HEALTHCARE RESPONSIBILITY AND TRANSITION READINESS IN ADOLESCENTS WITH TOURETTE SYNDROME

by

Lauren F. Quast

(Under the Direction of Ronald Blount)

ABSTRACT

Objective: This study sought to characterize healthcare responsibility, caregiver involvement, and transition readiness for adolescents with Tourette syndrome (TS). *Method:* Participants included 38 adolescent-caregiver dyads (adolescent M_{age}= 14.45, *SD*= 1.52). *T*-tests compared caregiver- and adolescent-reports of healthcare responsibility and transition readiness to one another and adolescent transplant recipients. Correlations and regression analyses examined the influence of demographic, medical, adolescent, and family variables on transition readiness. *Results*: Adolescents and caregivers reported low adolescent healthcare responsibility and transition readiness and high caregiver involvement. Younger adolescent age, comorbid conditions, executive functioning deficits, caregiver depression, and poor family functioning related to lower adolescent responsibility and transition readiness, and higher caregiver involvement. Only behavior regulation accounted for additional variance in transition readiness, beyond medical and family factors. *Conclusions:* Adolescents with TS do not feel prepared to independently manage their healthcare and transfer to adult-care, likely due to limited training and lack of specialty care clinics.

INDEX WORDS: Tourette syndrome, adolescents, healthcare responsibility, transition readiness

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CHAPTER 1

INTRODUCTION

Tourette Syndrome

Tourette syndrome (TS) is a nervous system disorder with childhood onset characterized by the presence of multiple motor and vocal tics for more than one year (American Psychiatric Association, 2013). Tics are sudden, recurrent, and non-rhythmic movements or vocalizations (American Psychiatric Association, 2013) that are often proceeded by a premonitory urge or anticipatory sensation (Cox, Seri, & Cavanna, 2018). Common vocal tics include throat clearing, sniffing, yelling, repeating words or phrases, and grunting, whereas motor tics can include eye blinking, twitching, hitting, jerking of appendages, and facial grimacing (Schwam, King, & Greenberg, 2015). Tics wax and wane in form and severity over time and across contexts (e.g., setting, activity, affective state, others' reactions; Yadegar et al., 2019). For example, tics can be exacerbated during times of increased stress or when others attend to or react to the tics (Yadegar et al., 2019).

TS affects approximately .1% to 1.5% of children worldwide (Bitsko et al., 2014; Knight, Steeves, Day, Lowerison, Jette, & Pringsheim, 2012), with symptoms often emerging between the ages of five to seven years. TS is more commonly diagnosed in males compared to females (Cavanna et al., 2009). Although symptoms vary over time and can be difficult to predict, there is often an increase in tic severity during prepubertal years and a decrease in symptoms during adolescence, with individuals typically experiencing fewer and more mild symptoms in adulthood (Leckman et al., 1998; Lowe, Capriotti, & McBurnett, 2019; Peterson, Pine, Cohen, &

Brook, 2001). Approximately half to two-thirds of adolescents with TS experience a decrease or complete remission of tics by the end of adolescence (Bloch et al., 2006).

Comorbidities

Despite general patterns, the severity and presentation of TS varies widely across individuals and is complicated by high rates of comorbidity. Approximately 80-90% of children with TS are diagnosed with at least one comorbid condition, such as attention-deficit/hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), mood disorders, anxiety disorders, autism spectrum disorder, or learning disorders, and almost 60% of individuals with TS meet criteria for two or more comorbid disorders (Cavanna et al., 2009; Eapen et al., 2016; Hirschtritt et al., 2015; O’Hare et al., 2016). Difficulties with impulse control, self-injurious behavior, intermittent rage, and sleep issues are also common among youth with TS (Freeman, 2000; Robertson, Cavanna, & Eapen, 2015). Yadegar and colleagues (2019) found that symptoms of comorbid conditions or behavioral difficulties can be more impairing than symptoms of TS and impact the management of TS and outcomes of tic-specific interventions. For example, tics and comorbid ADHD may lead to distractibility and difficulty focusing one’s efforts to control tics (Eapen, Crncec, McPherson, & Snedden, 2013).

Impact of Tourette Syndrome

Prior research has shown that children with TS experience greater impairment across all aspects of executive functioning compared to their typically developing peers (Hovik et al., 2017). When compared to children with autism spectrum disorder and children with ADHD, children with TS have greater difficulty with emotional control, inhibitory control, and shifting (Hovik et al., 2017). Executive functioning consists of a “set of cognitive processes that subserve behavioral and cognitive regulation in goal-directed processes and encompass working memory, flexibility, generativity, monitoring, planning, and inhibition" (Rogers & Bennetto, 2000; Peng & Wallace, 2017). Difficulties with executive function have been described as one of the most debilitating aspects of TS due to the impact on multiple areas of everyday life (e.g., academic functioning, emotional control, peer relations; Carter, O'Donnell, Schultz, Scahill, Leckman, & Pauls, 2000; Singer, 2005). For instance, adaptive control of one's own behavior is dependent on executive function, which may impact adolescents' ability to take primary responsibility for their own care across settings (e.g., school, healthcare, social settings; Jurado & Rosselli, 2007).

Symptoms of TS and comorbid conditions can interfere with everyday life and completing activities at school, home, or work, affecting an adolescent's ability to reach their full potential at school, gain independence, and cultivate and maintain close relationships with family and friends (Eapen et al., 2016). Further, TS is strongly associated with poor quality of life and adverse psychological, behavioral, social, and academic consequences, particularly when accompanied by comorbid disorders (Cavanna et al., 2009; Conelea et al., 2011; O'Hare et al., 2016). Compared to youth with TS only, those with TS and a comorbid diagnosis report significantly worse quality of life, impaired emotional and school functioning, and greater emotional symptoms (Eapen et al., 2016; O'Hare et al., 2016). Of note, the literature suggests that TS also carries a greater stigma than common comorbid conditions only (e.g., ADHD, OCD; O'Hare et al., 2016).

Diagnosis and Symptom Management

Given high rates of comorbidity and the waxing and waning nature of tics, TS can be challenging to diagnose. Many times, there is a delay of approximately two years between the onset of symptoms and when a child receives a TS diagnosis (Yadegar et al., 2019). This delayed diagnosis may lead to confusion, frustration, and difficulties with symptom management or obtaining appropriate accommodations. Pediatricians and primary care providers are typically the first, and sometimes sole, provider for pediatric patients presenting with tics (Yadegar et al., 2019). This is important as there have historically been gaps in provider knowledge of and experience with tic disorders, leading to less than optimal patient care. There is not usually a specialty clinic available for diagnosis and symptom management as is common for other pediatric conditions (e.g., cancer, solid organ transplant, diabetes). Rather, TS may be diagnosed and managed by clinicians across various pediatric subspecialties, including primary care, psychiatry, neurology, and psychology (Black, Black, Greene, & Schlaggar, 2016; Ganos, Martino, & Pringsheim, 2017). Thus, children may not get specialized care and families may not receive appropriate psychoeducation and support, at least initially. Ongoing care and routine assessment and monitoring are essential due to the changing nature of tics and significant risk for developing comorbid conditions, as well as for forming trusting relationships with families to provide support and targeted interventions for symptom management (Boreman, Thomasgard, Fernandez, & Coury, 2007; Cuence et al., 2015; Marcks, Wood, Teng, & Twohig, 2004).

There is wide variety in clinicians' ability to recognize, assess, and treat children with TS, often due to limited education or focused training in the assessment and management of TS and other tic disorders (Efron, Payne, Gulenc, & Chan, 2020). It is recommended that treatment begin with psychoeducation about TS and referrals to local or national resources, encouraging families to become more familiar with the diagnosis and connect with support networks (Billnitzer & Jankovic, 2020). Due to the high variability of symptoms between individuals, it is suggested that treatment recommendations are individualized to treat the most troublesome symptoms. Current treatment options for tic management include behavioral interventions, pharmacological interventions, and surgical interventions. Behavioral treatments, such as Habit

Reversal Training (HRT), Cognitive Behavioral Intervention for Tics (CBIT), and Exposure and Response Prevention (ERP), are highly effective for treatment of TS (Frundt, Woods, & Ganos, 2017; Piacentini et al., 2010) and are often the first line of treatment for individuals with TS due to their ability to manage tics without medication. Specifically, HRT trains individuals to attend to early warning signs that precede tics, perform a competing response that is incompatible with a specified tic, recognize the impact of tics in social and environmental settings, and generalize these skills to other tics (Frundt, Woods, & Ganos, 2017). CBIT combines techniques from HRT with psychoeducation, relaxation training, and identification of situations that exacerbate tic severity (Billnitzer & Jankovic, 2020). ERP treats tics as conditioned responses to premonitory urges and aims to weaken the association between tics and premonitory urges in order to reduce tics, as well as premonitory urges (Frundt, Woods, & Ganos, 2017). In this sense, ERP is able to target multiple tics at once, whereas HRT and CBIT focus on a specified tic, one at a time.

If behavioral treatments are not appropriate, ineffective, unavailable or inaccessible, medication may be considered to help manage the most impairing tic-related symptoms or symptoms of comorbid conditions (Billnitzer & Jankovic, 2020; Efron et al., 2020; Yadegard et al., 2019). Pharmacological treatment of TS continues to be challenging as the biological and neuropathological aspects of TS are not currently well-understood (Quezada & Coffman, 2018). As a result, medications commonly reduce TS symptoms by approximately 25-50% rather than completely eliminating tics (Quezada & Coffman, 2018), which can lead to frustration or disappointment for patients and families. Antipsychotic agents have been shown to be effective in reducing tics, although these medications are rarely used in children and adolescents due to their significant side effects (Quezada & Coffman, 2018). Other medications with less severe side effects tend to be prescribed more often for children and adolescents with TS, including clonidine, guanfacine, baclofen, topiramate, tetrabenazine, and deutrabenazine (Billnitzer & Jankovic, 2020). Of these, Alpha-2 agonists (e.g., clonidine and guanfacine) tend to be the most recommended given their effectiveness in reducing tics and more tolerable side-effects compared to antipsychotics. Alpha-2 agonists are also effective in treating mild ADHD and impulse control (Billnitzer & Jankovic, 2020). Additionally, there is growing research on cannabis-based therapy for TS, but further research is needed to determine the effectiveness of cannabis for individuals with TS (Billnitzer & Jankovic, 2020; Quezada & Coffman, 2018).

Providers may suggest alternative treatments, such as botulinum toxin injections, transcranial magnetic stimulation (TMS), or deep brain stimulation (DBS), for patients with severe tics that have been unresponsive to less intrusive interventions (Efron et al., 2020; Yadegar et al., 2019). Botulinum toxin injections have been effective in treating localized problematic motor or vocal tics for approximately 12 to 16 weeks but require repeated injections for long-term tic management (Billnitzer & Jankovic, 2020). TMS is a noninvasive procedure that delivers a repetitive magnetic pulse to stimulate nerve cells in the brain and has been shown to significantly reduce both tics and OCD symptoms (Billnitzer & Jankovic, 2020). DBS is only recommended for individuals with severe TS that is resistant to other treatments and works by modifying the basal ganglia-thalamo-cortical circuit (Billnitzer & Jankovic, 2020). Of note, DBS is not currently approved by the FDA for the treatment of tics and individuals must fail at least three different classes of pharmaceutical treatments before DBS can be considered (Billnitzer & Jankovic, 2020). Although multiple treatments have shown promising results for tic management, there are few providers who offer these specialized treatments, limiting the availability and accessibility of these services. Families may face additional barriers to accessing recommended treatments due to poor insurance coverage and time and compliance demands, particularly for behavioral therapies (Billnitzer & Jankovic, 2020).

