PARENT UNCERTAINTY, SELF-CARE, AND ADJUSTMENT OUTCOMES IN THE PEDIATRIC INPATIENT REHABILITATION SETTING

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Abstract: Children admitted for inpatient rehabilitation have complex medical needs that typically require intensive medical care and therapies. The psychosocial adjustment process for parents of children admitted for inpatient rehabilitation may be particularly difficult given the demands of extended hospitalization; however, limited data exists to characterize parent psychosocial adjustment in this unique context. Thus, the present study aimed to assess parent distress during a child's admission for inpatient rehabilitation, as well as factors which may impact parent adjustment. Thirty parents completed measures 4-10 days following admission to a pediatric rehabilitation hospital in a Midwestern city. Measures of depression, anxiety, posttraumatic stress, parent perceived uncertainty in illness/medical condition, and parent perceived success at engaging in self-care were completed. Parents reported high levels of psychological distress, with a substantial subset of parents reporting clinically concerning levels of depressive (36%), anxious (44.8%), and posttraumatic stress symptoms (41.4%). Overall, 57% of parents reported clinically concerning symptoms in at least one area of adjustment. Higher levels of uncertainty were associated with higher levels of posttraumatic stress symptoms ($p < .05$). Lower reported success in self-care and managing difficult emotions was associated with higher levels of depressive symptoms and posttraumatic stress symptoms ($p < .05$). This study is among the first to document parent adjustment during a child's admission for inpatient rehabilitation. Parents reported clinically concerning rates of depressive, anxious, and posttraumatic stress symptoms, indicating a clear need for psychosocial intervention. Further, given the elevated risk for child adjustment difficulties associated with parent adjustment difficulties (Bakula et al., 2019), these results are especially concerning. These data point to several areas of assessment and potential intervention, especially in addressing illness-related uncertainty and helping parents to improve self-care.

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CHAPTER I

INTRODUCTION

Background

Children admitted for inpatient rehabilitation have complex medical needs that typically require daily therapies and care, including physical therapy, occupational therapy, speech therapy, among others (Wade & Walz, 2010). Pediatric inpatient rehabilitation focuses on recovery of critical functions, such as cognition, mobility, and speech, for children recovering from spinal cord injuries (SCI), brain injuries, orthopedic injuries, strokes, and other chronic medical conditions (Matthews & Alexander, 2015). It is well-documented that both children with chronic medical conditions and their parents are at risk for negative psychosocial adjustment, including depressive, anxious, and posttraumatic stress symptoms (Cousino & Hazen, 2013; Pai et al., 2007; Patenaude & Kupst, 2005; Pinquart, 2017, 2018, Pinquart & Shen, 2011a, 2011b, 2011c). However, limited literature exists to characterize the experiences of children and families admitted for inpatient rehabilitation. Indeed, the extant research on rehabilitation populations does demonstrate similar patterns of increased distress among both parents and children. However, studies to date have not typically assessed psychosocial adjustment during inpatient rehabilitation admissions, specifically (Narad, Yeates, Taylor, Stancin, & Wade, 2016; Wade, Bolger, & Kurowski, 2017).

The psychosocial adjustment process for parents of children admitted for inpatient rehabilitation may be particularly difficult given the demands of extended hospitalization, which can result in financial strain and disruptions in work and social environments (Shudy et al., 2006; Wade & Walz, 2010). Evidence also exists to suggest that during the critical illness phase, which typically precedes intensive rehabilitation, parents often experience impaired physical and mental well-being, increased stress, and they express that their nutritional, rest, and communication needs are unmet (Shudy et al., 2006). Meanwhile, parents must also balance typical parenting responsibilities, and aid in medical care and activities of daily living for their admitted child. Further, injuries and illnesses that typically require inpatient rehabilitation are generally more medically complex and prognoses are often unclear for extended periods of time, potentially leading to a great deal of uncertainty about a child's potential for functional gains (Matthews & Alexander, 2015; Wagner, Hommel, Mullins, & Chaney, 2010). Thus, there are many unique aspects of parenting a child admitted for inpatient rehabilitation that may be particularly challenging.

Presently, little literature exist that focus on factors that predict adjustment outcomes among parents of children with conditions typically seen in inpatient rehabilitation. Some research has demonstrated relationships between injury-related factors (e.g., severity of injury) and demographic factors with parental adjustment (Yeates et al., 2002). However, there is virtually no data assessing modifiable factors, which may be of high clinical relevance to working with parents in the rehabilitation setting. According to the transactional stress and coping model of adjustment to chronic illness, there are multiple pathways by which parent adjustment is influenced following the onset of illness or injury (Thompson & Gustafson, 1996). This theory provides an overarching model for understanding both parent and child adjustment outcomes. As it relates to parent adjustment, this model posits that the medical condition serves as a precipitating event, from which parent cognitive processes, parent methods of coping, family functioning, and child adjustment subsequently influence parental adjustment. This model articulates that these processes interact to facilitate or hinder parental adjustment. Consistent with this model, research among families affected by pediatric chronic medical conditions has revealed significant associations between coping approaches, family and child functioning, and cognitive processes, such as specific cognitive appraisals (e.g., Kim, 2017;

McCarthy, Ashley, Lee, & Anderson, 2012; Peer, 2011; Tackett et al., 2015). However, further research is needed to understand the application and relevance of this model to inpatient rehabilitation populations.

