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PRIMARY CAREGIVERS OF CHILDREN WITH WILLIAMS SYNDROME:  
POSTTRAUMATIC GROWTH AND RELATED HEALTH OUTCOMES

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of  
Philosophy at Virginia Commonwealth University

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## **Abstract**

### **PRIMARY CAREGIVERS OF CHILDREN WITH WILLIAMS SYNDROME: POSTTRAUMATIC GROWTH AND RELATED HEALTH OUTCOMES**

By: Laura Elizabeth Slosky, MS

A dissertation submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, at Virginia Commonwealth University.

Virginia Commonwealth University, 2013.

Major Director: Marilyn Stern, PhD, Professor of Psychology and Pediatrics

**Background:** Current literature on caregivers of children with chronic illnesses and developmental disabilities primarily focuses on negative aspects of adjustment, with maternal stress and depression as common outcome variables (Duvdevany & Abboud, 2003; Shin and Crittenden, 2003). While these pediatric caregivers have been shown to struggle more than caregivers of typically developing children, the possibility of positive psychological outcomes from such an experience is only beginning to be explored (Kim, Greenberg, Seltzer & Krauss, 2003; Scallan, Senior & Reilly, 2010). One such positive outcome is the idea of Posttraumatic Growth (PTG), a construct for which a widely accepted theoretical model exists (Tedeschi & Calhoun, 2004). This model has yet to be empirically validated and fails to provide an exhaustive picture of PTG. The current study aims to document this phenomenon among caregivers of children with Williams, empirically evaluate a portion of the proposed theoretical model, and explore possible extensions of the model in the form of health behaviors.

**Methods:** Participants included 90 primary caregivers of children with Williams syndrome who were recruited through the Williams Syndrome Association List serve. Caregivers completed an

online survey through SurveyMonkey software that included the posttraumatic growth inventory, the deliberate rumination scale, the MOS social support survey, and the taking care of yourself questionnaire.

Results: The vast majority of caregivers reported some degree of growth following a diagnosis of Williams syndrome ( $M = 55.91$ ,  $SD = 22.63$ ), consistent with reports of other pediatric caregivers (Polantinsky & Esprey, 2000). Further, perceived social support was found to predict posttraumatic growth,  $F(2,73) = 2.488$ ,  $p = .029$ , consistent with model predictions. However, perceived social support was not predictive of an increase in deliberate rumination,  $F(2,72) = 0.143$ ,  $p = .867$ , failing to support the mediational model. Finally, posttraumatic growth was not found to predict health behaviors, although those caregivers who reported more posttraumatic growth also reported being less bothered by sleep-related caregiving burdens.

Conclusion: Posttraumatic growth is prevalent among Williams syndrome caregivers, indicating the need for future research in facilitating this process among pediatric caregivers and patients alike. Further, a better understanding of the cognitive constructs involved in the posttraumatic growth process is essential. This improved understanding will facilitate more accurate measurement tools for evaluating these cognitive processes along with additional clarity with regards to the theoretical model. Finally, the identification of health behaviors and health belief constructs that are impacted by posttraumatic growth would improve the depth of the theoretical model and improve overall understanding of the construct.

## Primary caregivers of children with williams syndrome: Posttraumatic growth and related health outcomes

The birth of a child is considered to be a major life event for caregivers. Any significant event in an individual's life is considered to be stressful, even when the event is perceived as positive. Hans Selye first described this concept in the literature in 1976 as eustress. He defined this construct as "the positive effect of the non-specific physiological stress response" or the agreeable and healthy stress that each individual experiences (Selye, 1976). While challenging, this type of stress is not harmful in isolation and can produce positive effects. The addition of a child into a home calls for schedule changes and increased financial burdens among a myriad of other changes. Having a child with developmental problems incorporates this traditional eustress but also violates expectations for what the birth of a child brings and challenges parents to adapt to a number of exceptional parenting challenges.

The current body of literature primarily focuses on negative aspects of parental adjustment to having a child with a disability, with maternal stress and depression as common outcome variables (Duvdevany & Abboud, 2003; Shin and Crittenden, 2003; Kim, Greenberg, Seltzer & Krauss, 2003). While these caregivers have been shown to struggle more than caregivers of typically developing children, the possibility of positive psychological outcomes from such an experience is only beginning to be explored (Kim, Greenberg, Seltzer & Krauss, 2003; Scallan, Senior & Reilly, 2010). These studies, along with others, have clearly indicated the need for further research, especially within the emerging area of posttraumatic growth.

The concept of posttraumatic growth (PTG) extends beyond wellbeing and indicates that an individual's development must exceed their level of baseline functioning prior to the traumatic event. The construct is comprised of five domains: increased appreciation for life,

more meaningful interpersonal relationships, increased sense of personal strength, changed priorities, and a richer spiritual life (Tedeschi & Calhoun, 2004). While these domains are the current focus of PTG, the list is by no means exhaustive (McMillan, 2004). Tedeschi & Calhoun proposed a model for the emergence of growth among those who have experienced some form of trauma.

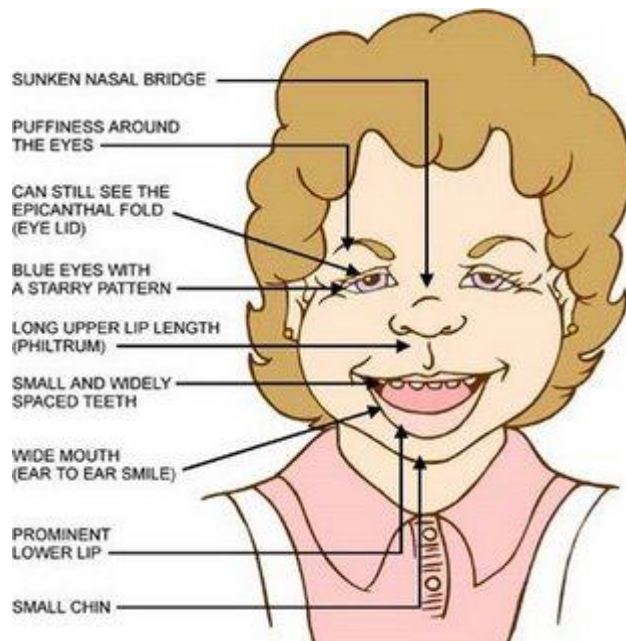
The current study aims to evaluate posttraumatic growth within primary caregivers of children with Williams Syndrome and then moves towards evaluating a portion of the most commonly accepted model of posttraumatic growth development (Tedeschi & Calhoun, 2004). Finally, an exploratory extension of this model will be evaluated. First, I will present an argument for the appropriateness of an examination of this construct within the WS caregiving community. I will then provide a review of the posttraumatic growth literature and discuss the model proposed by Tedeschi and Calhoun. Within this model presentation, I will review the literature associated with the constructs relevant to the proposed study which include social support and ruminative style. Finally, I will review health behaviors and their relationship to posttraumatic growth in order to provide a basis for their inclusion within a model of posttraumatic growth.

### **Williams Syndrome: An Overview**

Williams syndrome (WS) is a complex neurodevelopmental and medical disorder that results from a deletion of the 7q11.23 region of chromosome #7. This contiguous gene syndrome involves the elastin allele (Peoples et al., 2000). The syndrome affects approximately 1 out of 7,500 individuals worldwide and is a sporadic syndrome, typically not an inherited characteristic from a parent (Strømme, Bjømstad, Ramstad, 2002). Individuals are affected equally across genders and racial groups. Once the syndrome is suspected by a clinician, the diagnosis is made

using the FISH test. This fluorescent in situ hybridization test is a chromosome analysis utilizing specially prepared elastin probes looking for a deletion of one of the individual's two elastin genes. Williams is a multi-system disorder characterized by physical, developmental, and behavioral features along with medical problems. Common features among those diagnosed with WS include characteristic craniofacial anomalies, supraaortic stenosis, hypertension, hypercalcemia, low birth weight, feeding problems, learning difficulties, developmental delay, mental retardation, hyper sociability, dental, kidney and ophthalmologic abnormalities, musculoskeletal problems, and hyperacusis (Burn, 1986).

Children are typically identified by their clinicians as probable for receiving a diagnosis of Williams syndrome due to their characteristic phenotypic appearance. These facial features can range from subtle to striking and as such may lead to some variation in time in receiving a diagnosis. These features include a flat nasal bridge, short upturned nose, long philtrum, delicate chin, periorbital puffiness, full lips, wide mouth, increased interdental spacing, microcephaly and general hypotonia. These individuals are commonly described as having an "Elphin Face" due to this combination of features.



<http://dailypostal.com/2010/04/13/williams-syndrome-removes-racial-bias/>

The presence of these phenotypic abnormalities creates a number of ophthalmological, otolaryngological, and dental problems. Strabismus and altered visual acuity are common along with narrowed lacrimal ducts. Hyperacusis, high tone hearing loss and recurrent otis media are also seen frequently within this population (Poher, 2010). While none of these issues are life threatening, they require frequent doctor visits and can cause discomfort for the individual.

Along with these phenotypic abnormalities, there are a number of medical problems that characterize the presentation of Williams, with the most significantly affected system being the cardiovascular. Stenosis or abnormal narrowing of medium and large arteries is common and typically located above the aortic valve. When this occurs, the aortic valve fails to fully open which obstructs blood flow out from the heart, causing decreased blood flow and oxygenation to other areas of the body. This abnormal thickening is caused by an overgrowth of vascular smooth muscle. The extent of the stenosis varies by individual and can range from mild to severe.

Treatment of this abnormality typically corresponds with severity; some cases resolve without

intervention while others require an open heart procedure in order to replace the affected valve (Wang, et. al., 2007; Wessel, et. al., 1994). Along with supraaortic stenosis, hypertension is a common cardiovascular component of Williams Syndrome (Broder, et. al., 1999; Wessel, et. al., 1997). While the specific cause of this symptom is unknown, it has been suggested that it simply reflects a physiological adaptation to the different vascular structure present in these individuals (Faury, et. al., 2003). The blood pressure of these individuals requires monitoring and, in a majority of cases, treatment. The most common cause of death in individuals with Williams is cardiovascular complications and cardiovascular-related mortality was found to be 25 to 100 times that of healthy controls (Wessel, et. al., 2004), presenting a significant mortality threat. While cardiovascular abnormalities are significant within this population, other systems within the body are also implicated.

In addition to cardiovascular involvement, the endocrine system presents with abnormalities in those with a Williams diagnosis. A hallmark symptom of the disorder includes blood calcium abnormalities or hypercalcemia. While these episodes can be mild, they can also present as moderate to severe, especially in children (Morris, et. al., 1990; Cagle, et. al., 2004). Symptoms of a hypercalcemic episode include colic, hypotonia, poor appetite, and constipation. A severe episode is considered to be a medical emergency as it can result in a comatose state or cardiac arrest (Poher, 2010). Along with these episodes, those with Williams often have an impaired glucose tolerance, subclinical hypothyroidism and early pubertal onset accompanied by an attenuated growth spurt (Poher, 2010; Stagi, et. al., 2005; Cambiaso et. al., 2007). These concerns all require monitoring and the involvement of an endocrinologist in the care of the patient.

While these problems within the cardiovascular and endocrine systems are the most life threatening, problems within the gastrointestinal and genitourinary tracts significantly affect quality of life. Both reflux and constipation are prevalent as well as abnormal weight gain and non-organic abdominal pain. These symptoms are thought to contribute to feeding difficulties which are often accompanied by problems associated with texture sensitivity. This can require that the individual be followed by a gastroenterologist and even participate in intensive feeding therapy. Many of these children will be labeled as failure to thrive due to their chronic feeding issues. Along with these GI concerns are renal and kidney abnormalities, enuresis and frequent urinary tract infections which can require both nephrologist and urologist involvement.

While not every individual with Williams syndrome struggles with all of these medical issues, they typically struggle with a significant constellation of these concerns. The number of bodily systems involved typically corresponds with the severity of syndrome presentation in the individual but regardless, requires complex medical management by an integrated team of highly trained professionals. While these teams are largely made up of physicians, they must also include psychological professionals.

Along with medical problems and pronounced differences in appearance, individuals with Williams syndrome experience psychological, developmental and cognitive challenges. Sleep problems are expected in the WS population, with patients typically waking several times each night and exhibiting significant bedtime resistance (Annaz, et al., 2010). The development of both gross and fine motor skills is typically delayed along with initial language development (Udwin & Yule, 1991). Language begins to develop at approximately three years of age and is then believed to progress along a relatively “typical” trajectory (Mervis and Robinson 2000; Laing et al. 2002). As these individuals grow into adolescence and adulthood, they present with a



large and sophisticated vocabulary but this can be deceiving of their cognitive abilities as their understanding of these word meanings is rudimentary (Udwin, 1990). Children with Williams display a range of intellectual abilities that has been found to fall between 40 and 100 on traditional tests of intelligence (Martens, Wilson & Reutens, 2008). Average scores on these tests have been found to range from 50-60, indicative of a moderate intellectual disability (Meyer-Lindenberg, et al., 2006; Martens, Wilson & Reutens, 2008). Executive functioning is also affected as planning and problem solving skills fall in the impaired range. This level of functioning makes it difficult for the affected individual to live and function independently as an adult. It is of note that these measures of intelligence do not provide a complete picture of intellectual abilities. Individuals with Williams have been found to have relative strengths in facial recognition and discrimination skills, social and interpersonal skills and auditory memory. The weakest areas for these individuals are visuospatial and visuomotor skills (Martens, Wilson & Reutens, 2008; Mervis, et. al., 2000). Individuals with Williams have also shown exceptional musical abilities (Von Arnim & Engel, 1964; Lenhoff, 1996). These abilities are typically characterized by heightened levels of interest and emotional responsiveness to music. They also include an exceptional ability to learn, remember, and compose both lyrics and rhythm. Finally, many demonstrate perfect pitch. While not all children with WS will demonstrate these abilities, the percentage is significantly higher than in the general population (Lenhoff, 1996).

While cognitive abilities are typically impaired within this population, the hallmark behavioral symptom of the disorder is a lack of stranger anxiety and a “cocktail party personality.” These individuals are highly social and empathic but this lack of stranger anxiety can also cause problems for the individual. Interestingly, more than 80% of these patients also meet clinical criteria for an anxiety disorder, attention deficit disorder, or commonly a

combination of both (Leyfer, et al., 2006). Imaging studies have shown decreased activity in the amygdala when viewing threatening faces but increased activation when viewing non-social threatening stimuli ; findings that suggest a unique malfunction within the limbic system (Schumann, Bauman & Amarai, 2010). Other research has found that despite the overly social personality, many of these individuals become socially isolated as a result of their anticipatory anxiety (Dykens, 2003). These patients also prefer to interact with those older or younger than themselves, making age appropriate social interaction difficult (Tharp, 1986). The presence of obsessions and hyper attentiveness in some domains has also been noted and can interfere with social functioning (Davies, Udwin & Howlin, 1998). With these symptoms, the involvement of psychological professionals can be especially beneficial to patients and their families.

Williams syndrome is a contiguous genetic disorder that has medical, neurodevelopmental, cognitive and psychological involvement. While every individual is affected to a different degree, all exhibit some combination of the above described characteristics. Despite the extent to which an individual is impacted by the syndrome, they require a comprehensive care team in order to sustain their health and often require intensive medical intervention as an infant and young child. These broad based challenges make caring for an individual with Williams a constant and enduring task; increasing the overall caregiving burden that parents of typically developing children take on every day.

### **Caring for a child with Williams Syndrome**

Acting as the primary caregiver for any typically developing individual is a demanding task. Parents have taken on the monumental task of caring and providing for their children for at least the better part of two decades. While this alone is a significant financial and time commitment, most parents do not plan to incur significant medical bills, provide for exceptional

educational needs, or have to provide for their child throughout their adult lives. In addition to the challenges and responsibilities that a parent of a typically developing child must assume, a caregiver for a child with Williams must be able to readily adapt to the physical and behavioral features of the disorder as they fit within the typical developmental experiences across the lifespan. These include difficulty nourishing their child, adhering to intense medical regimens, handling a baby with a difficult temperament, managing chronic sleep deprivation, and handling frustration that comes with professionals not understanding the child's diagnosis or insisting that nothing is actually wrong. As the child ages, developmental delays emerge and maintaining a number of weekly therapy appointments becomes necessary. Additionally, caregivers must monitor the mental health needs of their child carefully as anxiety and depression can easily be masked by the child's friendly disposition. Perhaps most challenging is balancing the needs of one's self, spouse, other family members and friends with the needs of the child with WS. The cumulative effect of having the primary caretaking responsibility for such a child is a great degree of stress and caregiver burden (Fidler et al., 2000). Adding to this burden is the knowledge that this role will be needed for the duration of the child's life, as they are typically unable to achieve a level of adaptive functioning that surpasses a six-year-old level (Howlin, Davies, & Udwin, 1998). Further, parents often need to worry about care for this child after they themselves have passed. This accumulation of stressors has led many in the field to conceptualize having a child with a disability as traumatic (Turnbull & Turnbull, 1986) and to view caregivers as needing to grieve the death of a typically developing child (Seligman, 1985).

Empirical research examining the impact of having a child with Williams on caregivers and families is only just beginning to emerge. Because of the emerging nature of this area, studies of caregivers of children with other developmental and intellectual disabilities have been

used as a guiding framework. Stress can affect many different parts of a person's life, including mental and physical health (Lin & Ensel, 1989). A study on the health and well-being of caregivers of children with cerebral palsy showed such results and serves as a proxy for what may be expected among caregivers of individuals with WS (Raina et al., 2005). Results indicated that the best predictors of caregivers' well-being were child behavior, caregiving demands, and family function. Fewer caregiving demands were associated with better psychological and physical health. With the high levels of caregiving demands that a child with WS necessitates, it can be presumed that these caregivers would exhibit poorer levels of well-being and likely have a more difficult time caring for themselves and coping effectively.

