

Barriers to Adherence to Medical Recommendations Following Adolescent Injury

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Abstract

Adherence to treatment recommendations following medical care for pediatric conditions is critically important for promoting optimal physical and psychological well-being. While it has been a focus of many studies across pediatric chronic illness populations, there is a dearth of research examining adherence following pediatric unintentional injury. Empirical evidence from studies with pediatric chronic illness samples indicates that youth experience a number of barriers to adherence to medical recommendations. Adherence is especially difficult for adolescents due to the unique challenges of this developmental period. A mixed methods research approach was utilized to gain a holistic understanding of potential psychological barriers to adherence following adolescent injury. Quantitative analyses examined the potential predictive roles of adolescent psychological [i.e., posttraumatic stress (PTSD), depression, quality of life] and relational (i.e., parent PTSD and depression) factors on adherence. Results of analyses were insignificant; thus, qualitative data was collected to deepen the understanding of barriers to adherence. Findings from qualitative data analyses suggested that a number of barriers to adherence to treatment recommendations exist, including: concern of pain medication addiction, competing activities, treatment side effects, health status, desire for autonomy, and symptoms of depression. Results of qualitative analyses also revealed the presence of additional factors that could facilitate adherence to treatment recommendations. Taking into consideration findings from both quantitative and qualitative analyses, adherence may be best conceptualized as a result of a dynamic decision-making process influenced by numerous interacting factors. This study is the first to examine barriers to adherence among adolescents following unintentional injury and provides an initial roadmap for understanding the mechanisms involved in this complex process.

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Chapter 1 - Introduction

Millions of children and adolescents sustain an unintentional physical injury each year, which can affect physical and even psychological well-being. According to the World Health Organization (2008), injury is the greatest threat to survival to children over the age of five. More than 225,000 of children and adolescents are hospitalized annually, while another 9.2 million visit emergency departments (ED) each year (Center for Disease Control, 2008). Following pediatric injury, a significant number of youth experience symptoms of emotional distress, including posttraumatic stress disorder (PTSD; Kassam-Adams & Winston, 2004; Winston, Kassam-Adams, Garcia-España, Ittenbach, & Cnaan, 2003). PTSD is characterized by a constellation of symptoms including re-experiencing, avoidance, negative cognitions and mood, and hyperarousal (American Psychiatric Association, 2013), and is associated with poorer physical recovery and impaired family functioning after pediatric injury (Shudy et al., 2006).

According to the Center for Disease Control (2008), the most common causes of injury include falls, being struck by an object, animal or insect bites, overexertion, and motor vehicle occupant injuries. To facilitate optimal physical and psychological recovery after injury, medical providers typically provide specific treatment recommendations upon discharge. Although they vary from patient to patient, such recommendations may include: activity restrictions, medication, follow-up visits at the clinic, dietary restrictions, and wound care.

1.1 - Treatment Adherence

Research with pediatric chronic illness samples indicates that treatment adherence, or the “extent to which a person’s behavior taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed upon recommendations from a health care provider” (Sabate, 2003, p.17), is suboptimal. Empirical evidence examining adherence in children and adolescents following injury is limited; thus, the following discussion will be guided by studies that have been conducted with children and adolescents suffering from a chronic illness. Only 50% of children with chronic illnesses adequately adhere to prescribed regimens, and the rate is much lower for adolescents (Rapoff, 2010; Logan et al., 2003).

Understandably, health promotion, disease prevention, and successful medical management, particularly of chronic disease, can be difficult to attain in pediatric care. Simply adhering to a healthy lifestyle (limiting sun exposure, getting exercise, eating healthy foods, avoiding smoking, having recommended physician visits and immunizations) can be challenging enough for healthy children and adolescents (DiMatteo, 2004). The majority of chronic illness conditions require children and adolescents manage a medical treatment regimen, which may include tasks such as regular administration of medication, changes in diet, obtaining regular lab work, and going to clinic appointments. The complexity and time-consuming nature of these medical treatment regimens places substantial burden on families, often hindering their effective implementation (Pai & Drotar, 2010).

1.2 - Relationship between Nonadherence and Outcomes

Nonadherence can have some very serious consequences for children and adolescents suffering from chronic illness. It can result in decreased exposure to treatments, which can subsequently influence a number of psychological, medical, health care, and community-level outcomes. For instance, nonadherence is linked to lower quality of life (Fisak, Belkin, von Lehe, & Bansal, 2011; Hommel, Davis, & Baldassano, 2009; Fredericks et al., 2008), poor coping strategies (Mackner & Crandall, 2005), higher levels of anxiety and depressive symptoms (Gray, Denson, Baldassano, & Hommel, 2012), family dysfunction (Mackner & Crandall, 2005), and higher high school dropout rates (Lurie et al., 2000).

Poor adherence has been cited as the single greatest cause of treatment failure (Quittner, Modi, Lemanek, Ievers-Landis, & Rapoff, 2008), and has been linked to increased morbidity and mortality (Kennard et al., 2004; Falkenstein, Flynn, Kirkpatrick, Casa-Melley, & Dunn, 2004). According to one study, nonadherence can compromise the health outcomes of pediatric treatment by as much as 71% (DiMatteo et al., 2002). Furthermore, failure to follow medication prescriptions can be a major cause of the spread of drug resistant infections as well as of drug reactions and interactions, and may lead to increased dosages or discontinuation of medication believed to be ineffective (Dew et al., 2001; DiMatteo, Giordani, Lepper, & Croghan, 2002). Additionally, nonadherence may lead to healthcare professionals having fewer appointments and less time available for other patients (Bender & Rand, 2004).

Finally, evidence suggests that nonadherence has community-level ramifications. The excess cost associated with nonadherence is estimated to be as high as 300 billion dollars per year (DiMatteo, 2004). The economic burden of hospitalization attributable to nonadherence is thought to be 1.6 billion dollars and the cost of medication wasted or discarded is approximately 1 billion dollars per year (Iskedjian, Addis, & Einarson, 2002).

1.3 - Theoretical Framework

The Health Belief Model (HBM) is widely used to understand the mechanisms contributing to nonadherence across pediatric groups (Lee et al., 2014; Ingerski et al., 2011; Ingerski et al., 2010; Marhefka et al., 2008; Cox et al., 2014). It was originally developed in the 1950's as a systematic method to explain and predict preventive health behavior. Central tenets of the model include: perceived threat (i.e., perceived seriousness and susceptibility to threat associated with disease), perceived benefits (i.e., individual's opinion of the value or usefulness of a new behavior in decreasing the risk of developing disease), and perceived barriers (i.e., individual's evaluation of the obstacles in the way of adopting a new behavior). Modifying factors can include demographic variables, past experiences, and cues to action. The combination of these factors causes a response that often manifests into recommended preventive health actions. However, action may not take place, even though an individual may believe there are benefits to taking action. This may be due to barriers, which are the characteristics of a treatment or preventive measure that may be inconvenient, expensive, unpleasant, painful or upsetting. These characteristics deter a person from taking the desired action (Rosenstock, 1974; please refer to Figure 1).

As such, a primary component of the HBM is addressing barriers to treatment adherence. Perhaps unsurprisingly, previous research has shown that greater perceived barriers to adherence are related to poorer adherence (Marhefka et al., 2008; Modi & Quittner, 2006). A higher number of barriers is associated with greater difficulty adhering to medical recommendations across pediatric populations, underscoring the importance of studying perceived barriers in order to improve treatment adherence outcomes (Silverstein, Fletcher, & Moylan, 2014; King et al., 2014). As such, the understanding of barriers and other factors related to adherence has been described as a promising area in pediatric research (Fisak et al., 2011; Ingerski, Hente, Modi, & Hommel; King et al., 2014; Hommel, Denson, & Baldassano, 2011).

Pertinent literature regarding the HBM is discussed in subsequent sections. A review of factors promoting adherence will precede a more in-depth discussion of barriers to adherence, which is the primary focus of the current study.

1.4 - HBM: Factors Contributing to Adherence

Several components of the HBM are in place to account for factors that facilitate adherence to medical recommendations. Following is a brief review of individual perceptions (i.e., perceptions of threat and benefits) and modifying factors (i.e., cues to action) that facilitate adherence.

Perceptions of threat refer to individuals' beliefs about the severity of the condition as well as personal risk and susceptibility. The greater the perceived threat, the greater the likelihood of engaging in behaviors to decrease risk. Results of a meta-analysis indicate that greater perceived disease severity threat is associated with better adherence. Interestingly, based on objective measures, actual disease severity threat is associated with poorer adherence, highlighting the powerful effects of individuals' beliefs (DiMatteo, Haskard, & Williams, 2007).

Perceived benefits to adherence refer to individuals' beliefs about the value or usefulness of a behavior in decreasing risk associated with the disease or medical condition. Indeed, a high perceived need for treatment has been shown to be associated with treatment adherence in samples of children and adolescents with asthma (Klok, Kaptein, Duiverman, & Brand, 2012) and Type 1 Hereditary Tyrosinaemia (Malik, NiMhurchadha, Jackson, Eliasson, Weinman, Roche, & Walter, 2015). Furthermore, empirical evidence suggests that the desire to return to normal activities promotes adherence in adolescents following anterior cruciate ligament repair (Brewer et al., 2003).

Cues to action are events, people, or things that move people to change their behavior. Particularly relevant to pediatric populations are the influence of parents. Because medical recommendations are often unfamiliar and complex, parents play an important role in guiding adherence. Practical support from parents (e.g., encouraging dietary restrictions, bringing children to appointments) is also instrumental in helping children with chronic diseases (DiMatteo, 2004). Healthcare professionals also serve as important cues to action. Indeed, they are seen as a source of advice on how to overcome difficulties with the treatment regimens (Santer et al., 2014). When families have the opportunity to discuss treatment and treatment adherence with physicians, they are better able to engage in collaborative decision-making and

treatment management (Drotar & Bonner, 2009). Furthermore, having a good relationship with the health professional is imperative, as feeling judged or unsupported by the healthcare professional is directly related to adherence (DiMatteo, 2004).

1.5 - HBM: Barriers to Adherence

While the HBM emphasizes the importance of considering barriers to carrying out health behaviors, findings from the pediatric literature provide specific information regarding barriers to treatment adherence. Empirical evidence indicates that children and parents face a variety of barriers to adherence in the treatment of chronic medical conditions. Specifically, previous research with pediatric chronic illness has identified a number of factors relevant to understanding adherence in both children and adolescents (i.e., sociodemographic factors, health status and knowledge, cognitive factors, aversive properties of oral medication, logistical concerns, and relational factors.)

1.5.1 - Barriers to Adherence for Children and Adolescents.

Sociodemographic factors.

Findings from studies of children with asthma and HIV demonstrated that low socioeconomic status (SES) was associated with nonadherence (Drotar & Bonner, 2009; Shemesh et al., 2007). According to a review of studies pertaining to adherence to youth asthma treatments, single parent status and race were related to nonadherence (Drotar & Bonner, 2009). In sum, there is preliminary evidence for the role of sociodemographic variables in treatment adherence in pediatric conditions.

Health status and knowledge.

Previous research has demonstrated that health status may be associated with adherence. Absence of symptoms is a commonly reported barrier to adherence because patients may believe that their lack of symptoms suggests they no longer need to follow through with treatment recommendations (Rowe et al., 2005). Less sophisticated knowledge of treatments is associated with poorer treatment outcomes (Greenley, Stephens, Doughty, Raboin, & Kugathasan, 2010; Hommel & Baldassano, 2010). Furthermore, health literacy, or patients' ability to read, comprehend, and act on medical instructions, is also related to nonadherence indicating that patients' knowledge and understanding of the treatment recommendations is necessary for adherence (Crosby et al., 2012).

Cognitive factors.

A number of potential barriers to adherence related to difficulties with planning and organization have been identified, including forgetfulness and time management issues (Bregnballe et al., 2011; Gray et al., 2012; Modi & Quittner, 2006; Hommel et al., 2009). Factors such as lacking organization and not planning ahead are associated with higher rates of missed medication dosages in youth who received a transplant (Gray et al., 2012; Bregnballe, Schiøtz, Boisen, Pressler, & Thastum, 2011), while reports of forgetting to take medication and failing to plan ahead are barriers to adherence for patients with IBD (Hommel, Denson, & Baldassano, 2011; Hommel & Baldassano, 2010; Ingerski et al., 2011). Additional barriers to adherence related to cognitive functioning include difficulty remembering medication schedules (Silverstein, Fletcher, & Moylan, 2014), failure to refill prescriptions (Witherspoon & Drotar, 2006), and confusion regarding appointment dates and times (Crosby et al., 2012).

Aversive properties of oral medication.

Rates of oral medication adherence vary among pediatric conditions, although a significant percentage of children and families exhibit suboptimal adherence (Rapoff, 2010). Several specific factors related to taking medication make this form of adherence particularly difficult, including high pill number burden, large pill size, difficulty swallowing medication, and unpleasant taste of the pill (Ingerski et al., 2009; Silverstein, Fletcher, & Moylan, 2014; Hommel & Baldassano, 2010; van Elsland et al., 2012; Zhang et al., 2016).

Logistical concerns.

Additionally, incorporating treatment into everyday life can be inconvenient for children and families, thereby hindering treatment adherence. A consistent theme throughout the pediatric chronic illness literature is that treatment adherence competes with other activities in a child's life, making adhering to medical recommendations difficult (Crosby et al., 2009; Hommel, Denson, & Baldassano, 2011; Ingerski et al., 2011). Similarly, unfamiliar activities and/or changes in routine, such as when beginning a new treatment (i.e., physical therapy or psychological treatment) are associated with nonadherence in children with pain, suggesting that novel medical recommendations present significant challenges to adherence (Simons, Logan, Chastain, & Cerullo, 2010). Wait times at clinic visits were also considered burdensome and are thought to impact adherence in children with TB and SCD (van Elsland et al., 2012; Crosby et al., 2012).

Hidden costs of treatment, including time taken off from work and transportation costs can serve as barriers to adherence in children with TB and SCD (van Elsland et al., 2012; Crosby et al., 2012). Inconsistent medical insurance has also been linked to nonadherence in children across medical conditions, indicating that families with limited financial resources have more difficulty adhering to treatment recommendations (Shemesh et al., 2007).

Relational factors.

Family factors, including family conflict and disengagement, dysfunctional family relationships, and child abuse are related to nonadherence (Fiese & Everhart, 2006; Shemesh et al., 2007; Mackner & Crandall, 2005). Additionally, youths' oppositionality with taking medication and refusal of treatment have been noted to serve as barriers to adherence in samples of children with IBD as well as HIV (Hommel, Denson, & Baldassano, 2011; Marhefka et al., 2008). A review of treatment nonadherence across pediatric chronic medical conditions concluded that child resistance is a significant barrier to adherence and a source of stress for caregivers. Child resistance tended to occur when the treatment was aversive (e.g., caused adverse side effects) or time-consuming (e.g. physiotherapy for juvenile arthritis; Santer et al., 2014).

