the potential to deal with TS effectively and to have some hope in a meaningful future as reflected in the following sample of comments:

“There is no reason that Tourette's should stop [him] from doing anything that he wants.”

“He can do whatever he wants, this is not going to, hamper his future, that he’ll be able to pretty much take on whatever he wants to as far as schooling or career, or you know anything like that.”

“In the real-life world, I think he will be able to function, he will be able to figure or cope.”

Theme Four: Acceptance

Another major theme in the fathers’ stories was their struggle with acceptance. For example, one father reported on how hard it was initially for him to accept that his son had TS. His first thought at the time of diagnosis was, “I didn’t want to deal with him as a son.” Later, as this same father came to accept that he has three sons who have TS, he said

> I want … my kids to know it is not, it is not a disability. It is just something we have got to deal with just like putting your pants on every single day. You just do it. You deal with it. We’ll, we’ll fix it, we will make [it], we will, there is nothing we can’t accomplish. The Tourette's is not going to be the defining factor of who they are.

Another father, Chase, echoed the sentiments of many fathers about the difficulties they encountered before their son’s TS was diagnosed and the feeling that they were better able to move forward after receiving the diagnosis, “once we knew, I was able to accept it and deal with it and understand what his issues are.”

The theme of acceptance also played out in connection with the guilt and fear fathers felt about the genetic component of TS. Lowell expressed his waxing and waning guilt and fear for his sons’ future (he has more than one son with TS).

> I have had to come to grips with the idea that I have caused all this pain and suffering to my boys and it scares the hell out of me to think they are going to have children of their own and I do not want them feeling like I do … I have never told them that. I have never said anything about it because I don’t want them to know that is how I feel. I have had to come to grips and I still don’t think I have all the way.

This father felt his guilt and fear wane as his ability to accept waxed and vice versa. He recognized that he was still in a growing process. Responding with guilt created secondary challenges, such as the distancing that came from being unable to talk about something as significant as their shared genetic makeup. Waxing levels of acceptance were part of his resilient reintegration and a step forward in his personal growth and in his relationship with his sons.

Anger was another common reaction reported by the fathers which waxed and waned with their ability to accept their son and his TS related issues. Some directed their anger at their son, some towards others including family members, friends, and even strangers. Lowell, for example admitted that "I love to yell" and reported yelling at his son's teachers and even getting angry with the principal. He "got accused of bullying the principal" when he got mad at him for not doing enough to help protect his son. In fact, he told the principal, "do your job or get the hell out of it."

Michael found it difficult to control his anger when adults (especially strangers) were rude or insensitive to his son. He reported that, "I have gotten angry at adults [a] lot and that is where Emily (his wife) jumps in and saves me from going to jail." He described a time when Dale's tics were at their worst and they were in a hardware store. The father lost his composure and just "about killed a guy in Home Depot" because

> He was making fun, he was an adult and he was making fun. Dale was ticking and he couldn't see us and he is yelling, "It is not broken." 'If it ain't broken, shut up.' I was going around the corner and told him I was going to do bad things. I grabbed him and I was literally, viscerally. I came this close to literally pummeling the guy.

London spoke of his tendency to lose control of his temper and get angry and frustrated when dealing with his son's school failures. Like several other fathers, he reported that his son was capable and intelligent enough to get good grades and did very well on the tests, but he did not turn in his homework and as a result he failed his classes. "As a parent, I can't accept it and I'm fiery and he got my wrath." His response created secondary challenges and he and his son then had to deal not only with the son's school problems but with dad's anger as well.

Educational challenges created tension between many fathers and sons and the rest of the family. A common frustrating experience that seemed to cause a great difficulty for fathers was when the sons did not do their homework or did it and didn't turn it in. These fathers were frustrated because they knew their sons had the ability to do well in school. Cameron's frustration with his son Sherm was an example of the frustration many fathers experienced. Cameron elaborated his frustration, "He can get good grades. He is in the accelerated … ELP but, then he also will get C's and D's in the ELP classes … you know, it is like, if he want[s], he does it." He went on to explain that "this is a kid who gets 100% on his math test, who gets a C or D in math because he hasn't turned in the assignments he has done." Sherm is on his school's competitive math team that placed in regional competition.

Like many other fathers, Chase came to realize that an angry response "just exacerbates the situation" and so he worked "to avoid that as much as possible." He reported that learning more about TS and the difficulties commonly associated with it helped him become more accepting and deal more effectively with his son.

Not all fathers named anger as a personal challenge but they all reported feeling some level of frustration and stress about their son and his TS. They felt that through their ups and downs and over time, some more quickly than others, some more slowly, but all were learning to deal with the challenges in their own way as they navigated their journey.

Theme Five: Role Satisfaction

The fathers reported having had their share of ups and downs over the years in their ability to live up to their aspirations in their roles as fathers and husbands. They were very clear about the values by which they tried to live their lives and the goals they wished to attain in these areas, although, of course, as human beings they were not always entirely successful in living up to these ideals. Overall however they reported growing satisfaction in these roles and a less pronounced pattern of waxing and waning than found around the other themes.

Role satisfaction as a father. The fathers in this study seemed to take their role as a father very seriously and expressed the belief that being a father "is a lot of responsibility." Their understanding of their role as father can be divided into three basic areas: 1) provider, 2) protector, and 3) teacher. They spoke with a lot of depth about their sense of responsibility within each of these components and their realization that they were most successful when they worked as a team with their wife and relied on her expertise, talents, and abilities in raising their TS son as well as their other children. Lowell summarizes the feelings of many fathers

> I have got an incredible wife, an incredible woman who reads me and knows me and knows how to settle me down. … We have a special relationship. I think it only comes with … years of being together and understanding that individual and, and not holding back, giving everything, you know. So we have a great relationship that way.

Role satisfaction as a father: provider. As a whole the fathers in this study felt responsible to provide in both tangible and intangible ways for their families. They reported believing that both of these were essential to ensuring a positive life journey for their sons with TS and their other children, as well as for themselves and their wives.

The fathers recognized that a major part of being a father is to be “involved in making sure we have a roof and food and whatever else we need to survive as a family.” Or, as another father said, “I see my role as a provider, ensuring that they have the necessities of life and then beyond some of that, some of the wants in life.” “I feel it is my responsibility to be the breadwinner.”

Fathers stressed that providing tangible support meant being involved “not just monetarily” but in other tangible ways as well. For example, this same father believed that his responsibility included providing opportunities for his son to learn more about himself by helping him explore different options such as scouting, athletics, drama, etc. While this involved a monetary commitment it required much more of the father such as time and energy. He felt that the rewards were well worth the expenditure because he was able to empower his son to develop strengths and find talents that he might not have found otherwise. Providing these opportunities allowed the father to “mainstream him (his son) as much as possible.”

Fathers were tuned into the belief that a major responsibility was to be a provider for their children which included making “sure their needs are met in all three categories; physically, spiritually, and mentally.” Several fathers expressed that one of their roles included creating “an environment in my family, and a relationship with each of my children and my wife where, they could be the, the very best that they can be.” Cameron provided “a safe place” to live as well as “a safe place they can come home to” if they needed it. As one father put it, he was trying to create a home with “an atmosphere that gives them the best opportunity to succeed in their own personal lives. And, by that, runs the gamete from doing what I need to do to financially … so they have opportunities to do things that, they would like to be able to do. In addition to fostering an atmosphere where the kids, you know, want to excel academically, where they want to excel in their extracurricular activities."

The insight that these fathers shared about their role of provider was enlightening and encouraging. Some of the intangible provisions that fathers mentioned included: "approachableness"; spending time with his children; sensitivity; and hope and belief. "I think he can do whatever he wants," said one father, and then he added, "I didn't feel that way all the time" which demonstrated the progression he had made in developing and sharing this quality with his son. One final form of intangible support these fathers mentioned was finding ways to support their son's decisions, even when they were not what the father would have chosen himself.

In the overall scheme of things what the fathers wanted to provide to their children was a "good solid base from which to spring from as they (their children) are adults." Or as another father said, it is "our responsibility as parents to make sure that they become better than you are, more successful … so I think that's my responsibility overall." Cameron captured the thoughts expressed by most fathers as they described their ultimate role, "parenthood is an experience where you try and make yourself obsolete and hopefully end up where the people at the end, the adults that you raised still want to be around you but they don't really need you."

The fathers reported waxing and waning in the accomplishment of these goals, but a very clear sense of the direction they were trying to go.

Role satisfaction as a father: protector. Being a protector of their sons involved different connotations, feelings, meanings, and actions. For example, one father, McKay, believed that his responsibility included being a protector of his son and he wanted to accept this challenge but realistically he knew that “it’s hard sometimes when you, you feel you can’t protect your kid from this thing that’s just afflicting them.” His natural inclination as a protector was to be the “fixer of things” he can’t fix Gene “I can’t, you know, pull out the duct tape or whatever and fix that problem, I can’t go to the hardware store and fix it, it just, it’s not fixable, and accepting that I think is hard …” He waxed and waned in his hope and belief vs. his fear and doubt.

Another father, Michael, made a huge sacrifice in order to protect his son. Dale was experiencing extremely severe tics and he was incapable of functioning in all areas of his life. In fact Michael described this time as “every single day was hell.” He proceeded to describe what Dale went through during 7th and 8th grades:

> Those two years were hell and they were really hard… There was just no relief. I mean there was no. Nothing could take away the pain and the difficulty he was going through. So, as a dad you want to fix him.

Before Dale entered the 9th grade his tics began to wane. He wanted to act and applied to and was accepted by a special high school in his community that was geared towards the arts. Dale started doing better in school and enjoying it more than he had ever in the past. His father, who is a clinical psychologist, was not earning enough money to adequately provide financially for his family and had the opportunity to explore a job out of state for a significant increase in salary. Michael, along with his wife, made the decision to dip into his 401K and do “whatever we have to do to maybe stay right here until he is at least through high school. So, it is funny. It is a protective sort of mechanism for Dale.” He went on to explain why the decision to stay was worth it to him, “But when you have been so intensely into that anxiety of the hell of 7th and 8th grade, you know, you do, part of it is normal to react and try to save him…" Has it worked for Dale? His father sheds some light on this decision,

> He is functioning so well. He has quality of life beyond quality of life. It is just, yeah, I mean tonight we are having a surprise birthday party for him. I think he is going to have 25 or 30 people that are going to be here. Kids from his school. So, boy, there is a lot to be said for that after having gone through what we went through. I am a little, I am a little paranoid about getting thrown back into that. Let's say if we moved for example.

Another father, Lowell, described himself as not being "a nurturing kind of person but immediately I thought, well, no matter what, I will protect him." This father has three sons with TS and when asked how this condition impacted his life Lowell's response was filled with emotion.

> I think I am much more protective of my children with this Tourette's because of this disability and, and I want people to understand that it is not, they are not freaks. They are not weirdoes. They are not, they are not making fun, you know when Gordon repeats, they are not making fun.

He wanted to protect his sons from the hardships he knew they would face but he recognized that this was not possible. While he lashed out at insensitive adults he expected his sons to fight their own battles if kids teased or harassed them. "I am a firm believer that if kids at school are pickin' on him, they need to settle it. I am not going to come in and settle it for them. They either need to deal with it and settle it themselves …." He knew that he "can't beat up every high school bully or school bully or whatever you want to call it." But he realized that as their protector he could help by teaching them to understand that "they don't need to worry …. People can say and think what they want to say but what is really in your heart and what your real intentions are, there are only a few people who we need to make sure we satisfy and that is God, first and foremost."

Another father, Brian had a similar philosophy for his son Alton, “sometimes it’s worse if you try to fight that battle for him … I don’t know if it’s necessarily that right way to handle it, I, our approach was more to kind of let him handle it and then let it play out and give him ideas and ways to handle that…”

Role satisfaction as a father: teacher. Lowell showed his humorous side when he shared his belief about being a teacher for his children, “I think as a father I need to prepare them for life … and I laugh at my wife. I do everything I can to keep my kids out of the house and she does everything to keep my kids in the house.” While he was half joking he also described the belief that most of these fathers had about teaching and preparing their sons to survive on their own. His comment about his wife was an excellent example of the love, trust, security, and respect for the differences that he felt with her. A similar strong relationship with their wives was found in most of these fathers.