An important part of caregiving is taking care of oneself (Alzheimer's Association, 2006). Despite its importance, many caregivers experience difficulty balancing their own needs with those of their child. According to a study performed by Evercare®, a provider of health plans for people who have chronic or advanced illness and the National Alliance for Caregiving (NAC), a leading authority on caregiving, 91% of caregivers surveyed have seen a decline in their health as a result of caregiving (Washington, 2006). Ninety percent reported that their level of stress has increased as a result of caregiving. Eighty-two percent reported that their sleeping habits are worse, 63% reported that their eating habits are poorer, and 58% reported that their exercise habits are worse. Seventy-two percent reported not having gone to the doctor as often as they should, and 26% did not attend annual physicals. Fifty-one percent of those surveyed reported that they do not have time to care for themselves, while 49% reported that they are too tired to take care of themselves. Based on these findings, it is believed that caregivers of individuals diagnosed with WS likely encounter challenges maintaining their own level of wellbeing. This includes potential challenges with maintaining personal health care behaviors.

Unfortunately, no studies have been conducted that investigate wellbeing and related constructs among WS caregivers.

It is clear that having the primary care taking responsibility for another is an exceptionally stressful experience and along with this job comes a number of compromises for the caregiver. However, there are many caregivers who manage to take good care of themselves in addition to their special needs child; some even demonstrate growth. An increasing body of evidence is available that supports this idea that many caregivers and families successfully adapt and cope well with the challenges presented by having a child with a developmental disability (Scallan, Senior & Reilly, 2010). Contributing factors to this successful adjustment include cognitive appraisal of the situation (Lazarus et al., 1980), a functional family dynamic (Keller & Sterling-Honig, 2004), and social support (Perle-Slavik-Cowen & Reed, 2002; Hastings & Beck, 2004; Turnbull, 2004). With these factors known to contribute to a successful adjustment, it fits that these same factors, when sustained, would also facilitate the growth process.

Psychologists have worked to describe the adaptation process of caregivers of children with disabilities for decades. A popular adaptational model (Crnic et al., 1983) views the child as a stressor, analogous to any other stressor, to which the family must adjust. This adjustment is thought to occur within the context of a stress and coping model (Crnic, Friedrich & Greenberg, 1983). This viewpoint has marked a shift away from a view that focused on parental pathology that came out of a more Freudian perspective (Solnit & Stark, 1961). The newer “adaptational model” aimed to account for the full range of outcomes (i.e. both positive and negative) that a caregiver of such a child may experience. The child with special needs or cognitive challenges is seen as a stressor that precedes a number of challenges. The system’s response to these challenges is mediated by the coping resources of the entire family (Crnic, Friedrich &

Greenberg, 1983). Crnic and colleagues used Folkman's (1979) conceptualization of coping resources when describing these resources in their adaptational model. These resources include parental mental health, cognitive resources, support resources, socioeconomic status, and religious beliefs as possible mediators of the stress response within the ecological context. The model stresses the inclusion of the ecological context as it is thought to be qualitatively different for families with a child with exceptional challenges than for families of typically developing children (Crnic, Friedrich & Greenberg, 1983). This ecological component to the model is based on the work of Urie Bronfenbrenner who stressed a sociocultural view of development (1977). He described five concentric environmental systems that interact not only with each other but also with social agents and cultural influences to shape the developmental process of the individual. Bronfenbrenner's ecological systems range from the most proximal influences on an individual (i.e. family, school, peer relationships), to broad-based ideological and historical conditions. One ecological difference these authors cited between families with typically developing children and families with exceptional children was a decreased amount of social interaction and opportunities for support. Because of these significant differences, Crnic and colleagues felt that it was important to consider both an ecological and a stress and coping perspective when designing their own adaptational model.

A recent study identified common themes and challenges faced by caregivers of children with Williams. First, activities were found to be more restricted because of the child with WS and more supervision was required because of the child's overfriendly personality. Working to increase the affected individual's level of independence became a significant concern as the individual entered adulthood. Second was an increase in stressful interactions with professionals. Many caregivers reported a lack of awareness about WS among medical and educational

professionals along with an increased need to tirelessly advocate for the needs of their child. Many caregivers spoke to the need for counseling at the time of diagnosis centering on a sense of grief and loss. In addition to these challenges, many caregivers also spoke to a number of positive changes in their lives as a result of caring for a child with WS. Some examples include joy inspired by the child with Williams, closer family relationships, new friendships with parents in similar situations, a changed outlook on life, personal growth, and increased empathy in siblings (Scallan, Senior & Reilly, 2010). These described changes highlight the chronic and stressful nature of caring for such a child and suggest the presence of posttraumatic growth, although the construct was not specifically evaluated in this study.

Holding the primary caretaking responsibility for a child with Williams is a highly demanding and exceptionally stressful task. Providing for an affected child invariably necessitates changes in life style and changes in personal world views. While such a situation presents a number of challenges, many caregivers also report personal growth exceeding their level of functioning prior to providing care to their special needs children. Previous research has hinted at the presence of posttraumatic growth within this population but the construct has not yet been empirically examined. The development of such growth requires that an event be so stressful or traumatic that it shatters a person's assumptive view of the world. Receiving such a diagnosis and coming to terms with the meaning of such a new reality has significant potential for shattering caregiver beliefs and setting the cognitive processing required for growth into motion. In order to better understand this growth process among these caregivers, it is necessary to first examine a model of stress and coping that provides the basis for the process of growth.

### **Stress and Coping: A Transactional Model**

The concept of posttraumatic growth has been derived from theoretical work in the field of stress and coping. Specifically, this emerging construct is well framed using Lazarus & Folkman's transactional model of stress and coping (1984; 1997). This model is multidimensional in nature and grounded in cognitive constructs. It is transactional in that it views the process of stress and coping as an interaction between the individual and his or her environment. The model is widely used as a basis for research in both the stress and coping field and within the posttraumatic growth domain. A foundational principle of the theory involves the individual's appraisal of a situation, as this determines both the degree of the response and the style of coping used to deal with the situation.

Initially, the individual must appraise the situation with which they are presented using both primary and secondary appraisal (Lazarus & Folkman, 1991). Primary appraisal focuses on determining what is at stake for the individual in the situation. The value of this potential loss determines both the magnitude and quality of the response (Lazarus & Folkman, 1991). First, one must decide if a given event represents a challenge, a loss, or a threat. If the event is perceived as a challenge, the potential for growth is high. For example, a parent learning that their child has Williams may feel a need to reach out to others in similar situations and start a support group in the local area. On the other hand, if the event is perceived as a loss, they see damage as already having occurred. Parents learning that their newborn will likely have intellectual impairments may perceive a Williams diagnosis as a loss of the child that they had expected. Finally, if the event is perceived as a threat, they see the stressor as having the potential to produce loss. Parents learning that their child needs aortic valve replacement surgery may perceive Williams as a threat to the life of their child.



Once the interpretation of a stressful event has been established for the individual, he or she must decide how they are going to respond to the situation. This secondary appraisal process also involves assessing different avenues for coping and determining the response of others (Lazarus & Folkman, 1991). These assessments differ between individuals experiencing the same situation as appraisals are influenced by personal characteristics. A few examples of these differences that have been found to influence appraisals include sense of optimism, cultural background, and socioeconomic status. Once this two-part appraisal process has been completed, the individual must begin to actively cope with the situation.

Lazarus and Folkman (1991) define coping as constantly changing cognitive and behavioral efforts to manage specific external or internal demands. They break down this process into both problem-focused and emotion-focused efforts. When an individual perceives that they are able to effect change, problem-focused coping is more likely to ensue. Problem focused coping attempts occur when efforts are aimed at solving or managing the problem that is causing distress. Common examples of such a process include gathering information, planning, and resolving conflicts. A parent of a child with Williams may recognize that their child is not feeding normally, then extensively research and enroll in feeding therapy. In contrast, emotion-focused coping concentrates on managing distressing emotions rather than attempting to effect change. This type of coping is most common when an individual does not perceive that they are able to affect change. For example, if a child were to pass away, the outcome would not be reversible. As a result, the parents' coping strategies would likely fall into the emotion-focused category. Attempts at coping can fail but they can also be successful and resolve the source of distress.

Effective coping is posited to produce change in one of three ways. First, Lazarus and Folkman (1991) proposed that coping strategies can direct attention either towards or away from the source of stress. These coping strategies are referred to as vigilance and avoidance approaches respectively. An example of a vigilance strategy may include information gathering while an avoidant strategy may include substance use. Second, changing the personal meaning of the event or interaction has the potential to produce change. This can commonly involve cognitive restructuring processes in order to find positive aspects of difficult situations (i.e., developing closer family relationships as a result of a pediatric health scare). Finally, one may produce change by actively changing aspects of the situation. This way of coping may involve active problem solving efforts or attempts at changing the immediate environment. A parent who insists that their child be transferred to a hospital with expertise in caring for children with heart problems would serve as an example of such a way of changing the environment to affect the outcome. These processes can occur on many different levels and one may use a variety of different strategies throughout the process of dealing with a stressful situation. When these strategies produce desirable outcomes, the coping process for the given situation resolves and feelings of mastery and pleasant emotion are thought to result. Conversely, if the situation does not resolve to the individual's liking, the coping process must continue (Lazarus & Folkman, 1984). This is the case for caregivers of those with chronic health concerns such as Williams.

In 1997, Folkman revised this model to include three additional pathways that were to account for positive psychological change resulting from exceptionally stressful experiences. The first addition was meaning based coping which Folkman posited to evolve from both the event's result and from continual distress. This construct was defined as an appraisal based method in which an individual draws on his or her beliefs, values, and existential goals that

motivate and sustain the discovery of positive outcomes during stressful situations. This meaning based coping process first involves adjusting goals in order to gain a sense of control and meaning. Additionally, the individual may reexamine and inspire religious or spiritual beliefs which are thought to provide a sense of existential significance to the stressful situation. The individual may also direct their attention towards appreciating other positive events in his or her life and/or engage in positive reappraisal processes to view the stressor more optimistically (Folkman, 1997).

This process of meaning based coping is thought to lead to increases in positive emotion (Folkman, 1997); a hypothesis for which empirical support exists (Moskowitz, et al., 1996). This emergence of positive affect does not preclude the presence of negative affect as the two are reliably found to co-occur (Folkman, 1997; Androwski, et al., 1993). This hypothesis is also consistent with the model of posttraumatic growth presented in this literature review.

Finally, Folkman highlights that this experience of positive affect sustains the coping process and continues the cycle of active problem and emotion focused strategies (1997). The cognitive processes involved in sustaining these positive emotions indicate an active processing of the stressor and thus continual coping processes are indicated. This is especially true with chronic stressors, such as having a child with a developmental disability, as the individual is constantly dealing with medical, developmental, and psychosocial stressors in addition to lifestyle changes. This process of continued psychological processing provides an excellent basis for the emergence of posttraumatic growth and the continued focus on positive psychological outcomes following a highly stressful experience.

### **Posttraumatic Growth**

The idea that distress can lead to positive change dates back to ancient times (Tedeschi & Calhoun, 1995). Despite this long standing belief, scientific inquiry into this area did not begin to emerge until the 1980`s (Tedeschi & Calhoun, 2004). Terms used to study these ideas included stress-related growth (Park, Cohen & Murch, 1996) and positive psychological changes (Yalom & Liberman, 1991) among others. More recently, leading researchers in the field of pediatric psychology have studied this phenomenon but referred to it as challenge-related growth (Phipps, 2010). This perspective utilizes a positive psychology framework, conceptualizing what were originally termed traumatic events as significant life events. These significant life events can be a potential trauma, but can also be a catalyst for growth. This term is believed to focus more on adjustment, and less on pathology (Phipps, 2010). Tedeschi & Calhoun integrated these earlier constructs and introduced the idea of posttraumatic growth, while also presenting a hypothesized model for its development.

The term posttraumatic growth is defined as the positive psychological change experienced as a result of the struggle with highly challenging life circumstances (Calhoun & Tedeschi, 1999; 2001). This growth must exceed baseline functioning prior to the experience of the specified traumatic event in at least one area. These same authors identified five domains of posttraumatic growth including the development of more meaningful interpersonal relationships, an increase in spirituality, and an increased sense of personal strength, new life possibilities and a greater appreciation for life (2004). Changes in these domains are thought to result from reevaluating and redefining life goals in the face of coping with an especially challenging and stressful life event (Tedeschi & Calhoun, 1995). While this phenomenon has been documented in a wide range of populations, including caregivers of children with other chronic illnesses, it has not yet been examined in caregivers of children with Williams syndrome.

As previously noted, Tedeschi and Calhoun identified five primary domains of posttraumatic growth based on previous empirical findings and interviews with trauma survivors. These findings were factor-analyzed in order to produce the current gold standard for measurement of this construct, the Posttraumatic Growth Inventory (PTGI). Many survivors report an increased appreciation for life in general or a changed sense of what is truly important. Many individuals find that they appreciate smaller joys in life and feel that they are truly lucky (Jordan, 2000). For a caregiver of a child with Williams, this may be an appreciation for the time that they get to spend with their child or an appreciation of their child's positive disposition.

Second, many survivors report an increased sense of personal strength. This is typically evidenced in a realization that negative events do occur in combination with the reality of being able to handle these events. A Williams parent may acknowledge how awful it was to watch their child endure open heart surgery yet believe in their ability to handle future difficulties based on this past success.

Third, the survivor may be able to identify new possibilities for their life or be willing to recognize alternative paths not previously considered. A parent may be willing to cut down on overtime spent at his or her job to focus more on the family, be inspired to pursue a new career path, or to become an advocate for others coping with similar issues. These are things that may not have been considered prior to the questioning of schemas resulting from the birth of a child with special needs.

Another domain in which growth is observed is in an increased involvement in spiritual or existential matters. A stronger belief in a higher power is common as well as significant engagement with existential issues. This domain of growth is not limited to those who identify as

religious as individuals who identify as atheists also report greater involvement with existential issues (Tedeschi & Calhoun, 2004).

Finally, growth as conceptualized within this model can also be seen in the development of more meaningful interpersonal relationships. Individuals commonly report that people seem to appear out of the blue to support the survivor and the importance of such support becomes overwhelmingly obvious (Calhoun et al., 2000). The experience of “finding out who your true friends are” is also not uncommon along with the experience of empathy for others who are struggling. A caregiver for an individual with Williams may become a better friend and support for others and recognize the importance of significant relationships in their lives.

A review of the literature related to posttraumatic growth would not be complete without acknowledging the skepticism that many have vocalized regarding the validity and true prevalence of the construct. Greater than 50% of those having experienced trauma report at least one positive outcome from their experience (Hoeksema & Davis, 2004). Because this number is so high, some have suggested that PTG is merely a self-protecting illusion rather than reality (McFarland & Alvaro, 2000). Calhoun and Tedeschi counter this idea with empirical evidence that both distress and personal growth occur following a highly challenging event (2004). Because this distress is still very much present, PTG is not thought to be simply a self protective strategy, but rather a distinct and valid construct. Another debate that has surfaced in this area revolves around whether to consider PTG to be a process or an outcome. Those who advocate for a strictly process view argue that searching for benefits in a highly challenging circumstance should be viewed as an active coping strategy. While this meaning making method of coping with a highly negative experience is valid and frequently occurs, this process is more accurately descriptive of a strictly benefit finding construct. The constructs are also distinguished by

changes from baseline functioning as PTG requires that a higher level of functioning from baseline must occur whereas benefit finding does not have such a requirement. Tedeschi and Calhoun argue that the construct of PTG is both a process and an outcome (2004). This is reflected in how the construct is measured as the PTGI treats growth as an outcome variable yet Nolen-Hoeksema & Davis (2004) also discuss it as a process of development. Additionally, these authors talk about realizing growth as opposed to seeking it out. As such, PTG is a more comprehensive construct than benefit finding and will be looked at as both a process and an outcome in the proposed study.

The key element for an event to be perceived as traumatic is that the occurrence must violate the individual's core assumptions. Tedeschi & Calhoun (2005) have based their model of this construct's development on the assumption that people "rely on a general set of beliefs and assumptions about the world, that guide their actions, that help them to understand the causes and reasons for what happens, and that can provide them with a general sense of meaning and purpose." (p. 5). This assumption is heavily based on work previously done by Epstein, Parkes and Janoff-Bulman. These core assumptions or schemas begin to form in infancy and are so ingrained by adulthood that they are no longer evaluated. They provide us with a sense of security and safety and allow us to believe that we are protected from negative events (Janoff-Bulman, 2006). Trauma is thought to bring the individual to a place where they can no longer deny the imperfections within these assumptions. With the occurrence of a traumatic event, the affected individual is believed not to be ready to cope with both the realization of the world as a dangerous place and with living within this threatening world. When this happens, the good world assumption is shaken and individual must accommodate this new information into their world view, without an overwhelming sense of danger and fear (Janoff-Bulman, 2006). While

severe distress is common immediately following a traumatic experience, many are able to return to baseline or even exceed pre-trauma functioning. Tedeschi & Calhoun (2004) have used previous research findings and their own clinical experience to create a hypothesized model of how this growth may evolve.