Parental beliefs also play a crucial role in our understanding of adherence in pediatric chronic illness populations. A review of qualitative studies looking at treatment adherence across chronic pediatric conditions found that caregiver beliefs had a major impact on caregiver decisions regarding treatment adherence. This theme consisted of two sub-themes: parental concerns or fears (e.g., perceived long-term threat) about the condition and caregiver beliefs (e.g., perceived effectiveness or fear of side effects) about the treatment (Santer et al., 2014). Parents' beliefs that adherence can be dangerous vastly increase the chances of nonadherence (DiMatteo, 2004). Previous research has shown that, for some parents, nonadherence to recommended medication reflects well-reasoned, purposeful decisions (not usually shared with the provider) that weigh the perceived benefits versus burdens of treatment over the course of illness management (Drotar & Bonner, 2009), demonstrating the importance of parents when examining pediatric adherence.

Maternal psychological status (e.g., frequency of depressive symptoms and psychological distress) is related to treatment nonadherence (Drotar & Bonner, 2009), suggesting that parental psychological symptoms may interfere with their abilities to provide care and support for their

children. Further, parental anxiety can be transmitted to a child and affect his or her ability to engage in self-care (DiMatteo, 2004).

1.5.2 - Developmental Factors.

Older children tend to have lower rates of adherence compared to younger children (Rapoff, 2010), most likely due to a variety of developmental factors related to adolescence, which is universally regarded as a time of poor adherence across chronic medical conditions. The developmental changes of adolescence include a greater desire for autonomy, more time spent outside the home, increased academic and social demands, and an increased need to “fit in” with peers (Holmbeck, Greenley, & Franks, 2004). In addition, adolescence is often characterized by an inability to recognize one’s own mortality and the consequences of one’s actions (Hazen, Schlozman, & Beresin, 2008). These normative developmental changes are not generally conducive to the completion of treatment management tasks.

1.5.3 - Barriers to Adherence Specific to Adolescents.

Characteristics unique to the developmental period of adolescence can present an additional set of specific barriers to treatment adherence, which are not relevant to younger children. Such barriers are related to social factors, the diffusion of responsibility between adolescents and parents, competing activities, and psychological factors. Each of these will be discussed below.

Social factors.

More so than children with chronic illness, adolescents with chronic illness endorse barriers to adherence related to peer relationships (Cox et al., 2014). For instance, adolescents with asthma report barriers to adherence related to peers and feelings of stigma related to using an inhaler or taking medications (Riekert & Drotar, 2000). In another sample of adolescent asthma patients, the presence of peers was a powerful and detrimental barrier to adherence in about half of the instances when an inhaler was not used (Mulvaney et al., 2013). Social comparison with peers and consequent embarrassment about taking medications resulting in nonadherence presented challenges to adherence in adolescents with IBD (Hommel et al., 2011). Another study of adolescents with IBD concluded that adolescents who wished for friends not to know about their IBD, or those who did not like taking medication in public, had lower adherence rates (Schurman, Cushing, Carpenter, & Christenson, 2011).

Diffusion of responsibility.

A primary contributor to the increased rates of nonadherence during the adolescent years is the transition of treatment responsibility from parents to adolescents (Gray et al., 2012). Specifically, as children enter adolescence, they often assume increasing responsibility for medication administration, while caregivers play a decreased role in this process (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004). Caregiver report of greater youth responsibility has been associated with poorer adherence (Naar-King et al., 2009). The specific roles of adolescents and parents in pediatric treatment adherence may be ambiguous, with adolescents and parents reporting that the distribution of responsibility of treatment management was unclear (Ingerski, Baldassano, Denson, & Hommel, 2010; Hommel et al., 2011). It can be difficult for parents to determine the extent of their involvement in treatment management. Studies with youth with diabetes and asthma and their parents suggest that caregivers wish to encourage youths' independence in managing their own care but also desire to promote optimal treatment adherence by remaining involved (Santer et al., 2014). Indeed, in a sample of adolescent transplant recipients and their parents, reported barriers were related to adolescents relying on their parents to take medication and parents not always being present to remind adolescents to take their medication (Simons et al., 2010).

Further confusion in this diffusion of responsibility for treatment adherence comes with refilling prescriptions. For instance, adolescents with IBD reported that they had difficulty recognizing when they ran out of pills (Lee et al., 2014). Similarly, another study of adolescents with IBD demonstrated that patients' descriptions of the functions of medications are less explicit than their parents' descriptions, suggesting that although they may take primary responsibility for taking medications, their lack of knowledge could serve as a potential barrier to adherence (Hommel et al., 2011). Finally, high adolescent responsibility and low parental supervision are associated with poor medication adherence (Modi et al., 2008).

Competing activities.

Adolescents, in particular, have competing activities that can interfere with adherence to treatment recommendations. For instance, in a sample of adolescents with IBD, forgetting medication due to extracurricular activities such as sports and sleepovers was identified as a

barrier to adherence (Hommel et al., 2011). The belief that medication interferes with other activities is a potential barrier to adherence in adolescence (Greenley et al., 2010; Ingerski et al., 2010).

Psychological factors.

Adolescents aged 12-17 have higher rates of emotional and behavioral problems than children aged 6-11, highlighting the importance of examining psychological distress in adolescence (Vandivere, Gallagher, & Moore, 2004). Indeed, psychological variables, such as depression, self-esteem, anxiety, avoidant coping, and symptoms of PTSD, are associated with adherence to treatment recommendations in adolescents with chronic illnesses. A study of adolescents with cancer demonstrated that children who do not adhere to their medication regimen have higher levels of depression and lower self-esteem (Kennard et al., 2004). Depression was significantly associated with nonadherence to medication regimens in adolescents with HIV, as well (Murphy, Wilson, Durako, Muenz, & Belzer, 2001). A study of adolescent transplant recipients concluded that higher anxiety and depressive symptoms are positively associated with poor medication adherence (King et al., 2014). In a sample of adolescents with IBD, anxiety and depressive symptoms moderated the relationship between barriers to adherence and medication adherence, suggesting that the presence of anxiety and depressive symptoms may be a critical risk factor in adherence among youth with IBD (Gray et al., 2012). Parental psychological symptoms are also relevant to the understanding of adherence; indeed, parent fears and concerns predicted adherence following their children's recent epilepsy diagnoses (Loiselle, Ramsey, Rausch, & Modi, 2016).

Empirical evidence indicates that symptoms of PTSD are also related to adherence in pediatric chronic illness patients. A study examining PTSD symptoms and adherence in a sample of pediatric transplant recipients found that children with higher levels of PTSD symptoms are more likely to miss medication dosages and a higher number of total barriers to adherence. PTSD symptoms were also associated with three specific subscales of barriers to adherence, including regimen adaptation/cognitive issues, disease frustration/adolescent issues, and ingestion issues (King et al., 2014). Finally, PTSD symptoms, particularly avoidance symptoms, were significantly associated with general nonadherence as well as medication nonadherence in a sample of pediatric liver transplant recipients aged 8-20 years (Shemesh et al, 2007).

1.6 - Current Study

Although investigations with pediatric chronic illness samples to date have increased our knowledge of factors related to treatment nonadherence and specific barriers to adherence, there is an absence of research examining barriers to adherence following acute events, such as pediatric injury. Challenges to adhering to treatment recommendations may be different among youth with acute conditions given that medical care is required for a shorter period of time and families may be less prepared for the responsibility.

Barriers to adherence may be particularly salient for adolescents and their parents, given that adherence is considered to be particularly challenging during the developmental period of adolescence. Borrowing from the chronic illness literature, the following barriers to adherence relevant to children *and* adolescents have been identified: health status and knowledge, cognitive factors, aversive properties of oral medication, logistical concerns, and relational factors. Specific barriers relevant to the developmental period of adolescence exist, and include: social factors, diffusion of responsibility concerns, the effect of competing activities, and psychological factors.

A recent review of barriers to adherence in adolescence shows that mental well-being is a principal barrier to adherence in adolescents (Hanghoj & Boison, 2014). Psychological factors are particularly relevant in pediatric injury populations given that, even amongst minor injuries, strong stress responses can occur. Studies have shown that in addition to PTSD symptoms, children and adolescents are at risk for developing depression, anxiety, and phobia anxiety (Zatzick et al., 2008; Bryant, Mayou, Wiggs, Ehlers, & Stores, 2004; Caffo, Barbara, & Lievers, 2005; Keppel-Benson, Ollendick, & Benson, 2002).

The focus of the current investigation will be further exploration of adolescent psychological and relational (i.e., parent-related factors) barriers to adolescent adherence to medical recommendations following injury. Barriers within each of these two domains are particularly important because they are modifiable, which, according to the HBM, can lead to change in perceptions of barriers. Thus, gaining a better understanding of adolescent psychological and relational barriers can serve as a foundation for the development of effective interventions. These malleable barriers can subsequently be addressed, thereby significantly impacting the course of recovery and improving adherence. Thus, it is highly likely that the study of adolescent psychological and relational factors is integral for our understanding of

outcomes, including barriers to adherence to post-injury treatment recommendations, following unintentional injury in adolescence. It is important to understand the unique barriers contributing to nonadherence to treatment recommendations in adolescents following acute events, such as injury. With this knowledge, injury recovery can be improved.

Consistent with the HBM framework, the purpose of this sequential explanatory mixed methods study is to explore potential barriers to adherence in the context of injury. Implementing a mixed methods design will provide necessary data to gain a holistic understanding of barriers to adherence in the context of injury. Quantitative research methodology is a practical means of obtaining data in large samples. Qualitative data can nicely supplement quantitative data by deepening understanding of complex phenomena. In this way, mixed methods research is a promising approach for enabling a more complete analysis of barriers to treatment adherence among adolescents following injury and their families. In sum, the current study seeks to identify adolescent psychological and relational barriers associated with adherence in adolescents who have sustained an injury. Specific research questions that will be addressed in this investigation include:

- 1) Do adolescent psychological factors [adolescent PTSD and depression as well as adolescent quality of life (QOL)] and relational factors (parent PTSD and depression) serve as barriers to adherence in adolescents following hospitalization for pediatric injury?
- 2) Are there additional adolescent psychological and/or relational factors that may serve as barriers to adherence in adolescents following hospitalization for pediatric injury?

Chapter 2 - Quantitative Phase: Methods

The quantitative portion of this study was conducted to examine selected barriers (i.e., adolescent PTSD and depression, parent PTSD and depression, as well as adolescent- and parent-reported QOL) to adolescent adherence to medical recommendations following post-injury hospital discharge.

2.1 - Participants and Procedure

Data were collected at a large urban level 1 pediatric trauma center in Philadelphia, Pennsylvania as part of a larger study designed to assess the secondary prevention of traumatic stress in pediatric trauma care. To be eligible for the study, the adolescent had to be between 13-17 years of age, hospitalized for an unintentional injury, cognitively capable of assenting and completing the interview, proficient in English, and without a concurrent illness. Adolescents with moderate to severe TBI (Glasgow Coma Scale score of <13) were excluded from the overall sample.

Participants included 134 adolescents aged 13-17 ($M = 14.3$, $SD = 1.2$; 73% male) hospitalized for treatment of an unintentional injury sustained through various mechanisms (refer to Table 1 for specific injury information). Data were collected at three time points: Baseline (T1) occurred within two weeks of injury, a 6 week follow-up assessment (T2), and a 6 month follow-up assessment (T3). Of the original sample of 134 adolescents, 67 (50%) completed T2 assessments, and 11 (8%) had complete data for T3 assessments. Given attrition rates and power limitations, analyses in the current study were limited to T1 and T2 assessments.

Descriptive statistics for 67 participants with complete data at T1 and T2 are summarized in Table 1. The sample mostly consisted of Caucasian and African-American males. Families were mostly middle to upper-middle class and the majority was insured by Commercial Insurers. The average levels of adolescent PTSD, adolescent depression, adolescent-reported QOL, parent-reported QOL, parent PTSD, and parent depression were not clinically significant.

2.2 - Measures

Please refer to Table 2 for specific information regarding the means, standard deviations, ranges, and reliability coefficients for each measure described below.

The Child PTSD Symptom Scale (CPSS). The CPSS is a 17-item measure that is used to assess symptoms of PTSD in children and adolescents in regard to a specific traumatic event (Foa et al., 2001). In this study, adolescents were asked to think specifically about the recent injury event rather than other traumatic events they may have experienced. Items on the CPSS are rated on a 4-point scale (0 = ‘not at all’ to 3 = ‘5 or more times a week’). The CPSS yields scores for both continuous symptoms severity and the presence of each DSM-IV-TR symptom. The CPSS has shown excellent internal consistency and test-retest reliability. In the present sample, good internal consistency was demonstrated (T1 $\alpha = .84$; T2 $\alpha = .86$).

PTSD Checklist (PCL). The PCL is a 17-item questionnaire used to assess parent self-reported PTSS (Weathers, Litz, Herman, Huska, & Keane, 1993). It yields a continuous PTSD symptom severity score. Items on the PCL are rated on a 5-point scale (1 = ‘not at all’ to 5 = ‘extremely’). In the present study, good to excellent internal consistency was demonstrated (T1 $\alpha = .88$; T2 $\alpha = .94$).

Center for Epidemiologic Studies Depression Scale (CES-D). The CES-D is a 20-item self-report measure of depression symptoms that yields a total severity score (Radloff, 1977). Items on the CES-D are rated on a 4-point scale (0 = ‘rarely or never’ to 3 = most or all of the time). In the present study, good internal consistency was demonstrated for adolescent-reported depression (T1 $\alpha = .82$; T2 $\alpha = .84$), while good to excellent internal consistency was demonstrated for parent-reported depression (T1 $\alpha = .90$; T2 $\alpha = .92$).

Pediatric Quality of Life Inventory (PedsQL). The PedsQL is a measure of adolescent health-related quality of life (Varni, Seid, & Kurtin, 2001). Items are rated on a 5-point scale (0 = ‘never’ to 4 = ‘almost always’). In the present study, acceptable to good internal consistency was demonstrated for adolescent-reported QOL (T1 $\alpha = .79$; T2 $\alpha = .88$), while excellent internal consistency was demonstrated for parent-reported QOL (T1 $\alpha = .92$; T2 $\alpha = .90$).