These fathers understood the importance of and accepted their responsibility as a teacher and role model of core family values they wanted to instill in their children. Teaching through example was perhaps the most significant method these fathers used to teach their son. Each father emphasized those values that were important to him and his wife. Some representative examples follow.

One value emphasized by the fathers, not only by their words but also with their emotion, was the desire for their children to love and respect their mother. These fathers respected their wife and considered her as an equal partner with certain abilities that they didn’t have to ensure the children were raised properly and according to their family values.

McKay was one of the fathers who verified this,

> I wanna be a strong example, a role model as far as, you know respecting their mother … you know be an example as far as how we want them to grow up with their values system, helping to teach them some of that … we joke a little bit about how, I need to teach 'em how to be tough and Laura will teach 'em how to be soft, but I think we have a good mix there …. I'm a pretty sensitive guy too and I think it's ok that they know that you can be a man and still be compassionate and sensitive and soft….

A different but humorous take on being a teacher for his son was shared by Flint as he described his role, "my experience is kind of interesting because like I say, he is extremely bright, but I think like a lot of kids, of course he knows it all (laughing) and so getting him to understand that he doesn't necessarily know quite as much as he thinks." Flint also has learned to be creative to "to get some … lessons across" to his son.

Several fathers emphasized the importance of teaching their son to be responsible. For example London was trying to teach his son "responsibility and accountability" in many facets of his life to help prepare him for the future. He included in this being "good parents and being good providers and to just the most important things in life, roles in our church and being good humans to each other. Kind and service." Then he adds a caveat, "my kids get to do more service than they want to because I make them."

Several fathers talked about trying to teach their sons to make good decisions because they understood the importance and value of this aspect of life. London realized that he had to let his sons make choices so they could "find out on their own. I give them a long leash until they really mess up and then … [I] yank back." Chase had a similar philosophy "we allow him to make his choices but he … can't choose the consequences." While Chase believed this was important for his 17-year-old son he also admitted that it "has been a huge difficulty for me to overcome because I still want to be that protector."

Other values mentioned frequently about which fathers felt strongly enough to take an active role in teaching their children were: spiritual values, contributing to society, developing character, honesty, integrity, a strong work ethic, love, and building relationships.

The purpose of the fathers' efforts was to help their sons prepare for life by being successful, productive citizens, future husbands, and fathers. They understood the challenges their boys face and will face as they move forward, but they have hope and belief in their sons. While this hope and belief waxed and waned over time, at the time of interview, these fathers tended to be more positive and hopeful than negative and despairing.

Role satisfaction as a father: special considerations about impact on other children. Fathers wanted to teach all of their children the same core values, however, many fathers reported that having a son with TS took its toll on them and their relationships with their other children. Many of the fathers indicated that they needed to spend more time and energy with their son with TS than the other children and in some instances this led to feelings of guilt and discouragement. One father presented an alternative perspective and didn't think it took much more effort to raise his son with TS than his other children, perhaps "ten percent more because of that, you know talking in general terms."

As an example of fathers feeling torn between the needs of their son with TS and those of their other children, Michael spoke of trying to help his daughter Stephanie understand that her brother had serious issues and that as a dad he needed to spend extra time and energy with him. This father had to reassure Stephanie that he didn't "love Dale more" than her. He continued describing his dilemma, "I don't, you know, I love them all the same, but, Dale at that time he needed … a lot of attention. So, I probably feel a little bit guilty about that but at the time we were just trying to survive."

This father was being sensitive to his young daughter's needs as she was trying to cope with a brother who had a somewhat rare Tourettic condition known as coprolalia which resulted in him uncontrollably using vulgar words which offended this 12 year old sister. Blurting out the 'F-word' also went against the family standards of appropriate language which caused confusion and frustration in this sister.

As this father tried to help his young daughter understand what was happening to Dale, he was acting in his roles of provider, protector, and teacher. He was providing sensitivity, love, and understanding, protecting her from herself and the condemnation she felt towards her brother, teaching her to accept her brother and his struggles. This father felt guilty because he felt he did not meet important needs of his youngest child at a time he felt he had to devote more time and energy to his son. His thoughts and emotions waxed and waned, up and down, as he struggled to balance the needs of his children.

McKay admitted that his relationship with Gene "impacts everybody" in the family. Chase talked about the impact of his TS son on his other children

> They have certainly been aware of it because they have verbalized it. Well, that is why Ben gets all the attention because of this. And they have said that

> even at a very young age …. I think it has affected the relationship with the other children. Maybe not in a huge way, but I think it has.

Clearly, having a son with TS can be difficult and impact the relationship of the father with his children, but fathers reported a sense that their family had learned to deal with the situation and make the best they can with it. This study indicates that the time and energy a father spends with his son can lead to a negative relationship with his other children. Lowell, for example, believes

> The relationship that I have with them (his other children) is incredible and I think it is because of this Tourette's, this disability, that I think I have something a little special with each of my kids including my daughters because of that, because they have had to accept and allow more leeway with these kids. He admits that developing this relationship hasn't always been easy and that there were struggles and anger between the siblings and the father. The father describes a scenario in which his older daughter was angry with her brothers and this father jumped into the fight, "Laura, you stay out of it, you know, they have got Tourette's, leave them alone. You know, and her and I would get into, butt heads because of it. But, I think in the overall relationship … it has taught us as a family to pull together and not fight …

When asked how having a son with TS impacted him and his family, Alex summarized his feelings and in doing so provided an insight into the waxing and waning thoughts and feelings of many fathers

> In helping them (the other siblings) understand why he's doing some of the things he's doing, … that's caused us as parents to have to have conversations with our other children that we wouldn't have had if they wouldn't of had Tourette's and the associated challenges … it kind of forces a parent to be more patient … less controlling because the control just makes things worse, it doesn't work, it doesn't help, and so it forces a parent to change but then I'm a different parent for all my children, not just for him, so I think again, it makes me a better parent overall. But then the stress … when I'm worried about him, worried about what's going on with him at school, worried about, is he taking care of himself, the things he's most at risk for, that stress I think can then lower my resistance to deal with the other stress there is in the family, so that can put me more on edge …

For the most part the fathers in this study recognized that having a son with TS did impact their relationship with their other children. These fathers were aware of this problem and they recognized that this was a problem which needed to be addressed and many have indeed put forth the effort to find a better balance.

Role satisfaction as a husband. Another pattern which emerged in this research was satisfaction in fulfilling the role of a husband. Although the fathers reported ups and downs in their marriage satisfaction over time, this was one of the areas which for these fathers was more constant. This may have been influenced by the fact that based on the criteria for inclusion in the study all of the fathers had long term marriages and had never been divorced. Most of the fathers reported some conflict with their wife around dealing with their son with TS in addition to the other demands of ordinary life. However, overwhelmingly they reported that over time they and their wife had learned to work as a team and they greatly valued their wife's strengths and the sense of fulfillment or satisfaction they got from their relationship. They recognized the importance of their role as a father in their son's development and growth, but they also were quick to point out the contribution of their wife and expressed appreciation for what she did for their son with TS as well as for the other children.

For example, several fathers talked about their satisfaction in working together as a team with their wife. Alex recognized that he could not raise his son alone and revealed that he spent much time praying and looking for answers as to how and he and his wife could help Randy be successful. Flint and his wife took a team approach, worked on things together, and developed a proactive plan for handling problems that arose with their son, "We spent a lot of time talking about what ha[d] been going on and, I guess dual research into figuring out what the options were and what might happen," and "we needed to deal with to make sure whatever impact it was going to have on Christian long term, you know, we could be prepared to deal with that and get a jump on it early on. You know, hoping for the best."

Lowell greatly appreciated that he could count on his wife to help him control his anger. He described his anger when a teacher was not providing help as prescribed in his son's IEP, "You need to be paying attention to what you are doing and so my first impulse is I get damn mad. I, I, I don't like that. But, my wife usually hits me so I have to take a deep breath and take a time out and calm down and relax and then talk about it."

Cameron was very sensitive to his wife's relationship with their son with TS, Sherm, who was challenging her authority. The father showed respect and appreciation for his wife by trying to teach his son the importance of respecting his mother.

While London reported a very good relationship with his wife, there were frustrations with each other as well. He described how his son was good at playing the father and mother against each other.

Chase said "in some way it (a son with TS) has definitely affected our marriage relationship because we haven't had the time or the energy. Sometimes you are just too tired to work on your marriage because you are always focusing on Ben with his problem." But then he mentioned that as a couple they work hard "to make our relationship stronger" by addressing the "issues of our family instead of focusing on a couple."

Discussion

The results of this qualitative study cannot be generalized to others outside of this study population, however the current findings suggest some interesting directions for future research. Research should be expanded to more diverse study populations including daughters with TS, mothers, siblings, and families in which there has been divorce and/or remarriage. Also, future research should include fathers and other family members who are encountering high levels of stress due to factors other than the child with TS. Quantitative studies should follow qualitative research to generate generalizable results.

Each father had his own unique challenges with and responses to his son with TS which impacted his relationships with this son, his other children, and his wife. These responses appeared to follow a waxing and waning pattern influenced by the nature of TS itself which is characterized by an unpredictable course of waxing and waning symptoms. As a whole however, these fathers appeared to be finding effective ways over time to develop strong family relationships. Factors that seemed to propel these fathers forward included a clear understanding of and commitment to their roles as a father and husband, the successful development of a strong husband and wife team, and a deep love for their son with TS, their other children, and their wife.

Overall it was observed that the fathers in this limited study responded to disruptions from their son with TS in one of two ways: (a) with effective responses resulting in personal growth which helped lay a foundation for stronger, more positive relationships with their son and other family members, or (b) with ineffective response leading to the creation of additional challenges which introduced new difficulties and negatively impacted family relationships.

The fathers' waxing and waning pattern of responses in the face of an uncertain future occurred along five major themes: 1) the question of their son's normalcy, 2) pride in their son, 3) hope in his future, 4) acceptance of their son, and 5) satisfaction in the roles of father and husband.

Another perspective on the impact of having a son with TS came from cases which did not meet full selection criteria. One father, Talmage, was interviewed before it was determined that he no longer met study criteria as he and his wife had gotten divorced. He reported that unresolved conflict and stress related to his son Reagan's TS had plagued the marriage and contributed to the dissolution of their 20-year marriage:

> I think just the overall stress of this kid made it very difficult for the two of us to have any, relax time at home around the kids. Any kind of family outing was chronically affected by Reagan. Car, trips in the car, stopping every couple of miles trying to get Reagan to stop beating on someone, stop screaming, stop doing something. Staying in motels, you know, at night in the room trying to get him to stop carrying on. Sitting out in the car with him for hours until he would finally get control. I mean … there was just, there was never any peace. That added to the fact that my wife was unwilling to kind of divide up. She always wanted to do everything as a group. That was really important to her and to me it was like, that is ridiculous, you know, nobody gets a break that way. So I think her insistence of that, took its toll and, and that I think was is one of many issues that turned into kind of a power play in between the two of us. She had, a kind of dominant role in so many things at home, and it eventually just, you know, I got to the point where I couldn't live under those, conditions and as I began to challenge those things and confront her, it turned into a lot of conflict and eventually just, we quit.

The father further reported that the TS-related stresses continued to impact the family even after the divorce. He observed that the son "figured out very quickly that he could split us. He could play us against each other very effectively." The father's sense of himself as a capable and effective father was impacted as well:

> I really expected (fatherhood) to be this, more kind of rosy, kind of a romantic experience where you love your kids and they love you back and everything is great. And there has been so much turmoil with him. I mean, there were times early on where I wasn't sure I could, I was going to be able to survive being his father. And that, you know, one of us was going to have to go somehow somewhere.

