ASSOCIATION BETWEEN POSTTRAUMATIC GROWTH, MEDICATION NONADHERENCE, AND BARRIERS TO ADHERENCE IN PEDIATRIC SOLID ORGAN TRANSPLANT PATIENTS AND THEIR CAREGIVERS

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DEDICATION

There are not enough words to capture my overwhelming gratitude to everyone who has accompanied me on this journey. My many imperfections continue to make it abundantly clear that above all, I owe everything to Jesus Christ, my source of strength and inspiration. He has blessed me with a support system that is far more incredible than I deserve. First, I want to extend my immense gratitude to Dr. Sunita Stewart, whose willingness to open doors for me, challenge me, and encourage me in my endeavors will never be forgotten. She has been a source of constant inspiration and an invaluable component of my training. I also want to thank Dr. Kelli Triplett for her patience, encouragement, and valuable insight about pediatric solid organ transplant. Her guidance on this project has been greatly appreciated. I owe many thanks to the other members of my committee for the time and energy they invested in this project. I am very grateful for you all.

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To God be the glory.

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ASSOCIATION BETWEEN POSTTRAUMATIC GROWTH, MEDICATION NONADHERENCE, AND BARRIERS TO ADHERENCE IN PEDIATRIC SOLID ORGAN TRANSPLANT PATIENTS AND THEIR CAREGIVERS

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Living with a chronic illness can be a traumatic experience, yet there is also evidence that adverse experiences may facilitate positive psychological changes, such as posttraumatic growth (PTG). Little is known about PTG in pediatric solid organ transplant (SOT) patients and their caregivers or PTG's relationship with health behaviors. Study aims were to longitudinally

evaluate 1) the role of medication nonadherence and BTA on PTG, and 2) PTG's influence on medication nonadherence and barriers to adherence (BTA). It was hypothesized that 1) Greater baseline medication nonadherence and BTA would predict greater follow-up PTG, and 2) greater baseline PTG would predict lower follow-up medication nonadherence and fewer BTA. Participants included 43 pediatric SOT patient-caregiver dyads at baseline (range: .11-17.09 years post SOT) and follow-up (range: .87-3.37 years post baseline). Baseline measures of PTG, medication nonadherence, BTA, and psychosocial factors were obtained. Follow-up measures of primary outcomes were also collected. Baseline medication nonadherence (β = -.05, *SE* = .87), patient-rated BTA (β = -.17, *SE* = .10), and caregiver-rated BTA (β = -.24, *SE* = .12), did not predict follow-up patient PTG. More baseline caregiver-rated BTA (β = .29, *SE* = .30), but not medication nonadherence (β = .07, *SE* = 3.02) or patient-rated BTA (β = .20, *SE* = .20), predicted greater follow-up caregiver PTG. Baseline patient PTG (β = -.01, *SE* = .04) and caregiver PTG (β = -.25, *SE* = .01) did not predict follow-up medication nonadherence. Higher baseline caregiver PTG (β = -.25, *SE* = .08), but not patient PTG (β = -.07, *SE* = .26), predicted fewer follow-up patient-rated BTA. Greater baseline patient PTG (β = -.01, *SE* = .21), but not caregiver PTG (β = -.04, *SE* = .06), predicted more follow-up caregiver-rated BTA. Exploratory analyses were also conducted to identify psychosocial predictors of primary outcomes. Results suggest that strengthening PTG in caregivers of pediatric SOT patients may be important for reducing BTA. Further research needed to determine whether specific domains of PTG and BTA are associated. Findings have the potential to inform strength-based interventions focused on decreasing BTA for pediatric SOT patients.

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LIST OF DEFINITIONS

AMBS – Adolescent Medication Barriers Scale

CPSS – Child Posttraumatic Stress Disorder Symptom Scale

FES – Family Environment Scale

FRI – Family Relationship Index

IES-R – Impact of Event Scale-Revised

MLVI – Medication Level Variability Index

PMBS – Parent Medication Barriers Scale

PMTS – Pediatric Medical Traumatic Stress

PTGI – Posttraumatic Growth Inventory

PTGI-C-R – Posttraumatic Growth Inventory for Children, Revised Version

PTSD – Posttraumatic Stress Disorder

REDCap – Research Electronic Data Capture

SES – Socioeconomic status

SOT – Solid organ transplant

SPI – Serious pediatric illness

CHAPTER ONE
Introduction

Pediatric Solid Organ Transplant

The number of pediatric solid organ transplant (SOT) procedures has rapidly increased over the past decade due to improved survival rates, surgical procedures, and technology (United Network for Organ Sharing, 2019). As such, there is a growing need for further research that examines the long-term medical and psychosocial outcomes of transplantation (Kim & Marks, 2014; LaRosa et al., 2011). SOT has been shown to extend life expectancy and improve quality of life (Cousino et al., 2017; Shellmer, Brosig, & Wray, 2014). Yet, despite the health-related benefits of SOT, there is also evidence that SOT patients are at an increased risk for depression and posttraumatic stress disorder (PTSD) compared to the general population and those with other chronic illnesses (Cousino et al., 2017; Evan et al., 2014; Mintzer et al., 2005).

Youth may experience pediatric medical traumatic stress (PMTS) following a subjectively significant stressful and/or traumatic medical experience (e.g., undergoing a painful medical procedure and/or receiving a life-threatening medical diagnosis and/or treatment of a life-threatening illness) (Kazak et al., 2006; Price et al., 2016). Although PMTS is not characterized as a formal psychiatric disorder, its symptoms (e.g., re-experiencing the trauma, avoidance of reminders of the trauma, and hyper-arousal) overlap with those associated with acute stress disorder and PTSD (National Child Traumatic Stress Network, 2018). According to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, being exposed to life-threatening events and/or witnessing traumatic events occur to others may constitute a traumatic event (American Psychiatric Association, 2013). Similarly, caregivers of those with

life-threatening medical conditions may develop PMTS after witnessing their children experience medical trauma (Kazak et al., 2004).

Pediatric SOT patients often have multiple sources of serious medical stressors during the pre-transplant period, such as undergoing painful and fear-provoking medical procedures. There is also variability within this period as some patients require transplantation because of pre-existing chronic medical conditions while others may have been healthy and then experienced sudden onset acute organ failure (Shellmer et al., 2014). Although SOT is typically a lifesaving procedure, it is not curative, and patients may continue to experience subsequent stressors related to the transplant. For example, some recipients of organs provided by deceased donors report feeling extreme distress related to the realization that their lives are owed to another's death (Shellmer et al., 2014). In addition, SOT patients may experience complications with the transplanted organ and/or development of additional medical conditions such as steroid-induced diabetes (Hwang & Weiss, 2014). After transplantation, patients are also asked to adhere to complex treatment regimens (e.g., multiple daily medications and frequent follow-up medical appointments) to ensure the transplanted organ is functioning properly (Shellmer et al., 2014). All of these subsequent post-transplant medical stressors may be experienced as a continuation of pre-transplant medical trauma (Kazak et al., 2006).

Prior research suggests that 20-30% of caregivers and 15-25% of children and their siblings experience persistent PMTS that contribute to decreased medical recovery, impaired daily functioning, and decreased medication adherence (National Child Traumatic Stress Network, 2018). Pediatric SOT patients are at a high-risk for nonadherence to their post-

transplant treatment regimens, especially compared to adult SOT patients (Dew et al., 2009; Eaton et al., 2018; Shemesh et al., 2018). Of note, nonadherence is associated with serious health-related consequences. In Simons and colleagues' (2009) study with a sample of adolescent and young adult SOT patients and their caregivers, the perception of more barriers to adherence was associated with increased instances of organ rejection. Similarly, poor medication nonadherence to post-transplant medication and clinical follow-up requirements have been consistently associated with morbidity and mortality outcomes in this population (Dew et al., 2009).

Factors Associated with Medication Nonadherence and Barriers to Adherence in Pediatric SOT

Sociocultural and Demographic Factors

Regarding age, adolescent SOT patients have been identified as having more difficulty with adherence than younger SOT patients (Berquist et al., 2006; Meng et al., 2018). There have been mixed findings regarding the relationship between sex and nonadherence in this population. Some studies have found evidence for an increased risk of nonadherence among females (Berquist et al., 2006; Korsch, Fine, & Negrete, 1978), while other research suggests that males report greater nonadherence (Connelly et al., 2015; Meyers, Thomson, & Weiland, 1996). Further research is needed to understand the role of patient sex in medication nonadherence. Prior research also suggests that youth who are African American (Connelly et al., 2015) and have a lower SES (Berquist et al., 2006; Rovelli et al., 1989) are at an increased risk for nonadherence following SOT.

Caregiver Involvement and Family Functioning

Caregivers of SOT patients are often significantly involved in pre- and post-transplant treatment including management of post-transplant treatment plans (e.g., frequent appointments and strict medication regimens) (Cousino, 2017). Decreased caregiver involvement in managing medication regimens has been associated with greater medication nonadherence for pediatric transplant patients (Zelikovsky et al., 2008). In addition, prior studies have identified lower family cohesion (Meng et al., 2018) and negative parent-child relationships (Gerson et al., 2004) as risk factors for nonadherence in pediatric SOT patients.

Posttraumatic Growth

Domains of Posttraumatic Growth

Despite the negative psychological outcomes that may accompany traumatic medical experiences (e.g., PMTS), there is evidence that medical trauma may also facilitate positive change, such as posttraumatic growth (PTG) (Picoraro et al., 2014). PTG is a construct that describes gradual transformative growth following an adverse experience that significantly challenged one's adaptive resources, self-conceptualization, and understanding of the world (Tedeschi & Calhoun, 1996; 2004). Tedeschi and Calhoun proposed that PTG can occur in multiple domains including personal strength, recognition of new possibilities/goals, personal relationships, appreciation of life, and spirituality/existentialism. Personal strength refers to the realization that one can navigate future challenges in life. Recognition of new possibilities is described as the identification of new roles for oneself (e.g., changing career aspirations). Enhanced personal relationships involves experiencing greater compassion for others and more

meaningful and intimate relationships. Greater appreciation of life refers to a change in one's priorities and the appreciation of experiences that may have been previously taken for granted. Lastly, enhanced spirituality/existentialism encompasses strengthened faith and/or increased engagement with existential questions. Of note, PTG and posttraumatic stress symptoms often co-occur (Tedeschi & Calhoun, 1996; 2004). Prior research suggests that PTG may be greatest when posttraumatic stress is at a moderate level (Shakespeare-Finch & Lurie-Beck, 2014).

Models of Posttraumatic Growth Development

PTG has been primarily evaluated using medically healthy, adult samples. However, recent studies have also found support for PTG in the context of pediatric medical trauma (Picoraro et al., 2014). Picoraro and colleague's (2014) Serious Pediatric Illness (SPI)-PTG model outlines various factors underlying PTG in youth with SPI and their caregivers (Figure 1). In the SPI-PTG model, distal factors of SPI-PTG include individual characteristics (e.g., age and sex of child) and social support (i.e., general and local support). General social support refers to an individual's social values and cultural influences (e.g., race/ethnicity, spirituality, socioeconomic status). Local support consists of an individual's relationship dynamics (e.g., family and caregivers) and the impact of the medical trauma on the people in these relationships (e.g., caregiver PTG and PTSS). The SPI-PTG model posits that the nature (e.g., type of medical trauma) and subjective experience of the traumatic medical event contribute to PTG. Subsequent traumatic medical events, such as relapse and/or whether an individual is asymptomatic, are believed to contribute to cognitive and affective functioning, which are proximal factors of PTG. Cognitive processing (e.g., rumination) facilitates alterations in cognitive schemas regarding

personal worldview. In contrast, affective processing includes posttraumatic stress responses along with other psychological outcomes (e.g., anxiety and/or depression). Although the PTG-SPI model has been generalized to describe PTG in pediatric patients, Picoraro and colleagues (2014) acknowledge that the components of the model were derived from studies that primarily used samples of caregivers of youth with a SPI.