Healthcare Responsibility and Transition Readiness

Due to the need for ongoing medical management, high rates of comorbidity, and changing symptoms, particularly around the time of adolescence and young adulthood, it is important to understand the level of autonomy and independence adolescents have for their own healthcare and their readiness to take on greater healthcare responsibility as they prepare to transition from pediatric to adult-based care. The Society for Adolescent Medicine defines *transition* as an active process of “purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented healthcare systems” (Blum et al., 1993). Readiness to transition can be determined by measuring an adolescent’s capability and desire to assume primary responsibility for managing their healthcare needs (Stinson et al., 2014). In the current study, *transition readiness* is operationalized as the degree to which adolescents are prepared to assume complete responsibility for their healthcare and transfer to adult-based care, as defined on the Readiness to Transition Questionnaire (Gilleland, Amaral, Mee, & Blount, 2011).

Because of the limited specialty care clinics for adolescents with TS, adolescents and their families may not receive formalized training or preparation for this transition. That is, many primary care pediatric clinics do not have formal training plans or programs to assist patients during the transition from pediatric to adult care (McPheeters, Davis, Taylor, Brown, Poetter, & Epstein, 2014). This is important due to the consequences for disruption of care associated with poor transition, including adverse effects on adolescents’ health and well-being (Lamb, Hall, Kelvin, & Van Beinum, 2008; Singh, 2009), disengagement from services, and poor clinical outcomes (Singh, 2009). This is particularly notable as developmentally, adolescents are navigating multiple transitions in different areas of life, including possibly moving away from home, beginning college, starting a job, navigating new social relationships, and taking on new responsibilities (Cleverley, Rowland, Bennet, Jeffs, & Gore, 2020). These many changes and transitions may lead to new or changing tics as tics vary across contextual factors, such as new settings or activities, increased stress, and reactions of those around them (Godar & Bortolato, 2017; Yadegar et al., 2019).

Transition of healthcare should be a planned, orderly, and purposeful process that takes into account the developmental and condition-specific needs of the adolescent (Royal College of Paediatrics and Child Health, 2003). The shift of responsibility from parent to adolescent ideally begins gradually during early adolescence to prepare for a successful transfer to adult-based care between the ages of 18 and 23 years. Adolescents with neurodevelopmental disorders, including comorbidities commonly associated with TS (e.g., ADHD, autism spectrum disorders), and emotional disorders (e.g., anxiety, depression) are less likely to establish care with an adult provider and thus become lost to follow-up (Appleton, Connell, Fairclough, Toumainen, & Singh, 2019; Tatlow-Golden et al., 2018). This may be due in part to limited transition or specialty care clinics prior to transfer, as well as encounters with adult providers following transfer of care who are often ill prepared to provide for the specific and unique health, developmental, and social needs of adolescents and young adults with complex disorders, such as TS (Oswald et al., 2013). Caregivers can aid in the transition process as they help their child obtain the necessary knowledge and skills to increase independence in managing their symptoms and care, while also advocating for their child. Caregiver involvement has been linked to better outcomes for adolescents with special healthcare needs who are transitioning to adult services

(Colver et al., 2018; Singh et al., 2010). However, many adult clinics do not routinely include parents or caregivers in care, which present challenges for adolescents and young adults who are unprepared to independently manage their condition.

SMART Model

Schwartz, Tuchman, Hobby, and Ginsberg (2011) proposed a social-ecological model of adolescent and young adult readiness for transition (SMART; Figure 1) to provide a theoretical framework for transition that acknowledges reciprocal interactions among a patient and their environment. This model includes pre-existing factors (e.g., socio-demographic factors, medical status, neurocognitive and developmental status), modifiable variables (e.g., knowledge, skills, goals, relationships, psychosocial functioning), and the role of and interactions between multiple key players (i.e., patients, caregivers, and medical providers) in the transition process. SMART has gained support among pediatric clinicians and researchers due to its emphasis on individual characteristics of the patient, interactions between the patient, caregiver, and provider, and the inclusion of modifiable components that can be intervened upon in medical settings.

SMART has been primarily examined with adolescents and young adults with chronic medical conditions, including those with cancer (Schwartz et al., 2103) and sickle-cell disease (Mulchan, Valenzuela, Crosby, & Pow Sang, 2016). While the transition readiness literature continues to grow for adolescents with chronic medical conditions (e.g., diabetes, cancer, solid organ transplant), less is known about transition readiness and the acquisition of healthcare responsibility for adolescents with emotional, behavioral, and developmental disorders (Martel, 2018). Research suggests that only 40% of youth with special healthcare needs receive adequate support during the transition process (Allison, Baune, Roeger, Coppin, Bastiampillai, & Reed, 2013; Iles & Lowton, 2008) and even fewer (i.e., 17-20%) adolescents are provided with transition planning or successfully transition to adult healthcare services (Lebrun-Harris, 2018; Oswald et al., 2013). These estimates are likely even lower for youth who do not receive continued care or preparation through a specialty clinic (e.g., transition clinic, oncology survivorship clinic).

Planning for Transition to Adult-Based Care

Difficulties common among individuals with TS, and related comorbidities, are important to consider when planning for transition. For example, executive dysfunction and difficulties with organization and self-regulation can make coping with change and managing care particularly challenging (Ford et al., 2020; Young et al., 2016). Although the frequency and severity of tics typically decrease during adolescence, comorbid conditions (e.g., ADHD, OCD) can continue into adulthood and lead to other problems, including mood and anxiety disorders, interpersonal difficulties, substance use, and other risky behaviors, suggesting an even greater need for continued condition management and engagement with healthcare services (Young et al., 2016). Similar to research findings for adolescents with chronic medical conditions, improved transition planning has been shown to result in improved quality of life and decreased symptom-related impairment for young adults with ADHD (Inman, Scott, & Aleshire, 2017). Based on the unique, and sometimes complex, presentation for individuals with TS, an individualized approach to transition is likely needed. Successful transition planning can lead to improved condition management, reduced hospital admissions, better quality of life, and increased patient satisfaction (McPheeters et al., 2014). On the other hand, poor transition often results in greater rates of treatment non-adherence, decreased routine outpatient healthcare utilization, and increased emergency room visits (Varty & Popejoy, 2020). Adolescents and young adults have reported that they did not have adequate knowledge or self-management skills to successfully manage their condition following transfer to adult-based care and that they were unable to identify suitable adult providers (Varty & Popejoy, 2020).

Prior research suggests that multiple factors impact the acquisition of healthcare responsibility and perceived transition readiness among adolescents and young adults with a variety of conditions. Sociodemographic and patient characteristics (e.g., age, gender, life skills, cognitive ability) have been related to transition readiness and adolescent-reported responsibility for healthcare tasks leading up to their transfer to adult care (Bingham, Scalzi, Groh, Boehmer, & Banks, 2015; Pakdeeprom, In-Iw, Chintanadilok, Wichiencharoen, & Manaboriboon, 2012; Schwartz et al., 2013; Varty & Popejoy, 2020). Older age has been shown to relate to better self-management skills, greater responsibility for healthcare behaviors, and increased transition readiness (Haarbauer-Krupa et al., 2019; Stewart et al., 2017; Varty & Popejoy, 2020). Research also suggests that females have greater transition readiness and higher self-management skills compared to males across a variety of medical conditions (Haarbauer-Krupa et al., 2019; Varty & Popejoy, 2020). There are mixed findings in the literature regarding the impact of medical factors or symptom severity on transition readiness (Varty & Popejoy, 2020). Additionally, among adolescents and young adults with chronic illnesses, those with higher levels of psychosocial support and better self-esteem reported greater transition readiness, whereas those with higher levels of anxiety reported lower transition readiness (Pakdeeprom et al., 2012). This is important to consider as adolescents with TS often experience social difficulties and increased levels of anxiety, which may impact their perceived transition readiness and engagement with medical care (Schwartz et al., 2011). Executive functioning has also been shown to relate to transition readiness (Gutierrez-Colina et al., 2017), suggesting that adolescents with TS may experience additional challenges as they prepare to transition to adult healthcare due to executive functioning deficits. Further, family and caregiver factors, including higher maternal education, greater family household income, two-parent households, family cohesion, private insurance, and caregiver involvement in healthcare have been associated with higher transition readiness (Oswald et al., 2013; Stewart et al., 2017; Varty & Popejoy, 2020).

Transition Readiness in Healthy Populations

Much of the current research on transition readiness and self-management of healthcare focuses on adolescents and young adults with chronic conditions. Despite American Academy of Pediatrics' (2011) statement that "all youth and young adults deserve seamless access to a primary care medical home and any necessary specialty care though all of life's transitions," there is much less research on transition readiness with healthy populations (i.e., individuals without chronic conditions). The literature suggests that only 14% of youth in the United States who do not have special healthcare needs receive any form of transition planning support or resources (Lebrun-Harris et al., 2018). Additionally, youth without special healthcare needs are less involved in managing medical tasks compared to youth with special healthcare needs (Eaton et al., 2017; Lebrun-Harris et al., 2018). This is likely because youth with chronic conditions or other special healthcare needs are introduced to health-related tasks earlier and have greater alone time (i.e., without caregivers) with healthcare providers, which provides them with the opportunity to gain independence and better understand healthcare changes (e.g., reporting symptoms to physician, describing medication effects, transfer from pediatric to adult-based healthcare; Lebrun-Harris et al., 2018). Many pediatricians believe transition planning should begin at age 18 (McManus, Fox, O'Connor, Chapman, MacKinnon, 2008) and do not prepare healthy youth to manage their own healthcare until this time.

In a sample of college students, adolescents and young adults with medical conditions reported significantly higher transition readiness and higher involvement in completing medical tasks compared to their healthy peers (Eaton et al., 2017). Students with medical conditions also reported that their parents were less involved in their healthcare compared to those without medical conditions (Eaton et al., 2017). Higher levels of healthcare responsibility and transition readiness seen in adolescents and young adults with chronic conditions may be a result of having a consistent medical provider for both routine or preventive and specialty care, as well as seeing their healthcare provider more frequently than those without chronic conditions. Further, children with chronic conditions have greater experience with medical self-management (e.g., scheduling appointments, ordering and tracking medications) and more opportunities to receive training, or be involved, in specific healthcare tasks than their healthy peers. Greater research is needed examining healthcare management and transition planning in younger adolescents and individuals with unique healthcare needs, beyond chronic illnesses which are routinely managed by specialty providers.

The Current Study and Hypotheses

Healthcare responsibility and transition readiness are important domains to examine as adolescents take on greater responsibility for their own care in preparation for transition of healthcare responsibility from caregiver to child, as well as transition from pediatric to adult-based healthcare providers. The literature describes these processes primarily in populations with chronic physical illnesses; however, there is a need to examine healthcare responsibility and transition readiness for adolescents with a variety of special healthcare needs, including those with emotional, behavioral, and developmental conditions. Few youth with special healthcare needs receive adequate transition planning, despite research suggesting that transition planning leads to more successful transitions and a variety of positive outcomes, including improved healthcare utilization, better quality of life, and increased patient satisfaction (Cleverey, Rowland, Bennett, Jeffs, & Gore, 2020; Lebrun-Harris et al., 2018). TS is a unique neuropsychiatric disorder complicated by high rates of comorbidity and variable symptoms over time and across contexts. It is recommended that patients have regular medical follow-up for symptom monitoring and treatment of their TS and comorbidities. No known studies to date have examined healthcare responsibility or transition readiness in adolescents with TS.