Health Care Questionnaire. The Health Care Questionnaire asked parents to respond ‘yes’ or ‘no’ as to whether the adolescent followed various discharge recommendations. Items included questions related to dietary and activity restrictions, follow-up clinical services, contacting the physician with concerns, wound/drain/line care, medications, and miscellaneous discharge instructions. Given that each aspect of adherence (i.e., dietary instructions, activity restrictions, attending follow-up appointments, contacting physician, caring for wounds/drains/lines, miscellaneous discharge instructions, and medications) is measured on a

dichotomous scale, and each did not apply to every adolescent, a mean adherence level was calculated by dividing the number of “yes” responses by the total number of endorsed aspects of adherence. For domains of adherence with multiple subdomain options (e.g., three possible activity-related recommendations), an average was calculated prior to including the specific domain in the broader calculation to determine overall adherence. For instance, if an adolescent had two activity restrictions, and was adherent to one but not the other, the activity restrictions domain would be entered into the larger equation as 0.5 rather than 1 (adherent) or 0 (nonadherent). Domains for which this was relevant include *activity restrictions*, *follow-up clinical services*, and *other relevant* recommendations.

2.3 - Exploration of Possible Factors Contributing to Attrition

To examine potential factors contributing to attrition over time, key demographic variables of adolescent gender, adolescent age, adolescent racial identity, family income, and payor were examined comparing the T1 sample (N=134) to the T2 sample (N=67). No significant differences were identified for gender, age, racial identity, family income, or payor. Thus, differences in these demographic variables are unlikely to have contributed to attrition between T1 and T2.

Regarding adolescent psychological variables, results of an independent samples t-test indicated that adolescents who completed measures at both time points had higher levels of PTSD ($M=8.9$, $SD=8.0$) than those who did not complete T2 measures ($M=6.2$, $SD=5.2$), $t(135) = -2.4$, $p=.001$. Furthermore, adolescents who completed measures at both time points had higher levels of depression ($M=8.5$, $SD=7.8$) than those who did not complete T2 measures ($M=5.6$, $SD=4.8$), $t(135) = -2.6$, $p=.000$. In contrast, no significant differences emerged for QOL reported by adolescents or parents. Regarding relational variables, no significant differences emerged between PTSD or depression levels of parents who completed measures at both time points. In sum, parent-adolescent dyads that completed T2 measures tended to be those with adolescents in greater psychological distress.

Chapter 3 - Quantitative Phase: Results

3.1 - Correlations among Variables

Bivariate correlations were conducted to gain a preliminary understanding of the relationships among variables (see Table 3). Correlations were computed for the following at both time points, unless otherwise specified: adolescent PTSD and depression, quality of life (adolescent- and parent-reported), parent PTSD and depression, adherence at T2, and relevant demographic variables (i.e., race and income).

3.2 - Prediction of Outcomes

Standard multiple regression analyses were conducted to explore the predictive roles of adolescent psychological factors (i.e., adolescent PTSD, depression, and QOL) and relational factors (parent PTSD and depression) at T1 on adherence at T2. Hierarchical multiple regression analyses were then conducted to explore the predictive roles of adolescent psychological factors and relational factors at T2 while controlling for T1 covariates. It was hypothesized that adolescent psychological and relational factors at T1 and T2 would serve as barriers to adherence.

Two theory-informed control variables (i.e., adolescent race and family income; Drotar & Bonner, 2009; Shemesh et al., 2007) were entered into the initial analyses and subsequently removed from further analyses in order to maximize power when it was determined that neither of these variables significantly contributed to overall variance, $F(2, 64) = .66, p > .05$.

T1 psychological and relational variables predicting T2 adherence. The overall model testing the predictive ability of adolescents' levels of PTSD and depression as well as QOL (adolescent- and parent-reported) at T1 on degree of adherence at T2 was not significant $F(4, 56) = .63, p > .05$ (see Table 4). Likewise, examination of the potential predictive ability of T1 parent PTSD and depression severity of T2 adherence yielded a non-significant model, $F(2, 62) = 1.88, p > .05$ (see Table 5).

T2 psychological and relational variables predicting T2 adherence. The overall regression model predicting T2 adherence via adolescents' levels of T2 PTSD, depression, and QOL (while also controlling for T1 covariates) was not significant $F(8, 39) = .57, p > .05$ (see

Table 6). Likewise, prediction of T2 adherence via parents' levels of T2 PTSD and depression (while also controlling for T1 covariates) was not significant $F(4, 60) = 1.15, p >.05$ (see Table 7).

3.3 - Post-hoc Analyses

3.3.1 - Predictive Role of Demographic Factors on Adherence Outcomes.

A standard multiple regression analysis was conducted to evaluate the predictive role of several demographic variables (adolescent age, gender, and race) on adherence. The purpose of conducting this analysis was to inform recruitment for the qualitative portion of the study, in order to ensure optimal basis for comparison between the quantitative and qualitative samples. It was determined that none of these variables significantly contributed to overall variance $F(3, 63) = .10, p >.05$; thus, these variables did not affect the recruitment strategy, as differences in these demographic variables would not affect the validity of drawing comparisons between the quantitative and qualitative samples.

3.3.2 - Exploratory Analyses with Less-adherent Participants.

Further analyses were conducted with a subsample of participants who demonstrated lower levels of adherence (i.e., 67% adherence and below; $N=17$); this sample was selected for additional analyses due to the limited range in variability of the adherence outcome variable. Indeed, most participants were generally adherent to the medical recommendations. Further exploration of factors contributing to lower levels of adherence was warranted. Exploratory regression analyses were conducted to evaluate the possible role of demographic, adolescent psychological, and relational factors on this subset of less-adherent adolescents.

Demographic variables predicting adherence. The overall model testing the predictive ability of gross family income and payor on degree of adherence at T2 was significant $F(2, 12) = 5.07, p=.025$.

T1 psychological and relational variables predicting adherence. The overall model testing the predictive ability of T1 adolescent PTSD, depression, and QOL on T2 adherence was not significant $F(4, 8) = 3.8, p >.05$. Examination of whether parent T1 PTSD and depression severity predicted T2 adherence similarly yielded a non-significant model $F(2, 15) = .20, p >.05$.

T2 psychological and relational variables predicting adherence. The overall regression model predicting T2 adherence via T2 adolescent PTSD, depression, and QOL (while controlling for T1 covariates) was not significant $F(8, 2) = 4.11, p >.05$. Likewise, prediction of T2

adherence via T2 parent PTSD and depression (while controlling for T1 covariates) was not significant $F(4, 13) = .56, p >.05$.

3.3.3 - Exploratory Analyses of PTSD Symptom Clusters.

Given the unexpected insignificant findings regarding the predictive role of PTSD on adherence outcomes, exploratory standard multiple regression analyses were conducted to explore the potential significance of T1 unique PTSD symptom clusters (i.e., DSM-IV symptom clusters of re-experiencing, avoidance, and hyperarousal) in explaining variance of adherence outcomes. Hierarchical multiple regression analyses were then conducted to explore the potential significance of T2 unique PTSD symptom clusters (i.e., re-experiencing, avoidance, and hyperarousal) in explaining variance of adherence outcomes

T1 psychological variables with PTSD symptom clusters predicting T2 adherence. The overall model testing the predictive ability of adolescents' levels of PTSD per individual symptom cluster and depression as well as QOL at T1 on degree of adherence at T2 was not significant $F(6, 49) = .666, p >.05$.

T2 psychological variables with PTSD symptom clusters predicting T2 adherence.

The overall model predicting T2 adherence via adolescents' levels of T2 PTSD by symptom cluster, depression, and QOL (while also controlling for T1 covariates) was not significant $F(12, 27) = .588, p >.05$.

3.3.4 - Exploratory Analyses with Individual Aspects of Adherence.

Exploratory logistic regression analyses were conducted to examine the relationships between adolescent psychological and relational variables and each aspect of adherence. Notably, only 2 of the 9 total aspects of adherence (i.e., activity restrictions and dietary restrictions) were included in the analyses. Analyses in the other 7 domains of adherence (attending follow-up appointments, contacting the doctor with concerns after discharge, adhering to proper care of wounds or drain lines, miscellaneous discharge instructions, taking medication, other relevant instructions) were not conducted, as an insufficient number of participants received discharge instructions relevant to the aspects of adherence to adequately power the analyses.

Activity restrictions. The overall model testing the predictive ability of adolescents' T1 PTSD, depression, and QOL on T2 activity restrictions was not significant $F(4, 28) = .14, p >.05$, nor was the overall model testing the predictive ability of adolescents' T2 PTSD, depression, and

QOL on T2 activity restrictions at T2 $F(4, 22) = 2.38, p >.05$. Similarly, the overall model testing the predictive ability of T1 parent PTSD and depression on T2 activity restrictions was not significant $F(2, 30) = 1.61, p >.05$, nor was the overall model testing the predictive ability of T2 parent PTSD and depression on T2 activity restrictions $F(2, 31) = 1.14, p >.05$.

Dietary restrictions. The overall model testing the predictive ability of adolescents' T1 PTSD, depression, and QOL on T2 dietary restrictions was not significant $F(4, 31) = .48, p >.05$, nor was the overall model testing the predictive ability of adolescents' T2 PTSD, depression, and QOL on T2 dietary restrictions $F(4, 24) = 1.50, p >.05$. Similarly, the overall model testing the predictive ability of T1 parent PTSD and depression on T2 dietary restrictions was not significant $F(2, 33) = .31, p >.05$, nor was the overall model testing the predictive ability of T2 parent PTSD and depression on T2 dietary restrictions $F(2, 35) = .80, p >.05$.

3.3.5 - Moderation Analyses with Demographic Variables.

Several demographic variables, including family income, family size, parental education level, race, and ethnicity, were examined as potential moderators between adolescent psychological and relational variables, and adherence. No significant findings emerged, suggesting that the strength of relationships between independent variables and adherence did not vary as a function of demographic factors.

Chapter 4 - Qualitative Phase: Methods

Results of the quantitative phase do not support the hypotheses that adolescent psychological and relational factors predict adolescents' adherence to medical recommendations following hospitalization for unintentional injury. No significant relationships emerged to provide insight into factors that may serve as barriers to adherence to such recommendations. Given these null findings, more research is needed to better understand adherence in adolescent patients post-injury. The aim of the follow-up qualitative component of this study is to explore whether additional adolescent psychological or relational factors exist that contribute to adherence to medical recommendations in the aftermath of adolescent injury.

4.1 - Procedure

Youth with a recent unintentional injury and one of their parents were invited to participate in an interview to further explore specific barriers that may contribute to adherence. Potential participants were identified through the electronic medical record system at Carilion Clinic Children's Hospital, located in Roanoke, Virginia, and mailed a packet of information about the study. Follow-up calls were completed two weeks after the information was mailed to assess potential participants' interest in participating in the study. Ten adolescent-parent dyads agreed to participate in the study and separate interviews were conducted over the phone with each member of the dyad.

Participants were recruited from Carilion Clinic Children's Hospital and were eligible to participate if they 1) were between the ages of 13-17 years; 2) were hospitalized for an unintentional injury within the past 6 months; 4) were cognitively capable of assenting and completing the interview, defined as an initial GCS score of 13-15 and lack of evidence of an intellectual or developmental delay; 5) spoke English proficiently; 6) did not have a concurrent chronic illness and; 7) if one parent provided consent and agreed to participate. Medical records regarding the adolescent's treatment while hospitalized and discharge information were available per the electronic medical record system. Approval was obtained from both the Carilion Clinic Children's Hospital Institutional Review Board and the Virginia Tech Institutional Review Board.

To assist participants' recall accuracy of treatment adherence barriers following injury up to 6 months prior to the interview, the Timeline Follow-Back (TLFB) interview (Sobell & Sobell, 1992) was utilized. The TLFB was designed to facilitate retrospective self-reports of daily alcohol consumption during a specific reporting period. Several interview aids are used to facilitate recall, including presenting respondents with a calendar, marking salient events in the reporting period, identifying lengthy periods of abstinence or patterned drinking, and anchoring the highest and lowest quantity consumed in the target interval. Empirical evidence supports the reliability of the using TLFB regarding alcohol use and sexual behavior (Sobell, Maisto, Sobell, & Cooper, 1979; Weinhardt, Carey, Maisto, Carey, Cohen, & Wickramasinghe, 1998). In the present study, participants were oriented to the time of their injury by identifying salient events preceding or around the time of the injury. For instance, the start of school, preseason for sports, and Thanksgiving vacation were among salient events used to orient participants in the present sample to the period of time during which they sustained and were recovering from injury.

A screening phone call was conducted prior to making an appointment for the interview to ensure that participants met study criteria. Once it was established that study eligibility criteria were met, interviews were scheduled. Adolescents and parents were interviewed separately. Adolescent interviews lasted between 10 and 41 minutes ($M = 21.70$, $SD = 10$) while parent interviews were longer, lasting between 20 and 60 minutes ($M = 40.60$, $SD = 12.53$). An advanced graduate student in clinical psychology, who had been trained in the administration of all measures, interviewed each participant separately. Following their respective interviews, adolescents and parents completed self-report measures for the purposes of obtaining demographic information and psychological symptoms (i.e., PTSD, depression, QOL). Each adolescent-parent dyad was compensated \$25 for their time. Informed consent was obtained from parents and assent was obtained from adolescents.

4.2 - Participants

Detailed information for all variables is displayed in Table 8 for the participants included in the qualitative phase of the study. Please refer to Table 1 for specific information regarding mechanism of injury. The study sample was composed of 10 adolescent-parent dyads. The adolescents ranged in age from 14-17 years old with a mean age of 15 years old. Nine were male and 1 was female. The ethnic makeup of the group was as follows: 7 Caucasians, 2 African-Americans, and one unspecified race. Parents were 10 mothers and all identified as the same

racial and ethnic background as their children. The median income was \$50,000-74,999 annually, which was also the common mode. Most families were insured with a Commercial Insurer Indemnity, followed by Commercial Insurer Managed Care, and Medicaid Managed Care. Adolescents' injuries predominantly included broken bones (e.g., arm, leg, jaw), although one child experienced a head injury, another child was treated for a laceration, and one additional child sustained an organ injury. The cause of children's injuries included sports and recreation, falls, and a motor vehicle crash.

The mean levels of all adolescent psychological (i.e., PTSD, depression, QOL) and relational (parent PTSD and depression) fell below the thresholds for clinical significance. Please refer to Table 8 for specific information regarding the means, standard deviations, ranges, and reliability coefficients for each measure.

Regarding adherence characteristics, an average of 4.4 treatment recommendations upon discharge were provided for each adolescent. Activity restrictions (e.g., not lifting heavy objects, wearing a back brace, not running) were the most frequent recommendations provided upon discharge, followed by follow-up clinical services (e.g., appointments with orthopedist or concussion specialist), and taking medication. As a whole, activity restrictions and taking medication appeared to be the most difficult recommendations to follow. Across participants, 100% adherence was noted for dietary restrictions, contacting the physician with concerns, and caring for wounds/drain lines. Please refer to Table 9 for more detailed information regarding adherence characteristics in the current sample.