This process of rebuilding highlights the critical point that trauma itself is not simply a precursor to growth; rather it is the struggle with the trauma that is necessary for growth to occur (Tedeschi & Calhoun, 2004). Traumatic experiences have undoubtedly been shown to cause significant distress and even dysfunctional thought patterns (Rowan, Rodriguez, Gallers, & Foy, 1990). For a parent learning that their child has WS, they may feel numb and have a difficult time believing that their child has such an illness. Anxiety, fear and anger are all common responses to threatening and adverse experiences and these responses can persist long after the threatening stimulus is removed. Such negative responses to stress have been documented in the literature among mothers of children with disabilities, even though the stressor is not necessarily removed, but is accommodated to (Glidden and Schoolcraft, 2003). For a caregiver of a child with Williams, such a diagnosis may cause increased anxiety about care giving demands and ability of their child to survive invasive medical procedures. In addition to these risk factors for psychological symptoms, the experiencing of these exceptional circumstances places the individual at an increased risk of developing psychiatric problems (Rubonis & Brickman, 1991) as major life crises can set dysfunctional patterns of thinking in to place. Along with these psychological consequences, these individuals are likely to experience increased physical symptoms (Friedman & Schnurr, 1995). Examples of such physical consequences include fatigue, gastrointestinal problems, muscle tension and general malaise. While all of these negative outcomes have been found to be associated with the experience of traumatic events,



they do not preclude the presence of concurrent positive change. Calhoun and Tedeschi (2004) have found that this is due to the nature of how these experiences are psychologically processed.

The cognitive processing that is required to restore meaning and an understanding of the world following this destruction of previously held schemas is thought to be implicated in the process of growth in a number of models of the development of this construct (Martin and Tesser, 1996; Tedeschi & Calhoun, 2004). Social support has also been found to facilitate this type of cognitive processing and contribute to growth (Cordova, 1999; Cordova et al., 2001). Recently, there have been a number of studies examining the role of rumination within these cognitive processes and their relationship to growth (McAdams, 1993; McAdams, Reynolds, Lewis, Patten, & Bowman, 2001; Tedeschi & Calhoun, 1995). Findings from this area of research have led Tedeschi and Calhoun to include this style of cognitive processing in their proposed model of posttraumatic growth (2004). A portion of this model will be evaluated in the proposed study among primary caregivers of children with Williams syndrome.

### **Posttraumatic Growth Model**

Based on both their empirical work and clinical experience, Tedeschi & Calhoun proposed a model for the development of PTG (2004). It is a cognitive model derived from the etiological theories of stress and coping; the most recent version of which was published in 2006 and is presented in Figure 1. This model represents the most comprehensive picture of this construct to date but the authors acknowledge that the model has not been validated and that there exist alternative paths to growth (McMillen, 2004). This model is currently the most widely studied and accepted, providing an excellent starting point for the examination of this construct.

The model begins with the person as they existed before the traumatic event. While we typically are not privileged to information about pre-morbid functioning, the authors

acknowledge the contribution of individual differences in responding to exceptional stressors. Once the event occurs and the individual's assumptive world is shattered, the person must find ways to manage the distress that they are experiencing. It is during the attempts at management of these feelings that more automatic and intrusive ruminative thought processes are thought to occur and the individual's schemas and life narrative are beginning to be challenged. Through the support of other individuals, those dealing with trauma are hypothesized to create narratives about why the event occurred, actively processing the event and its aftermath. This social support is thought to offer additional perspectives and facilitate integration and schema change. It is through this active cognitive processing that rumination is hypothesized to become more deliberate and growth to occur.

Event related rumination involves a distinct dissonance between schemas and events that have occurred. When individuals are engaging in such a thought pattern over past events, they are conceptualized as working through the event and event associated affect. Here the trauma is seen as the turning point, where a goal was possible before but no longer (McAdams, 1993). In the case of a parent of a child with Williams, parents may have held the belief that they would raise their son or daughter to become independent and self-sufficient and have this goal shattered at the point of receiving this diagnosis. The parent must give up dreams and expectations that they previously had for this child.

The idea of rumination contributing to a positive psychological outcome is one that can seem counterintuitive given the empirical associations found between such thought processes and depression (Lyubomirsky, Caldwell & Nolen-Hoeksema, 1998; Horowitz, 1986).

Additionally, we have learned that trauma survivors present as emotionally distinct from those struggling with depression (Robinson & Fleming, 1992). It has been suggested that the definition

of rumination in the context of depression is limited to simply include negative, intrusive thought processes at the exclusion of more positive processes. In a parent of a child who had recently been diagnosed with Williams Syndrome, this may present with the parent automatically thinking about losing their child to complications of heart surgery. These negative and unwanted thoughts surface at inopportune times, say when the individual is trying to concentrate on completing a project for his or her job. Rumination in the context of posttraumatic growth incorporated these negative processes and expands upon them to include more deliberate, controlled and positive thought processes. Rumination within this context is referred to simply as cognitive processing and is based on the work of Martin and Tesser (1996). This definition of rumination includes thinking that is conscious, revolves around a key theme, and occurs without direct environmental cueing. At the same time, this type of thinking is easily cued in an indirect fashion as it is intertwined with important goals and leads to recurrent thoughts. This definition of deliberate rumination is viewed as a deliberate effort to deal with the traumatic event and is both reflective and constructive. This more deliberate ruminative process may present as the same parent discussed above setting aside time specifically to struggle with finding meaning in receiving a Williams diagnosis. This broader definition that was theoretically proposed in the mid 1990's has been supported empirically in more recent work (Treyner, Gonzalez & Nolen-Hoeksema, 2003).

While this broader definition highlights a more constructive process of rumination, it does not discount the more negative processes traditionally associated with automatic rumination. Thought processes that are negative, automatic and intrusive are common after the experiencing of trauma and such cognitive activity immediately after the event is actually viewed as an indicator that the event had a significant impact, enough to shatter the person's assumptive

views of the world (Taku, et al., 2009). These same authors also posit that this automatic rumination immediately following the experience of trauma establishes the framework for further cognitive processing necessary for growth. It is when these intrusive, negative processes continue for extended periods of time that significant levels of distress occur and growth is inhibited (Nolen-Hoeksema, et al., 1997; Tedeschi & Calhoun, 1995).

The shift to more deliberate cognitive processing and “working through” of the event is believed to be a core process necessary for the development of posttraumatic growth as it is conceptualized as an attempt to rebuild an individual’s view of the world and to adapt to the trauma (Greenberg, 1995). This more deliberate form of rumination is constructive and may be seen in thinking about ways to make sense out of the event or recognizing positive effects from the experience. This deliberate rumination is thought to be an ongoing process even as growth is attained. When this type of cognitive activity is continuing well after the traumatic event, it is thought to indicate active and enduring processes that focus on rebuilding and incorporating changes into evolving schemas. This may be seen clinically as benefit reminding and keeping salient the positive changes that have been recognized (Helgeson, Reynolds, & Tomich, 2006). While this has been anecdotally reported, there also exist a handful of studies that have empirically supported this claim. The first empirical examination of this hypothesized relationship between rumination and growth was published in 2000 by Calhoun, Cann, Tedeschi & McMillan. This study confirmed hypotheses in that the more rumination reported soon after the traumatic event, the more likely growth was to occur. This study was however correlational in nature and the authors explicitly called for further evaluation of the role of deliberate cognitive processing in the process of growth. More recent work has focused on *when* certain types of rumination occur, as type of thought process in addition to when these processes occurred were

found to be important factors in determining the development of growth (Calhoun et al., 2000). Taku and colleagues (2009) found that both recent deliberate rumination and intrusive rumination soon after the event were predictive of posttraumatic growth. These findings have also been substantiated within the realm of health psychology. A study of HIV positive men grieving the loss of a loved one reported a relationship between deliberate, repeated thought processes that occurred recently and PTG (Bower, et al., 1998). There is significant empirical support for the relationship between more deliberate cognitive processing of a traumatic event and the development of growth; however mechanisms that facilitate this type of cognitive processing and their impact on growth has only been theoretically posited and remains to be empirically examined.

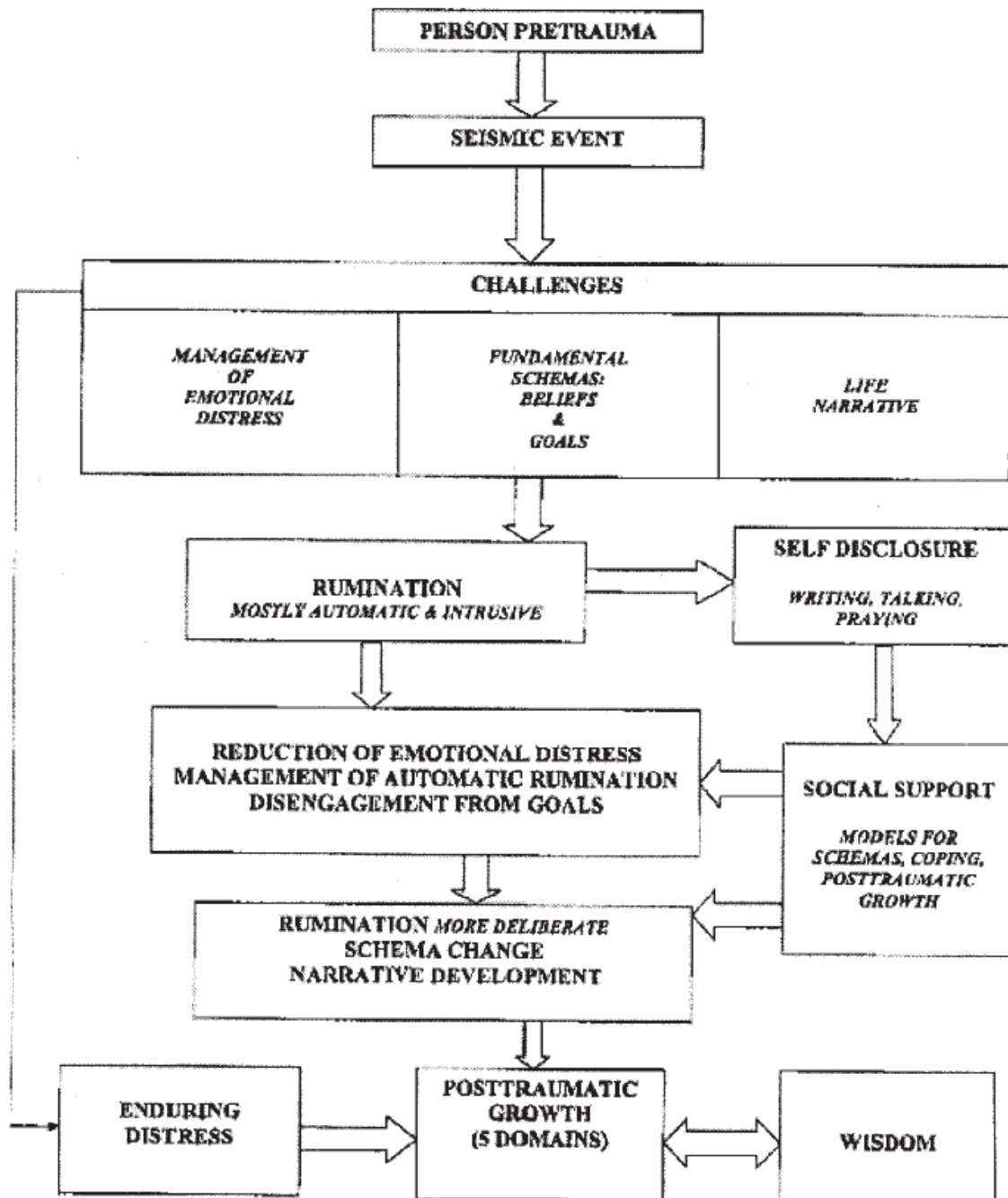


Figure 1. Tedeschi and Calhoun's (2006) proposed model of posttraumatic growth.

### Social Support and Posttraumatic Growth

Social support is thought to facilitate the coping process by helping to restructure worldviews and experiences (Sarason & Sarason, 1995). Methods that have been used to assess

this construct however encompass a great deal of variability, as the overarching construct does not have a clear and widely accepted conceptualization. This variability is also thought to reflect the multidimensional nature of the construct and as such is often examined as distinct domains that comprise the larger idea of social support.

Three primary types of supportive social interactions have been identified in the literature. These domains include emotional support, instrumental support, and informational support (House, 1981; House & Kahn, 1985; Kahn & Antonucci, 1980; Thoits, 1985). Emotional support is characterized by empathy, compassion, reassurance, and encouragement. This type of support is seen as an expression of both caring and concern for another individual, contributes to a person's feelings of worth, and is thought to facilitate growth processes. Informational support typically takes the form of advice received from others during a significant life event. In the case of a child with Williams, a number of physicians and genetic counselors are likely to provide such support to the patient's caregivers and families. Finally, instrumental support is thought of as tangible aid that an individual receives. This may take the form of a meal brought to a family while in the hospital or providing transportation to and from a doctor's appointment. These resources can be invaluable to a family in crisis whose attention is necessarily devoted elsewhere. These categories are also referred to as functional support as they examine the degree to which interpersonal relationships serve given functions (Sherbourne & Stewart, 1991). While all of these domains of functional social support are important and contribute to belonging within a support system, different types of support are thought to facilitate different stress and coping processes. Both emotional and instrumental support have been found to be most strongly related to posttraumatic growth (Manne et al., 2004; Pollard & Kennedy, 2007; Thornton & Perez, 2006) and as such are examined in this study.

A second approach to measurement of this construct examines the structure of the interpersonal relationship and as such is referred to as structural social support. This is often measured in terms of the number of contacts or frequency of contact with potentially supportive others (Sherbourne & Stewart, 1991). This type of support is not as frequently examined as it can be correlated with factors unrelated to support. One example would be the busy nature of one's life. Because of this significant potential confound, the current study will not examine structural support.

Another distinction that must be made when considering the social support literature is perceived versus received support. Received support is the individual's retrospective report of the helpful or well-intended actions of others. It is important to highlight that this type of support centers around support that was remembered as received during past stressful times but does not account for support in the present or future tense. Perceived support focuses on support that the individual believes they will receive if needed in the future. While both of these constructs center on the individual's perceptions, the time frame in which received (or believed to be available) is the differentiating factor between the two. Because of this difference, these areas of support should be thought of as different constructs (Sarason, Sarason, & Pierce, 1990). Perceived support is the most commonly examined construct and has been found to be most strongly associated with posttraumatic growth (Suls, 1982). As such, perceived support is examined in the current study.

The relationship between psychological adjustment and social support has been well established (Helgeson & Cohen, 1996). Higher levels of perceived functional support have been associated with better quality of life (Lewis et al., 2001), decreased distress (Alferi et al., 2001), and increased optimism (Gustavson-Lilius, Julkunen, & Hietanen, 2007). The association of this



type of social support with favorable outcomes is strengthened when the support is provided by those closest to the individual (Dakof & Taylor, 1990). While research has established the relationship between positive psychological adjustment and social support, empirical findings extending these results to social support and posttraumatic growth have been inconclusive. While many studies have found significant relationships between social support and posttraumatic growth (Karanci & Erkam, 2007), others have failed to find such a relationship (Abraldo-Lanza, et al., 1998; Joseph, et al., 1993). One school of thought posits that the reason for this discrepancy lies in inconsistent domain measurement and a lack of a widely accepted conceptualization of the social support construct. For example, Abraldo-Lanza and colleagues reported no significant relationship between received emotional support and PTG among women with chronic illnesses (1998). Further, Weiss and colleagues found structural support to be unrelated to growth in a similar population (2004). Finally, Joseph and colleagues (1993) found both structural and received functional support to be unrelated to growth.

While these studies did not support the hypothesized relationship between social support and growth, those looking at perceived functional support were more consistent. Perceived emotional support from a spouse was found to predict posttraumatic growth among breast cancer survivors (Weiss, 2004) and perceived social support from others was found to predict growth in a similar population (Karanci & Erkam, 2007). These findings with perceived support have been substantiated in other populations, including college students (Armeli et al., 2001) and caregivers of HIV positive individuals (Cardell et al., 2003). Despite some variation on type of social support examined, perceived emotional and instrumental support are most strongly and consistently related to posttraumatic growth and as such will be focused on in the present study.

The mechanisms by which this perceived support leads to growth is not well understood. It is hypothesized that this increased level of support and processing of the experience with others increases deliberateness of rumination, which ultimately leads to growth. The posttraumatic growth model posited by Tedeschi and Calhoun specifies that the social environment facilitates engagement in constructive rumination, thereby leading to growth. This facilitation is provided through emotional support and the provision of alternative schemas (Weiss, 2004). Specifically, this social support is thought to encourage the processing of difficult emotional material, something not engaged in as frequently by the individual alone. The processing of a traumatic event is exceptionally painful emotionally and the social environment is thought to reduce the negative affect associated with this process, preventing the individual from becoming overwhelmed and shutting down. Social support is also thought to provide models for ways that life can be improved after the traumatic event (Weiss, 2004). These hypotheses further support the use of perceived emotional and instrumental support when empirically evaluating these proposed pathways.

The current literature clearly highlights the idea that social support is a multidimensional construct (Sarason et al., 1990). The perceived availability of emotional and instrumental support is most strongly related to the process of posttraumatic growth. It is believed that those providing such support offer alternative perspectives and beliefs about the traumatic situation as well as space for schema revision. This facilitation of cognitive processing and assumption rebuilding is the believed mechanism for growth to emerge (Calhoun & Tedeschi, 1999). Empirically evaluating this proposed pathway will significantly contribute to a large deficit in the literature and to the conceptualization of posttraumatic growth.