Kilmer and colleagues' (2014) PTG model (Figure 2) may be of use as an adjunct to the PTG-SPI model because it is specific to PTG in children and adolescents but does not exclusively focus on PTG in the context of medical trauma. This model proposes that distal factors of PTG include broad contextual factors (e.g., cultural norms), child pre-trauma risks (e.g., prior/lifetime trauma exposure and adversities), child pre-trauma resources and functioning (e.g., temperament, perceived competence), and family/contextual pre-trauma resources (e.g., caregiver mental health, caregiver-child relationship). Following trauma exposure, these distal factors are believed to interact with child distress (e.g., anxiety and depression) and caregiver functioning and response (e.g., mental health, PTG). Proximal factors of PTG in this model are child cognitive factors (e.g., future expectations, self-efficacy, and rumination) and caregiver coping guidance (e.g., positive reframing and modeling).

Together, the SPI-PTG model (Picoraro et al., 2014) and Kilmer and colleagues' (2014) PTG model for children and adolescents provide a foundation for understanding relationships between important correlates of PTG in children and adolescents and caregivers of pediatric patients with serious illnesses. To date, much of the pediatric PTG literature has focused on identifying individual cognitive and affective correlates of PTG. More information is needed

about the role of social, cultural, and environmental influences in research evaluating responses to trauma (Harvey, 1996).

Influence of PTG on Health Behaviors and Medical Outcomes

Minimal research has evaluated the relationship between PTG and health behaviors and/or medical outcomes using pediatric samples. The few studies that have been conducted with adults have found support for PTG's association with improved health behaviors (e.g., more frequent primary care visits) in adults with chronic medical conditions (Leung et al., 2012; Milam, Ritt-Olson, & Unger, 2004). Additionally, in Latos and colleagues' (2015) study, PTG longitudinally predicted post-transplant medical outcomes in adults. Little is known about the influence of PTG on health-related outcomes in pediatric SOT patients.

Factors Associated with Posttraumatic Growth

Sociocultural and Demographic Factors

Some studies have examined the role of sociocultural and demographic factors in the development of PTG following pediatric medical trauma. In a study using a sample of adult lung-transplant patients, PTG was associated with fewer years of education obtainment (Fox et al., 2014). Of note, education level is often used as a proxy measure of socioeconomic status (SES) (Braveman et al., 2005), and SES is highly related to ethnicity and race (Meyerson et al., 2011). As such, it is important to account for the influence of ethnicity and race when examining the relationship between SES and PTG. Research with nonmedical adult populations also suggests that religiosity is related to increased PTG in nonmedical adult populations (Shaw,

Joseph, & Linley, 2005). Less is known about the role religiosity in facilitating PTG in pediatric populations.

Little is known about the influence of age and sex in pediatric samples with medical trauma. Meyerson and colleagues (2011) posit that PTG's development may be greatest during late adolescence and early adulthood due to an increased ability to engage in cognitive restructuring. In addition, Barakat, Alderfer, and Kazak (2006) reported greater PTG in children diagnosed when they were at least five years old compared to those who received the same diagnosis at a younger age. Investigators also found evidence that children's ages at the time of data collection were positively related to PTG (Barakat et al., 2006). However, investigators measured PTG using a non-standardized measure (i.e., Perceived Changes in Self). Findings from research with nonmedical, adult samples suggest PTG may be greater in females (Hungerbuehler et al., 2011; Vishnevsky et al., 2010). Additional research is needed to understand the role of age and biological sex in PTG development in pediatric populations.

Trauma and Family Functioning

Few studies have evaluated the relationship between caregiver and child PTG or PTG and family functioning in the context of pediatric medical trauma. However, the existing studies have found support for a relationship between caregiver and child PTG (Berger & Weiss, 2009; Picoraro et al., 2014). Positive family functioning is believed to facilitate beneficial cognitive and affective processing of trauma (Kilmer et al., 2014). Yet, there have been mixed findings regarding the association between family functioning and PTG. Relational components of family functioning, such as family cohesion, expressiveness, and conflict (Moos & Moos, 1994), have

been previously associated with psychological functioning in youth with various chronic medical conditions (Cousino et al., 2017; Van Schoors et al., 2017). Family cohesion is described as the degree of attachment, commitment, and support family members provide for each another (Moos & Moos, 1994; Olson, 2000). Family expressiveness is the acceptance of the direct expression of emotions among family members. Family conflict refers to the amount of openly expressed conflict and anger expressed within the family.

Hungerbuehler and colleagues (2011) evaluated aspects of family functioning (i.e., parent-rated family cohesion, expressiveness, and conflict) obtained one month after children were diagnosed with a chronic illness (e.g., cancer, diabetes) as a longitudinal predictor of PTG. In this Swiss sample, the aforementioned aspects of family functioning predicted PTG in the parents of the recently diagnosed children three years after the initial diagnosis. Of note, investigators in this study used an adjusted measure of PTG in this study, which may have weakened its construct validity and limited generalizability of results. Specifically, they reduced the Likert scale from six points to five points and excluded some items from the Posttraumatic Growth Inventory. In a separate study, child-rated family cohesion was not related to child PTG in a sample of medically healthy youth who experienced a natural disaster (Hafstad et al., 2010). Further information is needed to understand discrepancies among findings related to PTG and family function in pediatric patients.

Methodological Concerns and Limitations of Prior Studies

Measurement of PTG in the current literature presents several methodological concerns. First, many studies have used benefit finding and/or resiliency as proxy measures for PTG

(Barskova & Oesterreich, 2009; Jansen et al., 2011; Koutná et al., 2017; Michel et al., 2010; Phipps, Long, & Ogden, 2007). Benefit finding is described as reassigning positive meaning to a negative event (Sears, Stanton, & Danoff-Burg., 2003), and resiliency refers to maintenance of a baseline level of functioning following adversity (Levine et al., 2009). Given evidence that PTG is independent from these other positive outcomes of adversity (Sears et al., 2003; Westphal & Bonanno, 2007), the validity of findings in studies using benefit finding and resiliency as proxies for PTG is questionable. Second, the generalizability of prior research that evaluated PTG in youth following medical trauma may be limited due to use of primarily homogenous samples (e.g., middle/upper class and Caucasian) (Devine et al., 2010; Hungerbuehler et al., 2011). Findings from the few studies that have used diverse samples suggest that identification as a racial and/or ethnic minority is positively related to PTG (Meyerson et al., 2011; Tobin et al., 2018). Third, most studies that have evaluated PTG following pediatric medical trauma have consisted of retrospective, cross-sectional data (Meyerson et al., 2011). Findings have been mixed among the few studies that have evaluated the impact of time elapsed since a traumatic event on PTG in youth and adults (Barakat et al., 2006; Wolchik et al., 2009; Zhou, Zhen, & Wu, 2019).

Study Aims

The current study is guided by gaps in the literature as it uses an ethnically diverse sample, assesses PTG using standardized PTG measures, and is longitudinal, which allows for evaluation of directional relationships.

Primary Aims

The primary aims of the current study were to determine whether baseline medication nonadherence and barriers to medication adherence predict PTG over time and whether baseline patient and caregiver PTG predict medication nonadherence and barriers to adherence over time in a sample of pediatric SOT patients and their caregivers. It was hypothesized that greater medication nonadherence and barriers to adherence (patient- and caregiver-rated) at baseline would predict greater PTG (patient and caregiver) at follow-up. It was also predicted that greater PTG (patient and caregiver) at baseline would predict less medication nonadherence and fewer barriers to adherence (patient- and caregiver-rated) over time.

Exploratory Aims

To better understand factors contributing to PTG, medication nonadherence, and barriers to adherence in pediatric SOT patients and caregivers, the secondary aims of this study were to identify potential demographic, psychosocial, and medical correlates (i.e., type of transplant and time since transplant) and predictors of the primary outcomes over time.

CHAPTER TWO
Methodology

Participants

Forty-three pediatric SOT (i.e., liver, kidney, intestine, and/or heart transplant) patients (ages 7-19 years) and forty-three of their primary caregivers (ages 28-61 years) were recruited for baseline data collection. Participants were recruited during SOT follow-up appointments from a high-volume transplant center at a pediatric hospital in the Southwest. Exclusion criteria included patients who underwent transplant less than one month before baseline data collection, patients who were not currently prescribed tacrolimus (immunosuppression medication) and/or were not prescribed tacrolimus within two years prior to baseline data collection, and the presence of factors that might limit ability to participate or provide informed consent (e.g., intellectual disability, psychosis, and inability to read or speak Spanish or English) as determined by the SOT psychologist's clinical judgment and/or patients' medical records. The same forty-three patient-caregiver dyads that participated at baseline also completed follow-up measures. Participants received monetary compensation in the form of gift cards for participation in follow-up data collection. Table 1 provides demographics and clinical characteristics of the total study sample. Figure 3 includes a consort diagram that details participant recruitment and inclusion for baseline and follow-up data collection.

This study was approved by the Institutional Review Board at the University of Texas Southwestern Medical Center. Informed consent was obtained from caregivers and young-adult patients and assent was obtained from minors prior to initiation of study procedures. This study

received support from the Society of Pediatric Psychology's Mary Jo Kupst Student Trainee Grant for Research in Resilience.

Measures

The same measures were used to collect baseline and follow-up data. Only follow-up data for the primary outcomes were analyzed for the purposes of this study. Baseline data were collected for a larger PTG study between November 2016 and March 2019. The time of the administration of baseline measures varied between .11-17.34 years post SOT. Data collection for the follow-up time point were conducted between August 2019 and May 2020. Due to safety restrictions imposed by the COVID-19 pandemic, 69.76% of patients and caregivers completed follow-up measures for the primary outcomes using Research Electronic Data Capture (REDCap) tools (Harris et al., 2009; 2019) hosted at the University of Texas Southwestern Medical Center. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture, 2) audit trails for tracking data manipulation and export procedures, 3) automated export procedures for seamless data downloads to common statistical packages, and 4) procedures for data integration and interoperability with external sources. For the purpose of this study, the traumatic event of interest was the entire SOT experience including waiting for a new organ, undergoing transplantation, and SOT follow-up care.

Posttraumatic Growth

PTG was measured using the 12-item Posttraumatic Growth Inventory for Children, Revised Version (PTGI-C-R; Kilmer et al., 2009) and the 21-item Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996). The Posttraumatic Growth Inventory for Children, Revised

Version (PTGI-C-R) is a revised version of the original 21-item PTGI-C (Cryder et al., 2006). The PTGI-C-R is a self-report measure of the perception of positive change following stressful life events. The PTGI-C-R yields a total score and subscale scores for each of the PTG domains (i.e., New Possibilities, Relating to Others, Personal Strength, Appreciation for Life, and Spiritual Change). Patients rated the degree of positive change they have experienced from SOT on a Likert-scale ranging from 0 (*not change*) to 3 (*a lot of change*), where higher ratings indicate greater growth. The PTGI-C-R also contains two qualitative items that assess how patients' lives have changed since the traumatic event, but only the ten Likert-scale items were included for the purpose of this study. Prior research has identified total PTG scores of 20 or higher as representative of medium to high perceived change and PTG scores of 19 or below as indicative of little to no PTG development (Kilmer et al., 2009). For the purposes of this study, only the total score was used for primary and exploratory analyses. Andrades and colleagues' (2016) found support for good reliability and validity of the PTGI-C-R among children and adolescents in their study. The scale had good internal consistency within our sample at baseline (α = .84) and follow-up (α = .84).

The Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) is a 21-item self-report measure of the perception of positive change that can following stressful life events. The PTGI yields a total score (range: 0-105) and subscale scores for each of the five PTG domains (i.e. new possibilities, relating to others, personal strength, appreciation for life, and spiritual change). Caregivers rated the degree of positive change they have experienced from SOT on a Likert scale ranging from 0 (*I did not experience this change as a result of my crisis)* to 5 (*I experienced this change to a very great degree as a result of my crisis*). Brunet and

colleagues (2010) found support for good reliability and validity of the PTGI among adults. Only the total PTGI score was used for primary and exploratory analyses in this study. Prior research has identified total PTG scores of 45 and below as representative of no or low levels of PTG and scores of 46 and above as representative of medium to very high PTG levels (Mazor et al., 2016). The scale's internal consistency was excellent within our sample at baseline (α = .96) and good at follow-up (α = .81).