The total number of eligible participants between September 2014 and October 2015 was 46. Comparisons of characteristics between families who participated in the study and those of the families who either declined to participate or who did not return calls were broadly similar. Specifically, within the group of unenrolled eligible adolescents, the mean age was 15 and predominantly white (83% Caucasian; 11% African American; 6% Other), which is highly consistent with characteristics of the study sample. However, a higher percentage of females (24% females) were represented in the unenrolled eligible sample compared to the enrolled participants (10% females).

4.3 - Measures

Semi-structured interview (adolescent and parent versions). Guided by an interview developed by Hommel and Baldassano (2010), designed for children with IBD, an interview was

designed for this study utilizing open-ended questions to elicit adolescent and parent responses regarding treatment adherence barriers. Following review of each medical recommendation, children were asked “Tell me about the recovery process” and “What types of things, if any, made it difficult to follow medical recommendations during your recovery?” Parents were asked “Tell me about [Child’s] recovery” and “Was there anything that made it difficult to follow medical recommendations as [Child] was recovering?” Follow up probes were used for clarification and extension of responses by patients and parents. Interviews were tailored to each family, given that the treatment recommendations provided to each adolescent varied. Adolescents and parents were interviewed independently to avoid consensus effects. Overall, each interview consisted of a series of questions designed to facilitate the report of personal experiences pertaining to the injury and recovery period.

Questionnaires. The CPSS, PCL, CES-D (for parents and adolescents), and PedsQOL (adolescent- and parent-report) were also administered to assess the degree to which the qualitative sample was representative of the quantitative sample. The Health Care Questionnaire was administered to assess the degree of adherence to specific medical recommendations upon discharge.

4.4 - Coding and Data Analysis

A qualitative analysis was conducted on information obtained from the structured interviews. Interviews were audio-recorded, transcribed, and coded for analysis of themes regarding treatment adherence and barriers to adherence using an inductive coding methodology (Thomas, 2006). Two trained researchers, including the lead author of the study, with backgrounds in pediatric adherence and qualitative research independently coded each interview transcript for the presence of adherence barriers, per adolescent- and parent-report. The team approach was used in order to ensure credibility. The research team members each worked independently in their review of the data. Both researchers reviewed each transcript two times without taking notes with the goal of becoming generally familiar with the information included in every interview. During the third and fourth reviews of each transcript, adolescent and parent statements related to barriers to treatment adherence were extracted and categorized in accordance with themes. After initial coding of the data, the raters met to review, discuss, and address discrepancies in codes, which is a means of increasing credibility in qualitative research (Lincoln & Guba, 1985; Morrow, 2005). Triangulation was achieved by having the research

team members first complete their reviews independently of one another and then coming together to discuss the findings. Thematic saturation was attained after interviews with 10 adolescent-parent dyads, which is consistent with previous qualitative studies with pediatric injury samples (Marsac, Mirman, Kohser, & Kassam-Adams, 2011; Ramsdell, Morrison, Kassam-Adams, & Marsac).

Chapter 5 - Qualitative Phase: Results

Findings derived from the 20 interviews (10 adolescent and 10 parent) comprising the current study suggest that adolescents and their parents experience a variety of negative emotions in both the direct aftermath of sustaining unintentional injury as well as during the recovery process following discharge from the hospital. Adolescents experience a number of barriers to adherence to treatment recommendations during the injury recovery period. Furthermore, findings yielded additional information regarding factors that promote adherence. Results are best conceptualized within the framework of the HBM.

5.1 - Emotional Responses

Both adolescents and parents provided striking descriptions of their emotional responses to the adolescent's injury, both in the direct aftermath of injury as well as throughout the recovery process following discharge from the hospital.

5.1.1 - Adolescent Emotional Responses.

Adolescents primarily experienced sadness (6 parents and 7 adolescents) and frustration (5 parents and 6 adolescents) regarding the disruptive nature of the injury to their lives. Several adolescents commented on how difficult it was to miss the sports season while others noted sadness stemming from losing independence and missing out on normal activities (e.g., outings with friends, being at school). A 15-year old male participant with a facial fracture described feelings of sadness following his injury:

It was in the middle of the travel soccer season when it happened, so I couldn't participate in that anymore. It wasn't necessarily like...I didn't lose interest in things...I still wanted to go. I went and passed the ball against the wall and stuff like that, so I didn't really lose interest in it, but I was a little bit like...I guess you could say depressed that I wasn't part of the team anymore.

Frustration was similarly prevalent, in addition to, or in some cases instead of, sadness. Indeed, adolescents experienced irritability as well as feelings of anger and frustration regarding their lack of independence and activity restrictions that precluded them from participating on sports teams, spending time with friends, or returning to school. A 15-year old male participant who fractured his arm described feelings of frustration stemming from limited independence and activity restrictions:

I can remember sometimes if I was like trying to pick up a pencil and just not being able to use my hands. I remember one time just flipping out and I was just trying to do homework and eat. I just couldn't do it and I got so frustrated.

Further, feelings of vigilance (1 parent and 2 adolescents) were present in the current sample of adolescents. A 14-year old male participant who broke his leg indicated he was not planning to return to playing sports. When asked what led to this decision, he explained: "I'm not breaking my leg again like I did the last time. I'm going to lay off the sports a little bit." Some adolescents (reported by 1 parent and 2 adolescents) also suffered from symptoms characteristic of PTSD; symptoms of re-experiencing (e.g., nightmares) and hypervigilance were the primary symptoms reported. A 17-year old female participant who was injured in a car accident explained:

Just last month actually, we had a really bad storm and, since I wrecked in the rain, I got really scared to drive in the rain. I pulled over and I was crying because I was hydroplaning everywhere. So I pulled over at a gas station and waited for it to kind of stop a little bit. I called my dad because my dad always calms me down.

5.1.2 - Parent Emotional Responses.

Parents also described a variety of emotional reactions to their adolescents' injuries. Parents were often overprotective and vigilant about possible threats to the physical well-being of their adolescents (reported by 5 parents), resulting from increased vulnerability. Parents reported feeling more anxious about the well-being of their adolescents while doing routine activities. The parent of a 15-year old male participant, who was treated for a laceration, expressed increased awareness of the potential dangers to her son's health, stating "If I could wrap him in a cocoon, I would." The parent of 16-year old male, who sustained a mild traumatic brain injury, described increased vulnerability following her son's injury:

He got in trouble for something stupid not long ago...he stayed over at a friend's house and they decided to hike to the mall after midnight. I unleashed on him because, I was like, "Anything could have happened to you. You could have gotten hit by a car, you know?" my husband said "He did the same stupid thing I did when I was a teenager." I was like "It seems like a whole lot stupider to me now." So, I would say that my husband and I have an increased sense of vulnerability.

Experiences of sadness and depression were also common among parents (reported by 4 parents). In particular, parents were sad seeing their adolescents in pain and limited in their activities. One parent was upset about not being able to do activities with her son due to his limitations. The mother of a 17-year old female who sustained injuries in a car accident described her struggle seeing her daughter in pain and immobile in bed: “So you try to stay strong when you’re in front of them, but as soon as I’d get away from her, there wasn’t a day for two weeks, probably, that I didn’t cry at some point.”

Three parents reported symptoms characteristic of PTSD resulting from their adolescents’ injuries. Indeed, the mother of a 17-year old male who broke his arm discussed her ongoing symptoms of PTSD:

I have terrible flashbacks about it. I have a lot of anxiety about him participating in that again. I do think about his injury all the time. I think about the drive back...it was an awful drive back...and I tear up.

Finally, two parents expressed feeling helpless regarding their inability stop the injury from occurring as well as alleviate discomfort during the recovery process. When asked about the most difficult part of the recovery, the mother of a 16-year old male who broke his leg noted “Just picturing him on the ground and him saying it hurt so badly, and there wasn’t anything I could do.”

5.2 - Perceived Barriers

Analysis of the data yielded support for the presence of barriers to adherence to medical recommendations following adolescent unintentional injury. Most commonly reported was concern of pain medication addiction (reported by 5 parents and 3 adolescents), followed by barriers posed by competing activities (reported by 5 parents and 1 adolescent). Treatment side effects (reported by 3 parents and 1 adolescent), health status (reported by 4 parents), and desire for autonomy (reported by 2 parents and 1 adolescent) similarly emerged as themes. Two parents and one adolescent also endorsed psychological barriers to adherence to medical recommendations.

5.2.1 - Concern of Pain Medication Addiction.

While many adolescents were prescribed medication to manage their symptoms of pain, many did not use this form of treatment when they experienced pain, discontinued the medication early, or used this treatment option with caution. Interestingly, concern of addiction

was reported not only by parents but also by adolescents themselves. Awareness of the possibility of addiction was the driving factor behind nonadherence to pain medication recommendations following discharge from the hospital. Pain medications are prescribed with the intention that they are taken when experiencing pain; not taking the medication when experiencing pain can be considered a form of nonadherence to this recommendation.

A 17-year old female participant discussed her own concern regarding pain medication addiction, which was independent of her mother's opinion:

My Mom said I wouldn't get addicted to them [pain medication], but I didn't want to [become addicted] so I wouldn't take them unless my back was absolutely killing me. So I wanted to kind of make it heal without medicine so I would take it only when I needed it. And I didn't finish my pills.

However, most parents' and adolescents' reports suggested that the concern of addiction came from parents and families, rather than adolescents themselves. A 16 year-old male participant described his parents' fears of pain medication addiction:

The morphine itself, it helped a lot with the pain, especially with that first week after the surgery. I took it normally for a week and once my family had said they didn't want me like addicted to it, we just eased it off of the dosages.

This participant's mother discussed pain medication during her interview, as well, and provided more insight into the thought process behind wanting to wean her son from the pain medication:

We argued continuously about it [pain medication]. My husband argued about him not taking it unless he actually needed it and we kind of transitioned to just taking it at night. We felt like he was getting a desire for it.

The mother of a 15 year-old male similarly discussed her concern about accidental addiction to pain medication following her son's injury:

Of course the doctors did give him pain medicine and I was not very liberal with them. I didn't want him to take them if he didn't have to. You know, the fear of accidentally getting addicted... that scares me, so... he would just take half of it.

Thus, due to concern of possible addiction, many adolescents did not rely on medication to address their pain related symptoms, or relied on the medication to a lesser degree than they would have without concern of possible addiction. Caution around taking pain medication was reported by both adolescents themselves as well as their parents.

5.2.2 - Competing Activities.

Another frequently reported barrier to adherence throughout parent and adolescent interviews was the tension emerging between adhering to medical recommendations during the injury recovery period and managing the competing demands of daily life. A major theme, which is unique to injury, emerged throughout interviews regarding the disruption to adolescents' "normal" lives. Prior to their injuries, adolescents lived fairly routine lives consisting of going to school, spending time with friends, and playing sports, in addition to activities of daily living such as eating, independently ambulating, and managing hygienic needs. The desire to return to normal life, as well as the demands posed by normal life as adolescents slowly recovered, served as a significant barrier to adherence to medical recommendations following hospital discharge. A 17-year old girl discussed her difficulty keeping up with physical therapy exercises after she was finally allowed to return to school weeks after her injury:

So I have exercises to do but I just don't keep up with it. And they told me that when I get older I'd probably have, like, arthritis in my back...so I really need to but I just don't keep up with it. It's really difficult to because I have so much I do in a day, I just don't have time to do it at night. I should, but I just don't.

This particular participant also spoke at length about her strong desire to be normal again. When provided with greater opportunity to "just be normal", which occurred when she was in a better state of health than she was during the acute period after the accident, adhering to treatment recommendations for injury recovery was less important. Indeed, the busy lives of adolescents, managing their school and extracurricular responsibilities, leave limited opportunity for additional commitments, such as physical therapy exercises.

The mother of a 16-year old male participant described the conflict between following a recommendation to make an appointment with a specialist and taking into consideration the length of time her son had missed of school due to the injury:

This is going to sound terrible. My husband and I argued about this. He was like, “A concussion psychologist?” I felt like we dropped the ball on that...maybe because he missed so much school and my husband felt like it wasn’t necessary that he missed more school for that.

While parents and adolescents generally perceived that they were supported by school personnel during the recovery period, the reality is that school responsibilities are important for adolescents as they navigate standardized tests and the postsecondary education process. This was particularly salient for 17-year old female participant who returned to school after weeks due to extensive treatment for back and neck injuries, which required use of a brace as well as limitations in what she could carry. Her mother described this conflict:

She was out of school for six weeks, and then once she went back to school she had to carry her book bag and you know, her books. I think a lot of the time her boyfriend carried the stuff for her but she’s so independent she hated asking for help on a lot of things so she just did it.

Relatedly, homework responsibilities are difficult to ignore when adolescents have regained enough functioning to return to school following their injuries. Indeed, the mother of a 16 year old male adolescent explained:

And we had to weigh some of the things like letting him do his homework, when a lot of times when you have a concussion you’re not supposed to be looking at a computer or doing homework and stuff... so we tried to balance out okay you can do some homework now or you should probably do a little bit of homework.

In sum, one of the most difficulty aspects of injury recovery reported by adolescents and their parents was the disruption in daily life caused by the injury and subsequent care. Disruption occurred with regard to school attendance, extracurricular activities, and homework completion. Returning to normal activities was a high priority for all adolescents, and this often occurred at the expense of following medical recommendations. This appeared to be particularly salient during the period when adolescents regained some of their independence and mobility during the post-acute phase after injury. Once adolescents began to engage in normal activities, adherence to treatment recommendations for injury recovery was often suboptimal.

5.2.3 - Treatment Side Effects.

Adolescents often did not adhere to medical recommendations due to side effects of different forms of treatment. Side effects of medication (e.g., sluggish thinking, feelings of being dazed) emerged as a barrier for several participants, and one participant noted that the special toothpaste he was required to use following his jaw fracture was unpleasant and he occasionally did not use it as instructed. Discomfort associated with immobilizing treatments, such as braces and slings, often led to nonadherence to these treatment recommendations. A 17-year old female participant commented on the discomfort of her neck brace:

I absolutely hated it [neck brace], yeah. And so it was really difficult, I didn't like wearing it around the house and stuff if I was just laying in bed watching TV 'cause you can't like bend your neck with it so I'd have to lay, and then, I don't know it was just really difficult. So I didn't wear it unless I really went out.

The parent of a 17-year old male participant, who was required to wear a sling to treat his broken arm, reported that the discomfort associated with the sling affected his adherence to treatment recommendations:

He did not like wearing the sling and probably did not use it as long as he should have. It was just uncomfortable. It irritated his neck and, you know, he didn't like it so he just put it away.