In another case, the father, Shawn, had a great relationship with his son with TS and a strong marriage, but he did not meet the study criteria because he had too many other stressors in his life, including a wife with cancer and another son with pervasive developmental disorder. In spite of these additional stressors he appeared to be coping well. He talked about his role as a teacher, "I see my role as being an example of good choices, I fall short of that often but that's my role." He gave more insight into his values, "I'm trying to live up to, to be an example teacher, teaching respect for their mother probably first and foremost, teaching them responsibility, teaching them work ethic. I think it's changed over time but more so helping them feel loved."

The results of this research suggest some directions for practical application. Sharing the experiences of the fathers in this study with other fathers of sons with TS could increase their awareness of the positive potential of effective responses to primary challenges and the negative impact of ineffective responses which create secondary challenges. Trainings could be developed to help fathers recognize and deal with the disruptions of primary challenges and prevent or minimize the more devastating secondary challenges.

Prevention programs could be developed for use in various settings such as clinical, educational, and occupational sites, etc. The results of this research may have applications for mothers and siblings of both boys and girls with TS as well as for their fathers. It may also be of benefit to families who have children with other chronic illnesses as well.

In the last interview the researcher conducted, one father, Brian, provided a beautiful overview of his thoughts, feelings, and philosophy of life about his role as a father. This expression of love and hope captured the ultimate rewards of fatherhood which was shared in some way by most of the fathers involved in this study. “You know when you look on your life and reflect on your life that, you know, your legacy is your family and your service and what you’ve done … I take it very serious its important and sometime you think you do ok, sometimes you second guess it a little bit.”

While qualitative studies do not produce generalizable results, the findings of this study seem to be strong and consistent and are very likely to be very helpful in directing potentially powerful interventions for support and education of families with children who have Tourette syndrome. It is my hope that quantitative studies will follow this research and produce statistically significant results that corroborate this study’s findings, however, in the meantime I strongly believe that such studies will likely find only minor differences in the results. Such differences probably will not substantially alter the recommendations for developing training programs or the information shared in parental counseling.

Appendix A: Selection Criteria

Participating fathers were not selected if they were dealing with multiple significant life stressors other than having a son with TS because of the possibility that these other factors might have a major impact on their relationship with their son. For instance, conditions such as schizophrenia, pervasive developmental disorders, and other major medical illnesses are such significant stressors that these fathers were not included in this research. It would not be possible to distinguish the father's reaction to having a son with TS from his reaction to these other very intense stressors (Ferre, 2010).

The focus was on sons because TS is more prevalent in males and studying only male children eliminated possible gender related differences in how fathers interacted with their child with TS. Studying only sons who had had TS for at least 3-5 years was important as the length of a father's experience with his son following the manifestation of TS may impact their relationship (Ferre, 2008). The following selection criteria were used:

1) The father has at least one son with TS.
2) The father does not have TS himself.
3) The father must be the biological father.
4) The father is married to and has never divorced the mother of the son.
5) The father lives in the same physical household as the son with TS.
6) The father is experiencing no more than mild stress from life events as measured by a score of 200 or less on the Holmes and Rahe Social Readjustment Rating Scale (1967).
7) The son is between 10-21 years of age.

8) The son has had TS for at least 3-5 years.
9) The son has at least one biological sibling (i.e. is not an only child).
10) The son and his siblings may not have any other major medical illnesses.
11) The son and his siblings may not have a mood disorder nor rage attacks.
12) The son and his siblings may not have schizophrenia or a pervasive developmental disorder (such as Autistic Disorder, Asperger's Disorder, etc).

Appendix B: Interview Question Guide

Below are the general questions that guided the interviews. The interviews began with the most general questions and the interviewers tried to encourage the fathers to tell their story in their own way. Not all questions were asked of each father as frequently the fathers covered the relevant topics without direct questioning.

Research Question #1: From the perspective of fathers who have a son with Tourette syndrome, how have they reacted to and coped with having a son with Tourette's?

1) Please tell me a bit about you and your family. How long have you been married? How many children? Names and ages. Your education and occupation. Your wife's education and occupation.
2) How has having a son with Tourette's affected your life?
3) How would you describe your son with TS?
4) How would you describe the severity of your son's Tourette's?
5) When your son with TS was born – what were your hopes, dreams, and aspirations for this son? Have they changed? If so, how?
6) After your son began to exhibit some symptoms, but before he was diagnosed, what were your thoughts/feelings?
7) When your son was first diagnosed with TS, what were your thoughts? Fears? Concerns? Have they changed? If so, how?
8) Can you talk about any struggles your son with TS has had in school, your perceptions of his educational abilities, other interests/talents he has?
9) Do you know if your son tries to suppress his tics in certain situations? Explain.
10) Do you talk with your son about TS?

11) Do you view your son with TS as being ‘disabled’ or ‘handicapped’ or ‘special’? Please share your thoughts.
12) How has having a son with TS impacted your relationship with your wife?
13) How has having a son with TS impacted your relationship with your other child/children?
14) Has having a son with TS impacted other areas of your life?
15) What are your biggest challenges with having a son with TS? And how do you cope?
16) Do your aspirations, hopes, and dreams for your son with TS differ from those you have for your children without Tourette's? If so, how?
17) Do you think your social life is impacted as a result of having a son with TS? If so, how?

Research Question #2: How do fathers of sons with Tourette syndrome understand their role in the family dynamics?

1) How do you understand your role as a father?
2) How do you think having a child with Tourette's has impacted your family?
3) How do you perceive your responsibilities as a father to your son with TS?
4) Are these perceptions and responsibilities different towards your son with TS verses your child/children without TS? How?
5) Describe the energy it takes to provide for the needs of your son with TS.
6) How do you balance the needs of your son with TS and the needs of your other child/children?
7) Is the way you cope or discipline different in the home vs. out in the public?

8) What are your thoughts about your son’s perceptions of you as a father?

9) How do you cope with having a son with TS?

References

Bagheri, M. M., Kerbeshian, J., & Burd, L. (1999). Recognition and management of Tourette's syndrome and tic disorders. *American Family Physician,* 59(8).

Chowdhury U. (2004). Tics and Tourette syndrome, a handbook for parents and professionals. Jessica Kingsley Publishers Ltd. London.

Creswell, J. W. (2007). *Qualitative inquiry & research design: choosing among five approaches.* Thousands Oaks, CA: Sage.

Dick, B. (2007). Grounded theory: a thumbnail sketch. Retrieved 10/5/2007. http://www.scu.edu.au/schools/gcm/ar/arp/grounded.html

Edell, B. H., Motta, R. W. (1989). The emotional adjustment of children with Tourette syndrome. The Journal of Psychology, 123(1):51-57.

Fassinger, R. E. (2005). Paradigms, praxis, problems, and promise: grounded theory in counseling psychology research. *Journal of Counseling Psychology* 52(2):156-166.

Ferre, R. C. (2008). Personal Communication, November 18, 2008.

Ferre, R. C. (2010). Personal communication, January 25, 2010).

Flach, F. (1997). Resilience the power to bounce back when the going gets tough! Hatherleigh Press, New York, NY.

Haverkamp, B. E, & Young, R. A. (2007). Paradigms, purpose, and role of the literature: rationale for qualitative investigations. *The Counseling Psychologist,* 35(2):265-294.

Hawley, J. S. (2012). Pediatric Tourette syndrome. *http://emedicine.medscape.com/article/289457-overview#a0156* (Updated: Feb. 7, 2012).

HBO documentary. (2005). *I have Tourette's but Tourette's doesn't have me!* Aired December 5, 2005.

Hendren, G. (2002). Tourette syndrome: a new look at an old condition. *Journal of Rehabilitation*, 68(2):22-27.

Holmes, T. H., & Rahe, RH. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research,* 11, 213-218.

Leckman J. F. (2002). Tourette syndrome. *Lancet,* 360:1577–86.

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology, 52(2):250-260.*

Morrow, S. L. 2008). Sampling Procedures in Qualitative Research, class handout April 3, 2008).

Rennie, D. L (1998). Grounded theory methodology: the pressing need for a coherent logic of justification. [Electric version]. *Theory Psychology*, 8, 101-119.

Ulin, P. R., Robinson, E. T., & Tolley, E. E. (2005). *Qualitative methods in public health: a field guide for applied research*. San Francisco: Josey-Bass.

Wilkinson, B. J., Newman, M. B., Shytle, R. D., Silver, A. A., Sanberg, P. R., & Sheehan, D. (2001). Family impact of Tourette's syndrome. *Journal of Child and Family Studies*, 10(4):477-483.

Woods, D. W., Himle, M. B., & Osmon, D. C. (2005). Use of the impact on family scale in children with tic disorders: descriptive data, validity, and tic severity impact. *Child & Family Behavior Therapy*, 27(2):11-21.

Zinner, S. H. (2004). Tourette syndrome—much more than tics—moving beyond misconceptions to a diagnosis, pt 1. *Contemporary Pediatrics* 21(8):22-36.

CHAPTER 3

APPLICATION OF THE METATHEORY OF RESILIENCE AND RESILIENCY IN FAMILIES WITH CHILDREN WITH TOURETTE SYNDROME: WAVES ONE AND TWO

Abstract

Families that have children with Tourette syndrome are faced with significant medical issues and emotional, social, and cultural challenges. This theoretical paper examines the first two waves of resiliency inquiry described in The Metatheory of Resilience and Resiliency and provides a framework for families and professionals to use in facilitating optimal functioning in families.

The purpose of this paper is to: 1) provide an overview of the challenges associated with Tourette syndrome that create disruptions from the comfort zone; 2) examine the first wave of resiliency research which identifies resilient qualities and how they can be utilized to optimize family functioning; 3) explore the second wave of resiliency research, the processes through which families recognize and utilize their innate resilient qualities to grow stronger; and 4) suggest ideas for identifying appropriate family nurturing and intervention points in the resiliency process.

All families face adversity and must learn to adapt and surmount these challenges. Growth or stagnation can be measured or predicted by how a family handles the chaos created by disruptions. Resilient families recognize the chaos and turns it into a family

strength. Family resilience does not occur in a single experience, but develops through the family’s interactive processes as they learn to handle disruptions.

The disruptions reported by the fathers fell into two main categories. Some were created directly by the Tourette's and related comorbidities, which were categorized as primary challenges. Others, categorized as secondary challenges, were created by the fathers’ ineffective responses to the primary challenges.

If fathers responded effectively to primary challenges they reintegrated resiliently with personal growth which laid a foundation for stronger, more positive relationships with their son and other family members. Fathers who responded ineffectively experienced secondary challenges which created further difficulties and negatively impacted family relationships.

A child’s Tourette's is not what causes family dysfunction, but rather the outcome is dependent on the way family members react to their challenges and to each other. .

Resiliency is a process and resilient reintegration happens many times a day. With each new experience and challenge, families can become more skilled, knowledgeable, and experienced.

Introduction

Families that have children with Tourette Syndrome (FCTS) are faced not only with significant medical issues but also with additional emotional, social, and cultural challenges (Woods & Marcks, 2005; Hendren, 2002). This theoretical paper examines the first two waves of resiliency inquiry described in The Metatheory of Resilience and Resiliency (MRR) (Richardson, 2002) as a framework for families and helping professionals to use in facilitating optimal functioning in FCTS. The MRR describes qualities, processes, and driving forces involved in resilient adaptation to stressors. Most helping theories and methods can be housed under the umbrella of the MRR. Popular and efficacious theories, such as Self Determination Theory (Ryan & Deci, 2000), Hardiness (Kobasa, Maddi, & Kahn, 1982), and the construct of self-efficacy in Social Cognitive Theory (Bandura, 1989), can all find homes within the resilience and resiliency paradigms.