Posttraumatic Stress Symptoms

Posttraumatic stress symptoms were measured using the interview version of the 24-item Child Posttraumatic Stress Disorder Symptom Scale (CPSS) (Foa et al., 2001) and the 22-item Impact of Event Scale-Revised (IES-R) (Weiss & Marmar, 1997). For the purpose of this study, participants were asked to rate responses on both measures specific to their experiences with SOT. The CPSS assesses the severity of PTSD symptoms and degree of functional impairment associated with PTSD symptoms within the past 14 days in children between the ages of 7 and 18 years. The CPSS consists of 17 items that measure the severity of traumatic symptoms experienced. Patients rated the degree to which they identify with each item assessing PTSD symptoms on a Likert scale from 0 (*not at all or only once*) to 3 (5 or *more times a week/almost always*), where higher ratings reflected higher frequencies of respective constructs. The CPSS also contains seven items that measure functional impairment, but only items related to symptom severity were included and analyzed for the purpose of this study. The CPSS yields a total symptom severity scale (range: 0 to 51), where higher scores indicate higher levels of the respective constructs. Only the total score was used for the purposes of this study. The clinical cut-off score (i.e., greater or equal to 11) for the CPSS has been found to have 95% sensitivity

and 96% specificity (Foa et al., 2001). Previous studies have found evidence for good reliability and validity of this scale with children and adolescents who have experienced a traumatic event (Foa et al., 2018). The scale had good internal consistency at baseline (α = .81) and follow-up (α = .83) within our sample.

The IES-R assesses responses to traumatic events that have occurred within the past seven days in individuals who are at least 18 years of age. Caregivers rated each item on a Likert scale from 0 (*not at all*) to 4 (*extremely*), where higher ratings reflect greater levels of distress and/or symptoms. The IES-R has three subscales including Avoidance, Intrusion, and Hyperarousal. It also yields a total score, which is calculated by adding up the sum of the subscales. Only the total score was used for this study. The IES-R has a clinical cut-off score of 33, and prior research has found good reliability and validity for this scale (Beck et al., 2008). The scale had excellent internal consistency at baseline (α = .93) and at follow-up (α = .93) within our sample.

Family Functioning

Family functioning was measured using the 27-item Family Relationship Index (FRI) from the Family Environment Scale (FES) (Moos & Moos, 2009). The FRI is a subscale of the 90-item FES that evaluates the social environment of a family unit of respondents who are at least 11 years of age. The FRI measures the quality of family relationships and contains three subscales including Cohesion, Expressiveness, and Conflict. The Cohesion subscale measures the degree of commitment and support family members provide for each other. The Expressiveness subscale measures the extent to which family members are encouraged to directly express their feelings directly. The Conflict subscale assesses the amount of openly

expressed anger and conflict among family members. Prior research has found support for good internal consistency and construct validity for the FRI (Moos, 2009). In the present sample, the scale had acceptable internal consistency at baseline (α =.75) and follow-up (α =.77) for patients. Among caregivers, the scale had acceptable internal consistency at baseline (α =.73) and follow-up (α = .73).

Medication Nonadherence and Barriers to Adherence

Medication nonadherence was measured using the patients' Medication Level Variability Index (MLVI), the Adolescent Medication Barriers Scale (AMBS) (Simons & Blount, 2007), and the Parent Medication Barriers Scale (PMBS). The MLVI is the standard deviation of consecutive tacrolimus blood levels over time, and it reflects the degree of fluctuation between tacrolimus levels. A higher MLVI signifies worse tacrolimus adherence. Prior research has identified an MLVI score of 2.50 or higher as representative of medication nonadherence with higher numbers indicating greater frequencies of medication nonadherence (Shemesh et al., 2017). Baseline MLVI was calculated using tacrolimus blood levels collected up to two years before baseline measures. Follow-up MLVI was calculated using blood levels collected between data collection and up to two years before follow-up measures were administered. Patients' MLVI data were obtained through review of patients' medical charts. Previous studies using samples of pediatric SOT patients have used MLVI as a measure of medication nonadherence (Pollock-Barziv et al., 2010; Shemesh et al., 2004; 2018; Venkat et al., 2008).

The AMBS is a 17-item self-report measure that examines adolescents' perceptions of barriers to their prescribed medication taking regimen. Each item is rated on a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*), with higher scores indicating greater

barriers to adherence. There are three subscales including Disease Frustration/Adolescent Issues, Ingestion Issues, and Regimen Adaptation/Cognitive. Only the total score was used for the purposes of this study. In our sample, the scale's internal consistency was excellent at baseline (α = .92) and good at follow-up (α = .89) in our sample.

The PMBS is a 16-item measure that assesses caregivers' perceptions of barriers to their child's medication adherence. Each item is rated on a 5-point Likert scale from 1 (*strongly disagree*) to 5 (*strongly agree*), with higher scores indicating greater barriers to adherence. There are four subscales including Disease Frustration/Adolescent Issues, Ingestion Issues, and Regimen Adaptation/Cognitive, and Parent Reminder. Only the total score was used for the purposes of this study. In our sample, the scale's internal consistency was good at baseline (α = .87) and good at follow-up (α = .89).

Sociodemographic Information

Patient and caregiver demographic and sociocultural information (i.e., age [at time of SOT and at time of data collection], sex, religiosity (religious or not religious), race, ethnicity, SES (annual household income of $50,000 or less or annual household income of greater than $50,000) were collected through demographic questionnaires and review of patients' medical charts.

Solid Organ Transplant

Information regarding dates of SOT procedures and type of SOTs was obtained through review of patients' medical charts.

CHAPTER THREE
Results

Statistical significance levels were set at $p \leq .05$. Post-hoc power analyses revealed that all multivariate analyses were underpowered, and therefore, effect sizes are reported for all analyses. Descriptive statistics were computed first. Spearman's rank order correlation coefficient was calculated for simple correlations to account for the non-normal distribution of several variables. Bootstrapping was used for the same reason in all multivariate analyses. Bootstrapping utilizes random sampling with replacement to correct for non-parametric data and denotes significance using confidence intervals that do not include the number zero (Preacher and Hayes, 2008). A data-driven approach was used to determine which demographic variables should be controlled in the regression analyses relevant to the aims of the study. The analytic approach used to assess the aims was as follows: The first step in each of the following models included: time since baseline, the outcome at baseline, and any demographic variables that were found to be significantly correlated with the outcome at baseline in the partial correlation analyses. The second step included the predictor of interest, tested with one variable at a time. If multiple predictor variables were found to be significant, all significant predictor variables were entered in a third analysis to determine their unique contribution to the outcome. Exploratory analyses that examined the role of additional psychological variables in predicting PTG, medication nonadherence, and barriers to adherence utilized the same approach.

A series of independent samples t-tests were conducted to determine whether responses on follow-up measures differed between participants who completed the follow-up measures using REDCap and those who complete them in person (Table 2). Results revealed that

responses did not significantly differ between these groups. Yet, there was a large effect size for the difference in the number of follow-up barriers to adherence endorsed by patients, such that patients who used REDCap endorsed greater follow-up barriers to adherence than those who completed measures in person. In addition, there was a medium effect size for the difference in the number of follow-up barriers to adherence endorsed by caregivers, such that caregivers who used REDCap endorsed greater follow-up barriers to adherence than those who completed measures in person. Together, these results suggest that in a larger sample, the quantity of barriers to adherence endorsed by patients and caregivers at follow-up may have significantly differed based on whether participants completed measures using REDCap or in person.

Primary Analyses

Partial correlation analyses were conducted to determine which demographic variables would be included as controls in subsequent linear regression analyses for follow-up PTG (patient and caregiver), medication nonadherence, and barriers to adherence (patient- and caregiver-rated) (Table 3). Baseline scores for the outcomes were controlled in the partial correlation analyses to replicate the outcome tested in liner regressions across time. None of the demographic variables were significantly correlated with follow-up patient PTG, medication nonadherence, or caregiver-rated barriers to adherence. However, caregiver sex, specifically being a female, was significantly associated with more patient-rated barriers to adherence and higher caregiver PTG at follow-up. Patient's age at time of first SOT and a history of multiple SOTs were also related to follow-up caregiver PTG, such that caring for youth who were older at time of SOT and had only one SOT in their lifetime was related to higher levels of PTG for caregivers.

To understand the relationship between PTG (patient and caregiver), medication nonadherence, and barriers to adherence (patient- and caregiver-rated) over time, Spearman's correlation coefficient was first calculated among all of these outcomes at baseline (Table 4). Baseline patient PTG, caregiver PTG, and medication nonadherence were not significantly related to any of the other outcomes. However, there was a significant positive relationship between patient-rated barriers to adherence and caregiver-rated barriers to adherence.

Then, another set of partial correlations were conducted to examine the relationship between baseline and follow-up values for each of the outcomes (Table 4). Of note, the time between baseline and follow-up was controlled in each of these partial correlation analyses to account for elapsed time between evaluations. There was a moderate and positive relationship between baseline and follow-up patient PTG. In addition, caregiver PTG at baseline and follow-up were moderately and positively related. There was also moderate and positive relationship between baseline and follow-up medication nonadherence. For patient-rated barriers to adherence, baseline and follow-up responses were very strongly and positively correlated. Lastly there was a strong positive relationship between baseline and follow-up caregiver-rated barriers to adherence.

Next, multiple one-way analyses of covariance (ANCOVAs) were conducted to evaluate whether there was a significant difference between baseline and follow-up values for the primary outcomes (Table 5). Time between baseline and follow-up was controlled in all analyses. No significant differences were found between baseline and follow-up scores for PTG, medication nonadherence, and barriers to adherence, which suggests that these variables were stable over time.

Baseline Medication Nonadherence and Barriers to Adherence Predicting Follow-Up Posttraumatic Growth

Tables 6 and 7 present results for the following analyses. Control variables, baseline medication nonadherence, patient-rated barriers to adherence, and caregiver-rated barriers to adherence did not predict patient PTG at follow-up. Of note, greater caregiver-rated barriers to adherence at baseline had a medium-sized effect on greater patient PTG at follow-up, suggesting this relationship may be significant in a larger sample and supported hypotheses. Baseline caregiver-rated barriers to adherence, but not baseline medication nonadherence or patient-rated barriers to adherence, accounted for changes in follow-up caregiver PTG, thus providing partial support for the hypothesis. Specifically, more caregiver-rated barriers to adherence at baseline predicted more caregiver PTG at follow-up. Greater patient-rated barriers to adherence at baseline had a medium-sized effect on higher levels of caregiver PTG at follow-up, which suggests this relationship may be significant in a larger sample and consistent with hypotheses.

Baseline Posttraumatic Growth Predicting Follow-Up Medication Nonadherence and Barriers to Adherence

Tables 8, 9, and 10 present results for the following analyses. Contrary to hypotheses, baseline patient and caregiver PTG were not significant predictors of follow-up medication nonadherence. However, lower caregiver PTG at baseline had a medium-sized effect on greater medication nonadherence at follow up, suggesting that this relationship may be significant in a larger sample. Of note, the inverse nature of the relationship between caregiver PTG at baseline and medication nonadherence at follow-up supports hypotheses. Furthermore, higher ratings of caregiver PTG predicted fewer follow-up patient-rated barriers to adherence. However, baseline

patient PTG was not a significant predictor of patient-rated barriers to adherence at follow-up. These findings provide partial support for the relationship between baseline PTG and follow-up barriers to adherence. Higher ratings of baseline patient PTG predicted more follow-up caregiver-rated barriers to adherence, thus providing further support for the relationship between baseline PTG and follow-up barriers to adherence. Baseline caregiver PTG did not predict follow-up caregiver-rated barriers to adherence.

Exploratory Analyses

Exploratory analyses were conducted to aid in the understanding of the relationship between psychosocial variables and PTG, medication nonadherence, and barriers to adherence in pediatric SOT patients and their caregivers. Descriptive information for the psychosocial variables at baseline is provided in Tables 11, 12, and 13. Baseline patient religiosity was related to baseline caregiver religiosity and more patient-rated family cohesion. A greater number of baseline trauma symptoms in patients was associated with more baseline patient-rated family cohesion lower baseline caregiver-rated family conflict. Greater baseline patient-rated family cohesion was related to greater baseline caregiver-rated family cohesion. Higher ratings of baseline patient-rated family conflict were related to lower baseline caregiver-rated family expressiveness. Lastly, higher levels of baseline caregiver trauma symptoms were associated with less baseline caregiver-rated family conflict.