### **PTG and caregivers of children with special needs**

Events that are perceived as traumatic and serve as the impetus for growth are broad based with a wide variety of circumstances documented as promoting this process in the literature. The development of these growth processes have traditionally been studied in populations with chronic illnesses (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992; Collins, Taylor, & Skokan, 1990; Cordova, Cunningham, Carlson, & Andrykowski, 2001; Affleck, Tennen, Croog, & Levine, 1987; Laerum, Johnsen, Smith, & Larsen, 1987), in those who have experienced accidents (Joseph, Williams, & Yule, 1993), and in those experiencing bereavement (Calhoun & Tedeschi, 1989-1990; Edmonds & Hooker, 1992; Hogan, Morse, & Tason, 1996; Lehman et al., 1993). Additionally, this phenomenon has been found in populations less frequently thought of as experiencing these highly stressful life circumstances (i.e. college students experiencing negative events (Park, Cohen & Murch, 1996)). Notably relevant to the current study is documentation of this phenomenon in parents coping with the medical problems of children (Abbott & Meredith, 1986; Affleck, Tennen & Gershman, 1985) as well as parents of children with autism (Elci, 2004; Phelps, Wuensch & Golden, 2009). While posttraumatic growth has been examined in a wide variety of populations, it has not yet been explored within the Williams syndrome care giving community.

There is an inherent loss with receiving a pediatric diagnosis in that the parent must grieve when coming to terms with the reality of their child's condition. This loss involves both grieving some of the expectations that the parent had for the child that are no longer realistic as well as coping with the inevitable unexpected changes in their lives. Such an experience is clearly sufficient in challenging the parent's assumptive beliefs about the world and creating a level of distress. While a high level of distress is acknowledged, Tedeschi and Calhoun (1995;

1998) have shown that positive psychological change can occur as a parallel process along with this distress.

While the potential negative psychological effects of caring for a child with a disability has been well documented in the literature, the positive psychological effects have not been sufficiently established. The amount of information specifically on caregivers of children with Williams is even sparser and warrants further investigation. Much of the established research centers around caregiver well being and conceptualizes positive change as an absence of depressive symptoms (Duvdevany & Abboud, 2003; Shin and Crittenden, 2003) and other negative outcomes. For example, maternal coping style was evaluated and found to be a significant predictor of wellbeing among caregivers of children with an intellectual disability (Kim, Greenberg, Seltzer & Krauss, 2003). Maternal stress levels have also been utilized as outcome variables in this area of research (Hodapp, Ricci, Ly & Fidler, 2001). Only recently have calls for the direct assessment of positive outcomes in these populations emerged (Dykens, 2006; Konrad, 2006).

Early research in this area has found that parents of children with disabilities (Krauss & Seltzer, 1993) and those with medical illnesses (Patterson & Leonard, 1994) described benefits as well as drawbacks when discussing their differing caregiving experiences. Many of the benefits described reflect constructs that we now classify under the overarching construct of posttraumatic growth, including a shift in priorities and more durable interpersonal relationships (Affleck, Tennen & Gershman, 1985). Early theorists have linked the cognitive processes involved in the search for meaning making to cognitive adaptation theory, looking at the processes as an active coping strategy (Taylor, 1983). The cognitive processes involved in this benefit finding and adjustment process have also been associated with better adjustment

outcomes (Pakenham, Sofronoff, Samios, 2004). One of the caregiving populations that the phenomenon of growth has been more frequently explored in is parents of children with an acquired disability. These disabilities included paraplegia, limb amputation, visual and auditory impairment, motor impairment and visual scarring. All occurred in previously healthy children as a result of acute encephalitis, stroke, burns, falls, motor vehicle accidents, and complications from cancer treatment.

Overwhelmingly, caregivers in these populations have identified a change in how they perceive themselves. They describe these personal identity changes as informing attitudes about themselves and their own abilities to handle a child with special needs. Many mothers have described feeling a compelling need to remain strong in order to provide the best care possible for their child (Konrad, 2006). Interestingly, these events were also viewed as offering an unanticipated opportunity to enhance caregiving self-efficacy (Frantz et al., 2001; McMillen, 1999), as they necessarily provided novel and complex tasks needing to be mastered. This increase in caregiver self-efficacy allowed mothers to view themselves as stronger and able to handle complex demands, even in spite of their difficult circumstances (Frantz et al., 2001; Konrad, 2006). These mothers described a greater level of compassion and empathy for others in similar situations, findings consistent with a greater sense of interpersonal connectedness described by Calhoun & Tedeschi (2001). In addition to this facet of posttraumatic growth, mothers also described finding meaning in their experiences. Perhaps the most striking manifestation of this was gratitude for being able to continue to care for their child and still having the child in their lives, even if that life was now drastically different from before the trauma. They also described a newfound appreciation for the preciousness of life and a reconnection or reformulation of religious and or spiritual beliefs (Konrad, 2006).

Posttraumatic growth has also been documented among caregivers of children facing other exceptional challenges. Early work found these constructs in parents of high-risk infants (Affleck, Tennen & Gershman, 1985) and caregivers of children with an intellectual disability (Abbott & Meredith, 1986). Additionally, a significant growth presence was documented among caregivers of children with an autism spectrum disorder (Elci, 2004; Phelps, Wuensch & Golden, 2009), caregivers of children with cerebral palsy (Raina et al., 2005), and among mothers of children who had received a stem cell transplant (Rini, et al., 2004). As would be expected, the phenomenon is also well documented among caregivers of children and adolescents with cancer (Barakat, Alderfer & Kazak, 2006; Barakat, Kunin-Batson & Kazak, 2005; Kazak, Stuber, Barakat & Meeske, 1996). Prevalence rates for posttraumatic growth across populations vary widely with the average range being between 30 and 80 percent of survivors (Tedeschi & Calhoun, 2006). While this range is notably large, findings have been more focused within the pediatric caregiving literature, with prevalence rates typically between 80 and 90 percent (Chernoff, List, DeVet, & Ireys, 2001; Barakat, Alderfer, & Kazak, 2006). Even though these findings are not exhaustive, it is clear that facing the reality of caring for a child with exceptional needs is both distressing and presents the opportunity for personal growth and development. Because of the medical, developmental, and psychological similarities of Williams syndrome to many of the above listed diagnoses, it is hypothesized that levels of growth will be similar to the above described populations and that this population is appropriate for the study of such a phenomenon.

It is clear that caring for a child with a developmental disability is a challenging task that involves significant caregiver burden and distress. What is often overlooked is the paradoxical phenomenon illustrated by these increased feelings of vulnerability and distress with new found

personal growth precipitated by their child's diagnosis (Janoff-Bulman, 1992; Konrad, 2005; McMillen, 1999). These areas of growth that have been described are consistent with Tedeschi and Calhoun's factor structure of posttraumatic growth. Empirical work with posttraumatic growth and caregivers of children with Williams has only begun to emerge, although processes can be assumed to be similar to caregivers of children with other disabilities and medical challenges based on the similarity of their experiences. Recently themes involved in caring for a child with Williams were identified and suggest an empirical evaluation of posttraumatic growth within this population (Scallan, Senior & Reilly, 2010). Providing further support for the examination of growth within these caregiver populations is a recent review comparing rates of PTG across empirical studies. Ulman and colleagues found that mothers of children with developmental disabilities reported the 5<sup>th</sup> highest rates of posttraumatic growth on the posttraumatic growth inventory among 23 studies examining this outcome in a wide variety of populations (2008). As such, caregivers of children with Williams seem to be an ideal population for the examination of posttraumatic growth processes and potential extensions of the proposed model.

### **Posttraumatic Growth and Health Behaviors**

As noted earlier, Tedeschi and Calhoun acknowledge that their model is not complete and that alternative paths to growth may exist (McMillan, 2004). Among the additions some argue should be considered is the development of better health behaviors. Research that has come out of this idea has been primarily qualitative but a theme has begun to emerge; that those who report significant posttraumatic growth are also reporting taking better care of themselves. The majority of this work however, has been conducted with HIV positive men, who have been predominately white and middle class. While the sample alone limits the generalizability of the

findings, it warrants further investigation to see if this relationship exists when prognosis is not necessarily associated with these health care behaviors. Despite these potential limitations, the findings are compelling. Improvements were noted in a variety of areas among HIV positive homosexual men including better diet, decrease in smoking behavior, stress reduction, improved sleep behaviors, and actively seeking better health care (Gloerson et al., 1993). Bower and colleagues (1998) reported improved AIDS related mortality rates in individuals reporting posttraumatic growth. Finally, Siegel & Schrimshaw (2000) reported less frequent drug and alcohol use, a reduction in smoking behaviors, fewer risky sexual behaviors, improvements in diet and overall health awareness among women who had been diagnosed with AIDS. These authors suggest expanding the conceptualization of stress related growth to include similar behavior changes.

Research in other populations seeking to examine the relationship between posttraumatic growth and health behaviors has focused on substance use. Substance use and abuse are relatively common among those having experienced trauma, with dependence being the most common comorbidity with posttraumatic stress disorder (Kessler, et al., 1995; Kulka, et al., 1990). As these concerns are prevalent within those having experienced some sort of trauma, substance use and dependence function as powerful outcome variables when examining correlates of posttraumatic growth. McMillen (2004) found that survivors of adversity experienced many positive changes as a result of their experience with trauma that did not fit within the traditional model proposed by Tedeschi and Calhoun. Among these changes was resisting the use of drugs and alcohol. Additionally, Milam, Ritt-Olson, & Unger (2004) examined adolescents who had experienced a variety of traumatic events and found that



posttraumatic growth was predictive of lower rates of substance abuse. The authors acknowledge however that the overall base rates of substance abuse within their sample were notably low.

It is also of note that posttraumatic growth requires significant cognitive processing that is largely abstract in nature. It is possible that the cognitive processing required for growth to occur is impeded by substance use and abuse. The uses of alcohol and cocaine have been shown to have detrimental effects on cognition (Beatty et al., 1995; Hoff et al., 1996; Loberg, 1986; O'Malley et al., 1992), with the user being at an elevated risk of neurodegeneration and appearance of neurocognitive deficits (Zeigler et al. 2004). With this in mind, the likelihood of such a relationship also existing within a variety of populations is probable.

Finally, Affleck and colleagues (1987) found posttraumatic growth to be related to a lower frequency of second heart attacks in a population of first time acute MI patients. These health-behavior findings support the idea that positive change can be one outcome of a significant negative life event. These findings also provide support for the examination of further extensions of the model proposed by Tedeschi and Calhoun. These ideas are congruent with Folkman's revised model of stress and coping, accounting for potential positive outcomes in response to stressful life events. While this area of investigation is in its infancy, findings have the potential to inform a more complete conceptualization of the growth process as well as potential interventions for health promotion among survivors.

## **Summary**

Primary caregivers of children with Williams syndrome face a great number of challenges, above and beyond what a parent of a typically developing child would face. The developmental, medical, and psychological concerns that these individuals present with require that the caregiver be able to readily adapt to a number of exceptional challenges, all while

coming to terms with the diagnosis and grieving the perceived loss of a typical child. Receiving a Williams diagnosis and coming to terms with the reality of this diagnosis is sufficient to shatter an individual's assumptive views of the world, produce significant distress, and provide an opportunity for schema revision and growth to occur.

While a great deal of research has focused on negative outcomes from stressful life events, there have recently been calls for an examination of more positive outcomes of these experiences. Tedeschi and Calhoun (2004) have posited that posttraumatic growth is an additional outcome of the stress and coping process. The proposed study aspires to evaluate a proposed pathway for the development of posttraumatic growth, examining one process by which social support may facilitate this outcome.

There is still a debate in the literature surrounding a complete conceptualization and accurate measurement of social support. Findings related to social support and posttraumatic growth have been varied and it is possible that this is due to the examination of different types of social support and a lack of consistency in measurement. The present study provides an integration of the social support and posttraumatic growth literatures in order to aid in developing a more complete conceptualization of these processes. Additionally, little is known about the exact mechanisms by which social support actually promotes posttraumatic growth. Many hypotheses have been discussed but none have been empirically examined. As such, social support is a construct that has not been given adequate attention in relation to posttraumatic growth and the proposed study would fill a significant gap in the literature in this manner. Further, Tedeschi & Calhoun's proposed model is widely accepted and used to inform current research; however, few components of the model have been empirically evaluated. In order to better inform and advance future studies, this model must be further evaluated; another potential

contribution of the proposed study. Finally, it has been acknowledged that this model of growth is not necessarily complete and research has suggested that improved health behaviors may be related to posttraumatic growth. Examining this potential relationship would provide a basis for further evaluation of this hypothesis.

### **Specific Aims**

Given this background, several aims are proposed:

1. Evaluate reported levels of posttraumatic growth among primary caregivers of children with a developmental disability, specifically Williams Syndrome.
2. To empirically evaluate a portion of Tedeschi & Calhoun's 2004 model looking at the trajectory of posttraumatic growth development.
3. To examine the potential relationship between posttraumatic growth and self-care behaviors, namely exercise, smoking, and drinking behaviors.

### **Hypotheses**

1. Levels of reported posttraumatic growth among caregivers of children with Williams syndrome will show a range of responses and will be similar to those found in parents coping with other pediatric concerns such as cancer, autism, and other physical handicaps. Specifically, caregivers will report a mean score at or above a 45 on the PTGI, indicative of a moderate level of growth (Morris et al, 2005).
  - a. Amount of time elapsed since receiving a diagnosis will relate to posttraumatic growth in WS caregivers such that having more time to cognitively process the diagnosis will relate to greater levels of PTG.
2. Deliberate rumination will act as a mediator between perceived social support and posttraumatic growth.

- a. There will be a significant association between social support and posttraumatic growth such that higher levels of perceived social support will be related to higher levels of posttraumatic growth
  - b. There will be a significant association between perceived social support and deliberate rumination such that higher levels of perceived social support will be related to higher levels of deliberate rumination.
  - c. There will be a significant association between deliberate rumination and posttraumatic growth such that higher levels of deliberate rumination will be related to higher levels of posttraumatic growth.
  - d. The hypothesized relationship between perceived social support and posttraumatic growth will be significantly reduced when the overall meditational model is evaluated using a multiple regression analysis.
3. There will be a significant association between posttraumatic growth and self-care behaviors such that caregivers reporting higher levels of posttraumatic growth will also report better self care behaviors.
    - a. There will be a significant association between posttraumatic growth and exercise behaviors such that higher levels of growth will be related to greater exercise frequency.
    - b. There will be a significant association between posttraumatic growth and smoking behaviors such that higher levels of growth will be related to less frequent cigarette smoking behavior.

- c. There will be a significant association between posttraumatic growth and drinking behaviors such that higher levels of growth will be related to less frequent drinking behavior.
- d. There will be a significant association between posttraumatic growth and sleep behaviors such that higher levels of growth will be related to increased amount of sleep obtained and less frequent night time awakenings

## **Methods**

### **Participants**

Participants for the study were recruited through the Williams Syndrome Association Registry. This is a national network of families who are members of the Williams Syndrome Association (WSA) and who are interested in participating in research projects focusing on this disorder. All members have been affected in some way by Williams (i.e. friend, family member or child). The Williams Syndrome Association is a non-profit organization that is dedicated to enriching the lives of those affected by providing information, support, education, and research endeavors. The Michigan based organization serves individuals throughout the United States and is primarily an internet-based organization.

Participants received an email through the registry's listserve inviting primary caregivers to participate in this study of caregiver adjustment to a WS diagnosis. This email (Appendix A) was sent from the research team and provided contact information in addition to a link to the survey website. Those interested in participating clicked on a link and were able to complete all questionnaire information on a secure internet-based survey site. The same information was also posted on the association's website with the link to the study and research team contact information.

Eligible participants were over the age of 18, the primary caregiver for an individual with Williams syndrome, and had the ability to read and write in the English language. All instructions and questionnaires were written at or below a 6<sup>th</sup> grade reading level.

Sample size estimates were calculated based on a range of two to four predictors in the regression equation. Two predictors allowed for inclusion of one covariate along with the independent variable in the regression equation, while four predictors allowed for the inclusion of two covariates in the mediational model. The minimum sample size to detect a medium effect size ( $f^2 = .15$ ) with a power level of .80 and alpha of .05 varied from 67 participants (with two predictors) to 76 participants (with three predictors) to 84 participants (with four predictors). The targeted sample size for the proposed study was 84 participants.

## **Procedure**

Participants considered eligible for the study included anyone who identified as a primary caretaker of an individual diagnosed with WS. An initial email to the WSA listserv introduced the nature of the study, briefly described involvement if the caregiver chose to participate, and identified study goals. A link to the online survey was provided in the email. Participants followed the link and completed the questionnaires at a time and location that was convenient for them. This listserv reaches individuals who are themselves affected by WS or who care for those affected. At the time when study data was collected, there were 636 individuals with WS participating in the registry. Current research shows that 74 percent of Americans have access to the internet and 61 percent used this access to gather health related information (Fox & Jones, 2009). While this method of recruitment does not capture all individuals affected by WS, it is able to access a vast majority. Additionally, previous research has suggested that participants preferred online data collection methods over paper and pencil and that online assessment was

more reliable (Velikova et al., 1999). It was expected that all participants had access to computers; however, in cases when they did not, participants could opt to complete all measures through traditional paper and pencil methods. They could also opt to participate via this method if it was preferred over online methods, regardless of whether or not they had email access. In this case, the research team would mail the participant study questionnaires and modified consent along with a postage paid envelope in order to remove any costs to the participant for completing the study. All caregivers elected to complete the survey via the secure internet site. As such, post hoc analyses were not needed in order to determine differences between groups electing to complete the study via traditional versus electronic methods.