The current study examined perceived healthcare responsibility, caregiver involvement, and transition readiness in adolescents with TS, ages 12 to 18 years, as well as factors (i.e., medical, sociodemographic, neurocognitive, psychosocial, and family) associated with adolescent healthcare responsibility, caregiver involvement, and transition readiness. It was hypothesized that adolescents and their caregivers would generally report low levels of adolescent healthcare responsibility and transition readiness and high levels of caregiver involvement. Additionally, it was predicted that the majority of caregivers and adolescents would indicate that they (or their adolescent) were not yet ready to assume complete responsibility for healthcare or transfer to adult-based care. It was also predicted that although adolescent and caregiver reports would be correlated with one another, adolescents would report greater healthcare responsibility and lower caregiver involvement compared to their caregivers. Further, it was hypothesized that adolescents with TS and their caregivers would report lower levels of adolescent healthcare responsibility and transition readiness and higher levels of caregiver involvement compared to adolescent solid organ transplant recipients, a medical condition which requires frequent specialty care visits. Based on the literature, adolescents in the current sample were expected to have higher levels of executive functioning deficits, attention problems, and hyperactivity, as well as greater depressive and anxiety symptoms, compared to community norms. Similarly, it was hypothesized that a subset of caregivers would report increased levels of anxiety and depressive symptoms, and poor family functioning, compared to community norms. For correlational analyses, it was predicted that older adolescent age and better family functioning would be associated with greater perceived healthcare responsibility, lower caregiver involvement, and greater transition readiness. It was also hypothesized that medical (i.e., comorbid conditions, tic severity), neurocognitive (i.e., executive dysfunction), psychosocial (i.e., adolescent anxiety and depression), and caregiver (i.e., caregiver anxiety and depression) factors would be associated with lower perceived adolescent healthcare responsibility, higher caregiver involvement, and lower transition readiness. Lastly, it was hypothesized that when controlling for relevant sociodemographic factors, medical, neurocognitive, psychosocial, and family factors would account for significant additional variance in transition readiness.

CHAPTER 2

METHOD

Participants

Participants included 38 adolescents with TS who were registered for a weeklong, therapeutic recreational camp for children and adolescents with TS, and their caregivers. Family inclusion criteria specified that adolescents must be (1) between the ages of 12 and 18 years old, (2) registered to attend Camp Twitch & Shout, and (3) fluent in English. Caregivers were required to be (1) over the age of 18 years and (2) fluent in English.

Eighty-three of the 158 (53%) families registered for camp agreed to participate in research. Only 7 (4%) families actively declined participation, while 68 (43%) families passively declined participation (i.e., they were contacted by phone and/or email but never responded). Of the 83 families that provided consent, 34 (41%) completed only caregiver measures and 3 (4%) completed only child measures. Families with only caregiver or only child data were excluded from the current analyses. Eight (17%) of the caregiver-child dyads had children under the specified age range for the current study (i.e., under 12 years) and thus, the final sample consisted of 38 caregiver-adolescent dyads. See Figure 2 for CONSORT Flow Diagram. Adolescents (55.3% female) were on average 14.45 years of age (*SD* = 1.52). Most adolescents were Caucasian (*n* = 34; 89.5%), followed by Asian (*n* = 2; 5.3%), Black (*n* = 1; 2.6%), Hispanic/Latino (*n* = 1; 2.6%), and Multiracial (*n* = 1; 2.6%). The majority of adolescents had attended Camp Twitch & Shout previously (*n* = 22; 57.9%). All adolescents were diagnosed with TS and 97% of adolescents had at least one comorbid condition. The most frequent comorbidities included anxiety (82%), Obsessive Compulsive Disorder (OCD; 74%), Attention-Deficit/Hyperactivity Disorder (ADHD; 63%), and depression (34%). The majority of adolescents used medication (*n* = 26; 68.4%) to treat symptoms of TS. Approximately 32% of adolescents received psychotherapy, 32% received Cognitive Behavioral Intervention for Tics (CBIT), and 13% used holistic remedies to manage symptoms of TS. Over half of the sample (*n* = 23; 60.5%) used multiple methods (e.g., medication and psychotherapy) to manage their condition(s). The majority of caregivers were female (*n* = 35; 92.1%) and in a partnered relationship (*n* = 35; 92.1%). Caregivers ranged between the ages of 33 and 61 years (*M* = 44.84; *SD* = 6.11) and were primarily biological parents (*n* = 34; 89.5%). See Table 1 for complete sample characteristics.

Procedures

The current study is part of a larger study of children and adolescents with TS that included children between the ages of 7 and 18 who were registered to attend Camp Twitch & Shout in July 2018. All study procedures were approved by camp personnel and the Institutional Review Board of the participating institution. Leadership staff at Camp Twitch & Shout provided contact information for families registered to attend camp during the summer of 2018. Families were contacted by the research team via email to invite them to participate in the current study. Details regarding study aims and procedures were provided in the initial contact email. Adolescents and caregivers were asked to complete a secure survey battery via the Qualtrics platform for camp to use for their own planning purposes (e.g., behavior management). Families were asked for consent to allow the standard camp questionnaire to be used for research purposes by the research team at the University of Georgia. Families who had not responded to the email invitation were contacted by trained research assistants via telephone to invite them to participate in the study and answer any questions they had about the research procedures and goals. Participating adolescents were provided with a small token of appreciation (i.e., specialty camp button) at camp.

Measures

Sociodemographic and medical information

Sociodemographic (e.g., age, race, gender, annual income, employment, school supports) and medical information (e.g., medications, comorbid conditions, treatment for TS and comorbidities) were collected using a standard demographic questionnaire adapted for children and adolescents with TS.

Healthcare Responsibility, Caregiver Involvement, and Transition Readiness

Readiness for Transition Questionnaire (RTQ; Gilleland et al., 2011). The RTQ is a 26-item questionnaire that assesses adolescent responsibility for healthcare tasks, caregiver involvement in healthcare tasks, and adolescent readiness to assume responsibility for their healthcare and transition from pediatric to adult-based care. The RTQ was initially created for and validated with adolescents and young adults who had received solid organ transplants. To adapt the measure for individuals with TS, two of the responsibility and involvement items were removed given the rarity with which these tasks occur in youth with TS (i.e., "getting monthly labs" and "scheduling specialty care appointments"). Caregivers and adolescents each rated the level of adolescent responsibility and caregiver involvement for eight specific healthcare behaviors (e.g., scheduling appointments, taking medication, communicating with medical staff) on a 4-point Likert scale ranging from *Not responsible/involved at all* to *Almost always responsible/involved*. Scores of all eight items were summed to provide an overall rating of adolescent responsibility and caregiver involvement, with higher scores indicating greater level of responsibility or involvement. Caregivers and adolescents also rated how ready the adolescent was to assume complete responsibility for their healthcare and to transfer from pediatric to adult care. Perceived transition readiness items were rated on a 4-point scale ranging from *Not at all ready* to *Completely ready*. The two items were summed to represent overall perceived transition readiness, with higher values signifying greater perceived transition readiness. Each scale of the RTQ has demonstrated strong internal consistency with pediatric populations (Cronbach's α = .79-.94; Gilleland et al., 2011). For the current sample, internal consistency was questionable for caregiver-reported adolescent responsibility (Cronbach's α = .65), acceptable for adolescent-rated healthcare responsibility (Cronbach's α = .79), low for caregiver-rated caregiver involvement (Cronbach's α = .50), good for adolescent-rated caregiver involvement (Cronbach's α = .81) and questionable for both adolescent- and caregiver-rated transition readiness (Cronbach's α = .69 and Cronbach's α = .67, respectively). The low Cronbach's alpha values for the current study likely relate to limited variability in responses (e.g., most caregivers indicated that they were "almost always" involved for most healthcare tasks).

Tic Severity

Tic Severity Scale Report (TSSR; Allen et al., 2005; Scahill, Leckman, Schultz, Katsovich, & Peterson, 2003). Adolescents and caregivers completed the 40-item TSSR and TSSR-Parent Report, respectively to assess the severity of adolescents' motor (e.g., eye blinking, head jerks, hitting self, skipping or twirling) and vocal (e.g., grunting, throat clearing, humming, repeating other's speech) tics over the previous week. Items were rated on a 4-point scale ranging from *No symptoms at all this past week* to *Tics were very frequent and very forceful*. The TSSR yields two subscales: Motor Tic Severity and Vocal Tic Severity. A Total Tic Severity Composite score was also calculated by summing the motor and vocal tic severity ratings. In the current sample, internal consistency was excellent for both the TSPR (Cronbach's α = .91) and TSSR (Cronbach's α = .93).

Executive Functioning

Behavior Rating Inventory of Executive Function, Second Edition (BRIEF 2; Gioia, Isquith, Guy, & Kenworthy, 2015). Caregivers completed the BRIEF 2 to assess adolescent executive functioning. The BRIEF 2 consists of 63 items examining behavior, emotion, and cognitive regulation. Caregivers were asked to indicate how often their adolescent has had problems with various behaviors over the past six months using a 3-point scale ranging from *Never* to *Often*. Items were summed to calculate subscale scores, index scores (i.e., Behavior Regulation Index [BRI], Emotion Regulation Index [ERI], Cognitive Regulation Index [CRI]), and a Global Executive Composite (GEC) score. Raw scores were converted to age- and gender-normed *T*-scores, with higher scores indicating greater executive dysfunction. Only the index (i.e., BRI, ERI, CRI) and GEC scores were used in the current study. In the current study, internal consistency was excellent for the BRI (Cronbach's α = .91), ERI (Cronbach's α = .91), CRI (Cronbach's α = .96), and GEC (Cronbach's α = .97) scales.

Internalizing Symptoms

Behavior Assessment System for Children, Third Edition (BASC-3; Reynolds & Kamphaus, 2015). The BASC-3 was used to assess adolescents' psychosocial functioning. Only the Anxiety, Depression, Hyperactivity, and Attention Problems subscales were administered in the current study. Caregivers completed the Anxiety, Depression, Hyperactivity, and Attention Problems subscales from the Parent Rating Scale (PRS). Adolescents completed the Anxiety and Depression subscales of the Self-Report of Personality (SRP). Participants were asked to indicate how often a given statement was true on a 4-point scale from *Never* to *Almost Always*.

Adolescents were also asked to indicate whether specified statements were *True* or *False* for them. Raw scores for caregiver- and adolescent-report were converted to age- and gender-normed *T*-scores, with higher scores indicating greater symptoms. In the current sample, internal consistency was good for the Attention Problems (Cronbach's α = .90), Anxiety (Cronbach's α = .87), Depression (Cronbach's α = .86), and Hyperactivity (Cronbach's α = .93) subscales on the BASC PRS. Internal consistency was acceptable for the Anxiety subscale of the BASC SRP (Cronbach's α = .77); however, internal consistency was questionable for the Depression subscale of the BASC SRP (Cronbach's α = .56).

Beck Depression Inventory, Second Edition (BDI-II; Beck, Steer, & Brown, 1996). Caregiver depression was assessed using the BDI-II. Caregivers were asked to select the statement that best described the way they have felt during the past two weeks for 21 sets of items. Each set of items included a list of four statements arranged in increasing severity related to a particular depressive symptom. Item responses were summed to calculate a total score that could be used to classify depressive symptoms as minimal (scores from 0-13), mild (scores from 14-19), moderate (scores from 20-28), or severe (scores from 29-63). Internal consistency was excellent for the current sample (Cronbach's α = .91).

Beck Anxiety Inventory (BAI; Beck & Steer, 1993). Caregiver anxiety was assessed using the BAI. Caregivers were asked to indicate how much they have been bothered by 21 symptoms of anxiety (e.g., feeling hot, nervous, fear of the worst happening) over the past week. Items were rated on a 4-point scale ranging from *Not at All* to *Severely, I could barely stand it*. Item responses were summed to calculate a total score that could be used to classify anxiety symptoms as minimal (scores from 0-7), mild (scores from 8-15), moderate (scores from 16-25), or severe (scores from 26-63). Internal consistency was excellent for the current sample (Cronbach's α = .91).