Next, a series of stepwise regression analyses were conducted to elucidate the role of baseline psychosocial variables in changes in follow-up PTG, medication nonadherence, and barriers to adherence in separate models. The analytic approach resembled the one used for the primary aims of the study.

Psychosocial Variables Predicting Follow-Up Posttraumatic Growth

Results for the following analyses are presented in Tables 14 and 15. In the first model, follow-up patient PTG was the dependent variable. Baseline patient religiosity predicted more follow-up patient PTG. Although they were not significant predictors, caregiver's identification as religious, greater patient-rated family cohesion, and lower patient-rated family conflict at baseline had medium-sized effects on follow-up patient PTG and thus may be significant predictors in a larger sample.

Then, the contributions of baseline psychosocial variables to unique variance in follow-up caregiver PTG was evaluated. Lower levels of patient-rated family expressiveness at baseline predicted greater follow-up caregiver PTG. Though they were not significant predictors, patient identification as religious, lower patient-rated family cohesion, higher patient-rated family conflict, and greater caregiver-rated family conflict at baseline had medium-sized effects on greater caregiver PTG at follow-up. Therefore, these psychosocial variables may be significant predictors of caregiver PTG in a larger sample.

Psychosocial Variables Predicting Follow-Up Medication Nonadherence and Barriers to Adherence

Tables 16, 17, and 18 depict results for the following analyses. The predictive power of baseline psychosocial variables on follow-up medication nonadherence was evaluated. However, none of the baseline psychosocial variables were significant predictors of follow-up medication nonadherence. Of note, lower patient-rated family cohesion and caregiver-rated family conflict at baseline had medium-sized effects on greater medication nonadherence, suggesting these relationships might be significant in larger samples.

Then, the contributions of baseline psychosocial variables to variance in follow-up patient-rated barriers to adherence were evaluated. Greater patient-rated family expressiveness at baseline predicted fewer patient-rated barriers to medication nonadherence at follow-up. Caregiver's identification as nonreligious and greater patient-rated family expressiveness at baseline had medium-sized effects on greater patient-rated barriers to adherence at follow-up, which may indicate that these relationships might be significant in a larger sample.

Finally, the effects of baseline psychosocial variables on follow-up caregiver-rated barriers to adherence were evaluated. Greater baseline patient-rated family expressiveness and patient-rated family conflict predicted fewer caregiver-rated barriers to adherence. Therefore, both variables were tested in the same model in the third step to determine if they contributed unique variance above and beyond the variance explained by the other variable. Higher levels of patient-rated family expressiveness continued to predict fewer caregiver-rated barriers to adherence after baseline patient-rated family conflict was added into the same model. Patient-rated family conflict became nonsignificant but continued to have a medium-sized effect on caregiver-rated barriers to adherence at follow-up. Although they were not significant predictors, higher patient-rated family cohesion and lower patient-rated family expressiveness, patient-rated family conflict, and caregiver-rated family expressiveness at baseline had medium-sized effects on greater caregiver-rated barriers to adherence at follow-up. Therefore, these relationships might be significant in a larger sample.

CHAPTER FOUR
Conclusions and Recommendations

As previously mentioned, the facilitation of PTG requires the occurrence of at least one significantly adverse life events that challenges one's adaptive resources, self-conceptualization, and understanding of the world (Tedeschi & Calhoun, 1996; 2004). In this study, the adverse experience of interest included the full transplant experience (e.g., time spent on waiting list, medication management, and transplantation). Most patients and their caregivers endorsed moderate to high levels of PTG related to their SOT experiences at baseline and follow-up. PTG also appeared to be stable over time for both patients and caregivers.

Predictors of Follow-Up Posttraumatic Growth

In the present sample, baseline medication nonadherence and barriers to adherence (patient and caregiver rated) did not predict follow-up patient PTG as hypothesized. Although medication management can be stressful for patients, it is possible that the burden of patient medication management may not reach the threshold level of distress required to facilitate PTG. Therefore, other potentially stressful aspects of the transplant experience (e.g., type of medical condition and time spent on the transplant waiting list) may be better predictors of patient PTG than medication management as these challenges might be more likely to elicit the cognitive processing (Figure 1) necessary to facilitate PTG. In addition, total scores for barriers to adherence and PTG were evaluated for the purposes of this study. However, it might be that the struggle with specific aspects of adherence barriers at baseline, such as frustration with living with their medical condition, facilitates the cognitive work necessary for PTG in some of the PTG domains (e.g., new possibilities in life and appreciation for life) at follow-up. As such,

further investigation is warranted to better understand the relationships between PTG domains and specific barriers to adherence because total scores may not be sensitive enough to detect these associations.

Regarding psychosocial variables, baseline patient religiosity predicted more follow-up patient PTG. This result is consistent with a prior study that found that greater religiosity was related to increased PTG (Shaw et al., 2005). The relationship between religiosity and PTG might be explained in part because of the increased social support provided by religious communities as well as the sense of meaning and overarching life purpose that religion may provide for patients. Of note it is the patient's personal religiosity that appeasers to be particularly influential to patient PTG rather than the religiosity of the family unit. Together, these findings highlight the importance of supporting patient religiosity when developing and implementing strength-based interventions focused on coping for pediatric SOT patients. In this study, religiosity was defined as identification as religious. However, future studies evaluating the role of religion in PTG should further define the construct of religion to allow for understanding of whether religiosity is distinct from the spirituality domain of PTG. It would also be beneficial to elucidate whether certain religious denominations are better predictors of high PTG than others.

In the present study, caregivers who perceived greater barriers to adherence for patients at baseline experienced greater PTG at follow-up. This finding may be due to caregivers' experience of medication management as a substantially adverse experience, contributing to the facilitation of more caregiver PTG over time. Yet, medication nonadherence and patient's perceptions of their own barriers to adherence did not predict follow-up caregiver PTG. Although patients' and caregivers' perceptions of barriers to adherence were related, it is

possible that caregivers may experience more distress, and subsequent PTG, when they perceive patients to have difficulties in specific subdomains of barriers to treatment adherence (e.g., patient frustration with medical condition). In contrast, caregivers may experience less distress related to perception of other types of barriers of adherence (e.g., organization) and overall adherence management (Simons et al., 2009). Further examination of the relationship between domains of PTG and barriers to adherence is needed to better understand the role of barriers to adherence in fostering PTG in caregivers of pediatric SOT patients.

In the current study, higher patient-rated family expressiveness (i.e., the open expression of emotions between family members) at baseline predicted less caregiver PTG at follow-up. This finding is consistent with Moos and Moos' (2009) conceptualization of the relationship between family expressiveness and the trauma experience. Specifically, they posited that family expressiveness buffers the impact of trauma by increasing perceived support for those who experience traumatic events and providing an outlet for them to openly discuss their experiences, thereby reducing distress. Of note, PTG necessitates that a person must first engage in a certain degree of struggle with coping with the traumatic experience. High levels of family expressiveness may facilitate coping and therefore prevent a person from struggling with traumatic experiences to the extent needed to experience PTG.

Predictors of Follow-Up Medication Nonadherence and Barriers to Adherence

Patients were predominately nonadherent to their medication regimens at baseline and follow-up in this study. Furthermore, medication nonadherence and barriers to adherence (patient- and caregiver-rated) remained stable between baseline and follow-up. Contrary to hypotheses, baseline patient and caregiver PTG did not have notable effects on follow-up medication nonadherence. Similarly, baseline psychosocial variables did not predict follow-up

medication nonadherence. These results contradict the findings from Morris and colleagues' (2011) study in which quantitative and qualitative methods were used to examine PTG in a sample of adults with histories of cancer diagnoses. In addition to endorsing PTG development in the domains measured by the PTGI, participants in that study also reported experiencing significant growth specific to health-related behaviors in that study (e.g., including increased adherence to treatment and physical activity) during qualitative interviews. Perhaps the PTG measures used in the present study (i.e., the PTGI and PTGI-C-R) do not have the psychometrics needed to measure PTG in the domain of health. Underpowered analyses may also account for the present findings. Although there were high levels of nonadherence in our sample, patients were more adherent at follow-up if their caregivers had greater PTG at baseline. Despite the lack of significant findings regarding this relationship, lower caregiver PTG at baseline might be a significant predictor of greater medication nonadherence over time in a larger sample due to its medium-sized effect on medication nonadherence in this study. As such, future studies should further elucidate the relationship between PTG and medication nonadherence in pediatric SOT patient using larger samples. More qualitative studies and the addition of a health domain of PTG to PTG inventories are also warranted to better understand whether this population also experiences PTG related to health behaviors.

Results revealed that higher levels of baseline caregiver PTG, but not patient PTG, predicted fewer patient-rated barriers to adherence over time. Of note, some of the barriers to adherence assessed by the AMBS are dependent on caregiver involvement (i.e., "sometimes it's hard to make it to the pharmacy to pick up the prescription before the medicine runs out"). It is therefore possible that caregivers who experience greater baseline PTG are more actively involved in patient's adherence regimen at follow-up, thereby lessening barriers to adherence at

follow-up. As previously mentioned, the salience of the relationship between PTG and barriers to adherence might fluctuate depending on which subdomains of PTG and barriers to adherence are most experienced. Endorsement of certain aspects of PTG (e.g., appreciation of life) may contribute to experiencing less barriers to adherence in certain domains (e.g., disease frustration). Additional research is needed to better understand the relationship between PTG subdomains and health behaviors in this population.

Higher levels of patient-rated family expressiveness predicted less patient-rated barriers to adherence at follow-up. This finding is consistent with a cross-sectional study of pediatric transplant patients that found greater patient reported expressiveness was associated with fewer total barriers to adherence (Simons & Blount, 2007). It may be that high levels of family expressiveness allow pediatric patients to feel more comfortable with discussing barriers to adherence with their caregivers. This open communication may lead to increased opportunities for problem-solving strategies to reduce the barriers to adherence.

Greater baseline patient PTG, but not caregiver PTG, predicted more caregiver-rated barriers to adherence. This finding contradicts the hypothesis that baseline PTG would facilitate a reduction in follow-up barriers to adherence. It is possible that patients who experience greater PTG at baseline were more likely to independently take responsibility of their medication regimens as a result of the PTG-related changes in their values and perspective (e.g., increased appreciation of life). Of note, decreased caregiver involvement with child and adolescent transplant patients has been repeatedly demonstrated to be related to worse adherence and poorer medical outcomes (Zelikovsky et al., 2008). Perhaps patients in the current study who initially experienced PTG and began to manage their own medications demonstrated greater difficulty managing their medication regimen over time. Information about how families allocate and

monitor medication responsibility will be useful in future studies to further examining the relationship between PTG and barriers to adherence.

Higher baseline patient ratings of family expressiveness also predicted fewer caregiver-rated barriers to adherence. As previously stated, families that are high in expressiveness may be more open to having conversations about barriers to adherence. This openness in communication might allow for more opportunities to strategize ways to reduce barriers to adherence for patients. Further research evaluating the relationship between family expressiveness and barriers to adherence using pediatric samples is needed.

General Discussion

Limitations of this study include the small sample size, which reduced power for analyses and may limit generalizability of results. Due to the human subject safety precautions posed by the coronavirus (COVID-19) pandemic, follow-up measures were administered both online and in-person. Though it is possible that participants' responses were influenced by the method of administration at follow-up (e.g., REDCap vs. in person), measurement responses were similar between these groups (Table 2). There was also variability between time since SOT and baseline varied between participants. Similarly, the time between the traumatic event and completion of the PTGI varied between 13 months and 4 or more years among most of the sample on which the PTGI was developed (Tedeschi and Calhoun, 1996). Time between baseline and follow-up also varied between participants. However, time since baseline was controlled in all multivariate analyses to mitigate the influence of the variability in time among participants.