Thus, side effects associated with a variety of forms of treatment (i.e., medication, braces, slings, specialized toothpaste) served as barriers to adherence to medical recommendations for several adolescents.

5.2.4 - Health Status.

Another theme that emerged throughout interviews was nonadherence resulting from a perceived lack of need of treatment. Consistently, participants reported that lack of pain often served as a barrier to adherence to medical recommendations. Thus, the treatment recommendations were perceived as futile and adolescents did not recognize the benefit of following them. Indeed, the mother of a 15-year old male participant described this experience:

The doctor said, "You may read a book" and I was catching him pouring himself a glass of milk and I'm like, "You're not supposed to be lifting a gallon of milk." He said, "Oh, it's okay, it doesn't hurt," and I'm thinking I don't care if it doesn't hurt, you're not supposed to be doing that."

This quote was representative of the theme that emerged during several interviews; health status, specifically lack of pain, often served as a barrier to adherence to medical recommendations.

5.2.5 - Desire for Autonomy.

Another theme that emerged was nonadherence to medical recommendations stemming from the tension between adolescents' desire for autonomy and their limited ability to function independently in the wake of injury. A 17-year old female explained that her adherence to treatment recommendations regarding her back brace waned as she experienced increasing autonomy during her recovery process:

I'm a big hands on person and I like to do everything by myself and I couldn't even stand up straight without my brace. So I couldn't shower by myself...they told me halfway through that I could take a shower without my brace, finally. So I guess since they told me I could stand up, I kind of didn't wear my brace as much as I was supposed to, which I didn't tell my doctor.

Similarly, the mother of a 15-year old male participant discussed the effect of her son's autonomy on the degree of adherence to his activity limitations:

But the biggest frustrating part was I don't think he adhered to his limitations like the doctor said, and I wanted him to do. But that was very frustrating for me because of his independence that I love normally. In that situation, it worked against me because he would do things he wasn't supposed to do and I was afraid that would hinder his healing process.

Adolescence is an important developmental period when teenagers begin to gain independence and autonomy. Following discharge from the hospital, many treatment recommendations involve activity limitations in order to facilitate the healing process, which are often associated with decreased autonomy. In the present study, adolescents' desire for autonomy resulted in nonadherence to treatment recommendations for some participants.

5.2.6 - Psychological Factors.

Results suggested that psychological factors, particularly depression, served as barriers to adherence to treatment recommendations for several adolescent participants. A 16-year old male participant discussed how he experienced frequent symptoms of sadness and depression. For this participant, his decision to negate these symptoms with increased activity served as a barrier to

following medical advice to restrict activity: “Just sitting at home all day was kind of, like, boring and I would sit there and I would just be restless and I had nothing to do so I’d go shooting a soccer ball or light jogging.”

The mother of a 16-year old male participant described the decision she made with her husband to allow her son to return to normal activities (i.e., schoolwork), which was incongruent with medical recommendations to treat his concussion.

His jaw was broken and he was all in pain and he was depressed, and he was going through trauma...I mean the concussion was there too. We tried to balance out okay you can do some homework now or you should probably do a little bit of homework...it’ll make your brain start thinking to help with the depression.

Indeed, the participant was experiencing symptoms of depression resulting from his activity restrictions. His parents believed that the benefit of allowing him to return to schoolwork, which was inconsistent with treatment recommendations, outweighed the cost of nonadherence. The mother of a 14-year old male with a broken leg similarly described her son’s desire to return to normal activities (i.e., going outside and walking around) in order to address his symptoms of depression:

It was so many different mood swings. One minute he would cooperate and sit and watch movies or try to do something fun. And then he’d get depressed, like he was going “I’ve been in the house for too long, I mean when can I just go outside and at least walk around?” When he went outside he’d start walking around on the cast and running on the cast.

Thus, findings provide evidence for the notion that experiencing symptoms of depression may serve as a barrier to adherence to treatment recommendations for adolescents. This is particularly true for adolescents with activity restrictions. Indeed, inability to maintain their pre-injury level of functioning led to symptoms of depression for several adolescents. To contend with these symptoms, adolescents often attempted to engage in activities that were incongruent with treatment recommendations.

5.3 - Perceived Threat

According to the HBM, the combination of perceived seriousness and susceptibility results in the construct of perceived threat, which is an influential factor for understanding adherence. Awareness of the potential long-term ramifications of injury was a significant factor

in promoting adherence to medical recommendations for adolescents in the current study (reported by 6 parents and 4 adolescents). Several adolescents were motivated to adhere to medical recommendations due to concern of a longer recovery period. A 14-year old male participant was tempted begin walking on his broken leg sooner than permitted by medical recommendations; his mother describes the positive effect of explaining the ramifications of nonadherence to her son:

He was saying he wanted to walk without his crutches after they took the hard cast off...he had one of those boots but he still couldn't put weight on it. And we told him that there is a chance that it won't heal right and they will have to break it again and reset it. That shocked him and he did what he needed to do for his leg to get better.

Recognition of the possibility of permanent damage to physical or cognitive functioning and permanent disfigurement was also effective for promoting adherence to medical recommendations in adolescent participants. Specifically, adolescents reported concern about future arthritis, nerve damage, the possibility of paralysis, and cognitive deficits. These bases of perceived threat were powerful motivators to adhere to medical recommendations. A 17-year old male participant discussed how he took great care to protect his finger fracture when playing sports in order to avoid future complications:

I had it taped up really good and then I put a big pad on my hand so it wouldn't get hit. It's better to have it heal where I could use it again for the future than leave it destroyed and play, and not be able to move it again.

A 17-year old female participant, who struggled to wear her back brace as recommended due to discomfort and desire for autonomy, was motivated by the threat of long-term ramifications of nonadherence. Her mother explained:

But the back brace...she kept that on the whole time because they explained to her in the hospital if you don't do this and your back shifts even the least little bit, you can be paralyzed and you may end up with surgery.

Additionally, two adolescents demonstrated awareness of the potential effect of nonadherence to treatment recommendations on their career plans. One adolescent noted that he needed his finger to heal correctly in order to pursue his career goal. In addition, a 15-year old male participant described how his injury threatened his dream of joining the military, which motivated him to adhere to his activity restrictions in order to promote optimal recovery:

I want to join the military. And right now I can't bend my wrists enough to do pushups and stuff. I have my faith that I'll be able to do another pushup. I can do one or two right now but it feels kind of awkward. I'm working up that muscle in my arms. I think before too long I'll be able to do pushups and work more."

Perceived threat to future well being resulting from nonadherence to medical recommendations facilitated adherence. Many adolescents demonstrated awareness of the long-term effects of nonadherence, which often resulted in adherence to medical recommendations.

5.4 - Perceived Benefits

Consistent with the HBM framework, participants in this study endorsed a number of perceived benefits to adherence to medical recommendations (reported by 2 parents and 2 adolescents), which effectively promoted adherence. Adolescents reported that the desire to return to normal activities, which often meant returning to their sports teams, was motivating to follow treatment recommendations. A 17-year old male participant described how his desire to return to sports motivated him to do his strengthening exercises:

I think that's what helped me heal up faster – so I could be able to play again. Because everyday I took my cast off and worked it in the morning and at night, and sometimes in the middle of the day. Just like moving my fingers back and forward, and making a fist and opening it. I think that's really what helped and made it heal up fast.

Similarly, the mother of a 15-year old male participant discussed her son's desire to return to sports and how it facilitated adherence to medical recommendations.

I think his desire to play football again is what got him through physically. I mean wanting to do that physical recovery and make sure that he did everything that he was supposed to...I think that played a major role in it. He wanted to get back on that football field.

In addition to the benefit of returning to sports, the parent of a 17-year old female participant described how her daughter's desire to regain independence and return to normal daily activities effectively motivated her to adhere to medical recommendations:

She was tired of being like that so she was determined; she was going to do whatever she had to do to recover so she could get her independence back, get her freedom back, and get her friends back."

For several adolescents, identification of a tangible benefit to adherence (i.e., desire to return to sports and regain independence) was enough to facilitate adherence to medical recommendations.

5.5 - Cues to Action

Critically important for promoting adherence to medical recommendations following injury are cues to action, or external factors that serve as catalysts for individuals to change behavior. Several relevant factors emerged for adolescents in the current study, including: parents (reported by 7 parents and 2 adolescents), doctors (reported by 7 parents and 1 adolescent), friends (reported by 2 parents and 1 adolescent), and other healthcare professionals (reported by 3 parents).

5.5.1 - Parents.

According to parents and adolescents, the role of parents in the recovery period after injury was critically important for facilitating adherence to medical recommendations. Parents were catalysts for adherence via several pathways, including offering emotional support, providing practical assistance, generating creative solutions to potential barriers to adherence, and setting limits. Emotional support consisted of positive reinforcement for adhering to activity restrictions for the mother of a 14-year old male who broke his leg. Another adolescent benefitted from encouraging conversations with his mother when he was feeling down. A 17-year old female participant noted the importance of her mother's pep talks about long-term ramifications of nonadherence.

A primary pathway through which parents served as catalysts for adherence to medical recommendations was provision of practical assistance to their adolescents. For instance, parents provided wound care, gave medication, scheduled follow-up appointments, and assisted with putting on braces. A 15-year old male participant discussed the numerous ways in which his mother supported adherence to medical recommendations in the aftermath of his broken leg injury:

She, like, helped me out because she brought me drinks and stuff because I couldn't get up or anything. I was just going to, like, lie in bed. I mean, I could, but I didn't really feel like it. And she would just talk me through things like "It's going to be okay. There's no reason to be upset."

Another important role of parents was their willingness to set limits. In order to ensure adherence, parents had to set limits with regard to various treatment recommendations, including: enforcing elevation of broken arm, prohibiting premature return to sports, ensuring consistent use of the back brace, and enforcing the completion of recommended strengthening exercises. As stated by the parent of a 17-year old male participant: “He didn’t want to, you know. He didn’t like having it elevated. He didn’t like having ice on it all the time. But I made him do it.”

Parents also employed creative problem-solving skills to enable children to return to normal activities to the extent possible without comprising adherence to treatment recommendations. The mother of a 15-year old male participant with a broken jaw experimented with pureeing different foods (e.g., meat) that would be appetizing while adhering to a soft food diet. The mother of a 14-year old male participant was frustrated with her son’s constant setbacks and re-casting of the injury due to his nonadherence to activity restrictions. The adolescent participant frequently gave in to temptation to play outside with friends. His mother discussed how she balanced following the treatment recommendations while enabling her son to spend time with friends:

I told him “You can go sit outside but you can’t walk around.” So when he went outside, he’d start walking around on the cast and running on the cast, and his friends are telling him “Come on, come on, walk to the store. It’s all right! It can heal!” So I let his friends come spend the night. You know, just to keep him from going outside.

Given that parents are often the primary caregivers for adolescents the wake of injury, it is unsurprising that they play an important role in ensuring adolescents adhere to medical recommendations. Parents encourage adherence through multiple means, such as emotional support, providing practical assistance, problem-solving to allow adolescents to participate in normal activities to the extent possible given their limitations, and mandating that adolescents follow recommendations that they otherwise may elect not to follow.

5.5.2 - Doctors.

In the current study, parents and adolescents noted that doctors played an important role in promoting adherence to medical recommendations through several pathways, which include availability/approachability, content of communication, and manner in which they communicated.

Parents noted that approachability and availability were important factors that enabled them to ask necessary questions to understand treatment recommendations and follow-up with the provider with concerns. Specifically, parents commented on the benefit of perceiving doctors were approachable and available for questions. The mother of a 15-year old male participant commented: “Doctor X was very approachable, and I felt like he, you know, I could talk to him and ask questions and he gave pretty clear cut answers, which was very helpful.” Another parent noted that her son’s doctor called to check on him after he left the hospital. The mother of a 17-year old female participant discussed how easy it was to make an appointment with the doctor after she noticed unexpected symptoms in her daughter (e.g., high fever, increased pain).

The content communicated by doctors to participants proved to be an important factor for facilitating adherence to medical recommendations. The mother of a 15-year old male participant who broke his leg noted that the doctor encouraged her son to adhere to the treatment recommendations, as it would enable him to begin playing sooner. This was effective for promoting adherence in this particular participant. A 17-year old male participant discussed the impact of a conversation with his doctor regarding ramifications of nonadherence:

One of my doctors told me that if I broke it again within a year that there could be serious problems, like, in the future for me with that arm...it wouldn’t heal back the way it was supposed to...so I kind of knew that I needed to lay off and be careful for a year or so and just let it heal the way it’s supposed to.

Numerous parents also commented on doctors’ manner of communication. One parent noted that she appreciated how her son’s doctor communicated treatment recommendations in a direct and thorough manner, as it enabled to her understand them clearly. Similarly, the mother of a 16-year old male described how she appreciated the clear explanation and provision of information from her son’s doctor:

The doctor explained everything. He let him [adolescent participant] know ahead of time it was going to be awhile, and he sat down all the time and said ‘This is what comes next...’, ‘This is what we’re thinking...’ Because the doctor explained everything so well, we didn’t have any surprises and we didn’t have any issues following his orders.

Thus, doctors play a critical role in promoting adherence to medical recommendations. The manner in which they communicate as well as the content they communicate appear to be important to adherence.

5.5.3 - Friends.

Friends served as influential facilitators of adherence to medical recommendations for several adolescents in the current study. The mother of a 15-year old male participant who broke his leg discussed the important role of her son's friends in providing practical assistance to him, as he had limited mobility. She provided an example of her son's friends coming to the house to care for him, which allowed the rest of the family to attend church. A 17-year old female participant discussed the important role of friends in promoting adherence to her treatment recommendations:

My friends were a big motivation because they know that I'm impatient and they said that if I didn't wear my back brace then I'd have to wear it even longer...And they were just, like, they were obviously probably joking around, but then again, helping me through everything.

Furthermore, the mother of a 14-year old boy with a broken leg described the important role of peers in promoting adherence to his activity restrictions. She indicated that her son was sometimes reluctant to follow her rules, but tended to be more receptive to the advice of peers:

Mostly he had girls surrounding him, helping him. They'd sit beside him, walk with him, and were always telling him "You have to listen to your momma." So by girls saying it, he was all into it.

Given the importance of friendships during the developmental period of adolescence, it is unsurprising that friends were influential in adolescents' adherence to medical recommendations.

5.5.4 - Other Healthcare Professionals.

In addition to the important roles of parents, doctors, and friends, evidence emerged that suggested other healthcare professionals played a role in facilitating adherence to treatment recommendations following adolescent injury. Two parents noted the usefulness of in-home support from a physical therapist and a nurse. Indeed, the mother of a 15-year old male participant who had in-home support from a nurse had the following to say: "We actually had a nurse that came in for the first couple of days to just, make sure, you know, show me how to do the dressing and the wrapping...I could do it."