Family Functioning

McMaster Family Assessment Device, General Functioning Scale (FAD; Epstein, Baldwin, & Bishop, 1983). The 12-item General Functioning Scale from the Family Assessment Device (FAD) was used to assess general family functioning. Adolescents and caregivers rated how well statements (e.g., "In times of crisis, we can turn to each other for support") describe their family on a 4-point Likert scale ranging from *Strongly Agree* to *Strongly Disagree*. The FAD generates scores from 1 to 4, with higher scores indicating greater levels of family dysfunction and scores above 2.0 representing poor family functioning. The FAD is a well-established measure of family functioning and has been frequently used with families of children with a chronic health condition (Alderfer et al., 2008). In the current sample, internal consistency was excellent for caregiver report (Cronbach's α = .93) and good for adolescent report (Cronbach's α = .84).

Family Management Measure (FaMM; Knafl et al., 2011). The Family Life Difficulty subscale from the FaMM was used to assess the extent to which having a child with TS makes family life difficult. Caregivers rated 14 statements, such as "taking care of our child's condition is often overwhelming," on a 5-point scale ranging from *Strongly Disagree* to *Strongly Agree*. Higher values indicated greater family life difficulty. Internal consistency was excellent for the current sample (Cronbach's α = .95).

Data Analytic Plan

All statistical analyses were conducted using IBM Statistical Package for the Social Sciences, Version 26 (SPSS; IBM Corp., Armonk, NY). The overall goals of the study were to describe adolescent healthcare responsibility, caregiver involvement, and transition readiness for adolescents with TS and determine risk factors for poor healthcare responsibility and transition readiness in this population. Descriptive statistics, including means, standard deviations (*SD*s), and ranges, were calculated for all sociodemographic (e.g., parent and child age, gender, ethnicity, education level, and annual family income), medical (e.g., comorbid conditions), and study variables (i.e., caregiver involvement, healthcare responsibility, transition readiness, tic severity, executive function, internalizing symptoms, family functioning) to characterize the sample. Because the BRIEF 2 and BASC are norm-referenced tests, one-sample *t*-test analyses were conducted to compare adolescent executive functioning and emotional functioning *T*-scores with 50, the mean score of the normative sample used to derive *T*-scores for the BRIEF 2 and BASC. Norms were also used to categorize caregiver levels of anxiety and depression as minimal, mild, moderate, or severe and identify families at-risk for poor family functioning.

Preliminary analyses were conducted to determine if there were any significant associations between sociodemographic or medical variables and study variables. Paired samples *t*-tests were conducted to examine differences between caregiver and adolescent reports of adolescent healthcare responsibility, caregiver involvement, and transition readiness. Independent samples *t*-tests were conducted to examine differences between adolescent- and caregiver-rated adolescent healthcare responsibility, caregiver involvement, and transition readiness for adolescents with TS and those with solid organ transplant (Gilleland, Amaral, Mee, & Blount, 2011). Of note, mean rather than total scores were calculated to compare healthcare responsibility and caregiver involvement for adolescents with TS and organ transplant recipients due to two items being removed from the RTQ in the current study. *T*-tests, ANOVAs, and Pearson product-moment correlations were used to investigate associations between adolescent healthcare responsibility, caregiver involvement, and transition readiness, and sociodemographic variables, medical variables, executive functioning, internalizing symptoms, and family functioning.

Multivariate linear regression analyses were used to examine the unique contributions of risk factors associated with transition readiness. Specifically, hierarchical multiple regression analyses were conducted to examine the influence of sociodemographic, medical, neurocognitive, psychosocial, and family risk factors. Only variables that demonstrated significant relations with transition readiness were included in regression analyses. Consistent with the SMART model, pre-existing factors (i.e., sociodemographic and comorbid conditions) were entered on Step 1, modifiable variables (e.g., psychosocial risk factors and neurocognitive variables) were entered in Step 2, and interactions between individuals (e.g., family functioning) were entered in Step 3 of the regression model.

Power Analyses

Sample sizes necessary to detect significant statistical effects were determined a priori using G*Power (Faul, Erdfelder, Buchner, & Lang, 2009) with power = .80, α = .05, and a medium effect size. It was determined that a sample size of 34 participants was needed to have a medium effect size for one-sample and paired sample *t*-tests to examine differences in sample means compared to community norms (e.g., *T*-score mean of 50) and differences between caregiver- and adolescent-reported study outcomes, with power = .80 and α = .05. For independent sample t-tests, 128 participants were needed to detect a medium effect size, with power = .80 and α = .05 to compare outcome variables for adolescents with TS with adolescent transplant recipients. A sample size of 67 participants was required to detect medium effects for bivariate correlational analyses, with power = .80 and α = .05. Lastly, a sample size of 55 participants was needed to detect a medium effect size (.15) for multiple regression analyses with up to six predictors, with power = .80 and $\alpha = .05$.

CHAPTER 3

RESULTS

Descriptive Data

Means and standard deviations for all study variables are presented in Table 4. Distribution of responses for adolescent responsibility and caregiver involvement for individual healthcare tasks are reported in Figures 3 and 4. On the RTQ, 75% of adolescents reported being *not at all* or *somewhat ready* to assume complete responsibility for their healthcare. Only one adolescent reported that they were *completely ready* to assume complete responsibility for their healthcare and no caregivers reported that their child was *completely ready* to assume complete responsibility for their healthcare. The majority of caregivers (51%) reported that their child was *not at all ready* to assume complete responsibility for their healthcare. Twenty-six percent of caregivers indicated that their adolescent was *somewhat ready* to assume complete responsibility of their healthcare and 23% of caregivers reported their child was *mostly ready*. Seventy percent of adolescents reported being *not at all* or only *somewhat* ready to transition to adult-based care, and a similar 77% of caregivers reported their child as being *not at all* or only *somewhat ready* for transition. The majority of adolescents (91%) reported that one of their caregivers (i.e., mother or father) was primarily responsible for their healthcare and only 36% of adolescents indicated that they shared at least some responsibility for their healthcare. The majority of caregivers (89%) agreed that either one or both caregivers held primary responsibility for their child's healthcare and approximately 44% of caregivers reported that their child shares at least some responsibility for their healthcare.

Adolescent Psychosocial Functioning

Caregivers indicated that their adolescents generally had greater executive functioning difficulties (BRIEF 2 GEC T-score: $M = 65.89$, $SD = 11.40$) when compared to community norms, $t(34) = 8.25$, $p < .001$, with a large effect size (Cohen's $d = 1.48$). Caregivers reported that their children had greater difficulty with behavioral regulation (BRIEF 2 BRI T-score: $M = 61.69$, $SD = 12.09$; $t(35) = 5.80$, $p < .001$; Cohen's $d = 1.05$), emotional regulation (BRIEF 2 ERI T-score: $M = 65.08$, $SD = 12.99$; $t(35) = 6.97$, $p < .001$; Cohen's $d = 1.30$), and cognitive regulation (BRIEF 2 CRI T-score: $M = 64.80$, $SD = 11.08$; $t(34) = 7.90$, $p < .001$; Cohen's $d = 1.40$) compared to community norms. Caregivers also reported that their adolescents had higher levels of anxiety (BASC-PRS Anxiety T-score: $M = 59.49$, $SD = 10.90$; $t(36) = 5.30$, $p < .001$; Cohen's $d = 0.91$), depression (BASC-PRS Depression T-score: $M = 59.51$, $SD = 10.48$; $t(36) = 5.52$, $p < .001$; Cohen's $d = 0.93$), attention problems (BASC Attention Problems T-score: $M = 60.32$, $SD = 9.19$; $t(36) = 6.84$, $p < .001$; Cohen's $d = 1.07$), and hyperactivity (BASC Hyperactivity T-score: $M = 59.92$, $SD = 13.44$; $t(35) = 4.43$, $p < .001$; Cohen's $d = 0.84$) when compared to same-aged peers. Adolescents also reported higher levels of anxiety (BASC-SRP Anxiety T-score: $M = 55.62$, $SD = 7.95$; $t(36) = 4.30$, $p < .001$; Cohen's $d = 0.62$) and depression (BASC-SRP Depression T-score: $M = 59.27$, $SD = 6.54$; $t(36) = 8.62$, $p < .001$; Cohen's $d = 1.10$) compared to same-aged peers.

Caregiver Psychosocial Functioning

With regard to caregiver psychological functioning, the majority of caregivers reported minimal anxiety symptoms (57.1%). Twenty percent of caregivers reported mild anxiety symptoms, 17.1% reported moderate anxiety symptoms, and 5.7% reported severe symptoms. Similarly, the majority of caregivers reported minimal depressive symptoms (66.7%).

Approximately 14% of caregivers reported mild depressive symptoms, 11.1% reported moderate depressive symptoms, and 8.3% reported severe depressive symptoms. The majority of caregivers (61.1%) and adolescents (55.6%) reported general family functioning to be within normal limits (FAD scores < 2.0).

Comparisons of Adolescent and Caregiver Ratings of Adolescent Healthcare Responsibility and Transition Readiness

See Table 2 for full details regarding paired samples *t*-tests comparing adolescent and caregiver ratings of adolescent healthcare responsibility and transition readiness. Overall, adolescents reported that they had significantly greater healthcare responsibility than their caregivers reported them to have. Adolescents also reported their caregivers as having significantly lower involvement in their healthcare than caregivers reported. There were not significant differences in adolescent and caregiver ratings of overall transition readiness. Adolescent and caregiver ratings of adolescent responsibility, caregiver involvement, and overall transition readiness were correlated with one another. Specifically, greater adolescent-rated transition readiness was significantly related to greater caregiver-rated transition readiness ($r = .39$, $p = .02$), greater caregiver- and adolescent-rated healthcare responsibility (r's = .44 and .63, $p = .01$ and $p < .001$, respectively), and lower caregiver- and adolescent-rated caregiver involvement (r's = -.42 and -.37, p's = .02 and .03, respectively). Greater caregiver-rated transition readiness was also significantly correlated with greater caregiver- and adolescent-rated teen responsibility (r's = .51 and .57, p's = .002 and .001, respectively); however, caregiver-rated transition readiness was not related to either caregiver- or adolescent-rated caregiver involvement (p's > .05). Greater adolescent-rated healthcare responsibility was significantly related to greater caregiver-rated healthcare responsibility ($r = .38$, $p = .03$) and lower caregiver-and adolescent-rated caregiver involvement (*r*'s = -.46 and -.45, *p*'s = .008 and .006). Lastly, greater adolescent-rated caregiver involvement was significantly related to greater caregiver-rated caregiver involvement (*r* = .47, *p* = .005).

With regard to individual healthcare behaviors, adolescents rated themselves as being more responsible for taking medication daily as prescribed, knowing details about insurance coverage, attending medical appointments, and communicating with medical staff in person than their caregivers indicated. Adolescent and caregiver ratings were only significantly correlated with one another for particular healthcare behaviors (i.e., taking medication daily as prescribed, calling in or ordering medication refills, explaining Tourette Syndrome to others, communicating with medical staff in person).

Transition Readiness for Adolescents with Tourettes Compared to Adolescent Transplant Recipients

Independent samples *t*-tests compared adolescent healthcare responsibility, caregiver involvement, and overall transition readiness for adolescents with TS and adolescents who received solid organ transplants (Gilleland, Amaral, Mee, & Blount, 2011) in order to better characterize the current sample in relation to adolescents with a chronic medical condition. Adolescents with TS rated themselves as having significantly less responsibility for their healthcare compared to adolescent transplant recipients. Similarly, caregivers of adolescents with TS rated their children as having less responsibility for their healthcare compared to caregivers of transplant recipients. Adolescents with TS rated their caregivers as being more involved in their healthcare than was found for adolescent transplant recipients. Caregivers of adolescents with TS also reported that they were more involved in their child's healthcare than caregivers of transplant recipients. Lastly, adolescents with TS and their caregivers rated themselves, or their child, as being less ready to assume complete responsibility for their healthcare and transition to adult-based care compared to adolescent transplant recipients. Across comparisons, there were medium to large effect sizes (*d*'s = .49–1.64). See Table 3 for detailed results.