Purpose

The purpose of this paper is to: 1) provide an overview of the challenges associated with TS that create disruptions from the comfort zone; 2) examine the first wave of resiliency research which is the identification of resilient qualities and how they can be utilized to optimize FCTS functioning; 3) explore the second wave of resiliency research, the resiliency processes through which families gain access to or recognize and utilize their innate resilient qualities to grow stronger and reintegrate with gain; and 4) suggest ideas for application in identifying appropriate family nurturing and intervention points in the resiliency process. The third wave of resiliency research involves the family's discovery of their energy, passion, and motivation for taking the journey towards fulfilling their potential and is beyond the scope of this paper.

Overview of TS-Related Disruptive Challenges

While all people have difficulties and life in general is not always easy, children with TS are susceptible to many unique difficulties, frustrations, and challenges. These trials can provide opportunities for personal growth and development, but they can also lead to frustration, social miseries, academic problems and much heartache (Woods and

Marcks, 2005; Hendren, 2002). Children with TS are often misunderstood and subjected to teasing, bullying, and even to cruel jokes (Chowdhury, 2004; HBO Documentary, 2005). For the most part, society has little idea about what these children live with every day of their young lives. In turn, the challenges of these children can have a major impact on family dynamics and functioning and create distress and disruption in their lives.

Families are complex systems in which members are both independent and interdependent (Dickstein, 2002). Healthy or unhealthy interactions between members can impact overall family function as well as the development of each individual in the system. Growth or stagnation of a family can be measured or predicted by how a family handles disruption and the chaos created by disruption. The resilient family recognizes the chaos and turns it into a family strength, which can change the nature of the family (Flach, 1997). For example, in many FCTS, the family may start to notice and experience disruptions when the symptoms first begin to manifest themselves, perhaps as early as in infancy, although more typically when their child is about 7 years old (Hawley, JS. Downloaded 2012).

Some parents may not even realize at first that these symptoms are not part of the normal developmental process. However, as tics develop, parents, as well as siblings if there are any, may become impatient or frustrated with the child and try to get him to stop ticking or change his behavior. This disruptive process may initially be perceived by the family as a simple problem that should be easily correctable simply by just telling the child to stop. Over time, frustration may set in at what they perceive to be a willful disregard to their wishes. The disruption and ensuing chaos continue and may escalate as the child’s Tourettic symptoms become more noticeable, as comorbidities reveal themselves, and all of these come to impact the family. Zinner (2004, pt. 1) reports that parents often experience “incredible relief” when they eventually seek medical advice and their child receives a diagnosis. Education about TS may assist the family in dealing more effectively with the situation.

Rosen’s 2002 study of family dynamics in FCTS found that parental ability to accept things over which they have no control is particularly important to optimal family functioning. Parents may face social, emotional, and physical stresses as a result of having a child with TS. Ideally, parents need to find ways to effectively deal with the stigmas, impulsivity, obsessions, learning disabilities, etc. associated with their child’s Tourette's and comorbidities. They need to help their family to accept, cope, function, and live independently and interdependently with these and all the other challenges that may arise as a result of having a Touretter as a family member.

The development of family resilience does not occur in a single experience, but rather develops through the family’s interactive processes over time as they learn to handle the disruptions that come their way (Walsh, 1998). It seems reasonable to surmise that TS related disruptions can prompt a family to transition through the resiliency process and reintegrate into a stronger and more accepting and tolerant unit, or, on the other hand, such disruptions can contribute to a less functional family outcome.

The First Wave of Resiliency Inquiry: Resilient Qualities

It has been said that the road to success is always under construction (anonymous). This is a perfect description of the journey that children with TS and their families travel as they go down the road called life. Tourette syndrome is a lifelong condition with many challenges and bumps in the road (Hawley, JS. Downloaded 2012).

It seems likely that FCTS will need to create new pathways as they learn to cope with and adapt to a myriad of problems related to TS and its comorbidities, such as the waxing and waning of tics, the impulsivity of ADHD, and the frustrations of OCD. The development of resilient qualities identified by the first wave of resiliency inquiry as reviewed below may be helpful in their journey.

Resilient Characteristics of Individuals

The first wave of resiliency inquiry emerged through the phenomenological identification of the characteristics of survivors, mostly young people, living in high risk situations. Foundational studies cited in most of the phenomenological resilience literature identify qualities that predict the capacity to thrive in the face of personal and social challenge. The outcome of the first wave, which continues to this day, is the identification of resilient qualities.

Early work in the field drew on a variety of populations and used various methods to identify resilient qualities in young people (Benson, 1997; Garmezy, 1991; Garmezy, Masten, & Tellegen, 1984; Rutter, 1979, 1985; Werner 1992) These early researchers used longitudinal findings, epidemiological studies, children of schizophrenic parents, and a large study of 6th-12th grade students in 600 communities. The efforts of these men and women did much to identify resilient qualities in children and the results of their efforts helped trigger the positive psychology movement, which today is one of the most popular fields in psychology. This approach identifies the strengths, gifts, and talents of people rather than trying to identify and focus on their problems. Professionals then build upon these strengths with the expected result of seeing individuals blossom and problems overcome. It is interesting that the most studied qualities in positive psychology are the same as those identified as resilient qualities. Examples of resilient qualities studied in positive psychology include happiness, optimism, faith, self-determination, wisdom, creativity, self-control, gratitude, forgiveness, dreams, hope and humility among others.

Resilient Family Functioning

Research has shown that resilient qualities are crucial not only to individual functioning but to successful family functioning as well (Walsh, 1998). Individual members of a family system can face adversity and this adversity can have an impact on the family and create disruption to the family's functionality. No family is immune to adversity and they must learn to adapt and surmount the challenges they face, otherwise a functional family can become dysfunctional. Resilience allows families to face life's challenges, survive adversity and then move forward with their goals and aspirations and do so with acquired qualities that will protect the family in future disruptions (Bradshaw, 2006). Walsh (1998) and Simon (2005) point out the importance of honoring and not minimizing the family's pain and problems while identifying and focusing on their strengths and resources. Family resiliency enables the family to cultivate those positive strengths needed to help them face the challenges of their disruption (Family Resiliency: Iowa State University). Families emerging from adversity feel stronger and more confident after demonstrating their capacity to positively respond to a difficult situation (Simon, Murphy, Smith, 2005). Families who strengthen their abilities and learn to rebound from family crises are able to deal better with future challenges because they have gained resources that allow them to be more effective (Walsh, 1998). Resilient families are constantly weaving the social fabric of their familial society to strengthen and improve problem-solving, coping skills, positive support, openness, creativity, connectedness, etc., weaving a delicate but tightly knit structure made up of protective factors which lead to family resilience and survival (Family Resiliency: Iowa State University).

Researchers have suggested various ways of grouping resilient qualities in families. For example, Walsh (1998) developed a metaframework of family resiliency which focused on key family processes in three domains that reduce the risk of dysfunction, buffer stress, and encourage healing and growth from crisis. These domains are: 1. Family belief systems, 2. Organization patterns, and 3. Communication processes (Walsh, 1998, 2002). Patterson (2002) identified nine processes or strategies that strengthen families of children with disabilities: 1. Balancing the illness with other family needs, 2. Maintaining clear family boundaries, 3. Developing communication competence, 4. Attributing positive meaning to the situation, 5. Maintaining family flexibility, 6. Maintaining a commitment to the family as a unit, 7. Engaging in active coping efforts, 8. Maintaining social integration, and 9. Developing collaborative relationships with professionals.

The Second Wave of Resiliency Inquiry: Resiliency

The second wave of resiliency inquiry seeks to discover the process of attaining resilient qualities to illuminate “the process and experience of being disrupted by change, opportunities, adversity, stressors, challenges and, after some introspection, ultimately accessing innate resilience (gifts and strengths) to grow stronger through the disruption” (Richardson, 2010). A detailed model was originally proposed by Richardson, et al. in 1990 but has been modified many times since to help professionals and families better understand the process. Communication has been improved by using easily understood terms such as “comfort zone” to replace terms such as “biopsychospiritual homeostasis” used in the original 1990 model. These terms are defined in Table 3.1 just following Figure 3.1 to provide clarity in interpreting the model. As seen in Figure 3.1, this model presents resiliency as a linear process in which individuals or families have the opportunity to grow as they respond to disruptive life events.

Resiliency Mapping

Resiliency mapping helps increase families’ understanding of the processes involved in moving through crises and subsequent recovery. For example, use Figure 3.1 to follow the course of a family and a child’s first manifestation of TS symptoms. Prior to this manifestation the family was in the comfort zone, meaning that they were in a relatively stable, pre-crisis state. In this state they had settled into a pattern of functioning in major areas of life, such as their professional, home, social, and financial situation as well as to their physical state, mental capacities, and level of closeness to a source of spiritual strength. The child’s first manifestation of TS creates a challenge to life as usual and the family experiences a disruption. They may be expected to react with the normal emotions of hurt, loss, guilt, fear. etc. When the family is in this disruptive state, the helping professional may draw on the resiliency mapping model to help the family see and evaluate alternative outcomes. The model will highlight the potential for growth through resonation/quickening and identity formation, leading to the alternative resolutions of reintegrating with loss, or the potential for self-mastery and return to the comfort zone or resilient reintegration.

Some FCTS may try to return to the same conditions they had before the disruption, but TS is a lifelong condition and a return to the pre-manifestation comfort

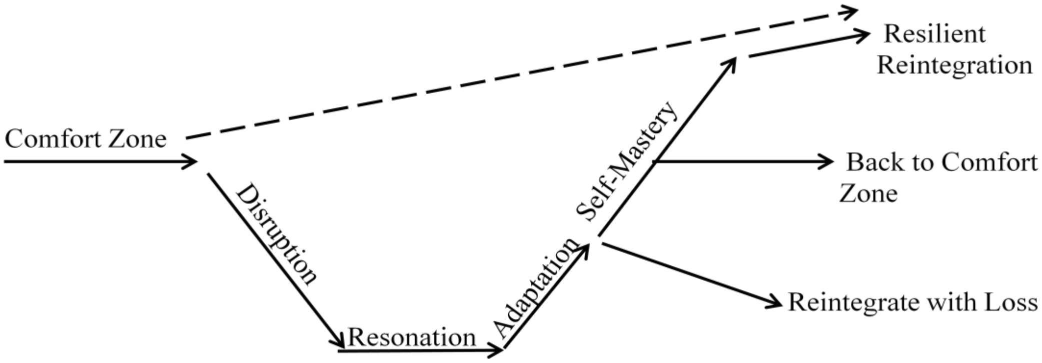

Figure 3.1 Richardson's Resiliency Mapping Model 2002

Table 3.1. Resiliency Mapping Model Terms Defined (Richardson, 2002).

Comfort Zone	A familiar, relatively stable state of existence. In the comfort zone people may have little sense of being at risk for disruption, which may result in a false sense of security.
Disruptions	Planned or spontaneous events which cause a break or interruption in the normal cycle of daily life. Such events may be minor or major with short or long term implications.
Resonation (quickening)	The development of virtues and qualities that enhance personal capability and empower individuals to move through a trough. According to the resiliency mapping model there are three exit points from which to emerge: 1) reintegration with loss; 2) return to homeostasis (comfort zone); and 3) resilient reintegration.
Self-mastery	The development of personal strengths which occurs to the extent to which individuals take control of disruptions and accept responsibility for moving forward to resilient reintegration.
Reintegration with Loss	Loss of personal strength that leads to coming out of a trough with a lower level of resiliency than before disruption.
Back to Comfort Zone	A return to the previous level of functioning with little or no growth.
Resilient Reintegration	Moving forward with growth or gain obtained during the process of going through disruptions.

zone is truly impossible. Others may become bitter, angry, and less functional than they were before the disruption, reintegrating with loss. The optimal outcome is for families to discover their inner strength, develop their skills, and resiliently reintegrate from life's disruption. Resiliency mapping can help the family recognize that they have some choice about which path they take. It can help them chart an effective path to potential growth as they progress through adversity towards resilient reintegration. As they do so, they will emerge stronger and more capable of living well with TS. Resilient FCTS will be able to recognize the challenges, accept them, make adjustments, and reintegrate with gain such that the family is stronger than it was at the time of the disruption.