This study highlights the difficulty of measuring PTG in the context of an ongoing medical trauma such as SOT due to the lack of a distinct beginning and end point of the trauma. Furthermore, the method of participant sampling used in this study warrants certain assumptions

about the directional nature of the relationship between PTG and medication nonadherence due to the large heterogeneity from time since transplant to completion of baseline measures and time between completion of baseline and follow-up measures. It was hypothesized that greater baseline medication nonadherence would predict greater follow-up PTG. In addition, it was predicted that higher baseline PTG would predict lower medication nonadherence at follow-up. Based on these assumptions it is possible to infer that PTG and medication nonadherence would fluctuate between high and low levels over time (Figure 4). Yet, results from this study are not consistent with the proposed model for the trajectory of PTG and medication nonadherence because medication nonadherence and PTG were stable over time. Prior research has also found support for the stability of medication adherence over time in pediatric SOT patients (Hoegyy et al., 2019). Little is known about the trajectory of PTG over time in pediatric samples. However, there have been mixed findings in the literature regarding the stability of PTG over time among studies using samples of adults with medical conditions (Danhauer et al., 2015). Specifically, some findings suggest that PTG remains stable over time while others suggest PTG continues to increase years after experiencing a medical trauma. Eliminating variability in time since transplant and time between baseline and follow-up among study participants would allow for enhanced understanding about the trajectory of PTG, medication nonadherence, and barriers to adherence over time. As such, future studies would benefit from using a uniform number of years for time since SOT and time between baseline and follow-up as inclusion/exclusion criteria. The current results also emphasize the need for further examination of factors that influence PTG trajectories.

To our knowledge, this study is one of the first to evaluate the relationship between PTG, medication nonadherence, and barriers to adherence in a sample of pediatric SOT patients and

their caregivers. Its longitudinal design also allowed for the examination of the direction of relationships. Of note, many of the previous studies that have examined treatment nonadherence in transplant populations have used samples that were mostly adherent to treatment (Shemesh et al., 2017). These skewed samples are likely attributable to selection bias related to the fact that individuals who are adherent to treatment are also more likely to adhere to a study protocol than those who are nonadherent. The current study is notable in that the sample was largely nonadherent, which increases the generalizability of findings and related clinical interventions to SOT pediatric patients who are nonadherent. The study also addresses gaps in the PTG literature by including patient-caregiver dyads, using a primarily Latinx sample, and using validated PTG measures. Overall findings from this study have the potential to inform strength-based clinical interventions focused on decreasing barriers to adherence for pediatric SOT patients. Specifically, results highlight the importance of addressing family functioning, especially family expressiveness, and suggest that there may be utility in strengthening PTG in caregivers of pediatric SOT patients in order to subsequently reduce barriers to adherence. Additional research is needed to better understand the associations between domains of PTG and barriers to adherence as well as the influence of PTG on other measures of adherence (e.g., attendance at follow-up SOT appointments).

Figure 1

Model Depicting the Underlying Mechanisms of Serious Pediatric Illness-Posttraumatic Growth Proposed by Picoraro and Colleagues (2014)

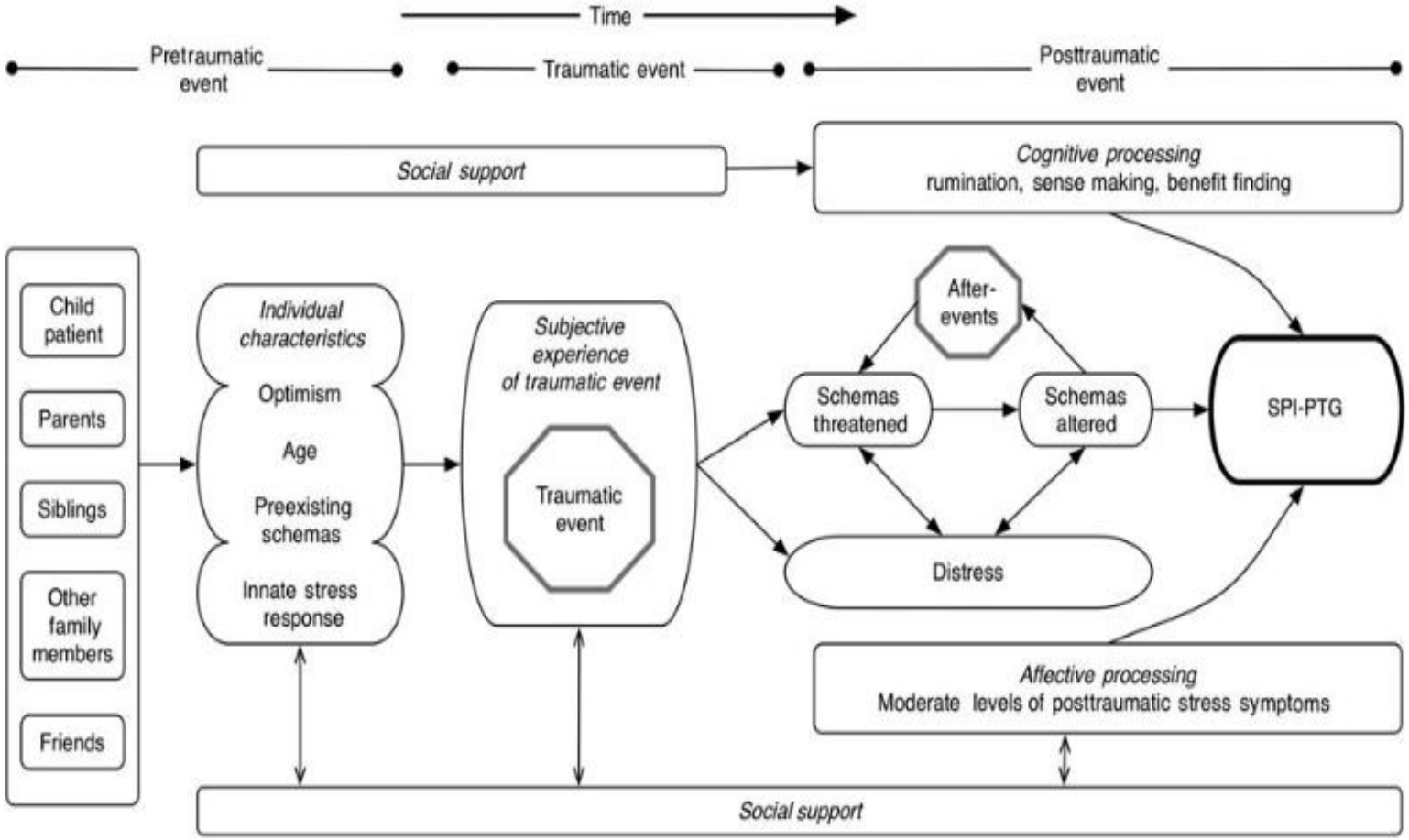


Figure 2

Model of Posttraumatic Growth in Children and Adolescents Proposed by Kilmer and Colleagues (2014)