Similarly, two parents with sons who were injured playing sports noted the important role of the athletic trainer in supporting treatment recommendations as adolescents began to return to sports. Indeed, the mother of a 17-year old male participant noted the following:

And the trainer was really, really good with him, and told him ‘We’ve got this stuff here that we can use if you come back on the field. We’ll wrap it every day. You know, fix it for you, whatever.’ And I think that helped more than anything.

Unsurprisingly, hospital-appointed personnel (i.e., physical therapist and nurse) were helpful for promoting adherence by teaching the adolescent patient and parent important skills for proper injury care. Multiple participants mentioned the important role of the athletic trainer in adhering to medical recommendations after injury. Thus, other healthcare professionals may facilitate adherence to medical recommendations with their skills and expertise, both in and out of the home environment.

Chapter 6 – Discussion

The findings from the present study advance the field of adherence by exploring barriers to adherence to medical recommendations following adolescent unintentional injury. While there is a significant body of literature regarding adherence to treatment recommendations in youth with chronic illnesses, this is the first study to examine adherence to medical recommendations following an acute event, such as injury. A mixed methods approach was employed to enable a holistic exploration of barriers to adherence to medical recommendations following hospitalization for unintentional injury in adolescents.

Findings from quantitative data indicate that adolescent psychological [i.e., adolescent posttraumatic stress disorder (PTSD) and depression as well as adolescent-reported and parent-reported quality of life (QOL)] and relational factors (i.e., parent PTSD and depression) did not significantly predict adherence to medical recommendations, contrary to hypotheses. Subsequent analyses of qualitative data revealed the presence of several barriers to adherence to medical recommendations, as well as support for factors that facilitate adherence, which are best understood within the framework of the Health Belief Model (HBM).

Prior to discussion regarding theoretical implications of findings, understanding the characteristics of the samples on which analyses from each portion of the study were based will provide context through which results may be considered. This is particularly important given the sequential explanatory mixed methods design of the present study, as the degree to which the samples are similar will determine the appropriateness of generalizing findings between samples. Quantitative data analyses revealed that demographic variables, including gender, age, and race were not significant predictors of adherence. Thus, while the quantitative sample was composed of younger participants, a higher proportion of females, and more racially diverse participants compared to the qualitative sample, these differences do not preclude generalizability of findings from the quantitative sample to the qualitative sample and vice versa. Across both samples, adolescents and parents reported subclinical levels of PTSD and depression, and quality of life was high. The meaning injury severity score suggests that adolescents in the qualitative sample had more severe injuries than those comprising the quantitative sample; however, two of the adolescents in the qualitative sample were severely injured, which affected the mean score given the small sample size.

However, it is important to note that participants comprising the quantitative sample were initially assessed in the direct aftermath of injury, during the initial hospitalization, while participants comprising the qualitative sample were assessed 3-6 months following the injury. Use of the Timeline Follow Back approach minimized the potential of recall bias for qualitative data participants. Thus, it is appropriate to generalize findings between quantitative and qualitative samples comprising the current study based on demographic factors, although results should be interpreted in light of the differences in elapsed time between injury and assessment.

6.1 - Adolescent Psychological and Relational Barriers to Adherence

Contrary to hypotheses, results of quantitative analyses did not support the predictive role of adolescent psychological and relational factors on adolescents' adherence to medical recommendations following discharge from the hospital after injury. Indeed, adolescent psychological factors [i.e., adolescent PTSD and depression, adolescent QOL (adolescent- and parent-reported)] and relational factors (i.e., parent PTSD and depression) were unrelated to adherence to treatment recommendations in the present study, which is inconsistent with the chronic illness empirical evidence. Indeed, adolescent symptoms of depression, anxiety, and PTSD are associated with nonadherence to treatment recommendations for adolescents with chronic illnesses (Vandivere, Gallagher, & Moore, 2004; Murphy et al., 2001, King et al., 2014; Shemesh et al., 2007; Drotar & Bonner, 2009; DiMatteo, 2004). Despite the lack of significance in regression analyses, it is important to note that the correlation between adherence and PTSD at T2 approached significance. Specifically, a negative correlation exists, which suggests that with a larger, more distress sample, there may have been a significant correlation between adherence and T2 PTSD. Indeed, lower levels of T2 PTSD may be related to better adherence. It is possible that the low levels of psychological distress in the adolescent and parent participants comprising the study sample may have contributed to the nonsignificance of findings, which may be particularly relevant in the current study given the correlation between adherence and T2 PTSD that approached significance.

Regarding demographic variables, family income and race were also statistically insignificant. However, post-hoc analyses with the subsample of least-adherent participants were suggestive of potential relevance of family income and race to the understanding of adherence. Specifically, racial minority status and lower family income were predictive of nonadherence in a small subsample of nonadherent youth. This is consistent with studies of children with asthma

and HIV (Drotar & Bonner, 2009; Shemesh et al., 2007). Hidden costs of treatment, including time taken off from work as well as transportation costs, and inconsistent medical insurance can serve as barriers to adherence for youth with chronic illnesses (van Esland et al., 2012; Crosby et al., 2012; Shemesh et al., 2007), which may help explain why families with lower SES and minority status might be less adherent to treatment recommendations.

The nonsignificance of adolescent psychological and relational factors on adherence suggested that additional variables might serve as barriers to adherence to medical recommendations. As such, qualitative data was collected in an effort to further explore potential barriers to adherence in this population.

6.2 - Exploration of Additional Factors Contributing to Adherence

Consistent with the HBM, findings from qualitative interviews suggested that a number of barriers to adherence to treatment recommendations exist for adolescents following hospitalization for injury. Barriers include: concern of pain medication addiction, competing activities, treatment side effects, health status, and desire for autonomy. Furthermore, although results from the quantitative portion of the study did not indicate psychological factors were significantly related to adherence, interview data suggested they might be relevant to our understanding of adherence to medical recommendations.

Results of the study also revealed the presence of several additional factors (i.e., perceptions of threat and benefit as well as cues to action) that could facilitate adherence to treatment recommendations, which is consistent with the HBM framework. Following will be a discussion regarding the barriers to adherence as well as facilitators of adherence, presented within the framework of the HBM.

6.2.1 - Barriers.

Concern of pain medication addiction emerged as an unexpected finding in the current study. Parents in particular, but several adolescents as well, expressed concern regarding potential addiction to medication. This often led to early discontinuation of the medication despite need for pain management. This is a problem given the risks of morbidity and mortality associated with untreated pain after medical trauma (Verghese & Hannallah, 2010). Further, the economic burden caused by discarded medication each year is significant (Iskedjian, Addis, &

Einarson, 2002). It is critical to consider parents' and adolescents' concerns regarding medication addiction when implementing best practice guidelines for the treatment of pediatric pain.

The majority of adolescents in the current study reported nonadherence to treatment recommendations associated with competing activities. This finding is consistent with the literature on children and adolescents with chronic illnesses; adherence competes with activities, such as sports and social events, which often results in nonadherence to treatment recommendations (Crosby et al., 2009, Hommel et al., 2011; Ingerski et al., 2011, Greenley et al., 2010). Returning to activities of normal life and adhering to treatment recommendations are often in direct opposition for adolescents who are recovering from injury. For instance, treatment recommendations limiting an adolescent's ability to carry heavy items may conflict with returning to school and needing to carry a backpack. Due to most adolescents' strong desires to return to their baseline levels of functioning, adherence to recommendations may decline as they become decreasingly limited by their injuries. Unlike youth with chronic illnesses who are accustomed to following a treatment regimen, acute injury represents a significant, sudden disruption to life for which adolescents and their parents are frequently unprepared to manage.

Treatment side effects, including medication side effects and discomfort associated with immobilizing treatment devices (e.g., braces and slings) precluded adherence to medical recommendations for several adolescents. Nonadherence resulting from medication side effects is relatively common across pediatric conditions (Meyers, Thomson, & Weiland, 1996; Rapoff, 2010). Unlike children and adolescents with chronic illnesses, a unique barrier to adherence in adolescents with injuries is the use of immobilizing treatment devices, such as slings and braces due to discomfort associated with these forms of treatment.

Adolescents with injuries and their parents report that health status, specifically absence of pain, often leads to nonadherence, which is consistent with the chronic illness literature. Indeed, health status, including absence of symptoms, can be a barrier to adherence in that youth may believe their lack of symptoms suggests they no longer need to follow through with the treatment regimen (Rowe et al., 2005). Thus, a lack of symptoms may be a risk factor for nonadherence to treatment recommendations in adolescents with both acute injury and chronic illness. The perception that treatment is unnecessary may mediate this relationship.

Given the unique developmental changes associated with the period of adolescence, which include a greater desire for autonomy, more time spent outside the home, and increased academic and social demands (Holmbeck, Greenley, & Franks, 2004), it is not surprising that adolescents' desire for autonomy served as barrier to adherence to treatment recommendations. Adolescents frequently lose the capacity to function independently (e.g., independently manage activities of daily living) due to activity limitations after they have sustained injury, which can create tension between dependence on others and their previously relatively independent lifestyles. For some adolescents in the current study, their desire for autonomy outweighed the perceived benefits of adhering to treatment recommendations.

Contrary to findings from the quantitative portion of the study, several adolescents in the current study reported that symptoms characteristic of depression served as a barrier to adherence to treatment recommendations. For instance, one adolescent reported that he ran and played sports earlier than permitted in order to contend with symptoms of depression that he believed resulted from his limited activity. This finding is consistent with previous literature with children and adolescents with chronic illnesses (Vandivere, Gallagher, & Moore, 2004; Murphy et al., 2001, King et al., 2014, Gray et al., 2012). Indeed, results of a meta-analysis examining the role of depression and anxiety on health status and healthcare utilization of patients found an inconsistent relationship between anxiety and health status but a consistent and strong relationship between depression and health status (DiMatteo, Lepper, & Croghan, 2000). This suggests that symptoms unique to depression may serve as a barrier to adherence that is distinct from commonly comorbid anxiety conditions, including PTSD. It may be that activity limitations lead to symptoms of depression for adolescents with injuries; thus, nonadherence to treatment recommendations represents adolescents' attempts to contend with their symptoms. The acute onset of limitations makes injury a unique pediatric condition in this regard, as youths' levels of functioning change abruptly.

6.2.2 - Perceived Threat.

Findings from the current study revealed that the perception of potential threat resulting from nonadherence could effectively facilitate adherence to treatment recommendations. Specifically, the possibility of a longer recovery period or permanent damage to functioning, potential disfigurement, and threat to long-term career goals were associated with adherence to treatment recommendations. Interestingly, both parents and adolescents noted the positive effect

of threat perceptions on adherence. This awareness is unique to the developmental period of adolescence given that adolescents have the capacity to think abstractly, whereas younger children might be less likely to garner motivation to follow treatment recommendations from the long-term negative outcomes that could result by way of nonadherence. The perceptions of threat resulting from nonadherence to future functioning are consistent with results of a meta-analysis supporting the strong, positive relationship between perceptions of disease severity threat and adherence (DiMatteo, Haskard, & Williams, 2007). The role of parents should not be undervalued, as parents were often the driving factors behind their adolescents' perceptions of threat. Indeed, parent beliefs about the potential long-term threats of treatment for youth with chronic diseases can affect decisions regarding treatment adherence (Santer et al., 2014).

6.2.3 - Perceived Benefits.

Parents and adolescents reported that recognizing potential benefits of following treatment recommendations facilitated adherence. Specifically, adolescents in the current study were motivated by the desire to return to normal activities (e.g., sports) and regain independence, consistent with previous literature examining adherence in adolescents following anterior cruciate ligament repair (Brewer et al., 2003). Indeed, a subset of adolescents in the current study chose to reach their goals of returning to sports and regaining independence by adhering to treatment recommendations to facilitate a faster recovery process. Interestingly, the desire to return to normal activities and regain independence also served as barriers in the current study, as adolescents exhibited nonadherence to treatment recommendations in order to achieve these goals. Thus, one group of participants demonstrated nonadherence because they sought immediate gratification, while the second group of participants followed treatment recommendations with an eye towards long term outcomes. This exemplifies the variability in cognitive functioning within the developmental period of adolescence, particularly the varying rates at which the prefrontal brain regions develop (Casey, Jones, & Hare, 2008). Future research should be conducted to gain a deeper understanding of the differences between adolescents who adhere to treatment recommendations with the goal of returning to sports and regaining independence versus those who do not adhere to treatment recommendations towards the same end.

6.2.4 - Cues to Action.

Parents were tremendously influential in promoting adherence to medical recommendations for adolescents in the present study. They offered emotional support, provided practical assistance, generated creative solutions to potential barriers to adherence (i.e., pureeing desired foods when an adolescent was on a soft foods diet and facilitating time spent with friends in a setting compatible with activity restrictions), and set limits with adolescents; all of these findings are consistent with chronic illness literature (DiMatteo, 2004). Generally speaking, parents play a crucial role in guiding adherence due to the unfamiliar and complex nature of medical recommendations.

The majority of parents and adolescents reported that their medical providers (i.e., doctors) were highly influential in their decisions to adhere to treatment recommendations. This finding is consistent with empirical evidence from the chronic illness literature (DiMatteo, 2004; Santer et al., 2014; Drotar & Bonner, 2009). Doctors facilitated adherence through various means, including being available and approachable, communicating helpful information, and communicating in an informative and pleasant manner. Indeed, overwhelming evidence with various pediatric populations supports that health professionals are a primary source of advice on how to overcome difficulties with treatment regimens (Santer et al., 2014). Indeed, health professionals can work in dual roles; providing advice regarding adherence to parents and communicating with children and adolescents about treatment goals (Drotar & Bonner, 2009). Given that coping with unintentional injury can be emotionally distressing and difficult to navigate, it is unsurprising that participants in the current study reported that the manner in which doctors communicated was helpful for promoting adherence (DiMatteo, 2004).

Interestingly, for several adolescents, friends played an integral role in promoting adherence to treatment recommendations. This is unique to adolescence given the prominent role of friends in their lives. This finding is inconsistent with the literature regarding peers and adherence in chronically ill populations, which has demonstrated that peers can be a barrier to adherence to treatment regimens. Stigma related to treatments (Rickert & Drotar, 2000) as well as social comparison and embarrassment (Hommel et al., 2011) can contribute to nonadherence. Thus, the finding that peers facilitated adherence by encouraging several adolescents in this study to follow treatment recommendations was unexpected. Whereas some types of chronic

illnesses may have more stigmas due to potential associated cognitive and social ramifications (Cheung & Wirrell, 2006), pediatric injury might be less likely to be stigmatized because it is temporary and adolescents are typically expected to return to previous levels of functioning.