FCTS who find themselves in resiliency troughs (see Figure 3.1) often learn much about themselves as well as what is important in life. In the trough they can gain an understanding of who they are and how they are going to respond to disruptions. It is in the disruptive troughs of life that people discover ways to embrace the challenges they face. They find fulfillment in spite of potential limitations. They find alternative sources of strength which maximize their human condition. They discover their resiliency.

While going through this journey, it is helpful for FCTS to fully appreciate that TS is a lifetime condition that will be filled with many hopes and frustrations, dreams and setbacks, and constant challenges for the family as well as the child with TS. Helping them to reflect upon times in the past when they have recovered with gain is an important boost to their ability to survive and thrive. The resiliency mapping model can be used to help them explore the process of living in the present while preparing for the future.

TS Specific Mapping Adaptations

Recurrent Course of a Single Tourettic Disruption

While the model depicted in Figure 3.1 accurately reflects the general principles of resiliency, the peaks and valleys in Figure 3.2 represent the recurrent nature of the course of a single tic or TS-related disruption to the child with TS and the family. The course of a single tic tends to wax and wane with varying intensity and frequency for an unpredictable period of time. The peaks and valleys heading in the negative direction in Figure 3.2 capture the recurring and additive nature of this repetitive course which, if not addressed and dealt with, can lead to reintegration with loss.

Multiple Tourettic Disruptions

Figure 3.3 further refines the representation of the challenges of FCTS. The diagnostic criteria for TS require at least two motor tics and one verbal tic (DSM-IV-TR, 2002, text revision) so every child with TS copes with multiple tics. Figure 3.3 captures the waxing and waning of multiple tics to more realistically depict the challenges faced by the child and family. Tics can happen separately or together or as a coordinated series of tics that must be done in the same sequence each time the child with TS has the urge to release that (Hawley, JS. Downloaded 2012). In Figure 3.3 superimposed on the bold arrows representing the basic resiliency model is a solid line representing a single tic and dotted arrows representing a combination of several tics. These tics may occur separately or together and each all of them can cause disruptions for the child and family. The frequency of Tourettic tics may range from minimal occurrences that only manifest themselves during times of anxiety or fatigue to tics that occur as often as 30 to 100 times per minute (Hendren, 2002).

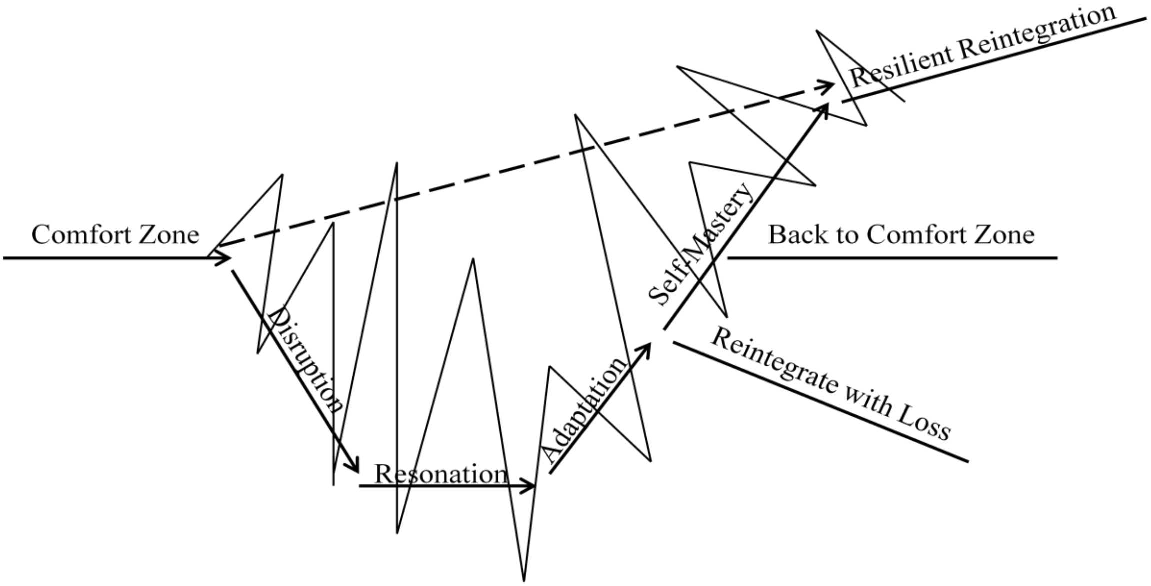

Figure 3.2 TS-Adapted Resiliency Mapping Model: Description of a Family's Journey: Single Tic

Resilient FCTS will need to accept and understand the waxing and waning and unpredictable course of TS, recognize how it impacts them, and take measures to counter the negative effects. Both Figures 3.2 and 3.3 show that even as the effects of TS and its co morbidities are constantly creating disruptions, the family's adjustments can be headed in a positive direction.

Primary and Secondary Challenges

The results of this researcher's 2012 study of fathers who have sons with TS suggest a further refinement for a TS-adapted resiliency model (Cazier). In this study it was noted that the disruptions reported by the fathers fell into two main categories. Some disruptions were created directly by TS and its related comorbidities, which were categorized as primary challenges. Others, categorized as secondary challenges, were created by the fathers' ineffective responses to the primary challenges. There appeared to

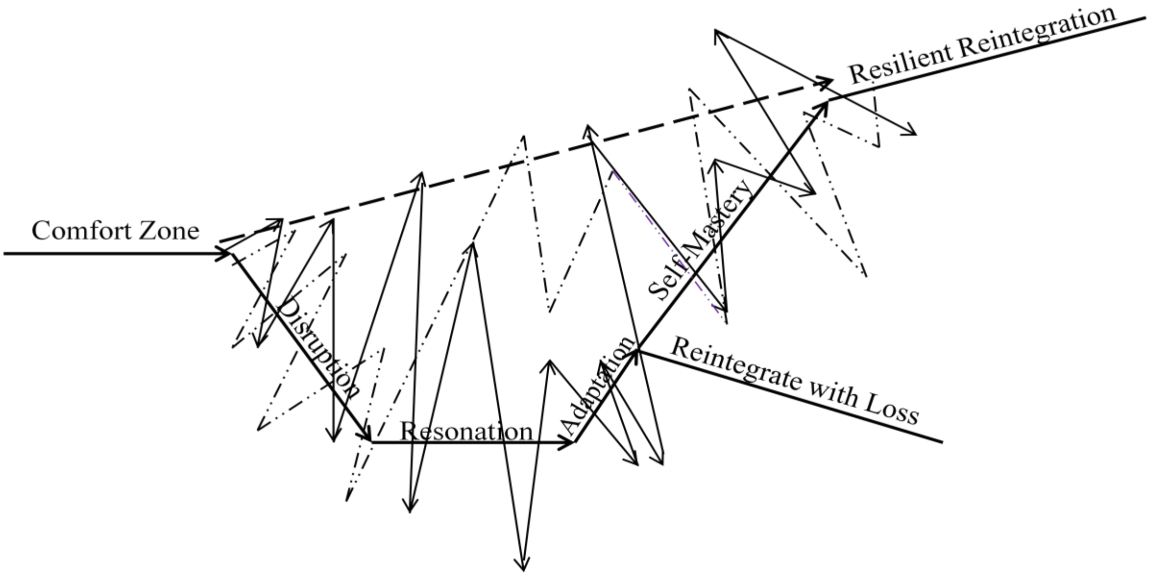

Figure 3.3 TS Resiliency Mapping Model: Description of Family's Journey: Multiple Tics

be a cumulative or additive dimension to the fathers' response patterns to these disruptions which led fathers to head down diverging paths.

In this same study (Cazier, 2012) it appeared that as the fathers processed their responses to primary challenges and reintegrated resiliently with personal growth they laid a foundation for building stronger, more positive relationships with their son with TS and other family members. On the other hand, as they struggled ineffectively and reintegrated with loss they experienced secondary challenges which created further difficulties and negatively impacted family relationships.

Consider a hypothetical example of a father who has an ineffective emotional reaction to a new experience with his son with TS. The new experience is the "primary challenge" and his ineffective emotional reaction would be his "secondary challenge."

Let us assume that the son yells at his father after coming home from school angry because his teacher embarrassed him in front of the class due to a Tourettic tic mimicking an animal sound. The teacher made him feel small and inferior and the other students picked up on the teacher's remarks and feelings.

The father's primary challenge is his son's angry outburst, which is a new experience with his son. If the father reacts to this challenge effectively and adapts and moves forward toward resolving the issue he will experience personal growth and develop greater strength to handle a similar situation should it occur again. If on the other hand the father adapts ineffectively, for example by becoming fearful of his son's anger, then this fear would be a secondary challenge to the father.

A further refinement of a TS-adapted RMM shown below helps depict the phenomena. The father begins the journey in a "comfort zone" with his relationship with his son. The primary challenge is the "disruption" (the son's anger in this case scenario). The father enters a disruptive trough created by the primary challenge. An effective adaptation moves him past the former comfort zone towards resilient reintegration. The time and energy expended getting out of the trough promotes personal growth or strengthening of the father which will benefit him later when he encounters this or another primary challenge in the future.

A secondary challenge is created when a father responds ineffectively and reintegrates with loss, creating a secondary challenge. In the example being used, this would be the father's fear, which becomes the new disruption/secondary challenge. The TS specific adaptation of the RMM continues by addressing this challenge. A father may have an effective response to this challenge and reintegrate resiliently with gain or an ineffective response and once again reintegrate with loss in a downward spiral. See Figure 3.4 for TS adapted RMM which accounts for secondary challenges.

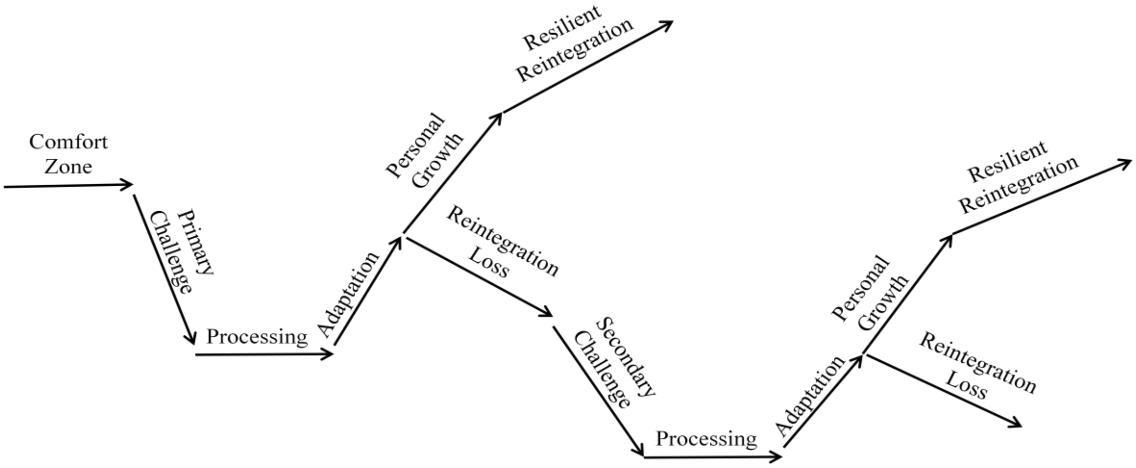

Figure 3.4 TS Adapted Resiliency Mapping Model:
Accounting for Secondary Challenges

A child's TS is not what handicaps or causes dysfunction in the family, but rather the family's outcome is dependent on the manner in which family members react to their challenges and to each other (Havens CA. 2005). Having a child with TS does not have to be catastrophic for the family system, the parents, siblings, or the child with the condition. All family members need to learn how to deal effectively with the situations that arise from having a child with TS in the family, and parents must be able to help not only the child with TS but also help the other children live and cope with this sibling (Havens, 2005). Proactively handling the disruption of TS, its waxing and waning nature, and associated comorbidities can strengthen the family and help it to become more resilient. According to Tusaie and Dyer (2004) resilience is not static but actually a dynamic process that parents should work to incorporate into their family system in an effort to help each member find a balance between protective and risk factors (2004). A prolonged journey with multiple and repeated disruptions takes significant time and adjustment. In the case of a FCTS, disruption begins with the manifestation of Tourettic tics, progresses through the demands for lifestyle and habit modifications over time, and optimally produces resilient reintegration as a family thriving in its own unique situation.