Because of the primarily internet-based nature of this study a full informed consent procedure was not a feasible option. Prior to obtaining access to the survey, participants were taken to a web page that provided them with consent related information. Information provided was consistent with the requirements of the VCU IRB for exempt research protocols. The consent-related information that was presented to potential participants included but was not limited to risks, benefits, right to refuse participation, right to withdraw at any time and appropriate contact information. Participants then had the option to click 'continue', indicating understanding of the information presented and an informed desire to participate, or a 'decline' button. By clicking the continue button, the participant was then directed to the study questionnaires. Once the participant had completed study questionnaires, the host software directed them to a final survey monkey page. This page thanked the participant for completing the surveys and invited them to follow a link to a secure external site if they wished to be entered into a gift card drawing. Participants were given the opportunity to provide an email address to be entered into a drawing for a \$100 amazon.com gift card and/or to be informed of study

results. Email addresses were separated from data provided, kept in a locked database, and were not connected to survey information.

Online data were collected using Survey Monkey software and were hosted on VCU's survey server (<https://survey.vcu.edu>). This survey was only accessible during active recruitment and was protected using encryption and firewall technologies. All data obtained were kept confidential throughout the course of the study. Collected data were coded with an assigned ID number and examined only in the aggregate. All data were maintained in a secure, locked location. Nothing was shared with anyone outside of the research project. No private contact information was requested from participants, with the exception of the email address the participant could choose to provide to receive research results, to be contacted for future research opportunities, and/or to be entered into the gift card drawing. This way, there was no way to link participants to the information they provided. Providing email does create a minimal risk to the participant's complete confidentiality; however, precautions were taken to protect the participants. The email addresses were kept in a locked location that was separate from answers to the survey. Additionally, participants could choose not to answer any question or even stop participation at any time. Participants were assured that they would never be identified in any public presentation or publication of study results.

In order to maximize participation, follow-up email reminders providing information about the study and a link to the online survey were sent two weeks after the initial email and again two weeks after the reminder email. Additional follow up emails were not needed given the response rate from these two rounds of recruitment. Those who have completed the survey received these emails since they must be sent through the WSA list serve. These participants were simply thanked for their time and encouraged to ignore the email reminder.



## **Instrumentation**

**Demographics.** The demographic questionnaire (Appendix B) assessed gender, race/ethnicity, age, level of education achieved, level of education desired, income, number of children in family, birth order of child diagnosed with WS, age of child with WS, time since diagnosis, employment status, occupation, hours spent per week on special care for child with WS (i.e., doctor's appointments, occupational therapy, physical therapy, psychological counseling, etc.), support from educational systems, support from others, caregiver physical/mental/dental health care, and primary stressors.

**Posttraumatic Growth.** Tedeschi & Calhoun's (1996) 21-item measure was used to assess personal growth experienced as a result of having a child with a WS diagnosis (Appendix C). This measure asked participants to indicate the extent to which they experienced a given change on a Likert scale of 0 (did NOT experience this change) to 5 (experienced this change to a great degree). The PTGI yielded a total score and scores for five factor derived subscales: New Possibilities, Relating to Others, Personal Strength, Spiritual Change, and Appreciation of Life. Internal consistency is high at .93 (Widows, Jacobsen, Booth-Jones, & Fields, 2005). An alpha value was calculated with the current sample and was found to be similar to previously reported estimates of reliability,  $\alpha = .94$ . Significant relationships were found between PTG and the majority of PTG subscales and all explored domains of rumination.

**Deliberate Rumination Scale.** Calhoun et al.'s (2000) 14-item measure was used to assess the self reported frequency of repeated thoughts about a life stressor, in this case the stress of caring for a child with Williams (Appendix D). Participants were asked to provide answers to the items focusing on their experience with receiving a diagnosis of WS for their child. The items provided a broad view of the cognitive work likely to be associated with the search for meaning and

resolution since it includes items assessing intrusive as well as actively engaged cognitive work. The same seven items were asked in two time frames: “soon after the event”, and “within the last two weeks”. Participants rated items on a four-point scale ranging from 1 (not at all) to 4 (often). Possible scores range from 7 to 28 for each time frame, with higher scores indicating more frequent rumination. Internal consistency was found to be high at .81 and .88 for rumination immediately after the event and within the past two weeks respectively (Calhoun, Cann, Tedeschi & McMillan, 2000). Alpha values based on the current sample were .75 and .78 respectively, indicating slightly lower yet similar estimates of reliability in the current sample.

***Medical Outcomes Study (MOS) Social Support Questionnaire.*** This measure was a brief (19-item), multidimensional, self-administered, social support survey that was developed for patients in the Medical Outcomes Study (MOS), a two-year study of patients with chronic conditions (Appendix E; Sherbourne, & Stewart, 1991). It is a comprehensive measure of different domains of social support (emotional, tangible, affectionate and positive social interaction) and has subsequently been used in studies of social support in primary caregiver populations (Grunfeld et al., 2004). Participants were asked to rate items on a 5 point likert scale from 1 (None of the time) to 5 (All of the time) asking how often each kind of support was available when needed. Alpha levels ranged between .91 and .97. Alpha for the current study was .92 indicating similar estimates of reliability of this measure in the current sample.

***Taking Care of Yourself Questionnaire.*** This measure was a revised scale from the original 27-item Prenatal Health Behavior Scale (Appendix F; Lobel, 1996). The earliest scale was developed through deliberations with professionals in the field of obstetrics as well as reviewing relevant literature (Lobel et al., 1999). Frequency of certain health behaviors such as smoking,

alcohol consumption, and exercise within the last two weeks were assessed using a Likert-like scale from 0 (never) to 4 (very often). Caregivers rated items on this scale which included, “In the last two weeks, how often did you: smoke cigarettes; drink alcohol, including wine, beer or liquor; exercise for at least 15 minutes?” Participants were also asked about different aspects of their sleep behaviors. The scale has been found to have acceptable reliability and has been used in previous research with parents (Lobel et al., 2000). Alpha for the current study was at the low end of the acceptable range at .62.

Internal consistency reliabilities for study scales and subscales can be viewed in Table 1.

Table 1

*Internal Consistency Reliability Estimates for Scales and Subscales*

Instrument	Alpha
Total Perceived Social Support	.98
Emotional Support, Perceived	.96
Tangible Support, Perceived	.91
Deliberate Rumination Scale	
Immediately after Diagnosis	.75
Within the past two weeks	.78
Posttraumatic Growth Inventory (PTGI)	
Total	.94
Appreciation of Life	.81
New Life Possibilities	.82
Personal Strength	.81
Spiritual Change	.93
Relating to Others	.84

## Results

All data analyses were completed using IBM’s Statistical Package for the Social Sciences (SPSS) – 20<sup>th</sup> Edition.

### Data Screening and Missing Data

A sample of 115 primary caregivers attempted participation in the study; however eleven caregivers provided extremely limited data and were excluded from analyses. Items with missing data were identified through the process of data screening. Participants were excluded from data analysis if more than 20% of items on a particular scale or subscale were missing. If less than 20% of items were missing, missing data were imputed using mean substitution. Means were based on the participant's scores for that particular scale or subscale. For two participants, missing data were imputed using mean substitution on scales measuring perceived social support. The majority of study participants completed all study questionnaires in their entirety and missing data was not of concern. An additional 14 caregivers reported that they were caring for individuals with Williams who were over 21 years of age. Child age distribution can be viewed in Table 2. Although results did not differ when these caregivers were included in analyses, only caregivers with children 21 and younger were included in study analyses.

Table 2

*Frequency Table – Child Age*

Child Age	Frequency
1	5
2	5
3	8
4	8
5	4
6	2
7	4
8	8
9	10
10	1
11	3
12	5
13	1
14	3
15	1
16	1

Table 2 (continued)

Child Age	Frequency
17	2
18	4
19	4
20	3
21	4

Participants completed study questionnaires online through Survey Monkey software. Therefore, no manual data entry was required. Prior to data analysis, appropriate steps were taken to check for errors in the data set. Frequencies were calculated and analyzed for all categorical variables. This was done in order to ensure that the minimum and maximum values for each item were within the acceptable response range. Descriptive statistics were run on all continuous variables in order to examine minimum, maximum, and mean values. All variables were found to be within the acceptable response range. The final sample used for data analysis was comprised of 90 primary caregivers of children with Williams syndrome.

### **Assumptions of Multiple Regression**

Assumptions of multiple regression analyses were verified through statistical analysis. Assessment for normality of the distribution along with outliers for each dependent variable was completed through visual inspection of histograms, normal probability plots, and box plots of the distribution. No violation of normality was detected. It was however discovered that the PTG scale had two respondents that reported scores at the scale's respective extremes. Upon the identification of these individuals, case-level data were examined for possible restricted responses, fit within the population, or error. There were no patterns or indicators to suggest error and no evidence of restricted response patterns, as there was limited response variability. As such, it was determined that these cases were part of the intended population and were not

removed from data analyses. Multicollinearity of target variables was also assessed to ensure that target variables were not highly correlated, thus measuring the same construct. This was assessed through correlations between variables. These correlations did not exceed .80 between any of the target variables and thus multicollinearity was not of concern.

### Descriptive Analyses

Means, standard deviations, and ranges for all measures used in analysis can be viewed in Table 3. The mean score on the posttraumatic growth inventory for the current study was 55.91 with a SD = 22.63. This mean is lower than the college aged sample on which the measure was normed (M = 71.48, SD = 21.66; Tedeschi & Calhoun, 1996) as well as lower than among bereaved parents (M=64.66, Engelkemeyer & Manvit, 2008). It is however higher than those reported by those with colorectal and breast cancer respectively (M = 43.8; SD = 29.6; Salsman et al., 2008; M = 49.0; SD = 25.7; Manne et al., 2004). Means for individual subscales were calculated, fell within expected limits, and can be found in Table 3.

Table 3

#### *Means, Standard deviations, and Ranges of Scales and Subscales*

Instrument	Mean	SD	Sample Range
Total Perceived Social Support	77.16	21.68	24 - 100
Emotional Support, Perceived	3.81	1.16	1.0 - 5.0
Tangible Support, Perceived	3.65	1.09	1.0 - 5.0
Deliberate Rumination Scale			
Rumination after Diagnosis	15.88	3.85	6.0 - 24.0
Rumination over last 2 weeks	12.96	4.13	6.0 - 23.0
Posttraumatic Growth Inventory			
Total	55.91	22.63	1-105
Appreciation of Life	9.73	3.96	0-15
New Life Possibilities	12.71	6.38	0-25
Personal Strength	12.30	4.97	0-20
Spiritual Change	3.66	3.33	0-10

Table 3 (continued)

Instrument	Mean	SD	Sample Range
Relating to Others	17.49	7.88	0-35
Taking Care of Yourself Questionnaire	13.92	4.07	3 -24
Exercise Frequency	1.98	1.45	0 - 4
Smoking Frequency	0.53	1.22	0 - 4
Alcohol Consumption	1.62	1.24	0 - 4
Adequate Sleep	2.02	1.22	0 - 4
Fatty Food Consumption	2.27	0.96	0 - 4

On the MOS social support survey, the mean for overall social support was 77.16 (SD = 21.68, range = 24 - 100). The range of responses was between one and five for both perceived emotional support and tangible support with means of 3.81 (SD = 1.16) and 3.65 (SD = 1.09) respectively. These findings are similar to values reported in a confirmatory study of the measure (M= 69.72, SD = 7.91).

The Deliberate Rumination Scale was broken down into rumination immediately following the traumatic event and rumination within the past two weeks. For Rumination occurring over the past two weeks, M= 12.96, SD =4.13. This is higher than rumination reported in the original study (Calhoun et al., 2000) with a M = 7.2, SD = 2.9. Rumination soon after the event was lower than that reported by Calhoun and colleagues (M= 20.7, SD = 4.5) with current findings yielding an M = 15.88 and a SD = 3.85. Current research utilizing this measure is limited and as such, direct comparisons are somewhat limited in their applicability.

Finally, descriptive statistics were run on the Taking Care of Yourself Questionnaire (M= 13.92, SD = 4.07). As only a subset of items from this questionnaire was examined, these means were also broken down on the item level. Ranges for all items were from 0 (never) to 4 (very often). Means are as follows; Exercise Frequency (M=1.98, SD=1.45), smoking frequency

( $M=0.53$ ,  $SD=1.22$ ), alcohol consumption frequency ( $M=1.62$ ,  $SD=1.24$ ), adequate sleep frequency ( $M=2.02$ ,  $SD=1.22$ ), and fatty food consumption ( $M=2.27$ ,  $SD=0.96$ ). These results are similar to results found in other caregiver studies in pediatric populations (Lobel, et al., 2008).

### **Preliminary Analyses**

Tests were conducted prior to analysis of hypotheses in order to examine whether any demographic variables were associated with the study's dependent variables. First, independent sample *t*-tests were conducted to examine the relations between caregiver gender and child gender with posttraumatic growth and its subscales. There were no significant differences between male and female caregivers on overall posttraumatic growth or its subscales. These results can be viewed in Appendix G. While significant differences were not found within this population, it is also of note the sample was predominately female, with only 6 participants identifying as male. While typical of pediatric caregiver studies, this imbalance makes differences exceptionally difficult to detect. However, given that there were no significant differences in results when males were and were not included in the data set, study analyses were conducted with male caregivers included in the data set. Significant differences between having a male or female child with WS and posttraumatic growth were also examined. Overall posttraumatic growth or subscales did not differ based on child gender. Given these results, gender was not included as a potential covariate in hypothesis testing.

Pearson correlations were calculated in order to determine if significant associations were present between caregiver age, child age, time since diagnosis and overall posttraumatic growth and subscales. Caregiver age, child age, and time since diagnosis were not significantly correlated with participants' scores on the PTGI or its subscales. As a result, caregiver age, child



age, and time since diagnosis were not included as a potential covariate in hypothesis testing. All calculated Pearson correlations can be viewed in Appendix G.

One-way ANOVAs were conducted to determine if caregiver ethnicity, education level, income, or marital status were associated with any of the outcome variables. Caregiver income and marital status were not associated with PTG or any of the described subscales. Relationships were found between education level and spiritual change following a diagnosis of WS as well as between caregiver ethnicity and both overall PTG and an increased sense of personal strength. As such, these variables were controlled for in relevant analyses. Because the vast majority of the sample size identified as Caucasian, ethnicity groups were defined as Caucasian and Other with 'Others' being comprised primarily of individuals identifying as African American, Biracial, or Hispanic. Results of hypothesis testing did not change when all individuals were included in analyses compared to when those identifying as 'other' were removed from analyses. Given these findings, all participants were included in study analyses. All results are presented in Appendix G.

### **Correlations Between Variables Used in Analyses**

Pearson correlations were computed to examine the inter-relations among variables used in hypothesis testing. All correlations can be seen in Table 4. As anticipated, significant relationships were found between PTG and all domain subscales at the  $p < .01$  level. All relationships were in the expected, positive direction. Overall PTG and the relating to others subscale also were significantly related to Perceived support; however this perceived support was not related to other sub scales of PTG. Finally, significant relationships were not found between PTG or subscales and the majority of self-care behaviors. Exceptions are detailed in Table 4.

Table 4

*Correlation Matrix*

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
PTG I Total	1															
New Poss.	.886**	1														
Relating Others	.893**	.713**	1													
Appreciation of life	.821**	.644**	.639**	1												
Spiritual Change	.678**	.565**	.502**	.462**	1											
Personal Strength	.89**	.726**	.717**	.789**	.528**	1										
Perceived Support	.23*	.211	.368**	.072	.038	.103	1									
Intrusive Rum . Soon After	.243**	.292**	.292**	.261*	.118	.25*	-.017	1								
Deliberate Rum . Soon After	.383**	.398**	.398**	.315**	.357**	.344**	-.120	.614**	1							
Intrusive Rum . Recent	.273**	.327**	.327**	.299**	.194	.181	-.163	.616**	.449**	1						
Deliberate Rum . Recent	.492**	.575**	.575**	.37*	.341**	.390**	-.059	.481**	.521**	.563**	1					
Exercise Freq	.184	.176	.285**	.086	-.071	.129	.37**	-.043	-.049	-.192	.026	1				

Table 4 (continued)

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.
Smoking Frequency	.006	.086	-.05	-.066	-.80	.048	-.061	.038	.042	-.028	-.156	-.08	1			
Drinking frequency	.052	.063	.118	.006	-.198	.095	.18	-.111	-.194	-.174	-.194	.331**	-.053	1		
Hours Sleep Obtained	.086	.025	.123	.055	.056	.076	.319*	-.125	-.076	-.133	-.021	.174	-.151	.017	1	
Times Awakened at Night	.031	-.217	-.11	.169	-.086	.068	-.337*	.104	.155	.327*	.138	-.212	.19	-.13	-.20	1
Bothered by Night time Awakenings	-.228	.063	.118	-.096	.015	-.243*	-.396*	.126	.202	.259*	.075	-.301**	-.030	-.119	-.234*	.401**

\*\* p<.01, \* p<.05

Intrusive and deliberate rumination were examined in relation to other target variables both soon after diagnosis and recently. As expected, all rumination styles and time points were significantly correlated with PTG and the majority of sub domains except as detailed above. Also as expected, all types of rumination were highly correlated with one another.

While perceived social support was found to be related to overall PTG and relating to others, it was also found to be related to a number of self-care behaviors. These correlations can be viewed in Table 4 and are consistent with predictions and previous findings.

Finally, relations between a number of health behaviors and other target variables were examined, were primarily consistent with predictions, and can be viewed in Table 4.