Additionally, other healthcare professionals, including home-based nursing and physical therapists, as well as school-based athletic trainers served as catalysts for adherence to medical recommendations. Indeed, athletic trainers are often a better source of support than even coaches or assistant coaches during the recovery period from injury (Robbins & Rosenfeld, 2001). These non-hospital based medical professionals may serve as facilitators of adherence due to the higher level of accessibility and personalized care they can offer. Indeed, having personalized and accessible care can negate potential barriers to adherence, including lack of knowledge or skills.

6.3 - Integrating Findings: What is Adherence?

Results of the present study have advanced the understanding of adherence to medical recommendations following adolescent unintentional injury. There is a general lack of consensus regarding the construct of adherence in the literature and virtually nothing is known about the application of this construct in the pediatric injury literature.

The few studies examining why youth are nonadherent to treatment regimens have identified broad constructs including health status, side effects of treatment, and competing activities that predict nonadherence. The current study supported these factors as well as others specific to injury, including symptoms of depression, desire to regain independence, and concern of pain medication addiction. However, based on the complexities that clearly exist in understanding adherence [e.g., 1) why peers; 2) wish to return to normal activities, and; 3) desire to regain independence can serve as both barriers to adherence as well as promote adherence, depending on the adolescent], it is more appropriate to conceptualize it as the result of a complex process in which adolescents consider multiple factors in determining their behavior, as opposed to a static process.

Understanding adherence as a dynamic decision-making process influenced by numerous factors departs from previous research by emphasizing the concurrent role of such factors in adherence decision-making. Specifically, the decision to adhere to treatment recommendations was supported when adherence resulted in a desired outcome or prevented consequences. Support from medical professionals, parents, friends, and other healthcare professionals

bolstered adherence. Conversely, the decision to skip or forgo medication was attributed to health status, side effects, desire for independence, depression, competing activities, and concern of pain medication addiction.

A primary concept to consider when understanding the dynamic interplay of potential barriers and protective factors on an adolescent's decision to adhere to treatment recommendations following injury is the disruptive nature of injury to what can be considered homeostasis of "normal life." Whereas normal life for youth with chronic illnesses includes an ongoing medical treatment regimen, the burden imposed by the demands of injury recovery are far from normal and represent a significant disruption in day to day functioning for a period of weeks to months. It may be that adherence is dependent on the extent to which it disrupts homeostasis, which will manifest differently for each child. For instance, if an adolescent is able to spend time with friends while adhering to activity restrictions, he may be more willing to follow the treatment plan since his peer relationships are not being significantly disrupted. On the other hand, an adolescent who runs and plays sports before being permitted to do so may be attempting to counteract the disruption in the homeostasis of normal life caused by his lack of sports involvement and associated depressive symptoms. Thus, to achieve this homeostasis, he engages in these activities, which are incongruent with treatment recommendations. This tension is unique to injury because treatment is unexpected, unfamiliar, and temporary.

Developmental factors may enable further understanding of this complex relationship. Several adolescents considered the long-term impacts of their adherence while others primarily focused on the extent to which adherence would disrupt their normal daily activities. As previously noted, this reflects the inconsistent development of higher order cognitive abilities during the period of adolescence.

Thus, specific barriers to adherence, perceived consequences of nonadherence, benefits to adherence, and social factors are unlikely to affect adherence in isolation. It is critical to view adherence as a dynamic decision-making process involving the interactions among numerous factors within the context of a significant disruption to adolescents' daily lives.

6.4 - Limitations

The findings of this study should be interpreted in the context of several limitations. Quantitative and qualitative analyses were conducted with different samples of participants; quantitative analyses were conducted with a sample of participants from an urban location in the

northeastern United States while qualitative analyses were based on interviews with participants from a rural location in the southeastern United States. However, given that demographic factors (i.e., gender, age, income, and race) were not significantly related to adherence, it is unlikely that differences between the two samples preclude generalizability of findings.

Additionally, this investigation utilized a small sample of adolescents with diverse injuries. However, given that thematic saturation was achieved in qualitative interviews, the sample size was likely sufficient to address the study questions (Bowen, 2008; Padgett, 2008). Thus, future research can expand on these findings by utilizing larger sample sizes and examining possible subgroup differences in adolescent adherence to various types of treatment recommendations after injury.

The lack of significance of quantitative data analyses may in part be due to nonnormality of adolescent psychological (i.e., adolescent PTSD and depression as well as adolescent- and parent-reported QOL) and relational variables (parent PTSD and depression). Indeed, data were positively skewed and mean scores for adolescent and parent PTSD and depression did not reach the threshold for clinical significance. QOL was negatively skewed and adolescents tended to have a high QOL. Thus, this sample was not highly distressed and the lack of variability may have contributed to nonsignificant findings. However, the general linear model is robust for validity against violations of abnormality so it may be that the overall lack of distress characterizing the study contributed to nonsignificant findings more than nonnormality of the data.

Given that adherence, to this investigator's knowledge, has not been assessed with a sample of injured adolescents, the measurement of adherence in the quantitative dataset serves only as a baseline for future research. Indeed, the manner in which adherence was measured in the quantitative data was not optimal for enabling a full understanding of the nuances and mechanisms involved in this highly complex process. Additionally, the mean percentage of adherence was negatively skewed, meaning that most participants were adherent. Thus, this lack of variability may also have contributed to nonsignificant outcomes.

Several limitations associated with qualitative research methodology should be noted. First, it is possible that a self-selection bias was present during the recruitment phase, as participants who agreed to participate in the study may have been more adherent and/or more psychologically-minded. Furthermore, qualitative research can be affected by researchers'

personal biases, which is not a limitation of quantitative research. Regarding the particular strategy used in the present study, it was not ideal to conduct interviews and obtain data for self-report questionnaires over the phone, as it may have contributed to participants underreporting symptomatology and nonverbal communication was missed.

Finally, as the purpose of this study was to identify overarching mechanisms that impact adherence decision-making among adolescents with injuries, differences between individual treatment recommendations were not examined. In addition, as actual adherence behavior was not assessed, longitudinal research is needed to determine if the identified mechanisms predict adherence decision-making over time. Given that adherence demands are different in different stages of recovery, this will also be an important area of investigation for future research.

6.5 - Implications for Practice

Based on the findings, it is recommended that medical professionals place emphasis on the potential for barriers to adherence for adolescents after discharge from the hospital following unintentional injury. Explicit acknowledgement of the social and practical barriers to adherence may facilitate a transparent conversation and encourage adolescents to openly discuss individual barriers. Medical and psychosocial teams could consider providing psychoeducation regarding 1) the importance of adherence despite lack of pain or other symptoms; 2) side effects of treatments, and; 3) information regarding pain medication addiction. Given the role that psychological distress may play in nonadherence, anticipating the possibility of these symptoms and their interaction with adherence is also important. Indeed, most parents interviewed expressed that they did not receive any information regarding potential emotional reactions to injury and wished they had. Assessment of protective factors, or people who can serve as cues to action, is worthwhile in anticipation of potential barriers.

Furthermore, understanding the goals, protective social factors, and potential barriers to adherence for a given adolescent may provide insight as to the most salient method of explaining treatment recommendations. For example, one adolescent described his decision to adhere as driven by his desire to return to playing sports and the belief that doing his exercises and caring for his injury as prescribed would help him reach that goal faster. Identifying and building on these unique factors contributing to this dynamic decision-making process will be beneficial.

Chapter 7 – Conclusion

Adolescents experience numerous barriers to adherence to treatment recommendations following unintentional injury. However, a host of additional factors may effectively facilitate adherence to these recommendations. The interactions of barriers and protective factors characterize the dynamic decision-making process that results in adherence or nonadherence. These findings provide an initial roadmap for understanding the mechanisms involved in adherence following adolescent injury and will serve to inform future treatment approaches.

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Figure 1: Health Belief Model

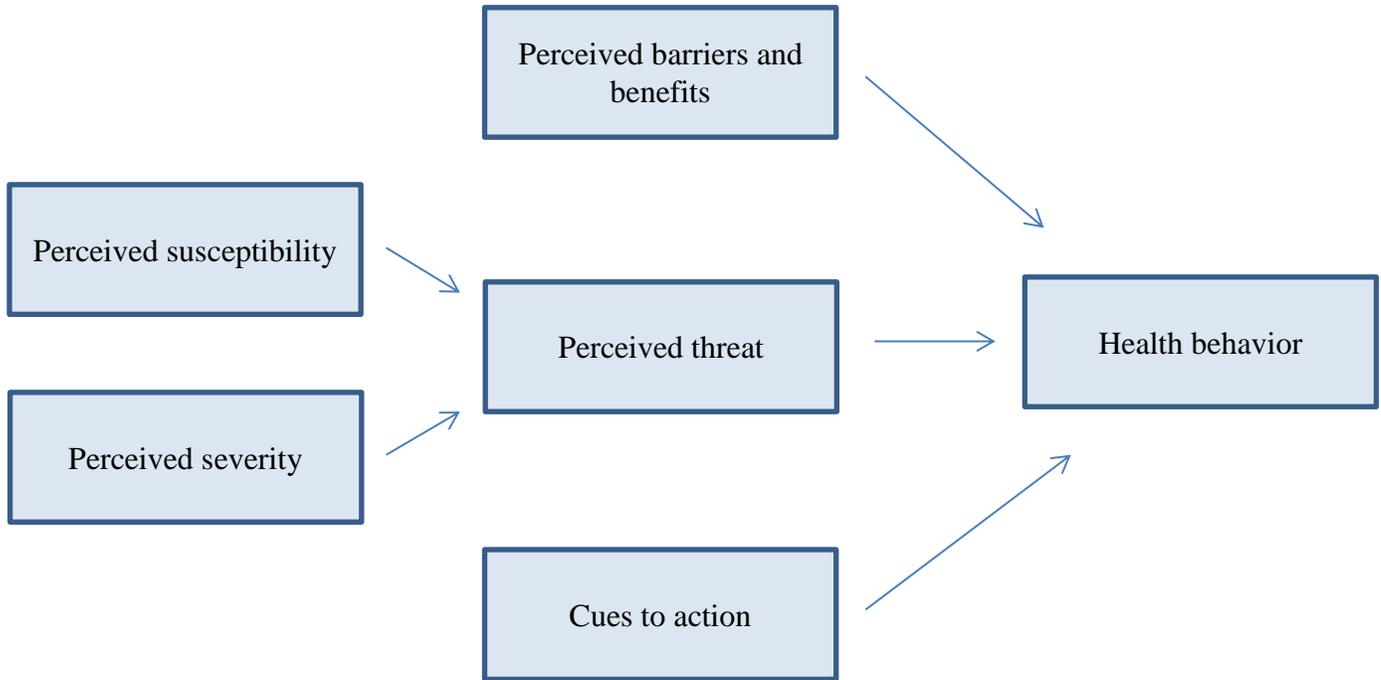


Table 1

Mechanism of injury for both samples

| | Quantitative sample (N=67) | | Qualitative Sample (N=10) | |
|---|---------------------------------------|------------|--------------------------------------|------------|
| | Total | Percentage | Total | Percentage |
| Motor vehicle crash | 3 | 4 | 1 | 10 |
| Bicycle struck by motor vehicle | 3 | 4 | -- | -- |
| Pedestrian struck by motor vehicle | 3 | 4 | -- | -- |
| ATV crash | 2 | 3 | -- | -- |
| Fall from bike | 4 | 6 | -- | -- |
| Fall from horse | 1 | 1 | -- | -- |
| Fall down stairs | 2 | 3 | -- | -- |
| Fall from ladder | 1 | 1 | -- | -- |
| Fall from one level to another | 3 | 4 | -- | -- |
| Fall from skates | 3 | 4 | 1 | 10 |
| Fall while snowboarding | 1 | 1 | 1 | 10 |
| Slip, trip, and fall | 3 | 4 | 2 | 20 |
| Fall in sports | 11 | 16 | 2 | 20 |
| Fall, general | 2 | 3 | 1 | 10 |
| Struck in sports, no fall | 5 | 7 | 2 | 20 |
| Insect bite (non-venomous) on foot/toe | 7 | 10 | -- | -- |
| Infected injury of foot/toe | 4 | 6 | -- | -- |
| Burn by hot object | 1 | 1 | -- | -- |
| Overexertion and strenuous movements | 7 | 10 | -- | -- |
| Crushing injury of lower limb | 1 | 1 | -- | -- |

Table 2

Descriptive Statistics for Quantitative Sample

| Variable | N | Mean | SD | Range | α | Skew-ness | Kurto-sis |
|---------------------------------|----|------|-----|-------|----------|-----------|-----------|
| Gender | | | | | | | |
| Male | 49 | -- | -- | -- | -- | -- | -- |
| Female | 18 | -- | -- | -- | -- | -- | -- |
| Age | 67 | 14.4 | 1.3 | 13-17 | -- | -- | -- |
| Income | | | | | | | |
| Less than \$5,000 | 3 | -- | -- | -- | -- | -- | -- |
| \$5,000-\$14,999 | 5 | -- | -- | -- | -- | -- | -- |
| \$15,000-\$29,999 | 7 | -- | -- | -- | -- | -- | -- |
| \$30,000-\$49,999 | 15 | -- | -- | -- | -- | -- | -- |
| \$50,000-\$74,999 | 8 | -- | -- | -- | -- | -- | -- |
| \$75,000-\$99,999 | 8 | -- | -- | -- | -- | -- | -- |
| \$100,000 or more | 20 | -- | -- | -- | -- | -- | -- |
| Payor | | | | | | | |
| Medicaid Managed Care | 15 | -- | -- | -- | -- | -- | -- |
| Commercial Insurer Indemnity | 22 | -- | -- | -- | -- | -- | -- |
| Commercial Insurer Managed Care | 16 | -- | -- | -- | -- | -- | -- |
| Other Third Party | 3 | -- | -- | -- | -- | -- | -- |
| Self Pay | 2 | -- | -- | -- | -- | -- | -- |
| Child Race | | | | | | | |
| American Indian/Alaskan Native | 0 | -- | -- | -- | -- | -- | -- |
| Hawaiian/ Pacific Islander | 0 | -- | -- | -- | -- | -- | -- |
| Black/African American | 24 | -- | -- | -- | -- | -- | -- |
| White/Caucasian | 37 | -- | -- | -- | -- | -- | -- |
| Other | 6 | -- | -- | -- | -- | -- | -- |
| Injury Severity Score (ISS) | 67 | 7.1 | 5.2 | 1-29 | -- | -- | -- |
| Child PTSD | | | | | | | |

| | | | | | | | |
|---------------------------|----|-------|------|-------|-----|------|------|
| Baseline | 67 | 8.9 | 8.0 | 0-29 | .84 | 1.1 | 0.2 |
| 6 weeks | 63 | 9.9 | 8.6 | 0-34 | .86 | 1.1 | 0.7 |
| Child Depression | | | | | | | |
| Baseline | 67 | 8.5 | 7.8 | 0-35 | .82 | 1.1 | 1.0 |
| 6 weeks | 63 | 10.94 | 8.85 | 0-48 | .84 | 1.6 | 2.8 |
| Child-reported QOL | | | | | | | |
| Baseline | 62 | 81.7 | 9.4 | 36-92 | .79 | -2.2 | 2.8 |
| 6 weeks | 56 | 66.8 | 15.9 | 19-92 | .88 | -0.5 | 0.3 |
| Parent PTSD | | | | | | | |
| Baseline | 65 | 25.3 | 9.5 | 17-63 | .88 | 1.9 | 2.9 |
| 6 weeks | 67 | 24.6 | 10.8 | 17-77 | .94 | 2.7 | 2.9 |
| Parent Depression | | | | | | | |
| Baseline | 65 | 12.6 | 10.1 | 0-46 | .90 | 1.3 | 1.6 |
| 6 weeks | 67 | 11.3 | 11.5 | 0-50 | .92 | 1.3 | 1.2 |
| Parent-reported Child QOL | | | | | | | |
| Baseline | 61 | 76.6 | 15.4 | 18-92 | .92 | -1.8 | 2.6 |
| 6 weeks | 55 | 64.8 | 17.0 | 26-92 | .90 | -0.3 | -1.1 |
| Adherence | | | | | | | |
| 6 weeks | 67 | 0.8 | 0.2 | 0-1 | -- | -1.4 | 2.9 |