Discussion

Due to the ongoing nature of TS, helping professionals will have many opportunities along the way during which they can identify appropriate family nurturing and intervention points. They can be most helpful to families when they discuss the disruptive nature of TS and reintegration from attendant challenges with a broad view of health including not only the physical and medical, but also the social, emotional, and spiritual components. Each person has many different roles in life and the helping professional may make inquiries regarding disruptions in all aspects of the family. In all likelihood, members of the family will be in different stages of the resiliency model depending upon their roles and available resources.

Resiliency truly is a process and resilient reintegrations can happen many times a day. With each new experience, new challenge, and new information families and helpers have the opportunity of becoming more skilled, knowledgeable, and experienced. Repeated experiential disruptions can and should lead to increasing wisdom upon wisdom. Conversely, some individuals and families may suffer repeated setbacks and become more helpless and discouraged with each disruption which leads to more decline.

The concepts of resilience go beyond just the individual. Resilient qualities and processes are evident in couples, families, organizations, and communities. It is clear that a positive relationship between people and helping professionals is vital in the healing process. Families under stress from TS-related issues may have difficulties working effectively with helping professionals. Understanding the resiliency process can help professionals take difficult situations and turn them into potential opportunities for growth through the application of the resiliency mapping model.

Resilience training itself can be a life event that triggers a disruption leading to resilient reintegration. Families may come in contact with helping professionals and be open to resilience training at any time along the course of dealing with TS and its comorbidities. The disruption following the initial diagnosis may provide a unique opportunity for professionals to educate families about the resilience process and help them develop the skills to reintegrate resiliently with gain.

References

American Psychiatric Association. (2000). Diagnostic and Statistical Manual of Mental Disorders. (4th Ed. Text revision). Washington, DC: Author.

Bandura, A. (1989). Human Agency in Social Cognitive Theory. *American Psychologist*, 44, 1175-1184.

Benson, P. L. (1997) *All kids are our kids*, Minneapolis; Search Institute.

Bradshaw B. (2006). *The efficacy of a resiliency training program in adults with type 2 diabetes mellitus.* Unpublished doctoral dissertation, University of Utah.

Cazier, C. F. (2012). *The relationship of fathers with sons who have Tourette syndrome and the impact on the family*. Unpublished doctoral dissertation, University of Utah.

Chowdhury, U., Heyman, I. (2004). Tourette's syndrome in children. *BMJ.* 329 (7479):1356 (Editorial).

Dickstein, S. (2002). Family routines and rituals—the importance family functioning: comment on the special section. *Journal of Family Psychology*, 16(4):441-4.

Family Resiliency: building strengths to meet life's challenges (Iowa State University) http://www.extension.iastate.edu/publications/edc53.pdf. Downloaded 8/10/2011.

Flach, F. (1997). Resilience the power to bounce back whe the going gets tough. Hatherleigh Press. New York.

Garmezy, N., Masten, A. S., & Tellegen, A. (1984) The study of stress and competence in children: A building block for developmental psychopathology. *Child Development*. 55, 97-111.

Garmezy, N. (1991) Resiliency and vulnerability to adverse developmental outcomes associated with poverty. *American Behavioral Scientist*, 34 (4), 416-430.

Havens, C. A. (2005). Becoming a resilient family: child disability and the family system. *Access Today, Spring, Special Vol. Issue 17.* http://www.indiana.edu/~nca/monographs/17family.shtml

Hawley, J. S. Pediatric Tourette Syndrome http://emedicine.medscape.com/article/289457-overview#a0156. *Downloaded February 2012.*

Hendren, G. (2002). Tourette syndrome: a new look at an old condition. *Journal of Rehabilitation*, 68(2):22-27.

HBO documentary. (2005). I have Tourettes but Tourettes doesn't have me! Aired December 5, 2005.

Kobasa, S., Maddi, S. & Kahn, S. (1982). Hardiness and health: A prospective study. *Journal of Personality and Social Psychology,* 42 (1), 168-177.

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64(2):349-60.*

Richardson, G. E. (2002) The metatheory of resilience and resiliency*, Journal of Clinical Psychology,* 58(3), pp. 307-321.

Richardson, G. E., Neiger, B. L., Jensen, S., & Kumpfer, K. L. (1990) The Resiliency Model. *Health Education* 21, (6), 33-39.

Richardson, G. E. (2010) *The ten Q-Nexus experiences: Thriving through adversity and challenge*. Q-Nexus LLC, Salt Lake City. Book 1, p. 10.

Rosen, L. (2002). Family dynamics in the treatment of Tourette syndrome. *Exceptional Parent*, December 2002.

Rutter, M. (1979). Protective factors in children's responses to stress and disadvantages. In Kent, M.W., Rolf, J. E. , eds. *Primary Prevention of Psychopathology, Vol III--Social Competence in Children. Hanover*, N.H.; University Press of New England. 49-74.

Rutter, M. (1985) Resilience in the face of adversity: Protective factors and resistance to psychiatric disorder. *British Journal of Psychiatry*, 147, 598-611.

Ryan, R. M. & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55* (1), 68-78.

Simon, J. B, Murphy JJ, Smith SM. (2005). Understanding and fostering family resilience. *The Family Journal, 13(4):427-36.*

Tusaie K., Dyer J. (2004). Resilience: a historical review of the construct. *Holistic Nursing Practice, 18(1):3-8.*

Walsh F. (1998). Strengthening Family Resilience. Guilford Press, New York.

Walsh F. (2002). A family resilience framework: innovative practice applications. *Family Relations, 51(2):130-43.*

Werner, E., & Smith, R. (1992) *Overcoming the odds: High risk children from birth to adulthood*. Ithaca; Cornell University Press.

Woods, D. W., Marcks, B. A. (2005). Controlled evaluation of an educational intervention used to modify peer attitudes and behavior toward persons with Tourette's syndrome. *Behavior Modification*, 29(6): 900-12.

Zinner, S. H. (2004, pt. 1). Tourette syndrome—much more than tics: Moving beyond misconceptions to a diagnosis (First of two parts). *Contemporary Pediatrics*, 21(8) 22-36.

CHAPTER 4

APPLICATION OF THE METATHEORY OF RESILIENCE AND RESILIENCY IN FAMILIES WITH CHILDREN WITH TOURETTE SYNDROME: WAVE THREE

Abstract

This paper focuses on the theoretical application of the third wave of resiliency inquiry as it applies to families with children with Tourette syndrome. This wave involves the identification of the energy, passion, and motivation that leads families along their resilient journey of living with Tourette syndrome.

It examines and defines the motivational forces which may drive their resilience. These forces include: essential resilience, childlike resilience, character resilience, noble resilience, ecological resilience, synergistic resilience, and universal resilience.

Helping professionals can facilitate resiliency by integrating the concepts of all three waves of resiliency inquiry, remembering that it is healthy to identify and pursue resilient qualities (first wave), to understand the processes of resiliency (second wave) and to access innate resilient drives to thrive (third wave).

Although Tourette is a lifelong condition which waxes and wanes and has an unpredictable course, children with Tourette and their families can experience enlightenment and a new identity as people functioning optimally for their situation – living their dreams. Helping professionals can see the difference in the countenances of

children with Tourette and their families who have found peace with their condition and those who are still living in fear.

Parents can learn to appreciate their children with Tourette while at the same time they can be frustrated and fear for their futures. Most importantly they can develop hope. After forming a new identity that thrives through the challenge of Tourette's, parents can learn about themselves and how to live and love with the challenges that are a constant to their children and families.

Helping professionals who work with the children with Tourette, their parents, and families can benefit from knowing and applying the Metatheory of Resilience. Understanding the resiliency process facilitates adaptation and optimization of life situations.

It is good for everyone to reflect upon who they are, what their dreams may be, and changes to identities that will help all people become healthier and happier.

Introduction

This paper focuses on the theoretical application of the third wave of the Metatheory of Resilience and Resiliency (MRR) (Richardson, 2002) to families with children with Tourette syndrome (FCTS). Richardson (2002) defines resilience as “the motivational force within everyone that drives them to pursue wisdom, self-actualization, and altruism and to be in harmony with a spiritual source of strength” (p. 309).

Postmodern multidisciplinary studies have identified several types of resilience such as: essential resilience, childlike resilience, character resilience, noble resilience, ecological resilience, synergistic resilience, and universal resilience (Richardson & Summerhays, 2011). Each of these motivational forces generates energy that can aid an individual or family along the journey to resilience. Each force has its own purpose and benefit in the building, enhancing, healing, and rehabilitation process. Following a brief review of the first and second waves of resiliency inquiry, this paper will explore ways in which helping professionals may assist FCTS in optimizing the use of these drives to foster healing and growth.

The First and Second Waves of Resiliency Inquiry

Together all three waves of the MRR (Richardson, 2002) provide a framework for examining how families and helping professionals can facilitate optimal functioning in FCTS. Cazier (2012) describes how the first and second waves may be applied to the journey of these families. Briefly, the first wave of resiliency inquiry identifies resilient qualities that are crucial to the functioning of not only individuals but of families as well (Walsh, 1998). The adversity of an individual family member with TS can create a disruption in the family and impact its functionality (Chowdhury, 2004; Hendren, 2002; Woods & Marcks, 2005). No family is immune to adversity and every family faces its own challenges. Successful families need to learn how to adapt and surmount the challenges they encounter (Flach, 1997). The second wave of resiliency inquiry moves from describing or identifying resilient qualities to understanding the processes involved (Reich, Zautra, & Hal, 2010). Richardson (2010) describes resilience as “the process and experience of being disrupted by change, opportunities, adversity, stressors, and challenges and, after some introspection, ultimately accessing innate resilience (gifts and strengths) to grow stronger through the disruption.”

The Third Wave of Resiliency Inquiry

The third wave of resiliency inquiry as it applies to FCTS involves the identification of the energy, passion, and motivation that leads them through their trough of chaos and along their resilient journey of living with TS (Richardson, 2002). Helping professionals and the families themselves may benefit from asking, “What drives this particular family to move forward in the face of adversity?” “How do they find the strength to face the challenges of having a child with TS?” “Where do they find their courage to move forward as productively and successfully as possible?” A theoretical examination of the motivational forces which may drive resilience in FCTS is explored in the following sections.

Essential Resilience

Essential resilience refers to the energy required to live and survive and is the most primitive and basic form of resilience. It is what drives us towards optimizing our lives and physical functioning. It is the inner strength that keeps enriching the body, the mind and the spirit. It is the energy, for example, that keeps a child with TS going instead of giving up and allowing TS to defeat him or her.

Understanding essential resilience helps professionals and families create optimal conditions for healing and promote the will not only to live, but to thrive. An integrated human soul can be sensitive to the yearnings and drives of the human physiology. People can learn to eat, sleep, and be active intuitively. For example, if people are not addicted to sugars, fats, and salts they can eat intuitively by listening to cravings for particular foods that provide needed nutrients to optimize physical functioning (Tribole & Resch, 2003). People who listen to the prompts that come from their bodies can sense when it is time to move and be active. Individuals with TS frequently report that they have a premonitory urge that precedes a tic (Leckman, 2003; Singer, 2005). They may have an intuitive sense about their body's need to tic, and they may listen when they feel a tic is about to manifest itself. At this point they can choose to release the tic as the body intuitively suggests, which temporarily relieves the inner tension in their body (Jankovic, 2001; Jimenez-Shahed, 2009), or they may try to suppress it to avoid the possible stigma imposed by society. To suppress the tic results in pressure building in the person with TS which continues until the tic is released. Releasing the tic occurs by letting it happen naturally. In this situation helping professionals may assist children with TS in optimizing their essential resilience by helping them explore the pros and cons of listening to their body and choosing whether or not to release their tics.