Demographic Variables and Transition Readiness

Adolescent age was related to lower caregiver-rated caregiver involvement, such that caregivers of older adolescents indicated they were less involved in their child's healthcare than caregivers of younger adolescents. Caregiver age and adolescent gender were not related to any study outcomes.

Comorbid Conditions and Transition Readiness

Caregivers reported that adolescents with a greater number of comorbid conditions (e.g., ADHD, OCD, anxiety, depression) had lower transition readiness. *T*-tests were used to determine whether adolescents with different comorbid conditions had differing levels of healthcare responsibility and transition readiness. Caregivers reported that adolescents diagnosed with ADHD ($n = 21$; $M = 14.19$, $SD = 3.31$) had lower responsibility for their healthcare compared to adolescents without ADHD ($n = 14$; $M = 18.00$, $SD = 3.33$), $t(33) = 3.33$, p < .01, $d = 0.35$.

Transition Readiness Related to Adolescent, Parent, and Family Variables

Aspects of executive functioning were related to adolescent responsibility, caregiver involvement, and transition readiness. Specifically, greater deficits in overall executive functioning (BRIEF 2 GEC) were related to lower caregiver-rated transition readiness. Deficits in cognitive regulation (BRIEF 2 CRI) were correlated with greater caregiver-rated caregiver involvement and lower caregiver-rated transition readiness. Deficits in behavior regulation (BRIEF 2 BRI) were related to lower adolescent- and caregiver-rated healthcare responsibility and lower caregiver-rated transition readiness. Greater caregiver-reported adolescent attention problems were related to lower adolescent-rated transition readiness and lower caregiver-rated adolescent responsibility. Similarly, greater caregiver-rated adolescent hyperactivity was correlated with lower adolescent-rated healthcare responsibility and lower caregiver-rated transition readiness. Greater levels of caregiver depression related to lower adolescent-rated healthcare responsibility. Lastly, worse caregiver-rated family functioning (FAD) and greater family life difficulty (FaMM) were correlated with lower caregiver-rated transition readiness. Caregiver age, adolescent gender, prior diagnoses of depression, OCD, or anxiety, tic severity, adolescent emotion regulation (BRIEF 2 ERI), adolescent anxiety and depression, caregiver anxiety, and adolescent-rated family functioning were not related to adolescent healthcare responsibility, caregiver involvement, or transition readiness. Correlations between all study variables are presented in Table 4.

Regression Analyses

Hierarchical regression models tested the strength of the associations between significantly correlated condition-related factors, adolescent cognitive and psychosocial functioning, and family variables and transition readiness. Significant demographic and comorbid conditions, if any, were entered on the first step; adolescent cognitive or psychosocial functioning was entered on the next step; and relevant family variables were entered on the following step. Only attention problems were significantly correlated with adolescent-rated transition readiness and thus, hierarchical regression analyses were only conducted for caregiver-rated transition readiness.

Caregiver-Rated Transition Readiness

In the first step, number of comorbidities explained a significant 20% of the variance in transition readiness, $F(1, 32) = 7.78$, $p < .01$. For adolescent factors, general executive composite

(BRIEF 2 GEC), cognitive regulation (BRIEF 2 CRI), behavioral regulation (BRIEF 2 BRI), and hyperactivity (BASC) were all significantly correlated with caregiver-rated transition readiness; however, given the overlap between general executive composite, cognitive regulation, behavioral regulation, and hyperactivity, only cognitive regulation and behavioral regulation were entered into Step 2 of the model. Adding CRI and BRI into the model significantly increased the amount of variance explained in transition readiness, $R^2\Delta = .20$, $p < .05$. Adding caregiver-rated family functioning and family life difficulty in the final step did not significantly increase the amount of variance explained in transition readiness, $R^2\Delta = .05$, $p > .05$. The total model explained 42% of the variance in transition readiness, $F(5, 28) = 4.08$, $p < .01$. Examination of the individual variables revealed that only behavior regulation difficulties (BRIEF 2 BRI) were significantly associated with lower transition readiness, $t = -2.76$, $p < .05$. See Table 5 for details.

CHAPTER 4

DISCUSSION

The current study aimed to describe healthcare responsibility and readiness to transition from pediatric to adult-based care for adolescents with TS, a neuropsychiatric condition often complicated by high rates of comorbidities and varying symptoms over time. The majority of adolescents and their caregivers indicated that adolescents were not at all ready, or only somewhat ready, to assume complete responsibility for their healthcare and transition to adult-based care. This is consistent with our hypothesis that adolescents with TS would have low levels of skills necessary to manage their healthcare independently. With regard to specific healthcare behaviors, adolescents and their caregivers indicated that generally, adolescents were not at all responsible for scheduling appointments, ordering medication refills, knowing details about their insurance, and communicating with medical staff over the phone. It is possible that because adolescents with TS don't often have frequent medical appointments, there are fewer opportunities for them to learn to schedule appointments, order refills, or communicate with medical staff over the phone. There was greater response variability in adolescent responsibility for more daily healthcare tasks, such as taking medication and explaining TS to others, as well as healthcare tasks that require adolescents to be physically present (i.e., attending medical appointments and communicating with medical staff in person). It is likely that adolescents are more involved in these specific tasks as they are unable to avoid these tasks completely. That is, even if caregivers take primarily responsibility or oversee these tasks, adolescents must physically take their medications and attend medical appointments.

Caregivers appear to be heavily involved in managing, or overseeing, all aspects of their child’s healthcare. Almost all adolescents and caregivers agreed that caregivers held primary responsibility for the adolescent’s healthcare, with less than half of adolescents sharing some of the responsibility. Caregivers reported that they were at least somewhat involved in all healthcare tasks, with the majority of adolescents and caregivers indicating that caregivers are almost always involved in all aspects of their child’s care. Of the healthcare tasks assessed, caregivers appear to be least involved in explaining TS to others. This is likely due, at least in part, to the child’s age and growing independence (e.g., spending time alone with friends or at events) and not having caregivers around to step in or explain their child’s condition in the moment. It is possible that caregivers are extra protective of their child, wanting to be involved in many aspects of their child’s life, due to high rates of stigma and rejection often experienced by children and adolescents with TS (Malli, Forrester-Jones, & Murphy, 2016). Additionally, TS is associated with executive functioning and organization deficits and thus, caregivers may not believe their child is able to independently manage and coordinate their own care. While caregiver involvement is important for positive health outcomes, it can also be problematic as adolescents and young adults transition to adult-based care given that parents and caregivers are not typically included in adult healthcare visits, due, at least in part, to adult institutional policies or privacy concerns.

Consistent with studies in other pediatric populations (Gilleland et al., 2011), adolescents in the present study indicated they had greater responsibility for healthcare tasks than caregivers indicated. Similarly, adolescents rated their caregivers as being less involved in their healthcare than caregivers rated their involvement in their child’s care. This is important to acknowledge as adolescents may believe they have their healthcare under control as they get older and may not be aware of all that their caregivers are doing behind the scenes. There needs to be a balance such that caregivers can oversee their adolescent's healthcare to ensure that medical needs are attended to, while also training adolescents to take on greater responsibility for their healthcare. Increasing adolescent responsibility while simultaneously reducing caregiver involvement helps prepare adolescents and young adults to ultimately manage their care independently and ensure their healthcare needs are appropriately attended to.

It is important to consider that the current sample includes adolescents between the ages of 12 and 18 and represents a range of developmental levels. Based on the literature (Haarbauer-Krupa et al., 2019; Stewart et al., 2017; Varty & Popejoy, 2020), it was hypothesized that older adolescents would have greater responsibility for healthcare tasks and greater overall transition readiness compared to younger adolescents. It was also hypothesized that caregivers would be less involved in care for older adolescents. In the current study, adolescent age only related to caregiver-rated caregiver involvement, such that caregivers of older adolescents reported being less involved in their child's healthcare than caregivers of younger adolescents. Although caregivers of older adolescents reported being less involved in their child's care, older adolescents did not report increased responsibility for their own healthcare. It is possible that adolescents are not stepping up and taking responsibility, leaving aspects of their healthcare to fall through the cracks, partly explaining why adolescents and young adults have poor health outcomes (e.g., poor adherence, limited medical visits). Further, adolescents may not be aware of all that goes into managing their healthcare if they have not received training or their caregivers have been fully managing their care. Alternatively, caregivers may not relinquish control of tasks or entrust their child to take over responsibility for certain tasks if they do not believe their child is competent to do so. This is a crucial developmental period when caregivers, or healthcare providers, need to take a more hands on approach to teach adolescents about the many aspects of healthcare, including information about insurance, scheduling appointments, identifying needs, and communicating these needs to the appropriate provider, while caregivers progressively relinquish control for tasks as adolescents demonstrate increased competence (Annunziato et al., 2014; Reed-Knight, Blount, & Gilleland, 2014; Schwartz et al., 2011).

Transition readiness has been primarily examined with chronic physical illness populations, including adolescents and young adults with cancer, solid organ transplant, and diabetes. While adolescents with TS have special healthcare needs (e.g., comorbid conditions, symptom management, advocating for accommodations and explaining their condition), they differ from other chronic conditions as they do not typically have access to a specialty care clinic with regular follow-up appointments or training on specific healthcare tasks. The Tourette Association of America has identified only 18 Centers of Excellence across the United States offering multidisciplinary care for individuals with TS (Tourette Association of America, n.d.). Thus, pediatric patients with TS appear to be a relatively neglected patient group in terms of transition readiness training. Compared to adolescents who received solid organ transplants (Gilleland et al., 2011), adolescents with TS had lower responsibility for healthcare tasks and lower overall transition readiness. Further, caregivers of adolescents with TS were more involved in their child’s healthcare compared to caregivers of adolescent transplant recipients. This is similar to patterns of healthcare responsibility, caregiver involvement, and transition readiness found between individuals with and without medical conditions (Eaton et al., 2017), such that adolescents and young adults with medical conditions demonstrated greater transition readiness than healthy peers. These differences may also reflect positive outcomes of existing efforts to provide education on transition readiness and skill training to adolescents and young adults with medical conditions (Grant & Pan, 2011; Griffin et al., 2013). It is possible that due to the life-threatening nature of their condition, transplant recipients are taught from a young age the importance of caring for their condition, including adhering to strict medication regimens and attending regular follow-up appointments with multidisciplinary teams (e.g., social work, psychology, physicians, child life). Due to the long-term nature of their condition, need for frequent appointments, and consistency of medical staff, adolescents and their families can develop trusting relationships with medical providers. This sets the stage for training children to independently manage their healthcare and gradually shift responsibility from caregivers to patients. Further, specialty care clinics may create a sense of community among families who have children with similar conditions and can support one another and share resources.

Based on the SMART model (Schwartz et al., 2011), the current study also examined whether medical, neurocognitive, psychosocial, or family factors relate to healthcare responsibility, caregiver involvement, and transition readiness. Among the medical variables assessed (i.e., comorbid conditions, tic severity), only the overall number of comorbid conditions related to lower caregiver-rated transition readiness. Consistent with past research (Cavanna et al., 2009; Eapen et al., 2016; Hirschtritt et al., 2015, O'Hare et al., 2016), much of the current sample had multiple comorbid conditions and high rates of OCD, anxiety, and ADHD which can be more impairing that symptoms of TS itself and impact the management of TS (Yadegar et al., 2019). Adolescents with a greater number of comorbid conditions (e.g., ADHD, OCD, anxiety) may experience more frequent and severe symptoms that impact their day-to-day functioning and make their condition harder to manage on their own (e.g., more medication, psychotherapy, greater impairment). Of the comorbid conditions present in the current sample, only ADHD related to lower adolescent responsibility for healthcare tasks. There is evidence that individuals with neurodevelopmental conditions, such as ADHD, are less likely to transfer to adult services due to these challenges (e.g., reduced ability to plan and organize, difficulty with self-regulation; Appleton et al., 2019; Ford, 2020; Singh et al., 2010; Tatlow-Golden et al., 2018). The low variability (i.e., high rates of comorbidities) in the current sample may explain the lack of findings for specific comorbidities beyond ADHD, making it difficult to determine whether specific conditions place adolescents at risk for lower healthcare responsibility or transition readiness.