Table 3 Bivariate Correlations among Study Variables

| Variable | 1. | 2. | 3. | 4. | 5. | 6. | 7. | 8. | 9. | 10. | 11. | 12. | 13. | 14. | 15. |
|-------------|-------|------|--------|--------|--------|-------|-------|-------|--------|--------|--------|------|--------|------|------|
| 1. Race | 1.00 | | | | | | | | | | | | | | |
| 2. Income | .15 | 1.00 | | | | | | | | | | | | | |
| 3. CPSS T1 | -.01 | -.01 | 1.00 | | | | | | | | | | | | |
| 4. CCESD T1 | .02 | .03 | .53*** | 1.00 | | | | | | | | | | | |
| 5. CPQL T1 | -.04 | -.01 | -.12 | -.28** | 1.00 | | | | | | | | | | |
| 6. PPQL T1 | .27** | -.03 | -.03 | -.24** | .34*** | 1.00 | | | | | | | | | |
| 7. PCL T1 | -.16 | -.05 | .29** | .24* | .08 | -.18* | 1.00 | | | | | | | | |
| 8. PCESD T1 | -.10 | -.03 | .27** | .37*** | -.16 | -.20* | .70* | 1.00 | | | | | | | |
| 9. CPSS T2 | -.04 | -.01 | .61** | .64** | -.19 | -.05 | .33* | .41* | 1.00 | | | | | | |
| 10.CCESD T2 | -.04 | -.07 | .51** | .58** | -.13 | -.19 | .09 | .10 | .81** | 1.00 | | | | | |
| 11. CPQL T2 | .24 | 0.1 | .55** | -.39* | .08 | -.13 | -.18 | -.23 | .66*** | .59*** | 1.00 | | | | |
| 12. PPQL T2 | .11 | -.17 | .45** | -.32* | .01 | -.11 | -.29 | -.19 | -.26 | -.18 | .61*** | 1.00 | | | |
| 13. PCL T2 | -.02 | -.09 | .10 | .36* | -.04 | -.39* | .44** | .10 | .38** | .32* | -.35** | -.07 | 1.00 | | |
| 14.PCESD T2 | -.05 | -.10 | .16 | .42** | -.09 | -.33* | .39* | .53** | .03* | .21 | -.16 | -.03 | .82*** | 1.00 | |
| 15. Adher | -.14 | -.07 | -.00 | -.05 | .11 | .20 | .14 | -.04 | -.23 | -.11 | .12 | .05 | .12 | .05 | 1.00 |

Note. CPSS = adolescent PTSD; CCESD = adolescent depression; CPQL = adolescent-reported QOL; PCL = parent PTSD; PCESD = parent depression; PPQL = parent-reported adolescent QOL; Adher = adherence. *** $p < .001$. ** $p < .01$. * $p < .05$

Table 4

Standard Regression Analyses Predicting Adherence via T1 Adolescent Psychological Variables

| Predictor | ΔR^2 | <i>B</i> | <i>SE B</i> | β |
|-------------------------|--------------|----------|-------------|---------|
| Step 1 | .043 | | | |
| Adolescent PTSD | | .000 | .005 | .005 |
| Depression | | .000 | .005 | .009 |
| Adolescent-reported QOL | | .001 | .003 | .043 |
| Parent-reported QOL | | .003 | .002 | .190 |
| <i>Note. N = 67</i> | | | | |

Table 5

Standard Regression Analyses Predicting Adherence via T1 Relational Variables

| Predictor | ΔR^2 | <i>B</i> | <i>SE B</i> | β |
|---------------------|--------------|----------|-------------|---------|
| Step 1 | .057 | | | |
| Parent PTSD | | .008 | .004 | .331 |
| Depression | | -.006 | .004 | -.269 |
| <i>Note. N = 67</i> | | | | |

Table 6

Hierarchical Regression Analyses Predicting Adherence via T2 Adolescent Psychological Variables

| Predictor | ΔR^2 | <i>B</i> | <i>SE B</i> | β |
|----------------------------|--------------|----------|-------------|---------|
| Step 1 | 0.43 | | | |
| Adolescent PTSD T1 | | .000 | .005 | .005 |
| Depression T1 | | .000 | .006 | .009 |
| Adolescent-reported QOL T1 | | .001 | .004 | .043 |
| Parent-reported QOL T1 | | .003 | .002 | .190 |
| Step 2 | .104 | | | |
| Adolescent PTSD T2 | | -.010 | .007 | -.430 |
| Depression T2 | | .005 | .006 | .218 |
| Adolescent-reported QOL T2 | | -.001 | .004 | -.051 |
| Parent-reported QOL T2 | | .000 | .002 | .038 |
| <i>Note. N = 67</i> | | | | |

Table 7

Hierarchical Regression Analyses Predicting Adherence via T2 Relational Variables

| Predictor | ΔR^2 | <i>B</i> | <i>SE B</i> | β |
|-----------------------|--------------|----------|-------------|---------|
| Step 1 | .057 | | | |
| Parent PTSD T1 | | .008 | .004 | .331 |
| Depression T1 | | -.006 | .004 | -.269 |
| Step 2 | .071 | | | |
| Parent PTSD T2 | | .003 | .005 | .186 |
| Depression T2 | | -.004 | .004 | -.215 |
| <i>Note.</i> $N = 67$ | | | | |

Table 8

Qualitative Sample Characteristics

| Variable | N | Mean | SD | Min-Max |
|----------------------------|----|------|-----|---------|
| Gender | | | | |
| Male | 9 | -- | -- | -- |
| Female | 1 | -- | -- | -- |
| Age | 10 | 15.8 | 1.0 | 14-17 |
| Income | | | | |
| Less than \$5,000 | 1 | -- | -- | -- |
| \$5,000-\$14,999 | 1 | -- | -- | -- |
| \$15,000-\$29,999 | 0 | -- | -- | -- |
| \$30,000-\$49,999 | 2 | -- | -- | -- |
| \$50,000-\$74,999 | 3 | -- | -- | -- |
| \$75,000-\$99,999 | 2 | -- | -- | -- |
| \$100,000 or more | 1 | -- | -- | -- |
| Payor | | | | |
| Medicaid Managed Care | 2 | -- | -- | -- |
| Commercial Insurer | 5 | -- | -- | -- |
| Indemnity | | -- | -- | -- |
| Commercial Insurer | 3 | -- | -- | -- |
| Managed Care | | -- | -- | -- |
| Other Third Party | 0 | -- | -- | -- |
| Self Pay | 0 | -- | -- | -- |
| Child Race | | | | |
| American Indian/Alaskan | 0 | -- | -- | -- |
| Native | | -- | -- | -- |
| Hawaiian/ Pacific Islander | 0 | -- | -- | -- |
| Black/African American | 2 | -- | -- | -- |
| White/Caucasian | 7 | -- | -- | -- |
| Other | 1 | -- | -- | -- |

| | | | | |
|-----------------------------|----|------|-----|---------|
| Injury Severity Score (ISS) | 10 | 11.3 | 8.6 | 1-34 |
| Child PTSD | | | | |
| Baseline | 10 | 6.0 | 3.5 | 0-11 |
| Child Depression | | | | |
| Baseline | 10 | 5.0 | 3.1 | 0-11 |
| Child-reported QOL | | | | |
| Baseline | 10 | 85.6 | 6.4 | 77-92 |
| Parent PTSD | | | | |
| Baseline | 10 | 26.0 | 6.5 | 18-36 |
| Parent Depression | | | | |
| Baseline | 10 | 10.3 | 7.5 | 0-25 |
| Parent-reported Child QOL | | | | |
| Baseline | 10 | 84.1 | 7.9 | 68-92 |
| Adherence | | | | |
| Baseline | 10 | 0.8 | 0.2 | 0.5-1.0 |

Table 9

Adherence Characteristics of Qualitative Sample

| Variable | N |
|--------------------------------------|-----|
| Endorsed recommendations per patient | |
| Mean | 4.4 |
| Standard Deviation | 1.6 |
| Range | 3-8 |
| Total adherence recommendations | |
| Total endorsed | 45 |
| Adherence | 33 |
| Non-adherence | 12 |
| Dietary restrictions | |
| Total endorsed | 2 |
| Adherence | 2 |
| Non-adherence | 0 |
| Activity restrictions | |
| Total endorsed | 13 |
| Adherence | 9 |
| Non-adherence | 4 |
| Follow-up clinical services | |
| Total endorsed | 11 |
| Adherence | 10 |
| Non-adherence | 1 |
| Contact physician with concerns | |
| Total endorsed | 2 |
| Adherence | 2 |
| Non-adherence | 0 |
| Caring for wounds/drain lines | |
| Total endorsed | 5 |
| Adherence | 5 |

| | |
|-----------------------------|---|
| Non-adherence | 0 |
| Miscellaneous instructions | |
| Total endorsed | 0 |
| Adherence | 0 |
| Non-adherence | 0 |
| Medications | |
| Total endorsed | 9 |
| Adherence | 5 |
| Non-adherence | 4 |
| Other relevant instructions | |
| Total endorsed | 4 |
| Adherence | 2 |
| Non-adherence | 2 |

Note: The Activity Restrictions and Follow-Up Clinical Services domains may total more than 10 as there were several subcategories within each domain to account for the possibility of multiple recommendations within each of these subcategories.

Appendix A

Health Care Questionnaire

| | | | | | | | |
|--|---|---|--------------------------------|------------|-----------|------------|-----------|
| ✓ if included in discharge summary. Write N/A if not.. | Discharge Instructions: | | | | | | |
| 1. DIET a. Did your child follow the diet recommendation(s) of _____ when he/she was discharged from the hospital? | | | | | | YES | NO |
| b. What, if anything, made it difficult for you to follow these instructions? | | | | | | | |
| 2. ACTIVITY a. Did your child [SEE BELOW] after s/he was discharged from the hospital, for as long as a doctor told you to? | | | | | | | |
| 1. Refrain from/do: _____ | | | | YES | NO | | |
| 2. Refrain from/do: _____ | | | | YES | NO | | |
| 3. Refrain from/do: _____ | | | | YES | NO | | |
| b. What, if anything, made it difficult for you to follow these instructions? | | | | | | | |
| 3. FOLLOW-UP CLINICAL SERVICES – How many services/follow-up visits recommended? _____ (do not ask parent) | | | | | | | |
| 3.1. Did your child attend the appointment with the recommended service? [IF YES, SKIP 3.1b.] | Trauma Clinic Ortho Clinic Primary Care Neurosurgery Ophthalmology Other | 3.1. Other Specify _____ _____ | 3.1a. YES | NO | | | |
| 3.1a_1. What doctor did your child see? _____? | | | | | | | |
| 3.1b. If not, did you f/u with someone else? Who? _____ | | | | YES | NO | | |

| | | | | |
|---|---|-----------------------------|------------------|-----------|
| 3.1c. What, if anything, made it difficult to keep this appointment? | | | | |
| 3.2. Did you child attend the appointment with the recommended service? [IF YES, SKIP 3.2b.] | Trauma Clinic Ortho Clinic Primary Care Neurosurgery Ophthalmology Other | 3.2. Other Specify _____ | 3.2a. YES | NO |
| 3.2a_1. What doctor did your child see? _____? | | | | |
| 3.2b. If not, did you f/u with someone else? Who? _____ | | | YES | NO |
| 3.2c. What, if anything, made it difficult to keep this appointment? | | | | |
| 3.3. Did you child attend the appointment with the recommended service? [IF YES, SKIP 3.3b.] | Trauma Clinic Ortho Clinic Primary Care Neurosurgery Ophthalmology Other | 3.3. Other Specify _____ | 3.3a. YES | NO |
| 3.3a_1. What doctor did your child see? _____? | | | | |
| 3.3b. If not, did you f/u with someone else? Who? _____ | | | YES | NO |
| 3.3c. What, if anything, made it difficult to keep this appointment? | | | | |
| ✓ if included in discharge summary. Write N/A if not. | Discharge Instructions: | | | |
| | 4. REASONS TO CONTACT PHYSICIAN a. Did your child have: | | | |
| | [IF ANY ARE TRUE] b. Did you contact the doctor about [ANY POSITIVES] _____? | | | YES NO |

| | | | |
|---|---|------------|-----------|
| | 5. WOUNDS / DRAINS/ LINES a. Were you able to _____ ? | YES | NO |
| | b. What, if anything, made it difficult to follow those instructions? | | |
| ✓ if included in discharge summary. Write N/A if not. | Discharge Instructions: | | |
| | 6. MISC. DISCHARGE ARRANGEMENTS (Supplies/Services) a. Where you able to get the _____ that you needed? | YES | NO |
| | b. What, if anything, made it difficult for you to obtain these supplies/services? | | |
| | 7. MEDICATIONS a. Did your child finish taking his/her medications? _____ | YES | NO |
| | b. Is your child still using any medications? | YES | NO |
| | c. What, if anything, made it difficult for you to follow the recommendations for medications? | | |
| | Other relevant instructions mentioned in the discharge summary: Did you/your child... | | |
| | 8. _____ _____ _____ | YES | NO |
| | 9. _____ _____ _____ | YES | NO |