Helping professionals may also assist parents of children with TS in increasing their appreciation of their own intuitive awareness of their child's struggles and will to conquer. These parents may sense that their child can overcome the difficulties they face as well as understand that the requisite energy or resilience may need to be nurtured and developed over time. Parents can be encouraged to help their children with TS and other family members cultivate that energy known as essential resilience.

Childlike Resilience

Childlike resilience is an innate energy-producing source within most people (Richardson, 2002). While people may bury their childlike nature in the wake of pain and difficult life experiences, nevertheless this energy source can still be found deep within them. By reflecting upon one's childlike nature one can sense the drive or yearning to have fun, to play, to be creative, to find humor and laugh, to be spontaneous, to take risks, to be genuine, to be curious, to be open, and to seek and enjoy pleasure. Childlike resilient qualities can enhance and draw others near but these same qualities can create challenges when taken to the extreme.

Due to common comorbidities (Bitsko, 2009; Stephens & Sandor, 1999) those with TS are frequently impulsive, which can contribute to a sense of fun loving humor and work to their benefit in creating positive experiences with others. However, this same spontaneous sense of humor can lead to hurt relationships if taken too far. For example, spontaneous funny comments may contribute to a fun interaction but if a child with TS doesn't also know when to stop and keeps going on too long the humor may be lost and people could start to get annoyed. Being overly spontaneous could create other problems such as jumping to wrong conclusions and then taking hurtful or poorly conceived action. Helping professionals can assist children with TS and their families understand and work to maximize the benefits of childlike resiliency while minimizing damage to relationships from being overly impulsive.

Character Resilience

Character resilience comes from the desire to live within a moral framework and entails having the ability and desire to learn from our mistakes, make adaptations in our behavior, change our attitudes, and resolve difficulties. In other words, this type of resilience encourages positive action by using concepts such as integrity, honesty, trustworthiness, kindness, self-regulation, hope, and spirituality. These qualities allow us to live a life that is consistent with our personal, family, and community values that strengthen us rather than weaken us. Character strengths contribute to life satisfaction and fulfillment (Seligman, Steen, Park, & Peterson, 2005). Children with TS and their families can be encouraged by helping professionals to explore their own moral framework to increase their sense of personal satisfaction.

These principles carry across cultures, genders, and the life span. A sense of freedom and energy result when living within one’s chosen character qualities. When people step outside their character code, the result is a feeling of guilt and regret. Guilt is an energy drain and compromises the healing process. Helping professionals can encourage patients to seek counselors or clergy to facilitate a self-forgiving experience.

A study of posttraumatic growth and strengthening character concluded that a person’s character may grow as a result of experiencing trauma (Peterson, Park, Pole, D’Andrea, & Seligman. 2008). Children with TS and their families face many difficulties, some of which may be traumatic, others may be less intense. Having difficulty fitting in, being teased and bullied are common stressors for children with TS and their families (Bruun, Cohen, & Leckman, 2009; Chowdhury, 2004) which may make it all the more important for helping professionals to assist them in actively clarifying their own belief system and moral code and developing the strength which comes from character resilience.

Noble Resilience

Noble Resilience is the yearning and drive to feel valued and important. Self-esteem, self-efficacy, and self-worth all reflect noble resilience. Feeling good about oneself is generally a product of having a purpose and meaning in life. Where noble resilience is the desire to acquire feelings of worth, it is acting on the noble drive for altruism and service that leads to feeling important. When people perform acts of kindness and service to others, the validation of goodness comes from external sources.

Wise helping professionals can encourage their patients to be involved in meaningful acts of service. Likewise, parents of children with TS can provide opportunities for their children as individuals and with their families as a whole to give service.

Ecological Resilience

Ecological resilience is the drive to connect with energy from one's surroundings. Walsh (1998) believes that over a lifetime there are many spheres in our surroundings that influence resiliency such as: family, friends, culture, school, religion, and so forth. The interplay of these spheres can lead the child with TS to either thrive and survive resiliently or retreat in fear and despair. Walsh (1998) said, "It is not enough to bolster the resilience of at-risk children and families so that they can 'beat the odds'; we must also strive to change the odds against them" (p. 12).

Candace Pert (1997) describes how vibrations that come from nature activate neuropeptides in the body. The receptive neuropeptides connect with receptors in the cells and send messages through the vibrations. Soft, life enriching, and healing vibrations come from natural settings. Plant therapy (Van Den Berg, & Custers, 2011), pet therapy (Barker, & Dawson, 1998), music therapy (Field, et al. 1998; Montello, & Coons, 1998), and other sources of soothing vibrations may help FCTS to thrive even as they struggle with adversity. Helping professionals and parents can help create nurturing ecosystems around FCTS that facilitate optimal growth and healing. TS is a neurological disorder and strong ecological sources of strength may help children with TS rebound from their own internal neurological struggles as well as help them and their families heal and move past the negative reactions of others and the frustrations of societal misunderstanding.

Synergistic Resilience

Synergistic resilience is the yearning and drive to connect with others. The drive to connect is in essence love. The most effective helping professionals may be those who make connections with their patients (Rakel, et al. 2009). Helping professionals can also help create situations for family and friends to make connections with and thereby promote the well-being of children with TS and their family members. As loved ones speak optimistically, instill hope, and generate courage in patients, the resilient qualities will emerge which, according to the field of psychoneuroimmunology, will help fortify the immune system (Richardson, 2002). Tics may prompt children with TS to do things which may be socially unacceptable or annoying to others, such as odd facial grimaces, irritating noises at inappropriate times, shoulder or leg tics which cause them to bump others, etc. Such tics may interfere with the desire for positive connection with others and impede synergistic resilience. Helping professionals can assess the needs of each individual child and family member and assist in creating effective interventions, such as educating peers, family, school personnel and others in the community.

Universal Resilience

Universal resilience is the yearning and drive to connect to a strength, power, and energy beyond normal capacity. Studies have demonstrated that faith facilitates healing and rehabilitation (Richardson, 2002). As in the general population, many FCTS are likely to believe in some form of deity, but spirituality does not have to be linked to any specific religion or belief system. Helping professionals working with FCTS can educate them about the vast wisdom of the collective unconscious mind which reflects a universal wisdom, or about string theory which describes how everything is connected to everything else, or about other forms of theoretical physics that suggests that we are walking in, breathing in, and literally part of an energy field (Greene, 2003). FCTS can be assisted in exploring spiritual connections and find those that they feel comfortable with which can act as a foundation or moral compass to guide the family through the challenges they face not only with the TS but with other challenges in life as well. Integrative health modalities may provide the techniques and skills a family needs to access peace, energy, and comfort from a higher power. Helping professionals can help children with TS and their families connect with strengths beyond their own by encouraging practices such as meditation, Tai Chi, yoga, prayer, music therapy, journaling, and other evidenced based techniques and skills.

Integrating Resilient Qualities, Resiliency, and Resilience

Helping professionals can find many points at which to positively influence children with TS and their families. They can facilitate resiliency by integrating the concepts of all three waves of resiliency inquiry, remembering that it is healthy to identify and pursue resilient qualities (first wave), to understand the processes of resiliency (second wave) and to access innate resilient drives to thrive (third wave).

Life Dreams

FCTS can be encouraged to reflect upon whom they really are and how this connects with their childlike, noble, character, ecological, and universal drives. Physical limitations do not need to prevent these drives from being fulfilled. It is through the sensitivity of the resilient yearnings that one can formulate a dream for life. A dream is a vision of what a person's world will look like fulfilling the drives within whatever limitations exist.

Disruptions can occur from being blindsided by life events or from taking leaps of faith into new adventures. Whatever the impetus, the resulting disruption may be accompanied by feelings of disorientation, hurt, loss, guilt and fear. The sensitive helping professional will recognize and respond to the fear, the hurt and other painful emotions. Often it will be when children with TS and their families are at a low point that they are in the right state of mind and heart to experience infusions of resilient qualities.

Sources of Strength

The language of the universe is in the form of vibrations (Richardson, 2002). As FCTS seek a source of strength beyond their normal capacity they may receive insights, peace, and acceptance that will help them thrive. The source of the qualities will vary among patients. For example some patients may believe in Qi energy from the Eastern healing professions. Some may believe in the power of the Collective Unconscious mind which brings the wisdom of the ages to their consciousness. Some may believe in God's spirit that can bless them if they have faith.

In the Resiliency Mapping Model described by Richardson and Summerhays (2011) disruptive events precipitate a drop into the bottom of the resiliency trough which can bring about the possibility of experiencing insights, enlightenment, peace, and acceptance. FCTS may seek their source of strength through practices such as meditation, prayer, and mindfulness in attempt to resonate to desired resilient qualities. When gestalts, inspiration, energy, hope, and optimism come, they will receive an infusion of the qualities. Helping professionals can see the difference in the countenances of children with TS and their families who have found peace with their condition and those who are still living in fear.

New Identity

The outcome of enlightenment in the trough is often a vision of a new identity for the children and their families. They may see themselves with more hope, confidence, and vigor. The new identity may be more compliant. The new identity may listen to intuitive senses and eat, move, rest, and even tic accordingly. Although TS is a lifelong condition which waxes and wanes and has an unpredictable course, children with TS and their families can experience enlightenment and a new identity as people functioning optimally for their situation – living their dreams.

With the new identity in mind, helping professionals can act as coaches to promote self-mastery from within. The concept of self-mastery includes persistence, the refusal to quit when faced with adversity, and prudence, the use of reasoning and self-management in the new identity. Constant disruptions are frequently the norm for children with TS, their families, and all those with whom they have relationships. Helping professionals can assist those with TS in developing the noble energies of self-esteem and self-efficacy in the lifelong quest to master themselves and the disruptions inherent in living with TS. Establishing a work ethic designed to motivate and direct the family out of the chaos of disruptions can also help.

Concepts of Self

Other “self” concepts include self-regulation, self-discipline, self-determination and self-control, which essentially describe the ability to override primitive thoughts and behaviors and work toward wise outcomes. These can present special challenges for children with TS and their families as the children face vocal and movement tics which seem to fly in the face of such concepts. For example, although coprolalia is quite rare, present in only about 10% of those with TS (Singer, 2005), children with TS who have coprolalia may have difficulty feeling that they have any of these self-control qualities when through their uncontrollable tics they produce vocal noises such as screams, animal sounds, vulgar or otherwise inappropriate words shouted out loud, etc. No matter how strongly children with TS want to exercise self-control with regards to Tourettic tics, they must let them out sooner or later (Woods et al., 2008). Comorbidities common with TS, such as OCD or ADHD, likewise may be controlled to a certain extent with medication and training, but in reality the children with these comorbid conditions will struggle with the effects for life. Nevertheless, they do not have to stay trapped in the disruptive trough but rather they can learn to live with, struggle with, and adapt to the thoughts and behaviors associated with these conditions. Helping professionals can assist children with TS and their families in developing the noble energies of self-esteem and self-efficacy as they learn to live with and accept the disruptions associated with TS.