Adolescents in the current sample had greater attention problems, hyperactivity, and executive functioning deficits across cognitive, behavioral, and emotional domains compared to community norms. Deficits in executive functioning are common among individuals with TS (Hovik et al., 2017) and were found to relate to adolescent responsibility, caregiver involvement, and transition readiness. This is consistent with past research indicating that executive functioning, including organization and self-monitoring, relates to self-management of care (Ford et al., 2020; Young et al., 2016) and transition readiness (Gutierrez-Colina et al., 2017). In the current study, difficulties with cognitive regulation related to greater caregiver involvement and lower transition readiness. Adolescents who have difficulty initiating tasks, planning, organizing, and monitoring progress appear to require greater caregiver involvement and oversight to ensure their condition is appropriately managed. Similarly, caregiver-rated adolescent attention problems were correlated with lower adolescent responsibility and transition readiness. Adolescents who have greater difficulty maintaining their attention may not follow through on tasks, resulting in lower responsibility for healthcare tasks. Additionally, deficits in behavior regulation and hyperactivity were associated with lower adolescent responsibility and lower transition readiness. Behavior regulation appears to be particularly relevant for transition readiness, as this is the only variable that emerged as significant in a regression model including medical (i.e., comorbid conditions), neurocognitive (i.e., executive function), and family (i.e., family functioning and family life difficulty) variables. Behavior regulation includes inhibitory control, impulsivity, and awareness of the impact of behavior on other people and outcomes. When adolescents are unable to see the long-term consequences of not attending to their condition, they may be less motivated to take on increased responsibility. Further, they may be distracted by other activities (e.g., social activities) and unable to redirect their attention back to the task at hand (e.g., taking medications as prescribed, scheduling and attending appointments, following up on referrals). Notably, deficits in emotion regulation and adolescent anxiety and depression were not related to any study outcomes. Thus, it appears that cognitive and behavioral skills are more relevant for concrete tasks and independently managing care than psychosocial factors, at least in the current sample.

Consistent with our hypotheses, aspects of caregiver psychological functioning and family functioning were also related to adolescent responsibility and transition readiness. Specifically, higher levels of caregiver depression related to lower adolescent responsibility. It is possible that caregivers who experience depressive symptoms are more withdrawn and less involved in teaching their children how to manage aspects of their healthcare. Caregiver mental health challenges may disrupt this process, making it even more challenging for adolescents to understand their healthcare and begin to take on greater independence. Further, poor family functioning and greater family life difficulty (i.e., the extent to which having a child with a chronic condition makes family life difficult) were related to lower transition readiness. TS impacts the entire family and when families are less able to adapt to their child’s condition(s), they may have fewer resources (e.g., time, energy) to assist their child in preparing to independently manage their healthcare.

Despite limited access to specialty care clinics, it is important to train adolescents with TS on healthcare responsibilities and how to manage their TS and comorbid conditions to prepare them for increased independence as they enter adulthood. Based on the risk factors identified in the current study (e.g., executive function, comorbid conditions, family factors), in addition to those reported in the literature, it is recommended that training be individually tailored to the adolescent's developmental level and abilities. Tic disorders are managed across multiple subspecialities (e.g., primary care, psychiatry, neurology, psychology) and medical providers are generally not well-versed with tic disorders (Black, Black, Greene, & Schlaggar, 2016; Ganos, Martino, & Pringsheim, 2017). Limited specialty care for children and adolescents with TS and related conditions impacts not only diagnosis and condition management, but also psychoeducation and assistance transitioning healthcare responsibility from caregiver to child. There is a growing number of pediatric programs aimed at promoting increased healthcare management and transition readiness (Griffin et al., 2013; Grant & Pan, 2011) that can be adapted for primary care or school settings to reach adolescents with special healthcare conditions, such as TS. Additionally, all participants in the current study were recruited through a summer camp specifically for children and adolescents with TS. Camp offers another possible avenue for psychoeducation and training on healthcare management and transition readiness. For instance, trained camp staff could disseminate programming for adolescents and caregivers, such as introducing the importance of healthcare management or providing resources for families to consult outside of camp. Camps have been shown to be a possible avenue for enhancing self-esteem, disease knowledge, social and emotion well-being, and adaptation to illness for children and adolescents with chronic medical conditions (Moola, Faulkner, & Kirsh, 2013; Walker & Pearman, 2009).

While this is the first known study examining healthcare responsibility and transition readiness in adolescents with TS, it is not without limitations. First, the sample size was small, which reduced statistical power and likely impacted variability within the sample. Relatedly, adolescents in the current sample had high rates of comorbidities and elevated rates of executive functioning deficits, anxiety, attention problems, and hyperactivity. Although high rates of comorbidities and executive functioning deficits are common among individuals with TS (Cavanna et al., 2009; Eapen et al., 2016; Hirschtritt et al., 2015; Hovik et al., 2017; O'Hare et al., 2016), greater variability within the sample may have allowed us to identify additional risk factors for low healthcare responsibility and transition readiness. Second, participants were recruited exclusively from a single camp. Although families attended camp from all over the United States, the sample was mostly representative of Caucasian children from two-caregiver families with higher household incomes. Thus, it is not clear how these results apply to families of children with TS from underrepresented groups or lower socioeconomic backgrounds. Greater diversity of participants in terms of demographics would increase the generalizability of our findings and allow us to better compare the experiences of families from different backgrounds (e.g., socioeconomic status, race/ethnicity, single parent families). Additionally, there may have been a self-selection bias related to the types of families who elected to send their children to a week-long, overnight camp. For instance, adolescents who are more independent and less impacted by TS-related symptoms may have been less likely to attend a specialty camp for children and adolescents with TS. Alternatively, caregivers of children with more severe symptoms or medical needs may not have been comfortable sending their child to a week-long overnight camp.

Another limitation relates to the RTQ (Gilleland et al., 2011) instrument used to assess adolescent responsibility, caregiver involvement, and transition readiness. Although the RTQ is well-supported in the literature and has been successfully used with pediatric populations (e.g., solid organ transplant), not all of the healthcare behaviors assessed were relevant for adolescents with TS. This may explain the limited variability and low internal reliability on some of the subscales (e.g., caregiver involvement). Further, the RTQ may not have captured healthcare behaviors unique to those with TS and related comorbidities, such as advocating for themselves and attending to mental health difficulties (e.g., attending psychotherapy appointments). Future studies should aim to evaluate healthcare responsibility and transition readiness in this population using additional questionnaires and possibly semi-structured interviews to better describe the healthcare tasks associated with TS and the transition of responsibility from caregiver to child. Lastly, the cross-sectional nature of the study prohibits us from examining how adolescent healthcare responsibility, caregiver involvement, and transition readiness change over time, as adolescents approach adulthood and transition to adult-based care. It is possible that as adolescents reach young adulthood and move toward other developmentally appropriate life transitions (e.g., moving out of parent’s home, attending college, starting a job), caregivers will naturally become less involved in their child’s care and adolescents will take on greater responsibility for their own healthcare, partly out of necessity (i.e., not having caregivers constantly present to schedule medical appointment or communicate with providers).

This study expands upon the transition readiness literature by examining healthcare responsibility, caregiver involvement, and transition readiness for adolescents with TS, a special healthcare population complicated by changing symptoms and high rates of comorbidity. Findings suggest that adolescents with TS have less experience with healthcare self-management, and less responsibility for healthcare behaviors, compared to other pediatric populations. Caregivers of adolescents with TS appear to take primary responsibility for their child's healthcare, highlighting the importance of increasing adolescent responsibility for healthcare behaviors while decreasing caregiver involvement. The transition of healthcare responsibility coincides with many other important life transitions (e.g., finishing high school, moving out of parent's home, starting work) and the symptoms associated with TS and comorbid conditions make each of these tasks harder to navigate or cope with. Future research should examine changes in healthcare responsibility and transition readiness for adolescents with TS over time, as well as the impact of transition programming on this unique population. This information will be important for developing and tailoring programming that can be incorporated into primary care settings, where adolescents with a variety of physical and mental health conditions receive ongoing care.

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Table 1.

Sample Characteristics of Participants.

Variables	*n* (%) or *M* ± *SD*
Adolescent age in years	14.5 ± 1.5
Adolescent Gender	
Male	17 (44.7)
Female	21 (55.3)
Adolescent Race/Ethnicity	
White	34 (89.5)
Black	1 (2.6)
Multiracial	1 (2.6)
Hispanic/Latino	1 (2.6)
Asian	2 (5.3)
Adolescent School Accommodations	
504 Plan	20 (89.5)
Individualized Education Plan (IEP)	14 (36.8)
Special Education Coursework	3 (7.9)
Documented learning disability	8 (21.1)
Comorbid Conditions	
Attention-Deficit/Hyperactivity Disorder (ADHD)	24 (63.2)
Obsessive Compulsive Disorder (OCD)	28 (73.7)
Depression	13 (34.2)
Anxiety	31 (81.6)
Autism Spectrum Disorder (ASD)	2 (5.3)
Sensory Processing Disorder (SPD)	2 (5.3)
Insurance	
Medicare/Medicaid	7 (18.4)
Private Insurance	28 (73.7)
Tricare	3 (7.9)
Treatment	
Medication	26 (68.4)
Psychotherapy	12 (31.6)
Cognitive Behavioral Intervention for Tics (CBIT)	12 (31.6)
Holistic Treatments	5 (13.2)
Other	7 (18.4)
Caregiver age in years	44.8 ± 6.1
Caregiver gender	
Male	3 (7.9)
Female	35 (92.1)
Caregiver Race/Ethnicity	
White	35 (92.1)
Black	1 (2.6)
Hispanic/Latino	1 (2.6)
Biracial	1 (2.6)
Relation to child	

Biological parent	34 (89.5)
Adoptive parent	4 (10.5)
Caregiver Education	
High school degree or less	3 (7.9)
Some college/Associate’s Degree	11 (28.9)
Graduated from college or trade school	10 (26.3)
Graduate/Advanced degree	14 (36.8)
Caregiver Relationship Status	
Single	2 (5.3)
Married/partnered	35 (92.1)
Separated/divorced	1 (2.6)
Caregiver Employment	
Working full time	18 (47.4)
Working part time	9 (23.7)
Not working/retired	11 (28.9)
Total Household Income	
< $25,000	2 (5.3)
$25,000-$49,999	4 (10.5)
$50,000-$74,999	7 (18.4)
$75,000-$99,999	6 (15.8)
>$105,000	18 (20.5)
Declined to answer	1 (2.6)

Note. *N* = 38.

Table 2.

Paired Samples T-Test Comparing Adolescent and Caregiver Ratings of Adolescent Healthcare Responsibility and Transition Readiness.