### Sample Characteristics

Table 5 summarizes the descriptive statistics for sociodemographic characteristics of the study population. Participants came from 38 US States and 5 Canadian provinces. The majority of the respondents were female (92.3%), all but two of whom were the mother of a child with WS. Two primary caregivers were grandmothers, six were fathers. On average, caregivers were 43.56 years of age ( $SD = 9.916$ , range = 27-77) and children with WS were 12.23 years of age ( $SD = 6.131$ , range = 1-21). Female children with WS comprised 43.7% of the sample. The majority of participants were Caucasian (92.2%) with a slightly smaller percentage of children with WS identifying as Caucasian (84.3%). The majority of participants were married (87.5%), a rate much higher than in the general population and uncharacteristic for caregivers of children with chronic illness. Given the similarities between WS and Down syndrome, the literature for this similar population was consulted and a higher rate of intact families among this group was also well documented (Urbano & Hodapp, 2007b). Caregivers were highly educated with 40% holding a college diploma, 12.6% completing some graduate school, and an additional 24.3% having earned a graduate degree. Further, approximately 70% of caregivers reported household incomes greater than \$60,000 annually and less than 3% made less than \$25,000 annually.

Table 5

*Descriptive Statistics*

	%	n
Caregiver Gender		
Female	92.3	96
Caregiver Relationship to WS Child		
Mother	91.3	95
Father	6.7	7
Grandmother	1.9	2
Child Gender		
Female	43.7	46
Caregiver Ethnicity		
Caucasian	92.2	96

Table 5 (continued)

	%	n
Latino	3.9	4
Asian American	1.9	2
African American	1	1
Biracial	1	1
<b>Child Ethnicity</b>		
Caucasian	84.3	88
Latino	4.9	5
Asian American	1	1
African American	1	1
Biracial	3.9	4
Other	4.9	5
<b>Caregiver Marital Status</b>		
Married	87.5	91
Separated	2.9	3
Divorced	7.7	8
Widowed	1	1
Living with non-parental partner	1	1
<b>Education Level</b>		
HS diploma	7.8	8
Some college	15.5	16
College diploma	39.8	42
Some graduate school	12.6	13
Graduate degree	24.3	25
<b>Annual Income</b>		
<\$25,000	2.9	3
\$25,001 - 44,999	17.3	18
\$45,000 – 60,000	10.6	11
> \$60,000	69.2	72

### Testing of Hypotheses

**Hypothesis 1.** Levels of reported posttraumatic growth among caregivers of children with Williams syndrome will show a range of responses and will be similar to those found in parents coping with other pediatric concerns such as cancer, autism, and other physical handicaps. Specifically, caregivers will report a mean score at or above a 45 on the PTGI, indicative of a moderate level of growth (Morris et al, 2005).

- a. Amount of time elapsed since receiving a diagnosis will relate to posttraumatic growth in WS caregivers such that having more time to cognitively process the diagnosis will relate to greater levels of PTG.

**Analysis of Hypothesis 1.** A variable was created to calculate the summation score for responses on the Posttraumatic Growth Inventory. Similar variables were created to calculate summation scores for each subscale of the PTGI. Means and standard deviations were calculated for each of these six variables. For the overall score on the PTGI among caregivers of children with WS,  $M = 55.91$ ,  $SD = 22.63$ . These findings are consistent with the hypothesis that reports of growth would exceed a mean score of 45, indicative of moderate growth within this population. Results for each subscale were also in the expected range and are as follows; strengthened interpersonal relationships ( $M=17.49$ ,  $SD= 7.88$ ), new life possibilities ( $M=12.72$ ,  $SD=6.38$ ), increased personal strength ( $M=12.31$ ,  $SD=4.97$ ), spiritual change ( $M=3.66$ ,  $SD=3.33$ ), and appreciation for life ( $M=9.73$ ,  $SD=3.96$ ). Findings are further detailed in Table 5. These results were found to be similar to analyses of PTG in other pediatric caregiver populations. Parents of children with an autism spectrum disorder reported slightly higher levels of PTG ( $M=60.9$ ,  $SD=16.15$ ) while parents coping with NICU hospitalization reported slightly lower PTG ( $M=51.35$ ,  $SD=23.70$ ). Parents who had lost their children have also been studied and reported means of PTG between 60.1 (Polantinsky & Esprey, 2000) and 64.66 (Endelkemeyer & Marwit, 2008). Subscale means were also consistent with previously reported findings. Caregivers of individuals with cancer reported means and standard deviations as follows; appreciation for life ( $M=10.50$ ,  $SD=3.61$ ), new life possibilities ( $M=13.50$ ,  $SD=5.47$ ), personal strength ( $M=12.24$ ,  $SD=5.03$ ), spiritual change ( $M=5.77$ ,  $SD=3.00$ ), and strengthened interpersonal relationships ( $M=22.67$ ,  $SD=8.85$ ) (Tallman, 2011). Reported PTG in caregivers of

children with Williams syndrome were within these expected ranges and current study findings are consistent with previous research.

As amount of time elapsed since receiving a diagnosis was not found to be correlated in the current study with PTG, further analyses were not completed in order to examine this aspect of the hypothesis.

**Hypothesis 2.** Deliberate rumination will act as a mediator between perceived social support and posttraumatic growth.

- a. There will be a significant association between social support and posttraumatic growth such that higher levels of perceived social support will be related to higher levels of posttraumatic growth
- b. There will be a significant association between perceived social support and deliberate rumination such that higher levels of perceived social support will be related to higher levels of deliberate rumination.
- c. There will be a significant association between deliberate rumination and posttraumatic growth such that higher levels of deliberate rumination will be related to higher levels of posttraumatic growth.
- d. The hypothesized relationship between perceived social support and posttraumatic growth will be significantly reduced when the overall mediational model is evaluated using a multiple regression analysis.

**Analysis of Hypothesis 2.** According to Barron & Kenny (1986), four conditions must be met in order for a mediation effect to exist. First, the independent variable, perceived social support, must be significantly related to the dependent variable, posttraumatic growth. Second, perceived

social support must be significantly related to the proposed mediator variable, deliberate rumination. Third, change in deliberate rumination must be significantly related to posttraumatic growth. Finally, after controlling for deliberate rumination, the relationship between social support and posttraumatic growth must be significantly reduced.

A hierarchical multiple regression analysis was first conducted to examine the relation between perceived social support and posttraumatic growth. As caregiver ethnicity was previously found to be related to overall posttraumatic growth, it was entered in the first step of the regression analysis. This was followed by posttraumatic growth in the second step and perceived social support in the third. The overall model was significant,  $F(2,73) = 2.488$ ,  $p = .029$ . The more support that caregivers of children with WS perceived in their lives, the greater posttraumatic growth they reported. Step one of the model shows an insignificant association between caregiver ethnicity and posttraumatic growth, with caregiver ethnicity accounting for 0.1% of the variance,  $F(1,73) = .003$ ,  $p > .10$ . Step two of the model indicates that perceived social support significantly predicted 6.5% of the variance in posttraumatic growth beyond the small portion accounted for by caregiver ethnicity,  $\Delta F(1, 71) = 4.973$ ,  $p = .02$ . Examination of the beta weights indicated that the more social support that a caregiver perceived ( $\beta = .262$ ,  $p = .029$ ), the more posttraumatic growth they tended to report. This is above and beyond the effect of caregiver ethnicity ( $\beta = .061$ ,  $p > .50$ ). These findings indicate that the first portion of this hypothesis is supported and further investigation of the mediational model is indicated.

The second step in evaluating the hypothesized mediational model involved conducting a second hierarchical multiple regression analysis to examine the relationship between perceived social support and deliberate rumination. Caregiver ethnicity was again entered in the first step of the regression analysis, followed by perceived social support and deliberate rumination



respectively. The overall model was not significant,  $F(2,72) = 0.143$ ,  $p = .867$ , indicating that the more support caregivers perceived was not predictive of increased deliberate rumination. Step one again shows an insignificant association between caregiver ethnicity and deliberate rumination accounting for 0.0% percent of the variance,  $F(1,72) = .032$ ,  $p = .86$ . Step two of the model indicates that perceived social support predicted 0.4% of the variance in deliberate rumination,  $\Delta F(2, 70) = 0.143$ ,  $p = .87$ . These findings indicate that the second portion of this hypothesis is not supported and further evaluation of the proposed mediational model is not indicated. Subscales of social support were also examined in the context of this mediational model and were found to predict overall posttraumatic growth, but were not found to predict deliberate rumination.

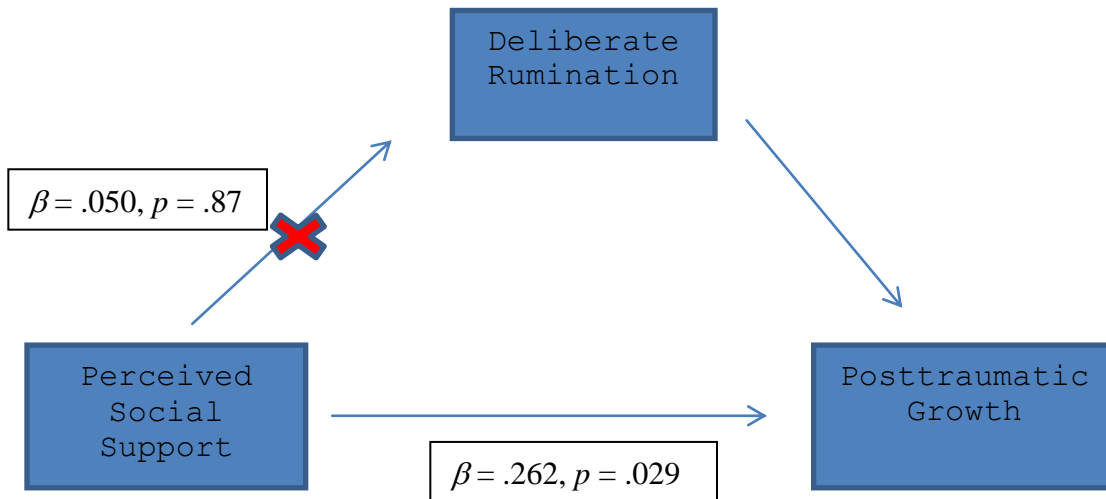


Figure 2. Illustration of proposed Mediational Model with results

Given the current debate in the literature regarding type and timing of rumination implicated in the process of posttraumatic growth, post hoc exploratory analyses were conducted to ensure that a different aspect of ruminative style was not more supportive of this model. These

results are detailed in Table 6. Intrusive rumination was examined both soon after diagnosis and within the two weeks prior to study completion. The change in intrusive rumination was also looked at within the context of this model and was computed by subtracting recent intrusive rumination from intrusive rumination soon after diagnosis with positive scores indicating a decrease in intrusive rumination over time. None of these three types of intrusive rumination were significant within the context of the mediational model. The same non-significant results were found for deliberate rumination when evaluated at the same time points within the context of the proposed model. Change in deliberate rumination was calculated by subtracting deliberate rumination soon after diagnosis from recent deliberate rumination, with higher scores indicating an increase in deliberate ruminative processes over time. As rumination defined in different contexts and at different time points was not significantly associated with perceived social support, further analyses were not conducted in relation to evaluating the proposed mediational model.

Table 6

*Summary of Hierarchical Regression Analyses examining Rumination in relation to Perceived Social Support*

Variable	df	R <sup>2</sup>	ΔR <sup>2</sup>	ΔF	B	SE B	β	t
Predicting Deliberate Rumination Recently								
Step 1	1, 72	.000	.000	0.032	-.095	.535	-.021	-.178
Caregiver Ethnicity								
Step 2	2, 72	.004	.004	.255	-.147	.292	-.062	-.505
Perceived Social Support								
Predicting Deliberate Rumination Soon After Diagnosis								
Step 1	1, 71	.006	.006	.424	.311	.477	.078	.651
Caregiver Ethnicity								
Step 2								

Table 6 (continued)

Variable	df	R <sup>2</sup>	ΔR <sup>2</sup>	ΔF	B	SE B	β	t
Perceived Social Support	2, 71	.017	.011	.744	-.261	.251	-.105	-.863
Predicting Change in Deliberate Rumination								
Step 1 Caregiver Ethnicity	1, 70	.009	.009	.602	-.389	.501	-.093	-.776
Step 2 Perceived Social Support	2, 70	.011	.002	0.163	.110	.273	.050	.404
Predicting Intrusive Rumination Recently								
Step 1 Caregiver Ethnicity	1, 72	.015	.015	1.104	.495	.471	.123	1.051
Step 2 Perceived Social Support	1, 71	.034	.019	1.389	-.291	.247	-.141	-1.179
Predicting Intrusive Rumination Soon After Diagnosis								
Step 1 Caregiver Ethnicity	1, 70	.001	.001	.046	.100	.467	.026	.214
Step 2 Perceived Social Support	1, 69	.001	.000	.013	-.029	.248	-.014	-.116
Predicting Change in Intrusive Rumination								
Step 1 Caregiver Ethnicity	1, 71	.014	.014	.965	-.395	.402	-.117	-.982
Step 2 Perceived Social Support	2, 71	.039	.025	1.799	.283	.211	.162	1.341

\*All p values were greater than .10 for the above regression analyses

**Hypothesis 3.** There will be a significant association between posttraumatic growth and self-care behaviors such that caregivers reporting higher levels of posttraumatic growth will also report better self-care behaviors.

- a. There will be a significant association between posttraumatic growth and exercise behaviors such that higher levels of growth will be related to greater exercise frequency.

- b. There will be a significant association between posttraumatic growth and smoking behaviors such that higher levels of growth will be related to less frequent cigarette smoking behavior.
- c. There will be a significant association between posttraumatic growth and drinking behaviors such that higher levels of growth will be related to less frequent drinking behavior.
- d. There will be a significant association between posttraumatic growth and sleep behaviors such that higher levels of growth will be related to increased amount of sleep obtained and less frequent night time awakenings

### **Analysis of Hypothesis 3**

Given the emerging nature of the literature surrounding posttraumatic growth and health behaviors, exploratory analyses were conducted in order to determine if posttraumatic growth was associated with improvements in identified health behaviors. First, a multiple regression analysis was conducted to examine the relationship between posttraumatic growth and frequency of exercise behaviors. As caregiver ethnicity was previously found to be related to overall posttraumatic growth, it was entered in the first step of the regression analysis. This was followed by posttraumatic growth in the second step and frequency of exercise behavior in the third. The overall model was not significant,  $F(2,86) = 1.315$ ,  $p = .274$ ,  $\beta = .174$ ,  $p = .110$ . This suggests that caregiver report of posttraumatic growth is not predictive of frequency of engagement in exercise behaviors. Because the overall model was not significant, subscales of PTG were not examined as predictors of exercise behavior frequency.

Second, a multiple regression analysis was conducted to examine the relationship between posttraumatic growth and frequency of smoking behaviors. Caregiver ethnicity was again entered into the first step of the regression analysis. This was followed by posttraumatic growth in the second step and frequency of smoking behaviors in the third. The overall model was not significant,  $F(2,86) = 0.013$ ,  $p = .987$ ,  $\beta = -.016$ ,  $p = .881$ , suggesting that posttraumatic growth is not a reliable predictor of smoking behavior. Because the overall model was not significant, subscales of PTG were not examined as predictors of smoking behavior frequency. It is of note that the majority of participants in this study reported that they did not engage in smoking behavior, however, a significant portion, 18%, reported smoking at least on occasion. As 19.3% of Americans engage in smoking behaviors (CDC, 2010), the current sample was considered representative of the overall population and analyses were determined to be appropriate to conduct.

Third, a multiple regression analysis was conducted to examine the relationship between posttraumatic growth and frequency of drinking behavior. Caregiver ethnicity was again entered into the first step of the regression analysis followed by posttraumatic growth in the second step and frequency of drinking behaviors in the third. The overall model was not significant,  $F(2,87) = 0.169$ ,  $p = .845$ ,  $\beta = .025$ ,  $p = .821$ , suggesting that posttraumatic growth is not a reliable predictor of drinking behavior. Because the overall model was not significant, the subscales of PTG were not examined as predictors of drinking behavior.

Finally, a series of multiple regression analyses were conducted in order to examine the relationship between posttraumatic growth and aspects of sleep behaviors. First, the relationship between posttraumatic growth and average hours of sleep per night was evaluated. Caregiver ethnicity was entered into the first step of the regression analysis, followed by posttraumatic

growth in the second step and average hours of sleep in the third. The overall model was not significant,  $F(2,84) = 0.997$ ,  $p = .373$ ,  $\beta = .098$ ,  $p = .374$ , suggesting that posttraumatic growth is not a reliable predictor of amount of sleep caregivers were able to obtain. As the overall model was not significant, the subscales of PTG were not examined as predictors of amount of sleep obtained.

The association between posttraumatic growth and the amount of times the caregiver awoke in the middle of the night to care for their child with WS was also examined. Caregiver ethnicity was entered into the first step of the regression analysis, followed by posttraumatic growth in the second step, and average number of awakenings during the week in the third. The overall model was not significant,  $F(2,50) = 0.109$ ,  $p = .897$ ,  $\beta = .050$ ,  $p = .730$ , suggesting that posttraumatic growth is not a reliable predictor of sleep lost through having to wake to care for their child with WS throughout the night. Given the non-significance of the overall model, subscales were not examined.