Self-mastery also includes faith in one’s ability to accomplish goals and develop a new identity. Self-mastery may include faith to accomplish with the help of a universal resilient strength. Helping professionals can encourage FCTS to believe in their children with TS, to have hope in their ability to live well with TS and its associated comorbidities and accomplish their dreams. Such families can learn to recognize the struggles their children with TS face and support them as they work to develop the resilience to get out of disruptive troughs, never giving up or accepting defeat. They can learn to work hard to develop and incorporate faith and religious guidelines and morals to anchor their families and serve as a family compass for right and wrong, love and appreciation, acceptance and tolerance, and family love, support, and togetherness. They may face many unknowns, suffer embarrassment and frustration, but never give up on their children with TS. This is part of the universal energy that they can depend on to lead their families along the journey filled with constant challenges.

Resilient Reintegration

The final stage of the resiliency process is resilient reintegration which also reflects wisdom. As helping professionals assist parents in learning more about TS and its effects on their children, parents and children alike can work towards reintegrating with resilience. FCTS can learn to appreciate the benefits they receive from having a child with TS in the family. Some of the benefits may include developing patience, improved relationship and appreciation between parents, tolerance, and gratitude for a child who has TS rather than some other challenge that could be worse. Parents can learn to appreciate their children with TS while at the same time they can be frustrated and fear for their futures. Most importantly they can develop hope. After forming a new identity that thrives through the challenge of TS, parents can learn about themselves and how to live and love with the challenges that are a constant to their children and families. Recognizing and accepting the challenges, working to live within their parameters, experiencing growth associated with this challenge, and recognizing the accomplishments of the family is part of resilient reintegration. Parents and children alike can reflect upon lessons learned and apply those to future disruptions. The resilient quality of appreciation is a reflection of that wisdom.

Discussion

Helping professionals who work with the children with TS, their parents, and families can benefit from knowing and applying the Metatheory of Resilience. Understanding the resiliency process facilitates adaptation and optimization of life situations. Upon reflection, helping professionals may realize that they not only experience the resiliency process as they work with families, but also when dealing with their own personal and professional challenges. It is good for everyone to reflect upon who they are, what their dreams may be, and changes to identities that will help all people become healthier and happier.

References

Barker, S. B. & Dawson, K. S. (1998). The effects of animal-assisted therapy on anxiety ratings of hospitalized psychiatric patients. *Psychiatric Services,* 49(6). (CA&P #28).

Bitsko, R. H. (2009). Report on epidemiologic findings from CDC. Proceedings of the 5th International Scientific Symposium on Tourette Syndrome, USA, p. 11.

Bruun, R. D., Cohen, D. J., & Leckman, J. F. (2009). Guide to the diagnosis and treatment of Tourette syndrome. Retrieved from http://www.tsausa.org/Medical/guidetodiagnosis.html 12/18/09.

Cazier, C. F. (2012). Application of metatheory of resilience and resiliency in families with children with Tourette syndrome. Unpublished manuscript.

Chowdhury, U. (2004). Tics and Tourette syndrome a handbook for parents and professionals. Jessica Kingsley Publishers, London.

Field, T., Martinez, A., Nawrocki, T., Pickens, J., Fox, N. A., & Schanberg, S. (1998). Music shifts frontal EEG in depressed adolescents. *Adolescence, 33*(129):109–116.

Flach, F. (1997). Resilience the power to bounce back when the going gets tough. Hatherleigh Press. New York.

Greene, B. (2003). The elegant universe: superstrings, hidden dimensions, and the quest for the ultimate theory. New York: W.W. Norton.

Hendren, G. (2002). Tourette syndrome: a new look at an old condition. *Journal of Rehabilitation*, 68(2):22-27.

Jankovic, J. (2001). Tourette's syndrome. *N Engl J Med*, 345(16):1184-1192.

Jimenez-Shahed, J. (2009). Tourette syndrome. *Neurol Clin* 27, 737–755.

Leckman, J. F. (2003). Phenomenology of tics and natural history of tic disorders. *Brain & Development* 25 Suppl. I S24-S28.

Montello, L. M., & Coons, E. E. (1998). Effect of active versus passive group music therapy on preadolescents with emotional, learning, and behavioral disorders. *Journal of Music Therapy, 35,* 49–67.

Pert, C. (1997) *Molecules Of Emotion,* New York; Scribner.

Peterson, C., Park, N., Pole, N., D'Andrea, W., & Seligman, M. E. P. (2008). Strengths of character and posttraumatic growth. *Journal of Traumatic Stress, 21(*2):214-217.

Rakel, D. P., Hoeft, T. J., Barrett, B. P., Chewning, B. A., Craig, B. M., & Niu, M. (2009). Practitioner empathy and the duration of the common cold. *Family Medicine*, 41(7):494-501.

Reich, J. W., Zautra, A,. Hal, J.S. (2010). *Handbook of adult resilience.* The Guilford Press. New York, NY.

Richardson, G. E. (2002) The metatheory of resilience and resiliency*, Journal of Clinical Psychology.,* 58 (3), pp. 307-321.

Richardson, G. E. (2010). Developing personal resilience. Presented to Corporate Telelink Network. sganetwork.org/hwdvideos/docs/CTNMarch3_8_07Handouts.pdf. Downloaded 3/14/2012.

Richardson, G. E., & Summerhays, J. F. (2011). Magnify your life: a progressive bombardment approach to preventing childhood obesity. http://health.utah.gov/obesity/documents/Richardson. Downloaded 3/11/2012;

Seligman, M.E.P., Steen, T.A., Park, N., & Peterson, C. 2005). Positive psychology progress – empirical validation of interventions, *American Psychologist*, 60(5):410-421.

Singer, H. S. (2005). Tourette's syndrome from behaviour to biology. *Lancet Neurol,* 4:149-159.

Stephens, R. J., & Sandor, P. (1999). Aggressive behaviour in children with Tourette syndrome and comorbid attention-deficit hyperactivity disorder and obsessive-compulsive disorder. *,Can J Psychiatry*, 44(10):1036-42.

Tribole, E., & Resch, E. (2003) *Intuitive Eating: A Revolutionary Program That Works*, St. Martin's Griffin.

Van Den Berg, A., Custers, M. H. G. (2011). "Gardening Promotes Neuroendocrine and Affective Restoration from Stress." *Journal of Health Psychology* 16(1):3-11.

Walsh, F. (1998). *Strengthening family resilience*. The Guilford Press, New York.

Woods, D. W., & Marcks, B. A. (2005). Controlled evaluation of an educational intervention used to modify peer attitudes and behavior toward persons with Tourette's syndrome. *Behavior Modification,* 29(6): 900-12.

CHAPTER 5

CONCLUSION

Review of Findings

Two research questions guided this study: 1) How do fathers cope with sons who have Tourette syndrome (TS); and 2) how does this impact the family dynamics? The main finding of this study is that fathers showed an overall pattern of response to having a son with TS which seemed influenced by the nature of TS itself. TS is a lifelong disorder whose symptoms wax and wane over an unpredictable course (Bagheri, Kerbeshian, & Burd, 1999; Leckman, 2002; Chowdhury, U. 2004; Edell, & Motta, 1989). The fathers in this study experienced the unpredictable waxing and waning their sons' symptoms and responded in a waxing and waning pattern of their own as they accompanied their sons along a path filled with uncertainty about the course ahead. These fathers faced all of the normal and expected challenges that other fathers experience raising their children in addition to the unique challenges influenced by the intrinsic nature of TS itself.

Early in the data analysis process the researcher noted that many of the fathers' stories contained elements that seemed to fit into theories of resiliency. Chapters 3 and 4 outline the theoretical application of Richardson's Metatheory of Resilience and Resiliency (MRR) (2002) to families that have children with TS. These two chapters provide a TS-adapted theoretical framework that describes qualities, processes, and driving forces involved in resilient response to stressors.

The Resiliency Mapping Model (RMM) introduced in Chapters 3 and 4 did not fully explain the father's response to the TS-related course of disruptions. Based on the data gathered in this study, Richardson's resiliency model was adapted to explain this difference in Chapter 3.

The TS-related disruptions reported by the fathers fell into two main categories. Some disruptions were created directly by their son's TS and its related comorbidities and were categorized as primary challenges. Others were created by the fathers' ineffective responses to the primary challenges and were categorized as secondary challenges.

Primary challenges are life events/stimuli that are related to the son's TS and/or comorbidities which impact the father either directly or indirectly. If a father reacts effectively to a primary challenge he experiences personal growth and an increase in resiliency. If on the other hand he reacts with an ineffective response he creates a secondary challenge which takes him into a new disruptive trough which he and his family must now go through in addition to facing the original primary challenge. Creating one secondary challenge can lead to an iterative process in which there is a downward spiral of disruptions and ineffective responses.

Every father's story outlined his own issues with his TS son that was part of his life and challenge of being a father. Although there were similarities between the fathers, each was uniquely challenged to develop his personal strengths in response to the waxing and waning and unpredictable course associated with his particular son's TS. The pattern of waxing and waning responses in the face of an uncertain future occurred along five major themes: 1) the question of normalcy, 2) pride in son, 3) hope in the future, 4) acceptance, and 5) role satisfaction.

Fathers reported experiences along a continuum of success, ranging from effective responses which seemed to lead to personal growth and resilience and stronger relationships with his son and family, to ineffective responses, difficulty developing personally, and relationship strain or deterioration. The level of personal growth and resilience appeared to lay the foundation for and give direction to the developing relationships. Fathers reported that as they became more knowledgeable about and experienced with the course of TS, they learned to recognize the waxing and waning of their son’s symptoms. The fathers themselves experienced a waxing and waning course of thoughts and feelings in response to their sons’ struggles with TS-related issues along an unpredictable course. For example, many of the fathers reported a waxing and waning sense of confidence and pride in their son with TS, sometimes having bursts of confidence and pride and at other times becoming fearful that their son would never be able to live a normal life.

Suggestions for Future Research

As with all qualitative research the results of this study cannot be generalized, however this research does provide introductory insights into the lives of these fathers, their relationships with their sons who have TS and the impact on the family. The knowledge gained from this study can be transferred (Marshall & Rossman, 2006) and used as a foundation for a larger quantitative study involving a broader and more diverse demographic population.

The fathers in this study had sons who had had TS for at least 3 years and the fathers were asked to retrospectively share their thoughts and feelings back to the time when they first noticed their son's TS symptoms. Although many fathers had clear and powerful memories of these events, others could not remember pertinent details which could have shed a new or different light on this research. Additional research should be done which captures this data closer to the time of occurrence.

TS is much more common in boys than girls and the study population of this exploratory qualitative study was limited to fathers who have a son with TS. Additional studies should be done to examine the possible differences between sons and daughters.

Based on participant selection criteria of the study participants all were men in long term marriages to their son's biological mother. Further research should explore potential differences between this population and ones with more diverse family structures, such as families in which there has been a divorce, single parent families, blended families, etc. Although there has been more research focused on mothers that data is still limited and more should be done.

While qualitative studies do not produce generalizable results, the findings of this study seem to be strong and consistent and are very likely to be helpful in directing potentially powerful interventions for support and education of families with children who have TS. It is my hope that quantitative studies will follow this research and produce statistically significant results that corroborate this study's findings, however, I strongly believe that such studies will likely support the major findings of this research.

References

Bagheri, M. M., Kerbeshian, J., & Burd, L. (1999). Recognition and management of Tourette's syndrome and tic disorders. American Family Physician, 59(8).

Chowdhury, U. (2004). Tics and Tourette syndrome a handbook for parents and professionals. Jessica Kingsley Publishers, London.

Edell, B. H., & Motta, R. W. (1989). The emotional adjustment of children with Tourette syndrome. The Journal of Psychology, 123(1):51-57.

Leckman, J. F. (2002). Tourette syndrome. *Lancet,* 360:1577–86.

Marshall, C., & Rossman, GB. (2006). Designing qualitative research, 4th edition. Sage Publications, Thousand Oaks, CA.

Richardson, G. E. (2002) The metatheory of resilience and resiliency, *Journal of Clinical Psychology.*, 58 (3), pp. 307-321.

Seligman, M., & Darling, R. B. (1997). Ordinary families, special children a systems approach to childhood disability. Second Edition. The Guilford Press. New York.