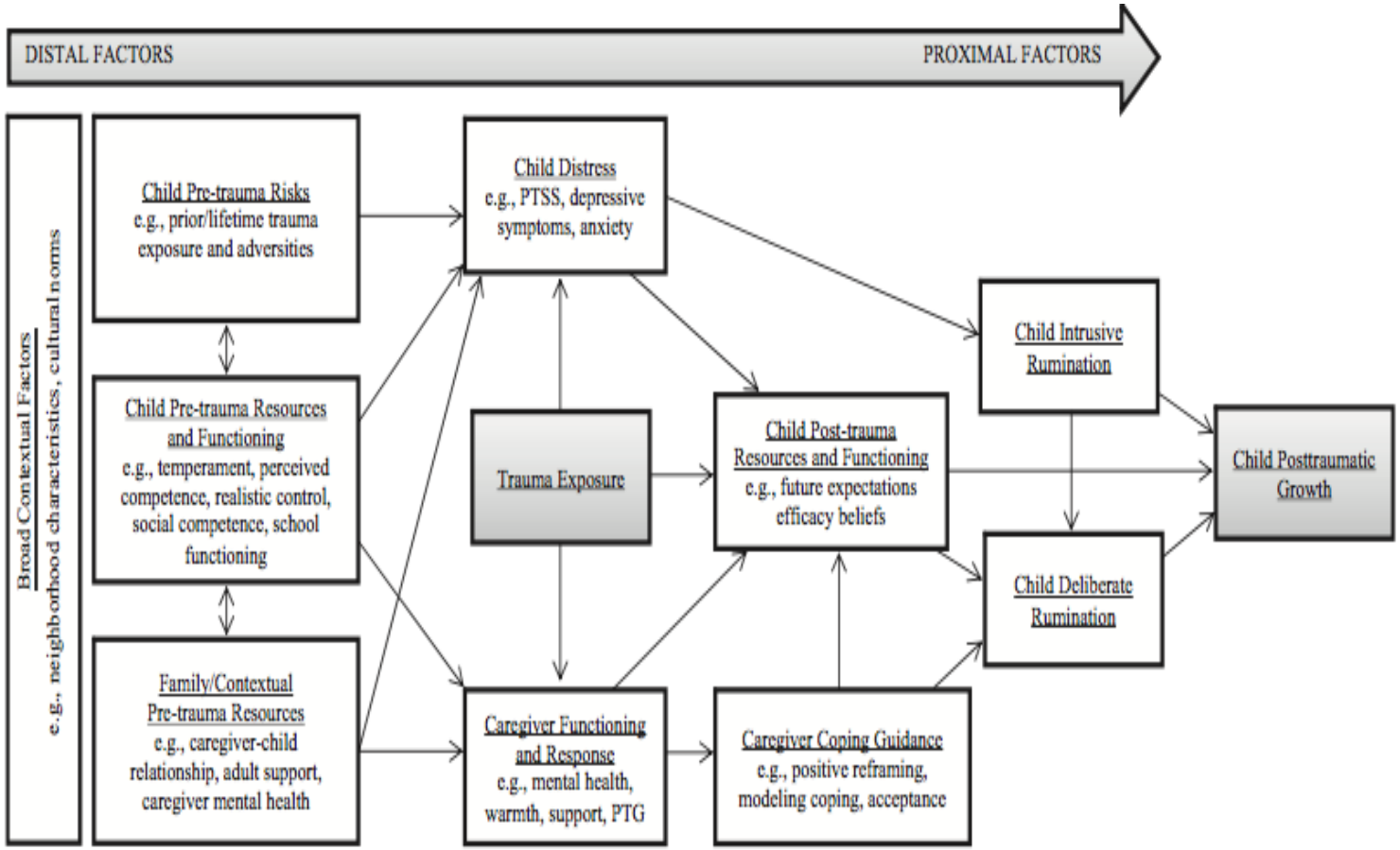


Figure 3
Consort Diagram for Follow-Up Recruitment

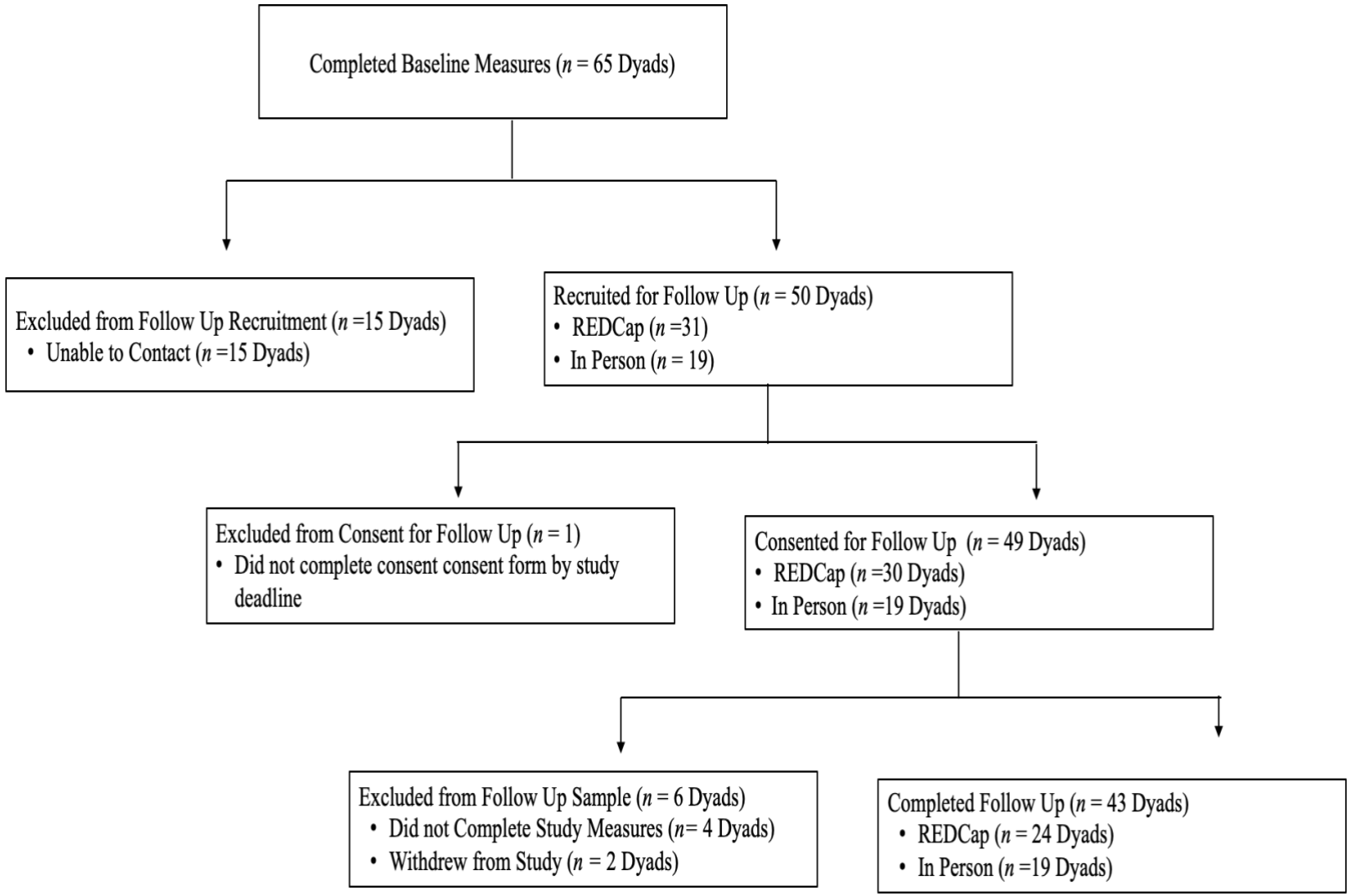
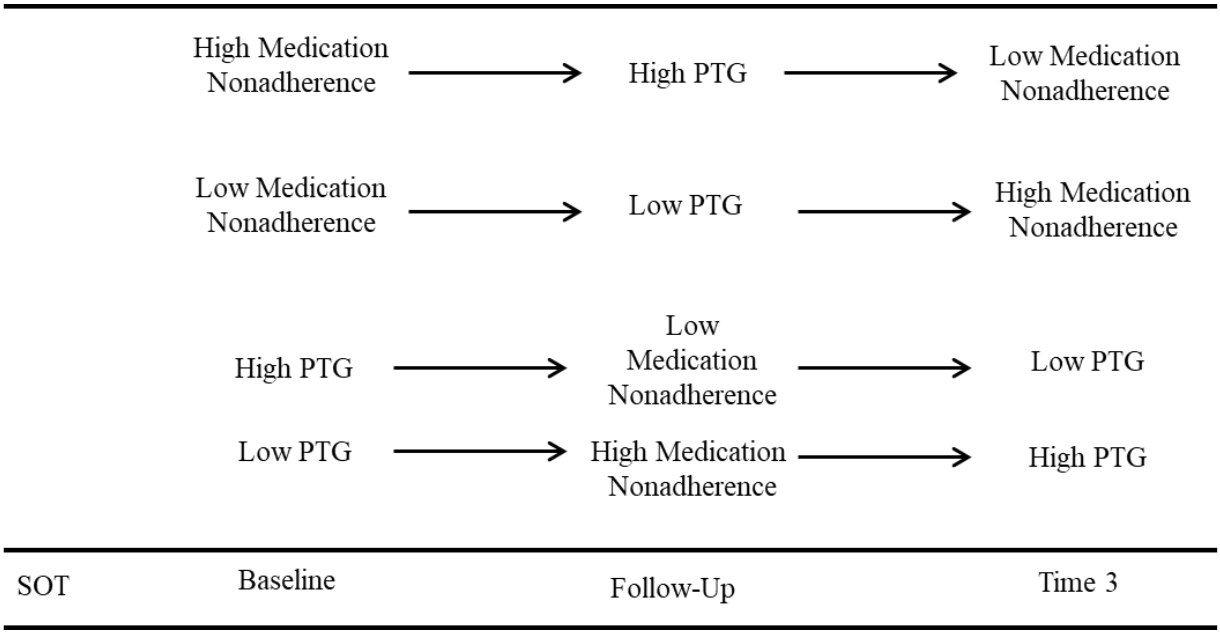


Figure 4

Model Depicting Hypothesized Relationships Between PTG and Medication Nonadherence Over Time



Note. PTG = Posttraumatic growth; SOT = Solid organ transplant

Table 1
Sample Demographics and Clinical Characteristics (N = 43)

Variable	*n* (%) or Mean (*SD*)
Patient Sex	
Female	24 (55.80%)
Male	19 (44.20%)
Caregiver Sex	
Female	40 (93.00%)
Male	3 (7.00%)
Age at time of Data Collection	
Baseline	
Patient	13.13 (3.37)
Caregiver	40.19 (7.29)
Follow-Up	
Patient	15.31 (3.21)
Caregiver	42.11 (6.91)
Patient Age at Time of First Transplant	6.99 (5.43)
Patient and Caregiver Race	
White	26 (60.50%)
Black/African American	10 (23.30%)
Multiracial	2 (4.70%)
Asian	5 (11.60%)
Patient and Caregiver Ethnicity	
Hispanic	27 (64.30%)
NonHispanic	15 (34.90%)
Not Reported	1 (1.20%)
Annual Household Income	
Less than $50,000	23 (54.80%)
Above $50,000	19 (45.20%)
Not Reported	1 (1.20%)
Type of Transplant	
Kidney	16 (37.20%)
Liver	20 (46.50%)
Heart	6 (14.00%)
Multiple Transplants	1 (1.20%)
Years Between Transplant and Baseline	6.53 (4.66)
Years Between Baseline and Follow-Up	2.11 (.67)

Table 2

Difference in Measurement Responses between Participants Who Completed Follow-Up Measures Using REDCap and Those Who Completed Measures in Person

Variables	*M*	*SD*	*g*	*F*	*t*	*df*
Patient PTG [a]			.06	.001	-.18	38
REDCap (*n* = 18)	20.17 [b]	7.80				
In Person (*n* = 22)	20.59 [b]	7.28				
Caregiver PTG [a]			.53	1.87	1.60	35
REDCap (*n* = 15)	89.27 [c]	18.65				
In Person (*n* = 22)	77.68 [c]	23.40				
Medication Nonadherence [a]			.03	.76	.80	38
REDCap (*n* = 18)	36.22 [d]	14.45				
In Person (*n* = 21)	35.38 [d]	15.02				
BTA-PR [a]			.54	.02	.18	37
REDCap (*n* = 17)	33.82 [e]	11.45				
In Person (*n* = 22)	28.18 [e]	9.53				
BTA-CR [a]			.26	1.33	1.68	37
REDCap (*n* = 16)	2.64 [e]	1.87				
In Person (*n* = 24)	2.25 [e]	1.29				

Note: Medium effect size indicated by *g* = .21-.50; Large effect size indicated by *g* = .51-.80

PTG = Posttraumatic growth; BTA= Barriers to adherence; PR = Patient rated; CR = Caregiver rated

[a] Follow-Up

[b] Scores of 20 or higher indicate medium to high PTG

[c] Scores of 46 or higher indicate medium to high PTG

[d] Scores of 2.50 or higher indicate medication nonadherence with higher numbers indicating greater frequencies of medication nonadherence

[e] Higher numbers indicate a greater quantity of the respective construct

Table 3

Partial Correlations Among Demographic Variables and Follow-Up Outcomes

Variables	Patient PTG [a]	Caregiver PTG [a]	Medication Nonadherence [a]	BTA-PR [a]	BTA-CR [a]
1. Patient Sex [b]	.15 (*n* = 39)	-.35 (*n* = 37)	-.03 (*n* = 36)	.01 (*n* = 38)	.09 (*n* = 39)
2. Caregiver Sex [b]	.08 (*n* = 40)	.55* (*n* = 37)	.32 (*n* = 40)	.69** (*n* = 39)	.36 (*n* = 39)
3. White Race	.06 (*n* = 40)	.17 (*n* = 37)	-.39 (*n* = 40)	-.14 (*n* = 39)	.20 (*n* = 39)
4. African American Race	.02 (*n* = 40)	-.01 (*n* = 37)	.09 (*n* = 40)	-.12 (*n* = 39)	-.19 (*n* = 39)
5. Asian Race	.08 (*n* = 40)	-.03 (*n* = 37)	-.08 (*n* = 40)	-.02 (*n* = 39)	.34 (*n* = 39)
6. Biracial Race	-.01 (*n* = 40)	.14 (*n* = 37)	-.18 (*n* = 40)	.12 (*n* = 39)	-.27 (*n* = 39)
7. Ethnicity [c]	-.13 (*n* = 40)	-.03 (*n* = 37)	.15 (*n* = 40)	.16 (*n* = 39)	-.03 (*n* = 39)
8. Patient's Age at Time of First SOT	-.09 (*n* = 39)	.54* (*n* = 36)	-.04 (*n* = 39)	-.22 (*n* = 38)	.36 (*n* = 38)
9. Patient's Age at Baseline	-.03 (*n* = 39)	.01 (*n* = 36)	-.16 (*n* = 39)	.03 (*n* = 38)	.23 (*n* = 38)
10. Patient History of Kidney Transplant [d]	.15 (*n* = 40)	.21 (*n* = 37)	-.07 (*n* = 40)	-.22 (*n* = 39)	-.10 (*n* = 39)
11. Patient History of Heart Transplant [d]	.33 (*n* = 40)	.01 (*n* = 37)	-.14 (*n* = 40)	.02 (*n* = 39)	-.07 (*n* = 39)
12. Patient History of Multiple Transplants [d]	.22 (*n* = 40)	-.68** (*n* = 37)	.11 (*n* = 40)	-.02 (*n* = 39)	-.28 (*n* = 39)
13. Patient History of Liver Transplant [d]	.21 (*n* = 40)	-.36 (*n* = 37)	.04 (*n* = 40)	-.25 (*n* = 39)	-.26 (*n* = 39)
14. Annual Household Income [e]	-.17 (*n* = 39)	-.22 (*n* = 36)	-.39 (*n* = 39)	-.35 (*n* = 38)	-.31 (*n* = 38)

Note: Baseline outcomes were controlled in analyses. Small effect size indicated by *R* = .10-.29; Medium effect size indicated by *R* = .30-.49; Large effect size indicated by *R* = .50-1.00

PTG = Posttraumatic growth; BTA = Barriers to adherence; PR = Patient rated; CR =

Caregiver rated; SOT = Solid organ transplant
[a] Follow-Up
[b] Coded as 0 = male and 1 = female
[c] Coded as 0 = NonHispanic and 1 = Hispanic
[d] Coded as 0 = no and 1 = yes
[e] Coded as 0 = annual household income of $50,000 or less and 1 = annual household income of greater than $50,000
** Significant at $p \leq .01$

Table 4
Correlations Among Baseline Outcomes

Variables	Patient PTG [a]	Caregiver PTG [b]	Medication Nonadherence [c]	BTA-PR [d]
1. Caregiver PTG [b]	.15 (n = 39)	_	_	_
2. Medication Nonadherence [c]	-.003 (n = 38)	.29 (n = 42)	_	_
3. BTA-PR [d]	-.02 (n = 28)	.03 (n = 31)	.33 (n = 30)	_
4. BTA-CR [d]	-.15 (n = 38)	-.30 (n = 41)	.28 (n = 40)	.51** (n = 31)

Note: Small effect size indicated by r = .10-.29; Medium effect size indicated by r = .30-.49; Large effect size indicated by r = .50-1.00
PTG = Posttraumatic growth; BTA= Barriers to adherence; PR = Patient rated; CR = Caregiver rated
[a] Scores of 20 or higher indicate medium to high PTG
[b] Scores of 46 or higher indicate medium to high PTG
[c] Higher numbers indicate a greater frequency of the respective construct
[d] Higher numbers indicate a greater quantity of the respective construct
** Significant at $p \leq .01$

Table 5

Partial Correlations and Analyses of Covariance (ANCOVAs) Among Baseline and Follow-Up Outcomes

Variable	Baseline Mean (*SD*)	Follow-Up Mean (*SD*)	*R* between Baseline and Follow-Up	*F* between Baseline and Follow-Up *(df)*
1. Patient PTG	21.72 [a] (6.72)	20.40 [a] (7.42)	.40*	.47 (1)
2. Caregiver PTG	77.98 [b] (21.98)	82.38 [b] (22.09)	.48*	.01 (1)
3. Medication Nonadherence	2.76 [c] (1.31)	2.41 [c] (1.53)	.42*	.47 (1)
4. BTA-PR	36.48 [d] (14.39)	35.77 [d] (14.57)	.80***	.17 (1)
5. BTA-CR	27.98 [d] (9.06)	30.64 [d] (10.65)	.68***	2.50 (1)

Note: Time between baseline and follow-up was controlled in analyses.