Finally, the association between posttraumatic growth and how much the caregiver was bothered by these awakenings caused by the child with WS was examined. Caregiver ethnicity was entered into the first step of the regression analysis, followed by posttraumatic growth in the second step and, how much the caregiver was bothered by these awakenings in the third. Interestingly, this overall model was significant with the more posttraumatic growth reported, the less bothered caregivers reported that they were by these awakenings;  $F(2,71) = 2.951$ ,  $p = .049$ ,  $\beta = -.271$ ,  $p = .022$ . This finding suggests that posttraumatic growth is not predictive of actual sleep behaviors or disruptions in sleep patterns, but rather the caregiver's perception of the burden inflicted by these disruptions in sleep patterns experienced. To further evaluate this relationship, the specific subdomains of posttraumatic growth were also examined as predictors

of the amount that a caregiver was bothered by these awakenings and two of the models were significant; Personal strength,  $F(2,71) = 2.662$ ,  $p = .047$ ,  $\beta = -.258$ ,  $p = .030$ ; Relating to Others  $F(1,72) = 5.597$ ,  $p = .02$ ,  $\beta = -.27$ ,  $p = .021$ . Caregiver ethnicity was controlled for in analyses examining personal strength as this was previously found to be related to these domains. These results indicate that certain aspects of posttraumatic growth, including relating to others and personal strength, were predictive of how much a caregiver was bothered by these interruptions in sleep.

## Discussion

The purpose of the current study was to define and describe posttraumatic growth among caregivers of children with Williams syndrome, to evaluate a portion of a commonly accepted model of PTG, and to evaluate an exploratory extension of this model. The study's findings are summarized below and integrated with the current literature in this area. Implications of these findings are then discussed along with strengths and weaknesses of this work. Finally, directions for future research are proposed.

Current literature primarily focuses on negative outcomes of having a child with a disability (Durdevarly & Abboud, 2003; Shin & Crittendan, 2003; Kim, Greenberg, Seltzer & Krauss, 2003), however work is beginning to emerge that examines more positive aspects of this experience (Scallan, Senior & Reilly, 2010). Previous qualitative work has indicated the presence of this phenomenon among caregivers of children with Williams, describing the joy that came from their child, personal growth opportunities, new friendships with parents in similar circumstances, closer family relationships along with increased empathy in typically developing siblings (Scallan, Senior, & Reilly, 2010). The current study empirically evaluated and documented the phenomenon of PTG among caregivers of children with Williams Syndrome. As

expected, significant PTG was reported well within the hypothesized range. Further, these findings were consistent with reports of PTG in other pediatric caregiving populations (Elci, 2004; Affleck, Tennan, & Gershmann, 1985; Polantinsky & Esprey, 2000; Endelkemeyer & Marwit, 2008) and with study hypotheses. While PTG was clearly documented within this population, the empirically evaluated portion of the theoretical model was not supported. Perceived support was found to predict posttraumatic growth among these caregivers; however perceived support did not predict change in deliberate rumination regarding their child's diagnosis. As such, the mediational model was not supported and further analyses were not conducted with regard to evaluating the model. Finally, posttraumatic growth was examined as a predictor of a variety of improved health behaviors. While PTG was not found to be predictive of many of these behaviors (e.g. smoking frequency, drinking frequency, exercise frequency), a relationship was found between PTG and the degree to which caregivers were bothered by nighttime awakenings, possibly further implicating the role of schema change in the process of PTG. As such, the study hypotheses were partially supported with PTG being documented among the current population as expected. However, the portion of the theoretical model evaluated was not empirically supported as predicted. Finally, PTG was not found to predict more positive health behaviors; however analyses provided additional support for examination of cognitive processes within this construct.

The concept of positive outcomes in dealing with having a child with special needs is beginning to emerge in the empirical literature with independent calls being issued for further examination (in 2006 by both Kondrad and Dykens). One of the more frequently studied populations focuses on pediatric oncology. A majority of adolescents studied, along with their mothers and fathers, report some degree of PTG once they have reached survivorship (Barakat,



Alderfer, & Kazak, 2006). These survivors were able to identify at least one positive consequence from their cancer experience and the majority of caregivers described positive changes in the way they view their lives. Qualitative research has shed light on this phenomenon among caregivers of previously healthy children with an acquired disability. Overwhelming changes in self-perception and a need to stay strong for the benefit of the child have both been described (Konrad, 2006). An increase in self-efficacy, increased sense of personal strength, and increased compassion and empathy for others have been documented (Frantz, et al., 2001; Konrad, 2006). Similar findings have been documented among caregivers of children in the NICU (Affleck, Tennan & Gershman, 1985), children on the autism spectrum (Elci, 2004; Phelps, Wuensch & Golden, 2009), children receiving a stem cell transplant (Rini, et. al., 2004), children with Cerebral Palsy (Raina, et. al., 2005), and children with an intellectual disability (Abbott & Meredith, 1986). Prevalence rates are commonly noted to be approximately 80-90% of caregivers (Chernoff, List, De Vet & Ireys, 2001; Barakat, Alderfer, & Kazak, 2006), and as such, similar findings were expected among caregivers of children with Williams. Study findings were consistent with these expectations and fit well within the current literature.

As theory suggests that time to cognitively process the traumatic event and to change initial schemas surrounding the trauma is required for PTG to emerge, it was hypothesized that time since diagnosis would be significantly related to the presence of PTG. Specifically, it was hypothesized that the more time elapsed since diagnosis, the higher the reported PTG. This hypothesis was not supported by current study findings, despite the fact that the majority of caregivers completing this study had had a significant amount of time to cope with the trauma of diagnosis. These findings are thought to suggest that levels of reported PTG and the cognitive struggle where questioning of values and beliefs primarily occurs, plateaus at a given point in the

adjustment process, making differences among amount of PTG experienced difficult to detect in the current study's population. A curvilinear relationship between time since diagnosis and posttraumatic growth is also hypothesized to exist, especially as it is consistent with other work theorizing trajectories of posttraumatic growth (Butler, et. al., 2005). Caregiver anxiety may also complicate this relationship, especially as the role of anxiety and depression within the posttraumatic growth process is highly debated and poorly understood. More focused work in the future is needed in order to determine if these hypotheses are correct. Specifically, a study where time since diagnosis is limited to the previous two to three years is warranted in order to detect subtle differences in amount of PTG reported throughout the early adjustment process.

Given current study findings, the phenomenon of posttraumatic growth is clearly present among caregivers of children with WS and these findings indicate future exploration of PTG among other pediatric caregivers along with methods for facilitating this process among caregivers and affected children alike.

### **Empirical Analysis of Theoretical Model**

Tedeschi & Calhoun's (2004; 2006) proposed model of posttraumatic growth is based on both their empirical work and their clinical experiences. The model is based on cognitive theory and the etiological theories of a stress and coping framework. An updated version of this model was presented by the same authors and can be viewed in Figure 1. This model of PTG is currently the most widely studied and accepted, however it is based entirely on theory and has not been empirically evaluated in any population prior to the current study. While theoretically sound, there has been considerable debate in the literature regarding the quality and timing of rumination within the context of PTG. Some early work focused on rumination soon after the traumatic event occurred and more rumination at this time was found to be predictive of PTG

(Calhoun, Cann, Tedeschi, & McMillan, 2000). Subsequent work focused on the importance of both when the rumination occurred and the quality of the rumination, as both were found to be important factors in the development of PTG (Calhoun, et al., 2000). Most recent work has found both deliberate and intrusive rumination soon after the traumatic event to be related to PTG (Taku, et al., 2009; Bower et al., 1998). Given this array of findings, multiple aspects of rumination were examined in the context of the model when initial hypotheses regarding change in ruminative style were not substantiated.

Although the current study did not yield empirical support for the proposed model, future research evaluating this model is warranted. First, given the controversy in the literature surrounding the timing and quality of rumination implicated in the PTG process, accurate measurement and evaluation of these constructs at this point in time is notably difficult. Future work should begin by identifying and targeting the exact facets of cognitive processing that are implicated in the development of schema change and PTG. Once these aspects of cognitive processing have been identified, they can be better targeted in terms of accurate measurement and documentation. This controversy and difficulty measuring as well as quantifying these cognitive constructs is reflected in current tools used for these purposes. The current measure of rumination utilized in this study is notably weak. While it psychometrically acceptable, it is not noted for its strength. The authors have acknowledged this weakness and have published a psychometrically stronger measure of cognitive processing, the Event Related Rumination Inventory (Cann, et al., 2011) since the current study's inception. As such, the model of PTG should be further evaluated using this more current and psychometrically sound measure in future research. Additionally, while proposed hypotheses evaluating the remainder of the mediational model were not directly tested, correlational data computed as a part of preliminary

data analysis can shed light on to these relationships. All proposed relationships that were not examined in regression analyses were significant when the data were examined at the correlational level. Posttraumatic Growth was related to both deliberate and intrusive rumination at both time points; deliberate rumination soon after  $r = .383, p < .01$ , intrusive rumination soon after  $r = .243, p < .01$ , recent deliberate rumination  $r = .492, p < .01$ , and recent intrusive rumination  $r = .271, p < .01$ . Additionally, social support was found to be significantly related to posttraumatic growth,  $r = .23, p < .05$ . As such, it is likely that other aspects of this mediational model will hold up in further testing. Notably high correlations have been reported in the literature and exist in the current study between subscales on the deliberate rumination scale and the PTGI. As the two measures assess highly similar constructs, these correlations are expected. In the current study, the model was not substantiated due to a lack of a significant relationship between perceived social support and rumination. Because a strong relationship is expected between PTG and different rumination styles, the difficulties found in substantiating the model are thought to lie in the measurement of rumination, not in a deficiency in the model itself. As such, future evaluation of the proposed model of PTG is warranted utilizing improved understanding of the constructs at hand as well as improved measurement tools.

### **Extensions of the Model**

Although comprehensive, Tedeschi and Calhoun acknowledge that their model of PTG is not necessarily comprehensive (McMillan, 2004). One emerging area includes improved health behaviors as a manifestation of PTG. Early work in this area has focused primarily on men who are HIV positive. This work has found improvements in diet, stress levels, smoking behaviors, sleep behavior, and health care utilization (Gluerson, et al., 1993). Similar findings have been reported in women diagnosed with AIDS and those having survived a heart attack (Siegel &

Scrimshaw, 2000; Affleck, et al., 1987). Other work has focused on substance abuse, given the higher incidence of these problems among individuals who have experienced trauma. Current literature has shown lower rates of substance abuse among adolescents who reported PTG (Milam, Ritt-lson, & Unger, 2004). The current study did not find PTG to be predictive of improved health behaviors, although it was found to predict those who were less bothered by nighttime awakenings having to do with their child with WS. Despite this preliminary finding, PTG was not found to be related to the amount of sleep obtained in a night or other factors related to this domain.

While preliminary, the current study's sleep related findings have the potential to shed additional light on the role of cognitive schemas and social support in the PTG construct. Interestingly, PTG was not predictive of average number of hours slept per night or the average number of times a caregiver was awakened during the night for reasons related to their child with WS. However, overall PTG, an increased sense of personal strength, and relating to others were each predictive of how bothered a caregiver was by nighttime awakenings related to their caregiving responsibilities. Specifically, the more overall PTG reported, the less bothered caregivers were by these nighttime awakenings. The same relationship was found for the aforementioned subdomains of PTG. As such, the more that a caregiver was able to recognize and focus on the more positive aspects of their caregiving experience, the less bothered they were by the challenges that it presented. While this is clearly demonstrated in the current study, it likely holds implications for other challenging aspects of the WS caregiving experience as well and speaks to a need to examine the role of self-efficacy in relation to posttraumatic growth development. Additionally, the amount that the caregiver was bothered by nighttime awakenings is the only health behavior evaluated that has direct implications on the parent-child relationship.

Parental perception of burden is likely to directly affect the quality of the relationship with their child, speaking to the importance of further evaluating the more subjective aspects of the caregiving experience as they relate to the experience of posttraumatic growth. This finding also has potential clinical implications, as caregivers who are able to shift their focus and remind themselves of the positive aspects of their experience, are likely to be less bothered by the more difficult aspects of having a child with special needs. This is similar to observations published by Helgeson, Reynolds, & Tomich in 2006 where schema change was observationally defined in a clinical context as benefit reminding and keeping salient positive aspects of an experience that have been personally recognized. Further, these findings suggest that cognitive behavioral intervention with caregivers shortly after diagnosis may not only aid in the adjustment process, but may be helpful in facilitating PTG and actually exceeding baseline levels of functioning in certain domains.

Further, the finding that those who reported that they were better able to relate to other people as a result of their caregiving experience were less bothered by nighttime awakenings further speaks to the importance of social support in facilitating this process. Those who endorsed this increased ability to relate to other people overwhelmingly reported that they know they can count on other people, have increased compassion for other people, have an increased sense of closeness with others, and learned how wonderful other people can be. Overall, these individuals feel that they have more support from other people and are not alone in their caregiving experience. Knowing that they can count on other people to help them cope with the challenges presented as well as share in the positive aspects of this experience aids in viewing challenges as more manageable and less burdensome.

### **Study Strengths and Limitations**

A number of strengths are noted in the current study. First, given the low base rate of WS in the general population, the sample size of participating caregivers is noteworthy. Current estimates are that approximately 5,000 individuals in the United States are directly affected by Williams, and only a subset of these individuals are willing to participate in research. While the current sample is limited in other ways (e.g. demographic diversity), the level of participation is a notable strength of the current work and thought to be a valid representation of caregivers of children with Williams. Further, Williams is a disorder that involves a wide range of functioning levels and a spectrum of affected individuals. As such, the caregiving experiences reported can be assumed to be representative of the Williams caregiving experience overall. The geographic diversity of the study sample is also a notable strength. Given the rare nature of this disorder, it was determined that a national recruitment effort was necessary in order to obtain a representative sample with sufficient power to evaluate the study hypotheses. As such, the study was approved by the Williams Syndrome Association National Registry and distributed among families across the country that indicated an interest in participating. As such, the resultant sample is not simply a reflection of families located in one specific area of the country, is not geographically limited, and is thought to be an accurate reflection of the experience of caring for a child with WS. Further, the current study empirically documented the experience of posttraumatic growth within the target population. While this construct has been qualitatively described previously, the current study is the first to empirically define PTG in caregivers of children with WS, filling a significant gap in the literature. Additionally, the most commonly accepted model of PTG is theoretically sound but has not been previously tested using empirical data. This is a significant weakness in the literature and one that the current study began to address. Finally, the current literature on caregivers of children with WS and the experience of

raising a child with this condition is extremely limited. As such, the current study provides an excellent starting point for continuing to address this gap in the field.

While the current study has a number of strengths, it also presents some significant limitations. First, the findings presented are based entirely on self-report measures. While the anonymity of participants and the geographic range of the sample were preserved by this method of data collection, the validity of the information obtained through self-report is potentially less accurate than had the information been obtained through more objective methods. Second, while geographic diversity is a notable strength of the current study, demographic diversity is a significant weakness. The vast majority of study participants was Caucasian, married, highly educated, and had household incomes greater than \$60,000 annually. These demographic factors indicate that the current sample was high functioning, able to understand the value of research, and had the financial means to provide for a special needs child. Having the skills and means to provide for such a child has the potential to reduce the stress involved in this experience, and to bias the information obtained. Although this demographic profile is typical of those choosing to participate in research, the results are less generalizable to those who do not come from similar backgrounds. Further, the majority of participants were the biological mothers of these children with WS. While this is again typical of studies focused on pediatric caregivers, the results are less representative of fathers and other primary caregivers and cannot be assumed to generalize to these non-maternal caregivers. Finally, the current study's most significant weakness is its use of a relatively weak measure of rumination. The current measure of rumination across time, while psychometrically acceptable, has poorer psychometric properties than is ideal. It has been acknowledged in the literature as in need of improvement and better, psychometrically stronger measures of the construct have been developed (Cann, et al., 2011). The lack of significant



findings in relation to the proposed mediational model may be due to weaknesses in measurement of the cognitive processing construct rather than failure of the model to be substantiated overall. As such, utilizing stronger measures of cognitive processing is critical to future evaluations of this model of posttraumatic growth.

### **Future Directions**

Future research in the areas of posttraumatic growth and caregivers of children with Williams Syndrome is indicated and should proceed in a number of different areas. First, further work is indicated in order to better understand the exact cognitive processes involved in schema change within the context of posttraumatic growth. This better understanding will allow for research to target the exact shift in cognition that is critical for PTG to occur and to improve measurement techniques for tracking this change. Further, additional testing of Tedeschi & Calhoun's 2006 model is indicated utilizing updated measurement techniques validated since the current study's inception. This improvement in measurement strategy is likely to substantiate the portion of the model tested in the current study. Additionally, testing of the full model is warranted to inform a more complete conceptualization of this construct and to aid in facilitating this process among individuals who have experienced a traumatic event. As suggested by the model's authors themselves, the framework presented is not exhaustive and other domains of PTG are likely to exist. One promising area pertains to self-care and health behaviors. While current study findings are mixed and preliminary, further investigation in this area is necessary. Identifying other health behaviors that may be influenced by the experience of posttraumatic growth is an important future direction. Examples of these behaviors may include frequency of attendance at personal doctors' appointments, amount of time taken to enjoy personal interests, and dietary practices. An examination of health beliefs in relation to the experience of

posttraumatic growth may also be warranted as these may vary more widely between those who report PTG and those who do not. Further, health beliefs may predict future behavior change, as significant time may elapse between the reporting of PTG and actual behavior change. Other potential facets of PTG should also be examined as they are identified both by clinicians working with victims of trauma and by researchers working with new theory and empirical data in the field. An important future direction for evaluating posttraumatic growth among caregivers specifically is controlling for abilities of the child. A child who is more significantly impaired places more demands on a caregiver than does a higher functioning child. Examining the role of the child's intellectual functioning on the caregiver's report of posttraumatic growth would provide additional insight into the role of the caregiving burden in this process. As values, schemas, and behavior of parents is often taught to and learned by children, an examination of PTG is indicated within the context of the family system. Working from this framework, children of parents who report PTG would report higher PTG themselves as compared to children of parents who did not report these same positive changes. This relationship is likely to be the case both for children affected by the trauma as well as unaffected siblings. If this relationship is empirically substantiated, it has significant implications for family intervention. Specifically for children undergoing a medical procedure or being hospitalized, parental intervention may be able to facilitate growth in parents and children alike. Such an intervention could potentially be carried out in a group context, providing a cost effective way of intervening with children and parents. Additionally, looking at posttraumatic growth within a developmental framework is an important future direction. More targeted work looking at this construct surrounding developmental transitions would provide insight into the consistency with which growth is experienced. Given the additional challenges that often present as children enter adolescence or

experience other transitions, it is likely that caregivers experience additional stress at these points in time and may not experience as many positive aspects at these times. Finally, future research is needed in order to better understand how the process of posttraumatic growth can be facilitated within a clinical context. Trauma survivors often seek treatment in order to deal with their traumatic experience as well as to learn better coping strategies to continue to manage their distress as they move forward with their lives. If PTG could then be facilitated through continued intervention, these survivors could not only improve their coping skills for managing this trauma, but many more could begin to experience positive changes from a traumatic experience, actually exceeding their baseline level of functioning.