	Adolescent-Rated RTQ		Caregiver-Rated RTQ		Intra-class Correlations	Paired Samples *t*-test		Cohen's *d*
	M	*SD*	*M*	*SD*	*r*	*t*	*p*	*d*
Adolescent Responsibility	**19.16**	**4.57**	**15.88**	**3.81**	**.38***	**3.94*****	**<.001**	**.70**
Caregiver Involvement	**27.76**	**4.12**	**29.94**	**1.89**	**.47****	**-3.46****	**.002**	**.60**
Overall Transition Readiness	4.12	1.49	3.67	1.45	.39*	1.61	.117	.28
Adolescent Responsibility for:								
1. Taking medication daily as prescribed.	**3.15**	**.97**	**2.73**	**1.13**	**.44***	**2.18***	**.04**	**.38**
2. Scheduling primary care appointments.	1.52	.97	1.18	.64	.30	1.94	.06	.34
3. Calling in or ordering medication refills.	1.44	.91	1.19	.54	.42*	1.68	.10	.30
4. Explaining Tourette Syndrome to others.	3.36	.93	3.09	.88	.53**	1.79	.08	.31
5. Knowing details about insurance coverage.	**1.41**	**.71**	**1.13**	**.34**	**.19**	**2.18***	**.04**	**.39**
6. Attending medical appointments.	**3.55**	**.79**	**2.58**	**1.39**	**.22**	**3.85****	**.001**	**.67**
7. Communicating with medical staff in person.	**3.09**	**.91**	**2.70**	**.95**	**.43***	**2.27***	**.03**	**.39**
8. Communicating with medical staff over the phone.	1.72	1.05	1.28	.68	-.07	1.91	.07	.34

Note. *$p \leq .05$; **$p \leq .01$; ***$p \leq .001$. Bolded rows are significant. Cohen's *d* interpretation: small effect = 0.20 - 0.49, medium effect = 0.50 - 0.79, large effect ≥ 0.80.

Table 3.

Independent Samples T-Tests Comparing Healthcare Responsbility, Caregiver Involvement, and Transition Readiness for Adolescents with TS and Adolescent Transplant Recipients

	Tourette Syndrome (Current Sample)		Transplant (Gilleland et al., 2011)		Independent Samples *t*-test		Cohen's *d*
	M	*SD*	*M*	*SD*	*t*	*p*	*d*
Adolescent-Rated:							
Adolescent Responsibility	2.34	.60	3.30	.57	-7.39***	<.001	1.64
Caregiver Involvement	3.46	.55	2.92	.90	3.21**	.002	0.71
Overall Transition Readiness	4.06	1.47	5.96	1.49	-5.82***	<.001	1.28
Caregiver-Rated:							
Adolescent Responsibility	1.96	.47	2.56	.69	-4.19***	<.001	1.03
Caregiver Involvement	3.75	.23	3.30	.71	3.55**	.001	0.87
Overall Transition Readiness	3.60	1.44	4.41	1.86	-2.00*	.049	0.49

Note. Possible range for Adolescent Responsibility and Caregiver Involvement is 1-4 (average of ratings for all items), whereas possible range for Overall Transition Readiness is 2-8. *$p \leq .05$; **$p \leq .01$; ***$p \leq .001$. Cohen's *d* interpretation: small effect = 0.20 - 0.49, medium effect = 0.50 - 0.79, large effect ≥ 0.80.

Table 4.

Bivariate Correlations Among Key Study Variables.

		Adolescent-Rated			Caregiver-Rated		
		Adolescent Responsibility	Caregiver Involvement	Transition Readiness	Adolescent Responsibility	Caregiver Involvement	Transition Readiness
	M (*SD*)	18.74 (4.79)	27.69 (4.45)	4.06 (1.47)	15.71 (3.78)	30.00 (1.86)	3.60 (1.44)
Adolescent Age	14.45 (1.52)	.26	-.32†	.24	.05	**-.45****	.19
Number of Comorbid Conditions	2.87 (1.30)	-.23	-.02	-.29	-.31	.15	**-.37***
Adolescent-Rated Tic Severity	36.56 (21.62)	-.12	.13	-.11	-.19	.15	-.12
Caregiver-Rated Tic Severity	22.46 (16.81)	.04	.03	-.05	.00	.09	.03
BRIEF GEC T-score	65.89 (11.40)	-.30	.04	-.24	-.27	.22	**-.47****
BRIEF CRI T-score	64.80 (11.08)	-.35†	.14	-.34†	-.25	**.35***	**-.42***
BRIEF ERI T-score	65.08 (12.99)	-.03	-.08	-.07	-.07	-.09	-.14
BREIF BRI T-score	61.69 (12.09)	**-.36***	.04	-.15	**-.37***	.16	**-.58****
Adolescent-Rated Anxiety (BASC)	55.62 (7.95)	.19	-.11	-.05	-.08	-.10	.03
Adolescent-Rated Depression (BASC)	59.27 (6.54)	-.06	-.16	-.16	-.13	.12	-.20
Caregiver-Rated Anxiety (BASC)	59.49 (10.90)	.21	-.17	.04	.21	-.28	-.03

Caregiver-Rated Depression (BASC)	59.51 (10.48)	-.27	-.23	-.29	.01	-.10	-.26
Caregiver-Rated Attention Problems (BASC)	60.32 (9.19)	-.33	.05	**-.35***	**-.36***	.29	-.33†
Caregiver-Rated Hyperactivity (BASC)	59.92 (13.44)	**-.37***	-.16	-.26	-.22	-.03	**-.49****
Caregiver Anxiety	8.74 (8.84)	-.24	-.15	-.09	.00	.14	-.13
Caregiver Depression	10.33 (9.91)	**-.43***	-.04	-.23	-.15	.16	-.28
Adolescent-Rated Family Functioning (FAD)	1.89 (.44)	.00	-.31†	.15	.25	-.27	.05
Caregiver-Rated Family Functioning (FAD)	1.77 (.55)	-.25	-.33†	-.15	-.22	-.18	**-.35***
Family Life Difficulty	34.82 (13.80)	-.19	-.23	-.07	-.15	.03	**-.38***

Note. *T*-scores for presented for BRIEF and BASC subscales. GEC = General Executive Composite; CRI = Cognitive Regulation Index; ERI = Emotion Regulation Index; BRI = Behavior Regulation Index. $^{\dagger}p \le .10$; $*p \le .05$; $**p \le .01$.

Table 5.

Hierarchical Regression Analysis for Comorbidities, Adolescent Executive Function, and Family Variables Associated with Caregiver-Rated Transition Readiness.

Transition Readiness	ß	*t*	R^2	ΔR^2	*F*
Step 1			.20		7.78**
Comorbidities	-.44	-2.79**			
Step 2			.37	.18*	5.94**
Comorbidities	-.24	-1.22			
BRIEF 2 CRI	.22	.86			
BRIEF 2 BRI	-.62	-2.68*			
Step 3			.42	.05	4.08**
Comorbidities	-.22	-1.10			
BRIEF 2 CRI	.31	1.17			
BRIEF 2 BRI	-.71	-2.76*			
Family Functioning (FAD)	-.26	-1.53			
Family Life Difficulty	.13	.65			

Note. CRI = cognitive regulation index; BRI = behavior regulation index. *$p \leq .05$; ** $p \leq .01$.

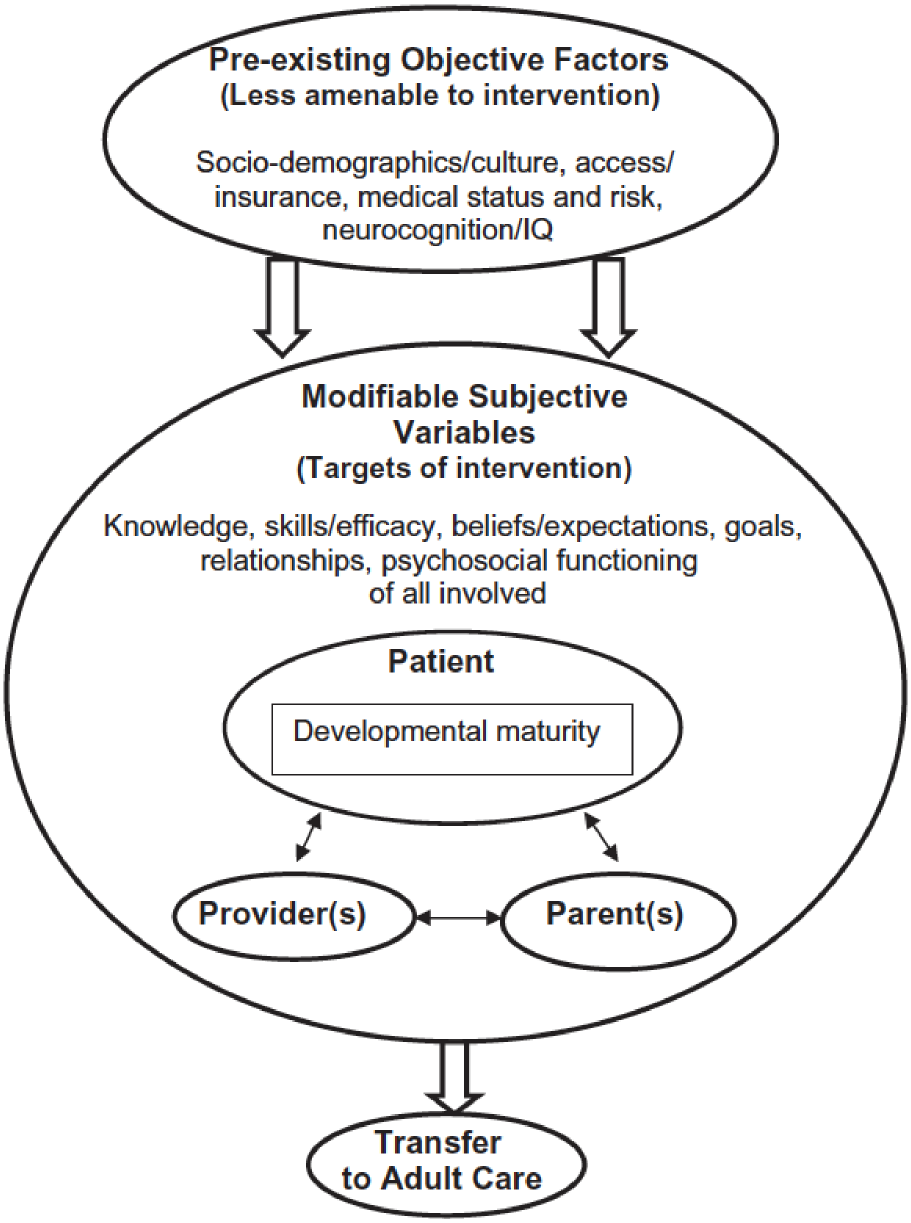


Figure 1. Social-ecological model of adolescent and young adult readiness for transition (SMART; Schwartz et al., 2011).