Small effect size indicated by R = .10-.29 and F = .01-.06; Medium effect size indicated by R = .30-.49 and F =.06-.14; Large effect size indicated by R = .50-1.00 and F >.14

PTG = Posttraumatic growth; BTA= Barriers to adherence; PR = Patient rated; CR = Caregiver rated

[a] Scores of 20 or higher indicate medium to high PTG

[b] Scores of 46 or higher indicate medium to high PTG

[c] Higher numbers indicate a greater frequency of the respective construct

[d] Higher numbers indicate a greater quantity of the respective construct

*** Significant at $p \leq .001$; * Significant at $p \leq .0$

Table 6

Contributions of Baseline Medication Nonadherence and BTA (PR and CR) to Variance in Follow-Up Patient PTG [a]

Predictors entered in step	R^2	R^2 change	*F* change	β	B	*SE*	Lower and upper values for 95% confidence intervals
Step 1 *(n = 34)*	.14	.14	2.50				
Patient PTG [b]				.39	.41	.21	-.04, .80
Time Since Baseline				-.22	-2.55	2.44	-6.76, 3.13
Step 2a *(n = 34)*	.14	.003	.10				
Medication Nonadherence [b]				-.05	-.28	.87	-2.00, 1.50
Step 2b *(n = 25)*	.28	.03	.80				
BTA-PR [b]				-.17	-.08	.10	-.31, .08
Step 2c *(n = 34)*	.21	.06	2.18				
BTA-CR [b]				-.24	-.19	.12	-.46, .03

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

BTA = Barriers to adherence; PR = Patient rated; CR = Caregiver rated; PTG = Posttraumatic growth;

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Baseline

Table 7

Contributions of Baseline Medication Nonadherence and BTA (PR and CR) to Variance in Follow-Up Caregiver PTG [a]

Predictors entered in step	R^2	R^2 change	F change	β	B	*SE*	Lower and upper values for 95% confidence intervals
Step 1** *(n = 32)*	.49	.49	5.11				
Caregiver Sex** [b]				.39	47.10	11.60	22.14, 70.60
Patient Age at Time of First SOT				.31	1.14	.72	-.13, 2.64
Multiple Transplants				-.07	-4.25	11.98	-24.52, 22.45
Caregiver PTG [c]				.25	.26	.19	.01, .74
Time Since Baseline				-.12	-4.09	4.21	-12.32, 4.52
Step 2a *(n = 32)*	.49	.003	4.15				
Medication Nonadherence [c]				.07	1.12	3.02	-4.87, 7.62
Step 2b (*n* = 23)	.67	.04	1.89				
BTA-PR [c]				.20	.28	.20	-.07, .76
Step 2c* *(n = 31)*	.61	.07	4.61				
BTA-CR*				.29	.65	.30	.12, 1.39

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

BTA = Barriers to adherence; PR = Patient rated; CR = Caregiver rated; PTG = Posttraumatic growth; SOT = Solid organ transplant

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Coded as 0 = male and 1 = female

[c] Baseline

** Significant at $p \leq .01$; * Significant at $p \leq .05$

Table 8

Contributions of Baseline PTG (Patient and Caregiver) to Variance in Follow-Up Medication Nonadherence [a]

Predictors entered in step	R^2	R^2 change	F change	β	B	SE	Lower and upper values for 95% confidence intervals
Step 1* *(n = 34)*	.20	.20	4.02				
Medication Nonadherence [b]				.45	.50	.23	.11, .99
Time Since Baseline				.02	.04	.33	-.57, .81
Step 2a *(n = 34)*	.20	<.001					
Patient PTG [b]				-.01	-.002	.04	-.08, .09
Step 2b *(n = 36)*	.25	.06	2.58				
Caregiver PTG [b]				-.25	-.02	.01	-.04, .002

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

PTG = Posttraumatic growth

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Baseline

* Significant at $p \leq .05$

Table 9

Contributions of Baseline PTG (Patient and Caregiver) to Variance in Follow-Up BTA-PR [a]

Predictors entered in step	R^2	R^2 change	*F* change	*β*	B	*SE*	Lower and upper values for 95% confidence intervals
Step 1*** *(n = 33)*	.78	.78	24.42				
Caregiver Sex [b]				.04	2.88	1.99	-.91, 6.89
BTA-PR*** [c]				.88	.84	.08	.67, 1.01
Time Since Baseline				-.05	-1.08	2.00	-4.83, 2.99
Step 2a *(n = 33)*	.78	.01	17.95				
Patient PTG [c]				-.07	-.16	.26	-.70, .36
Step 2b* *(n = 34)*	.79	.05	5.52				
Caregiver PTG [c]				-.24	-.15	.08	-.37, -.04

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

PTG = Posttraumatic growth; BTA = Barriers to adherence; PR = Patient rated

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Coded as 0 = male and 1 = female

[c] Baseline

*** Significant at $p \leq .001$; * Significant at $p \leq .05$

Table 10

Contributions of Baseline PTG (Patient and Caregiver) to Variance in Follow-Up BTA-CR [a]

Predictors entered in step	R^2	R^2 change	*F* change	*β*	B	*SE*	Lower and upper values for 95% confidence intervals
Step 1*** *(n = 33)*	.50	.50	15.32				
BTA-CR*** [b]				.71	.85	.14	.51, 1.07
Time Since Baseline				-.15	-2.26	2.40	-7.16, 2.54
Step 2a* *(n = 33)*	.56	.06	4.16				
Patient PTG* [b]				-.01	.45	.21	-.02, .79
Step 2b *(n = 34)*	.50	.001	.08				
Caregiver PTG [b]				-.04	-.02	.07	-.15, .11

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by $\beta = .20\text{-}.50$

BTA = Barriers to adherence; CR = Caregiver rated; PTG = Posttraumatic growth

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Baseline

***Significant at $p \leq .001$; * Significant at $p \leq .05$

Table 11

Descriptive Information for Psychosocial Variables at Baseline

Variable	Baseline Mean (SD) or *n* (%)
1. Patient Identification as Religious	
Yes	36 (85.70%)
No	6 (14.30%)
2. Caregiver Identification as Religious	
Yes	36 (90.00%)
No	4 (10.00%)
3. Patient Trauma Symptoms [a]	5.32 (2.32)
4. Caregiver Trauma Symptoms [b]	12.60 (13.67)
5. Family Cohesion-CR [c]	6.65 (1.58)
6. Family Expressiveness-CR [c]	4.32 (1.96)
7. Family Conflict-PR [c]	3.08 (1.64)
8. Family Cohesion-CR [c]	7.72 (1.59)
9. Family Expressiveness-CR [c]	6.90 (1.61)
10. Family Conflict-CR [c]	1.75 (1.17)

Note: PR = Patient rated; CR = Caregiver rated

[a] Scores equal to or greater than 11 indicate severe symptoms

[b] Scores equal to or greater than 33 indicate severe symptoms

[c] Higher numbers indicate a greater quantity of the respective construct

Table 12

Correlations Among Baseline Psychosocial Variables

Variable	1	2	3	4	5	6	7	8	9
1. Religiosity-PR	–	–	–	–	–	–	–	–	–
2. Religiosity-CR	.38* (*n* = 39)	–	–	–	–	–	–	–	–
3. Trauma Symptoms-P	.24 (*n* = 36)	.23 (*n* = 34)	–	–	–	–	–	–	–
4. Trauma Symptoms-C	-.30 (*n* = 42)	.04 (*n* = 40)	. 04 (*n* = 37)	–	–	–	–	–	–
5. Family Cohesion -PR	.50* (*n* = 23)	.32 (*n* = 21	.49* (*n* = 21)	-.12 (*n* = 23)	–	–	–	–	–
6. Family Expressiveness -PR	-.10 (*n* = 22)	-.18 (*n* = 20)	-.23 (*n* = 20)	.15 (*n* = 22)	-.09 (*n* = 22)	–	–	–	–
7. Family Conflict-PR	-.24 (*n* = 24)	-.25 (*n* = 22)	-.06 (*n* = 21)	-.02 (*n* = 24)	-.16 (*n* =23)	.07 (*n* = 22	–	–	–
8. Family Cohesion-CR	.32 (*n* = 38)	.09 (*n* = 36)	.21 (*n* = 35)	-.04 (*n* = 39)	.61** (*n* = 21)	-.28 (*n* = 22)	.03 (*n* = 22)	–	–
9. Family Expressiveness -CR	.24 (*n* = 40	.15 (*n* = 38)	-.17 (*n* = 36)	-.20 (*n* = 41)	.03 (*n* = 21)	.29 (*n* = 20)	-.47* (*n* = 22)	.25 (*n* = 39)	–
10. Family Conflict-CR	-.05 (*n* = 39)	-.14 (*n* = 37)	-.34* (*n* = 36)	-.38* (*n* = 40)	-.35 (*n* = 21)	-.03 (*n* = 20)	.27 (*n* = 22)	-.16 (*n* = 39)	.05 (*n* = 40)

Note: All variables are baseline measures. Small effect size indicated by *r* = .10-.29; medium effect size indicated by *r* = .30-.49; large effect size indicated by *r* = .50-1.00

PR = Patient rated; CR = Caregiver rated; P = Patient; CR = Caregiver

Table 13
Partial Correlations Among Baseline Psychosocial Predictors and Follow-Up Outcomes

Variable	Patient PTG	Caregiver PTG	Medication Nonadherence	BTA-PR	BTA-CR
1. Patient Religiosity	.40*** (*n* = 39)	-.12 (*n* = 36)	-.24 (*n* = 38)	-.07 (*n* = 40)	-.41*** (*n* = 38)
2. Caregiver Religiosity	.13 (*n* = 38)	.29 (*n* = 35)	-.21 (*n* = 37)	-.14 (*n* = 37)	-.17 (*n* = 37)
3. Patient Trauma Symptoms	.07 (*n* = 34)	.15 (*n* = 31)	-.22 (*n* = 33)	-.07 (*n* = 34)	-.18 (*n* = 33)
4. Caregiver Trauma Symptoms	-.03 (*n* = 40)	.19 (*n* = 37)	.00 (*n* = 39)	-.04 (*n* = 40)	.06 (*n* = 39)
5. Family Cohesion-PR	.11 (*n* = 21)	.07 (*n* = 20)	.08 (*n* = 21)	-.14 (*n* = 22)	-.14 (*n* = 20)
6. Family Expressiveness-PR	.30 (*n* = 20)	-.32 (*n* = 19)	-.43 (*n* = 20)	.25 (*n* = 21)	.08 (*n* = 19)
7. Family Conflict-PR	-.24 (*n* = 22)	-.06 (*n* = 21)	-.11 (*n* = 22)	.27 (*n* = 23)	.20 (*n* = 21)
8. Family Cohesion-CR	.06 (n = 36)	-.16 (*n* = 33)	-.19 (*n* = 35)	.11 (*n* = 36)	-.03 (*n* = 35)
9. Family Expressiveness-CR	.20 (*n* = 38)	-.24 (*n* = 35)	-.26 (*n* = 37)	-.03 (*n* = 38)	-.06 (*n* = 37)
10. Family Conflict-CR	.03 (*n* = 37)	.07 (*n* = 34)	.45*** (*n* = 36)	-.18 (*n* = 37)	.13 (*n* = 36)