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Appendix A  
Recruitment Email

Dear Williams syndrome community,

We are looking for your help with a research study in order to learn more about caregiver adjustment to the diagnosis of Williams syndrome. We understand that this can be a very difficult time for families and caregivers and that for most families, this is a life-long commitment. We hope to use this information to aid healthcare providers in educating new members of the community and to provide resources for those who are interested. Participation in the study requires that you be at least 18 years of age, English speaking, and are the primary caregiver for an individual affected by Williams syndrome. If you choose to participate, you will be asked to complete a number of questionnaires and may do so either online by following the link at the end of this letter, or by requesting a paper and pencil version along with a pre-paid envelope in which to return the forms. Your time commitment would be less than one hour and participation enters you into a drawing for one of two \$100 gift cards to [amazon.com](http://amazon.com).

We thank you for your time and consideration, and please feel free to contact our team with any questions or concerns that you may have.

Please click this link participate: <http://www.surveymonkey.com/s/39KGG9M>

Sincerely,

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Appendix B  
Demographics

### *Demographic Information*

**Information about you.** Please fill in the questions below. You may skip any questions you do not want to answer.

1. Today's date (MM/DD/YEAR): \_\_\_\_\_
2. Your current age: \_\_\_\_\_
3. Gender (*please circle one*):      Male                      Female              Transgendered
4. Your ethnic background (*please check all that apply*):
  - White, not of Latino background
  - Latino
  - African American
  - Asian American
  - Native American
  - Biracial or multiracial, please specify: \_\_\_\_\_
  - Other, please specify: \_\_\_\_\_
5. Relationship to child diagnosed with WS:
  - Mother
  - Father
  - Grandmother
  - Grandfather
  - Sibling
  - Aunt
  - Uncle
  - Other family relation, please specify: \_\_\_\_\_
  - Other non-family relation, please specify: \_\_\_\_\_
6. Highest level of completed education
  - Less than high school diploma
  - High School diploma
  - Some college
  - College degree
  - Some graduate school
  - Graduate degree
7. Highest level of education desired
  - Less than high school diploma
  - High School diploma
  - Some college
  - College degree
  - Some graduate school

- Graduate degree
8. Approximate annual household income
- Less than \$15,000  
 \$15,000- \$24,999  
 \$25,000-\$34,999  
 \$35,000-\$44,999  
 \$45,000-\$59,999  
 Greater than \$60,000
9. Marital status (please check as many as apply)
- Married  
 Single  
 Divorced  
 Widowed  
 Separated  
 Living with parent of child diagnosed with WS  
 In contact with child's other parent  
 Living with non-parental partner
10. What is your current occupation?  
 \_\_\_\_\_
11. What would you like your occupation to be?  
 \_\_\_\_\_
12. What was the month and year of your last physical exam with a medical doctor?  
 \_\_\_\_\_
13. What was the month and year of your last dental examination with a dentist?  
 \_\_\_\_\_
14. What was the month and year of your last eye examination?  
 \_\_\_\_\_
15. Do you get regular physical examinations (one time or more per year)?
- \_\_\_\_\_ Yes  
 \_\_\_\_\_ No
16. Do you get regular dental examinations (at least one time per year)?
- \_\_\_\_\_ Yes  
 \_\_\_\_\_ No

17. Do you get regular eye examinations (one time or more per year)?
- \_\_\_\_\_ Yes  
\_\_\_\_\_ No
18. Have you ever received counseling or medical treatment for depression or anxiety?
- |   |     |    |
|---|-----|----|
| a.) Within the past year?   | Yes | No |
| b.) At any time prior to beginning your<br>caretaking role with the individual with WS? | Yes | No |
| c.) At anytime after beginning your<br>caretaking role with the individual with WS?     | Yes | No |
19. Have you experienced any significant stressors or losses in the past year?
- |                                       |     |    |
|---------------------------------------|-----|----|
| a.) Change in relationship status?    | Yes | No |
| b.) Change in living arrangements?    | Yes | No |
| c.) Job change or loss?               | Yes | No |
| d.) Legal or financial problems?      | Yes | No |
| e.) Extra home-care responsibilities? | Yes | No |
| f.) Illness                           | Yes | No |
| g.) Illness or death of a loved one?  | Yes | No |
| h.) Witnessing a violent crime?       | Yes | No |
| i.) Other _____                       |     |    |
- \_\_\_\_\_
20. Who supports you in your caretaking role with your child with Williams syndrome?  
Please check as many as apply.
- Spouse/partner  
 Family members  
 Friends  
 Teachers/school system  
 Doctors, nurses  
 Mental health professionals  
 Social workers  
 Other, please specify:
- \_\_\_\_\_
21. If the individual with WS is in school, does he/she receive special accommodations?
- \_\_\_\_\_ Yes  
\_\_\_\_\_ No

If yes, how satisfied have you been with these accommodations? Please circle one answer.

1 = Unsatisfied

2 = Moderately satisfied

3 = Very satisfied

22. Approximately how many hours per week do you spend on special care for your child with WS (e.g., on doctors visits, occupational therapy, physical therapy, etc.)?

\_\_\_\_\_

23. Compared with other children with Williams syndrome, how do you compare your child's medical condition? Please check one answer.

- Worse than average
- About average
- Better than average

What specific attributes/ conditions do you use in making this comparison/judgment?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Information about the individual with Williams syndrome.** Please fill in the questions below. You may skip any questions you do not want to answer.

24. What gender is the individual with WS? Female Male

25. Ethnic background of individual with WS (*please check all that apply*):

- White, not of Latino background
- Latino
- African American
- Asian American
- Native American
- Biracial or multiracial, please specify: \_\_\_\_\_
- Other, please specify: \_\_\_\_\_

26. How old is the individual with WS? \_\_\_\_\_

When did you receive a WS diagnosis for your child?

27. Is the individual you are caring for with WS your biological child? Yes No

If yes, do you have other children? Yes No



- If yes, what are their ages? \_\_\_\_\_
28. Do you have any other thoughts about your experiences caring for a child diagnosed with Williams syndrome that you would like to share at this time?

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Appendix C  
Posttraumatic Growth Inventory

**For each of the following statements, please indicate the degree to which this change occurred in your life as a result of your experience as a Williams caregiver.**

0	1	2	3	4	5
I did NOT experience this change as a result of my experience with Williams.	I experienced this change to a VERY SMALL degree as a result of my experience with Williams.	I experienced this change to a SMALL degree as a result of my experience with Williams.	I experienced this change to a MODERATE degree as a result of my experience with Williams.	I experienced this change to a GREAT degree as a result of my experience with Williams.	I experienced this change to a VERY GREAT degree as a result of my experience with Williams.

My priorities about what is important in life. . . . .	0	1	2	3	4	5
An appreciation for the value of my own life. . . . .	0	1	2	3	4	5
I developed new interests. . . . .	0	1	2	3	4	5
A feeling of self-reliance. . . . .	0	1	2	3	4	5
A better understanding of spiritual matters. . . . .	0	1	2	3	4	5
Knowing that I can count on people in times of trouble. . . . .	0	1	2	3	4	5
I established a new path for my life. . . . .	0	1	2	3	4	5
A sense of closeness with others. . . . .	0	1	2	3	4	5
A willingness to express my emotions. . . . .	0	1	2	3	4	5
Knowing I can handle difficulties. . . . .	0	1	2	3	4	5

I'm able to do better things with my life. . . . .	0	1	2	3	4	5
Being able to accept the way things work out. . . . .	0	1	2	3	4	5
Appreciating each day. . . . .	0	1	2	3	4	5
New opportunities are available which wouldn't have been otherwise. . . . .	0	1	2	3	4	5
Having compassion for others. . . . .	0	1	2	3	4	5
Putting effort into my relationships. . . . .	0	1	2	3	4	5
I'm more likely to try to change things which need changing. . . . .	0	1	2	3	4	5
I have a stronger religious faith. . . . .	0	1	2	3	4	5
I discovered that I'm stronger than I thought I was. . . . .	0	1	2	3	4	5
I learned a great deal about how wonderful people are. . . . .	0	1	2	3	4	5
I accept needing others. . . . .	0	1	2	3	4	5

Appendix D  
Rumination Scale

Respond to the items by circling your response on the four point scale below each item.

1. Soon after my traumatic experience, I thought about the event when I didn't mean to.

1	2	3	4
Not at all	Rarely	Sometimes	Often

2. Recently, I have thought about my traumatic experience when I didn't mean to.

1	2	3	4
Not at all	Rarely	Sometimes	Often

3. Soon after the event, thoughts about the experience came into my mind and I could not get rid of them.

1	2	3	4
Not at all	Rarely	Sometimes	Often

4. Recently, thoughts about the event came to my mind and I could not get rid of them.

1	2	3	4
Not at all	Rarely	Sometimes	Often

5. Soon after the event, I decided to think about the experience to try and make sense out of what happened.

1	2	3	4
Not at all	Rarely	Sometimes	Often

6. Recently, I decided to think about the experience to try and make sense out of what happened.

1	2	3	4
Not at all	Rarely	Sometimes	Often

7. Soon after the event, I tried to make something good come out of my struggle.

1	2	3	4
Not at all	Rarely	Sometimes	Often

8. Recently, I have tried to make something good come out of my struggle.

1	2	3	4
Not at all	Rarely	Sometimes	Often

9. Soon after the event, I reminded myself of some of the benefits that came from adjusting to the traumatic experience.

1  
Not at all

2  
Rarely

3  
Sometimes

4  
Often

10. Recently, I reminded myself of some of the benefits that came from adjusting to the traumatic experience.

1  
Not at all

2  
Rarely

3  
Sometimes

4  
Often

11. As a result of what happened, soon after the event I found myself automatically thinking about the purpose of my life.

1  
Not at all

2  
Rarely

3  
Sometimes

4  
Often

12. As a result of what happened, recently I find myself automatically thinking about the purpose of my life.

1  
Not at all

2  
Rarely

3  
Sometimes

4  
Often

13. As a result of what happened, soon after the event I deliberately would think about and ask questions about whether or not life has a meaning or purpose.

1  
Not at all

2  
Rarely

3  
Sometimes

4  
Often

14. As a result of what happened, recently I will deliberately think about and ask questions about whether or not life has a meaning or purpose.

1  
Not at all

2  
Rarely

3  
Sometimes

4  
Often

## Appendix E

### MOS Social Support Questionnaire



Next are some questions about the support that is available to you.

1. About how many close friends and close relatives do you have (people you feel at ease with and can talk to about what is on your mind)?

2. Write in number of close friends and close relatives:

3. People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to YOU if you need it? (Circle One Number On Each Line)

None of the Time 1	A Little of the Time 2	Some of the Time 3	Most of the Time 4	All of the Time 5	
					4. Someone to help you if you were confined to <b>bed</b> .... 1 2 3 4 5
					5. Someone you can count <b>on</b> to listen to you when you need to talk . . . . . 1 2 3 4 5
					6. Someone to give you good advice about a crisis ..... 1 2 3 4 5
					7. Someone to take you to the doctor if you needed it 1 2 3 4 5
					8. Someone who shows you love and affection 1 2 3 4 5
					9. Someone to have a good time with ..... 1 2 3 4 5
					10. Someone to give you information to help you understand a situation.. ..... 1 2 3 4 5
					11. Someone to confide in or talk to about yourself or your problems ..... 1 2 3 4 5
					12. Someone who hugs you ..... 1 2 3 4 5
					13. Someone to get together with for relaxation.. ..... 1 2 3 4 5
					14. Someone to prepare your meals if you were unable to do it yourself.. ..... 1 2 3 4 5
					15. Someone whose advice you really want.. ..... 1 2 3 4 5
					16. Someone to do things with to help you get your mind off things ..... 1 2 3 4 5
					17. Someone to help with daily chores if you were sick 1 2 3 4 5
					18. Someone to share your most private worries and fears with..... 1 2 3 4 5
					19. Someone to turn to for suggestions about how to deal with a personal problem..... 1 2 3 4 5
					20. Someone to do something enjoyable with ..... 1 2 3 4 5
					21. Someone who understands your problems ..... 1 2 3 4 5
					22. Someone to love and make you feel wanted ..... 1 2 3 4 5

## Appendix F

### Taking Care of Yourself Questionnaire

## Taking Care of Yourself

The following items are things people sometimes do that affect their health. Please think about what you did in the last two weeks. Keep in mind that we want to know what you actually did, not what you would like to have done. Please use one of the following answers to describe how often you did each thing:

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

In the last two weeks, how often did you:

1)...exercise for at least 15 minutes?

What exercise did you do? \_\_\_\_\_

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

2)...get enough sleep?

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

3)...eat fatty or oily foods?

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

4)...smoke cigarettes?

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

5)...drink things with caffeine such as coffee or colas?

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

6)...eat high-fiber foods such as whole grain breads or cereals?

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

7)...drink alcohol, including wine, beer or liquor?

0	1	2	3	4
Never	Almost never	Sometimes	Fairly often	Very often

Appendix G  
Summary of Preliminary Analyses

Independent Sample t-tests evaluating PTG and subscales with caregiver and child gender

	Caregiver Gender	Child with WS Gender
PTGI Total	t(92) = -1.45, p >.10	t(93) = -1.29, p >.10
Appreciation of Life	t(92) = -1.46, p >.10	t(93) = 0.167, p >.10
New Life Possibilities	t(92) = -1.12, p >.10	t(93) = 0.112, p >.10
Personal Strength	t(92) = -1.45, p >.10	t(93) = -0.229, p >.10
Spiritual Change	t(92) = -1.23, p >.10	t(93) = 0.298, p >.10
Relating to Others	t(92) = -1.08, p >.10	t(93) = -0.53, p >.10

Pearson Correlations evaluating PTG & subscales with caregiver age, child age, & time since diagnosis

	Caregiver age	Child Age	Time since dx
PTGI Total	r = -.04, p = .689	r =.037, p = .721	r = .042, p = .71
Appreciation of Life	r = .005, p = .959	r = .085, p = .411	r = .073, p = .39
New Life Possibilities	r = -.034, p = .744	r =.004, p = .972	r =.01, p = .83
Personal Strength	r =.069, p = .509	r =.045, p = .665	r =.051, p = .51
Spiritual Change	r = -.023, p = .824	r = -.016, p = .879	r =.001, p = .81
Relating to Others	r = -.04, p = .689	r = .039, p = .708	r =.049, p = .71

One way ANOVA's evaluating PTG and Caregiver Income and Marital Status

	Caregiver Income	Caregiver Marital Status
PTGI Total	F(4,87) = .443, p = .777	F(4,90) = .371, p = .828
Appreciation of Life	F(4,87) = 1.076, p = .373	F(4,90) = .573, p = .683
New Life Possibilities	F(4,87) =.753, p = .559	F(4,90) =.243, p = .913
Personal Strength	F(4,87) =.304, p = .875	F(4,90) =.498, p = .737
Spiritual Change	F(4,87) = .468, p = .759	F(4,90) = 1.603, p = .18
Relating to Others	F(4,87) =.509, p = .729	F(4,90) =.320, p = .864

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One way ANOVA's evaluating PTG and Caregiver Education Level and Ethnicity

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	Caregiver Education Level	Caregiver Ethnicity
PTGI Total	F(4,90) = 1.838, p = .128	<b>F(4,89) = 2.958, p = .024</b>
Appreciation of Life	F(4,90) = 1.911, p = .115	F(4,89) = 2.255, p = .06
New Life Possibilities	F(4,90) = 1.653, p = .168	F(4,89) = 1.862, p = .124
Personal Strength	F(4,90) = 1.231, p = .303	<b>F(4,89) = 2.966, p = .024</b>
Spiritual Change	<b>F(4,90) = 2.852, p = .028</b>	F(4,89) = 2.112, p = .086
Relating to Others	F(4,90) = .821, p = .515	F(4,89) = 2.028, p = .097

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### *Vita*

Laura Elizabeth Slosky was born on December 28, 1983 in Milwaukee, Wisconsin. She is an American Citizen. She graduated from the University School of Milwaukee in 2002 and went on to earn her Bachelor of Science degrees in child development and psychology from Vanderbilt University in Nashville, Tennessee in 2006. She then moved to Richmond, Virginia for her graduate education at Virginia Commonwealth University. She earned her Master of Science degree in 2008 in child clinical psychology. She is currently a doctoral candidate and anticipates receiving her PhD from Virginia Commonwealth University in August of 2013. Laura worked for the Center for Human Genetics Research at Vanderbilt University prior to moving to Miami, Florida where she is currently completing her pre-doctoral internship in pediatric psychology at the University of Miami's Mailman Center for Child Development.