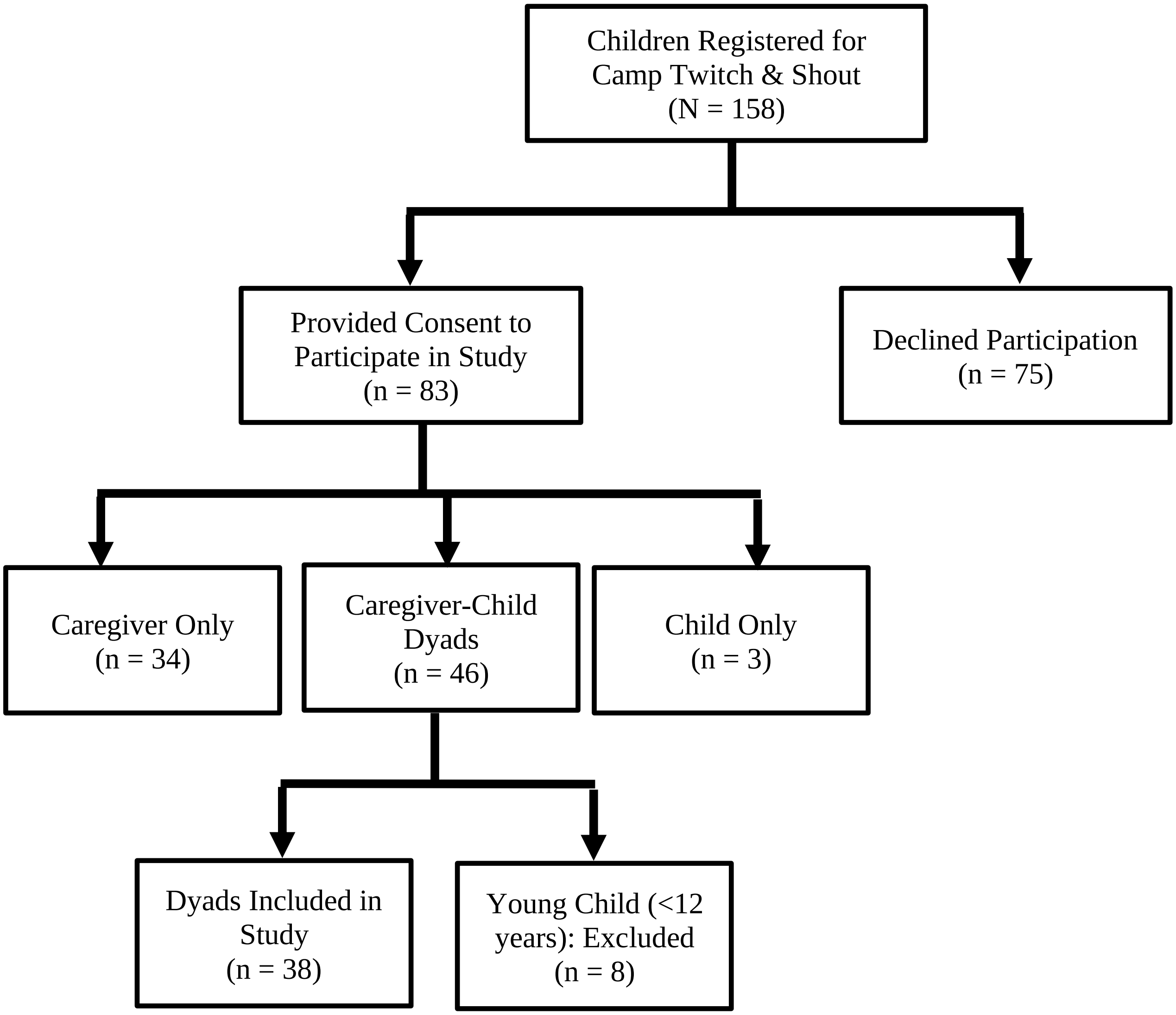
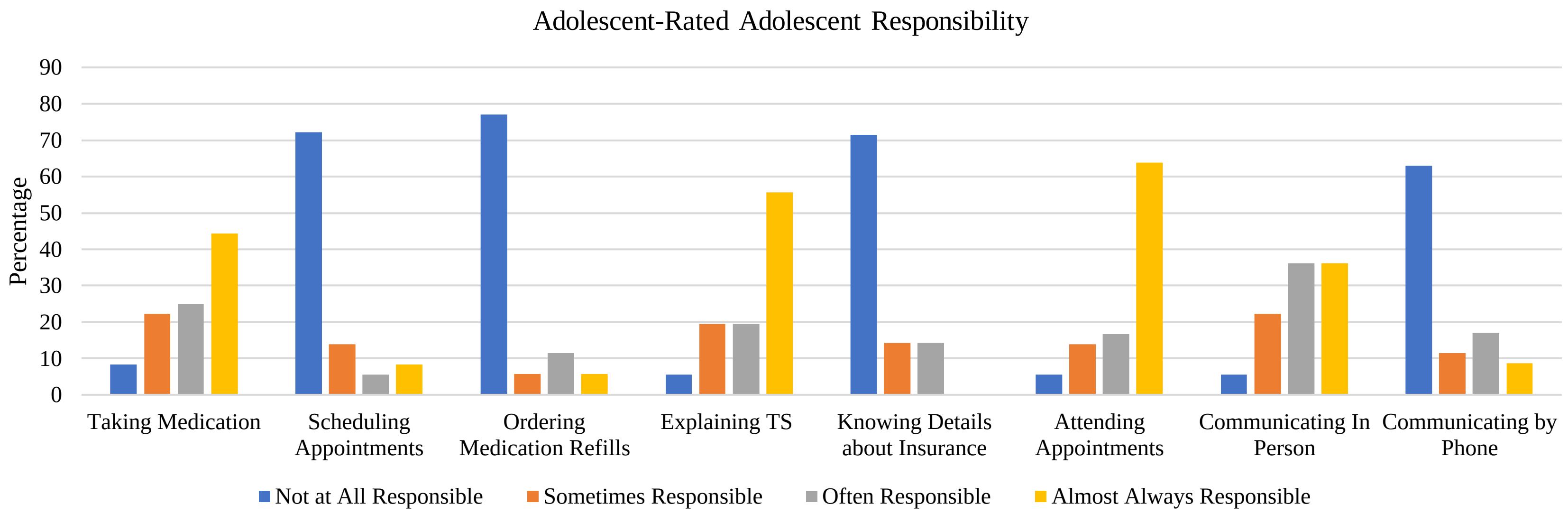


Figure 2. CONSORT Flow Diagram.



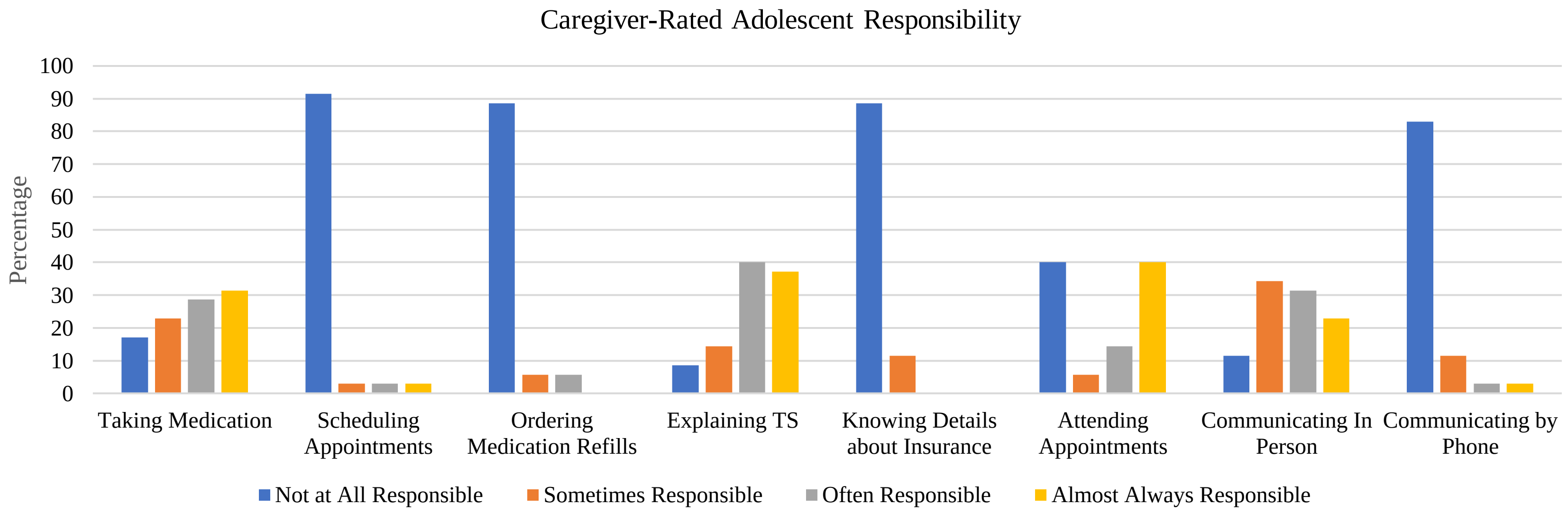
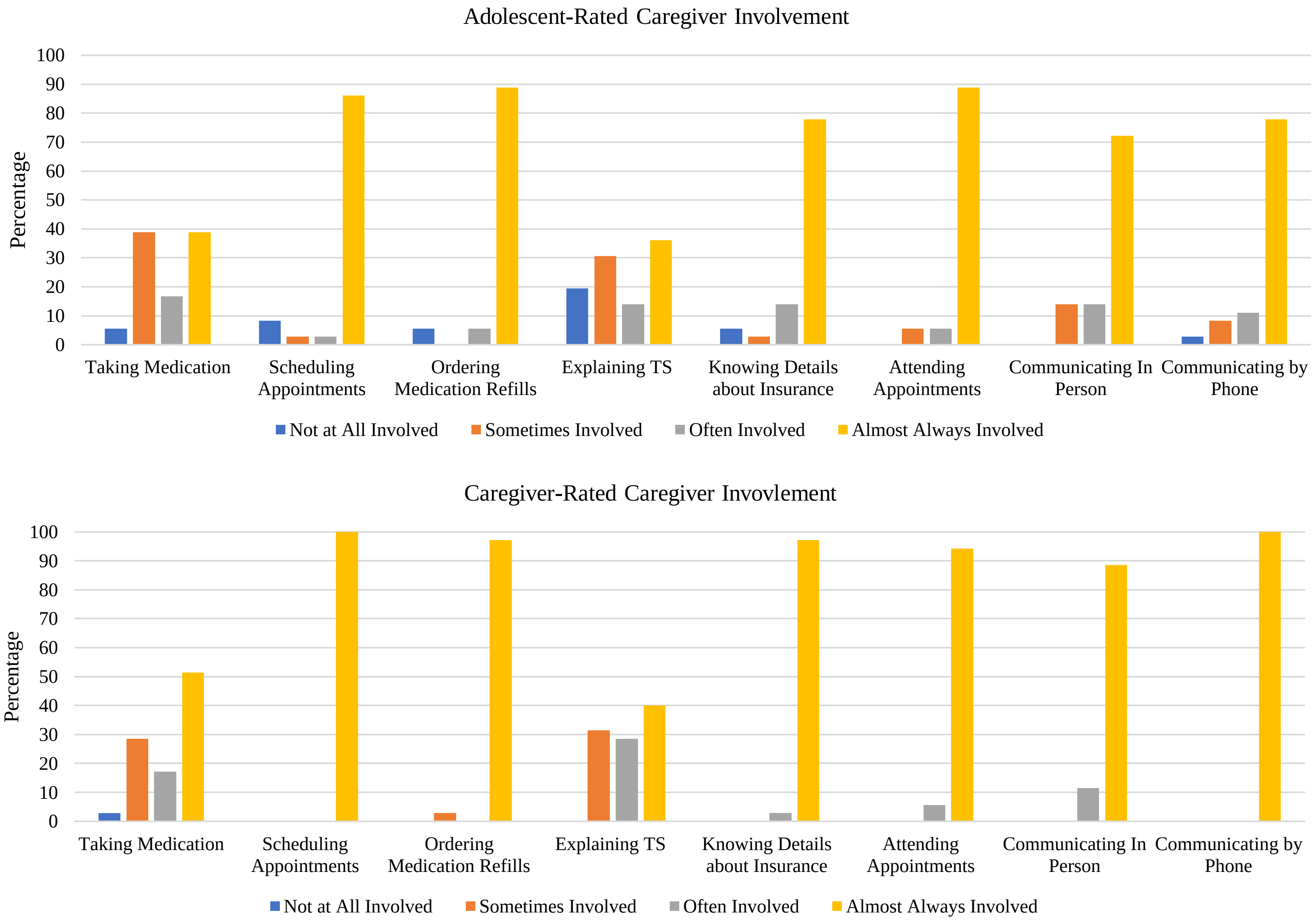


Figure 3. Adolescent- and Caregiver-Rated Adolescent Responsibility for Healthcare Behaviors.



Adolescent-Rated Caregiver Involvement

Caregiver-Rated Caregiver Invovlement

Figure 4. Adolescent- and Caregiver-Rated Caregiver Involvement for Healthcare Behaviors.