Note: Time between baseline and follow-up was controlled in analyses.
Small effect size indicated by $R = .10\text{-}.29$; Medium effect size indicated by $R = .30\text{-}.49$; Large effect size indicated by $R = .50\text{-}1.00$
PTG = Posttraumatic growth; BTA= Barriers to adherence; PR = Patient rated; CR = Caregiver rated
***Significant at $p \leq .001$

Table 14
Contributions of Baseline Psychosocial Variables to Variance in Follow up Patient PTG [a]

Predictors entered in step	R^2	R^2 change	F change	β	B	SE	Lower and upper values for 95% confidence intervals
Step 1 (n = 34)	.14	.14	2.70				
Patient PTG [b]				.39	.41	.20	.01, .83
Time Since Baseline				-.26	-2.87	2.20	-6.70, 2.11
Step 2a* (n = 34)	.29	.15	6.30				
Patient Religiosity** [b]				-.30	8.04	32.54	2.80, 12.67
Step 2b (n = 33)	.25	.10	3.83				
Caregiver Religiosity [b]				.32	10.01	2.72	5.00, 15.86
Step 2c (n = 31)	.23	.01	.50				
Patient Trauma Symptoms [b]				.12	.38	.56	-.45, 1.85
Step 2d (n = 35)	.15	.003	.12				
Caregiver Trauma Symptoms [b]				-.06	-.03	.09	-.22, .14
Step 2e (n = 18)	.16	.06	1.12				
Family Cohesion-PR [b]				.26	1.09	1.15	-2.10, 2.65
Step 2f (n = 17)	.05	.02	.31				
Family Expressiveness-PR [b]				.15	.48	.89	-1.54, 1.76
Step 2g (n = 18)	.21	.12	2.17				
Family Conflict-PR [b]				-.34	-1.32	1.32	-4.76, -.14
Step 2h (n = 31)	.29	.001	.02				
Family Cohesion- CR [b]				-.03	-.11	1.09	-1.68, 2.57
Step 2i (n = 33)	.22	.03	1.07				

Family Expressiveness-CR [b]				.18	.76	.81	-.99, 2.13
Step 2j (n = 32)	.26	<.001	.003				
Family Conflict-CR [b]				-.01	-.06	1.20	-2.33, 2.35

Note: Each predictor was tested separately in Step 2. All significant predictors at Step 2 were combined in Step 3. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

PTG = Posttraumatic growth; PR = Patient rated; CR = Caregiver rated

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Baseline

** Significant at $p \leq .01$; * Significant at $p \leq .05$

Table 15
Contributions of Baseline Psychosocial Variables to Variance in Follow up Caregiver PTG [a]

Predictors entered in step	R^2	R^2 change	F change	β	B	SE	Lower and upper values for 95% confidence intervals
Step 1** (n = 32)	.46	.46	4.65				
Caregiver Sex** [b]				.40	47.31	10.71	23.28, 65.95
Patient's Age at Time of First SOT				.30	1.14	.69	-.08, 2.67
Multiple Transplants				-.09	-5.26	11.46	-27.69, 18.95
Caregiver PTG [c]				.21	.22	.17	-.004, .66
Time Since Baseline				-.09	-3.00	4.49	-10.97, 6.68
Step 2a (n = 32)	.50	.03	1.75				
Patient Religiosity [c]				.26	-12.12	10.66	-35.09, 9.77
Step 2b (n = 31)	.29	.002	.09				
Caregiver Religiosity [c]				-.05	-3.81	13.92	-27.84, 19.13
Step 2c (n = 28)	.57	<.001	<.001				
Patient Trauma Symptoms [c]				.002	.02	2.43	-4.65, 3.31
Step 2d (n = 33)	.48	.01	.39				
Caregiver Trauma Symptoms [c]				-.10	-.13	.21	-.43, .38
Step 2e (n = 17)	.58	.05	1.18				
Family Cohesion-PR [c]				-.24	-3.49	4.00	-10.65, 5.84
Step 2f (n = 16)	.68	.13	34.00				
Family Expressiveness-PR [c]				-.42	-5.80	4.39	-13.67, 3.71
Step 2g (n = 18)	.60	.07	2.05				
Family Conflict-PR [c]				.33	4.43	4.47	-1.46, 15.83
Step 2h (n = 29)	.49	.002	.07				

Family Cohesion- CR [c]				-.05	-.58	4.01	-6.03, 8.23
Step 2i (n = 33)	.52	.03	1.39				
Family Expressiveness-CR [c]				-.20	-2.71	3.09	-9.23, 2.83
Step 2j (n = 32)	.54	.05	2.66				
Family Conflict-CR [c]				.24	4.50	3.21	-3.08, 9.65

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

PTG = Posttraumatic growth; SOT = Solid organ transplant; PR = Patient rated; CR = Caregiver rated

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Coded as 0 = male and 1 = female

[c] Baseline

*** Significant at $p \leq .01$

Table 16
Contributions of Baseline Psychosocial Variables to Variance in Follow-Up Medication Nonadherence [a]

Predictors entered in step	R^2	R^2 change	F change	β	B	SE	Lower and upper values for 95% confidence intervals
Step 1* (n = 36)	.19	.19	3.91				
Medication Nonadherence* [b]				.42	.48	.23	.11, .99
Time Since Baseline				.08	.19	.33	-.44, .83
Step 2a (n = 36)	.19	.001	.03				
Patient Religiosity [b]				-.03	-.11	.66	-1.56, .97
Step 2b (n = 33)	.18	.01	.18				
Caregiver Religiosity [b]				-.08	-.37	.96	-2.04, 1.99
Step 2c (n = 30)	.18	.003	.09				
Patient Trauma Symptoms [b]				-.06	-.04	.12	-.27, .20
Step 2d (n = 36)	.20	.01	.44				
Caregiver Trauma Symptoms [b]				-.10	-.01	.02	-.04, .02
Step 2e (n = 18)	.41	.04	.99				
Family Cohesion-PR [b]				-.20	-.14	.13	-.41, .10
Step 2f (n = 17)	.35	.001	.02				
Family Expressiveness-PR [b]				-.04	-.02	.12	-.27, .23
Step 2g (n = 19)	.40	.03	.73				
Family Conflict-PR [b]				.17	.11	.13	-.28, .28
Step 2h (n = 32)	.19	.01	.43				
Family Cohesion-CR [b]				.12	.12	.23	-.36, .51

Step 2i (n = 34)	.19	.01	.24				
Family Expressiveness-CR [b]				.08	.08	.18	-.29, .42
Step 2j (n = 33)	.25	.06	2.56				
Family Conflict-CR [b]				-.26	-.33	.20	-.69, .13

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.
Medium effect size indicated by β = .20-.50
PR = Patient rated; CR = Caregiver rated
[a] Only those demographic variables that showed a significant association with the outcome were included as controls
[b] Baseline
*Significant at $p \leq .05$

Table 17

Contributions of Baseline Psychosocial Variables to Variance in Follow-Up BTA-PR [a]

Predictors entered in step	R^2	R^2 change	*F* change	*β*	B	*SE*	Lower and upper values for 95% confidence intervals
Step 1*** (*n* = 25)	.75	.74	20.85				
Caregiver Sex [b]				.05	3.47	1.85	-.01, 7.29
BTA-PR** [c]				.85	.80	.09	.62, .96
Time Since Baseline				-.01	-.10	2.24	-4.40, 4.22
Step 2a (*n* = 25)	.76	.02	1.82				
Patient Religiosity [c]				.11	-7.00	3.82	-13.08, 2.48
Step 2b* (*n* = 23)	.79	.05	4.92				
Caregiver Religiosity [c]				-.26	-12.67	3.18	-17.90, -5.88
Step 2c (*n* = 22)	.77	.001	.07				
Patient Trauma Symptoms [c]				.04	.21	1.14	-2.68, 1.66
Step 2d (*n* = 25)	.74	.003	.28				
Caregiver Trauma Symptoms [c]				-.06	-.05	.11	-.33, .09
Step 2e (*n* = 15)	.76	.002	.08				
Family Cohesion-PR [c]				-.04	-.40	2.25	-2.75, 5.12
Step 2f* (*n* = 14)	.82	.10	5.29				
Family Expressiveness-PR* [c]				.32	-3.54	1.64	-6.94, -.33
Step 2g (*n* = 15)	.76	.002	.09				
Family Conflict-PR [c]				.05	.36	1.77	-3.32, 4.01
Step 2h (*n* = 23)	.76	.02	1.37				
Family Cohesion- CR [c]				.14	1.28	1.76	-3.43, 3.11

Step 2i (n = 24)	.74	.002	.14				
Family Expressiveness-CR [c]				.04	.38	1.07	-1.68, 2.48
Step 2j (n = 23)	.74	.002	.12				
Family Conflict-CR [c]				.04	.49	1.48	-2.41, 3.49

Note: Each predictor was tested separately in Step 2. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.
Medium effect size indicate by β = .20-.50
BTA = Barriers to adherence; PR = Patient rated; CR = Caregiver rated
[a] Only those demographic variables that showed a significant association with the outcome were included as controls
[b] Coded as 0 = male and 1 = female
[c] Baseline

Table 18
Contributions of Baseline Psychosocial Variables to Variance in Follow-Up BTA-CR [a]

Predictors entered in step	R^2	R^2 change	*F* change	*β*	B	*SE*	Lower and upper values for 95% confidence intervals
Step 1*** (n = 33)	.52	.52	16.51				
BTA-CR*** [b]				.72	.85	.13	.54, 1.07
Time Since Baseline				-.14	-2.27	2.41	-7.04, 2.36
Step 2a (n = 33)	.52	.001	.07				
Patient Religiosity [b]				.03	1.19	5.01	-8.46, 12.18
Step 2b (n = 32)	.48	<.001	<.001				
Caregiver Religiosity [b]				.002	.09	3.84	-7.72, 7.71
Step 2c (n = 30)	.51	.01	.29				
Patient Trauma Symptoms [b]				.08	.39	.68	-.98, 1.42
Step 2d (n = 34)	.50	.004	.28				
Caregiver Trauma Symptoms [b]				.07	.05	.14	-.29, .24
Step 2e (n = 17)	.52	.07	1.89				
Family Cohesion-PR [b]				.26	1.82	1.58	-2.30, 3.71
Step 2f* (n = 16)	.61	.15	5.05				
Family Expressiveness-PR* [b]				-.42	-2.86	1.32	-6.14, -.95
Step 2g* (n = 32)	.59	.13	4.60				
Family Conflict-PR* [b]				-.39	-2.42	1.54	-5.73, 1.41
Step 2h (n = 30)	.55	.01	.55				
Family Cohesion- CR [b]				-.10	-.70	1.09	-2.48, 2.18

Step 2i (n = 32)	.56	.04	2.60				
Family Expressiveness-CR [b]				-.20	-1.40	.87	-3.28, .20
Step 2j (n = 31)	.56	.004	.24				
Family Conflict-CR [b]				.07	.73	1.49	-2.70, 3.24
Step 3* (n = 16)	.73	.27	6.16				
Family Expressiveness PR* [b]				-.40	-2.73	1.21	-5.65, -.67
Family Conflict-PR* [b]				-.37	-2.31	1.51	-4.91, 2.08

Note: Each predictor was tested separately in Step 2. All significant predictors at Step 2 were combined in Step 3. Bootstrapping was used for all analyses to compute B, *SE*, and confidence intervals.

Medium effect size indicated by β = .20-.50

BTA = Barriers to adherence; CR = Caregiver rated; PR = Patient rated

[a] Only those demographic variables that showed a significant association with the outcome were included as controls

[b] Baseline

*** Significant at $p \leq .001$; * Significant at $p \leq .05$

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