Illness uncertainty is one well-established cognitive appraisal variable associated with parent distress that may be a particularly important cognitive process for understanding parental adjustment outcomes in the context of inpatient rehabilitation (Szulczewski, Mullins, Bidwell, Eddington, & Pai, 2017). *Illness uncertainty* is defined as lack of clarity, ambiguity, unpredictability, lack of information, or difficulty identifying meaning in events related to a medical condition (Mishel, 1988). Illness uncertainty is posited to lead to poor psychosocial adjustment when an uncertain illness-related event occurs, and is appraised as a threat. In the context of inpatient rehabilitation, prognoses are often highly uncertain, and especially for SCI and brain injuries, accuracy in predicting functional gains is highly variable due to the complex nature of these conditions (Marino & Graves, 2004; Matthews & Alexander, 2015). In addition, the ongoing complications associated with recovery from such debilitating illnesses and injuries may yield many situations that are ambiguous and may be negatively appraised. Surprisingly, no previous research has assessed illness uncertainty in the context of SCI, brain injury, or other populations commonly admitted for inpatient rehabilitation, with the exception of juvenile rheumatic diseases (Chaney et al., 2016; Fedele et al., 2011).

Coping processes, another important component of the transactional stress and coping model, include both instrumental coping and palliative coping. Instrumental coping is defined as altering the environment or one’s self, whereas palliative coping is defined as regulating one’s emotional states (Thompson et al., 1994). Self-care, the practice of prioritizing and taking care of one’s own emotional and physical health needs, involves the use of instrumental coping through seeking out social support, engaging in pleasurable activities, and palliative coping through addressing difficult emotions and prioritizing healthy diet, sleep, and exercise routines (Shapiro, Brown, & Biegel, 2007). Self-care is a construct that has received increasing attention in the clinician burnout literature, as it is composed of practical skills that can be easily taught. However, it has yet to receive attention in the literature regarding parenting and parent behavior in the context of pediatric health conditions (Barnett, Baker, Elman, & Schoener, 2007). Available data suggest that behaviors associated with a lack of self-care, including avoidance of negative feelings, lack of social support, lack of engagement in pleasurable activities, and poor diet, sleep, and exercise routines are associated with negative psychosocial adjustment (Barbour, Edenfield, & Blumenthal, 2007; Franzen & Buysse, 2008; Jacobson, Martell, & Dimidjian, 2006; Narad et al., 2016; Rao, Asha, Ramesh, & Rao, 2008; Trask et al., 2003). As such, there is a strong need to evaluate the extent to which parent self-care may be disrupted during the inpatient rehabilitation process, and how this may relate to poorer psychosocial adjustment.

Study Aims

In sum, the overarching goal of the present study is to identify potentially modifiable factors affecting parent adjustment in the context of pediatric inpatient rehabilitation. Specifically, the present study evaluates parent adjustment processes through the lens of the transactional stress and coping model, by assessing a specific cognitive process (i.e., illness uncertainty) and coping methods (i.e., self-care), which may influence parent adjustment during inpatient rehabilitation process. It was hypothesized that both illness uncertainty and parent self-care would relate to parent adjustment as assessed by depressive, anxious, and posttraumatic stress symptoms. Further analyses were conducted to assess the relationship between illness uncertainty and self-care in understanding parent adjustment, as there is a theorized interactional relationship between parent cognitive processes and coping approach. It was anticipated that self-care might moderate the relationship between illness uncertainty and parent adjustment, serving as a positive coping buffer against the negative effects of illness uncertainty. Finally, as an exploratory aim, the present study sought to compare rates of parent adjustment in the rehabilitation context to those observed in parents of children with other pediatric medical conditions.

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CHAPTER II

REVIEW OF THE LITERATURE

Pediatric Rehabilitation in the Context of Injury and Illness

The literature covered in this review will include the extant pediatric rehabilitation psychology research in relation to the challenges associated with having a child admitted for inpatient pediatric rehabilitation. A brief definition of pediatric rehabilitation will first be offered, followed by a summary of the literature focusing on parental adjustment in this context. As well, the potential importance of illness uncertainty and parent self-care in this setting will be highlighted as key variables of interest. There are a diverse range of injuries and illnesses that may necessitate pediatric rehabilitation. As such, traumatic brain injuries and spinal cord injuries will be highlighted as they are among the most common injuries seen in rehabilitation settings.

Pediatric Rehabilitation and Pediatric Rehabilitation Psychology

Pediatric rehabilitation is a growing, dynamic area of pediatric medicine. Advances in medical science have resulted in more effective life-saving and life-prolonging techniques that allow children with complex medical conditions and injuries to survive severe trauma (Matthews & Alexander, 2015). Pediatric rehabilitation medicine is devoted to the rehabilitation of children from injuries and illnesses that have resulted in deterioration in physical and cognitive functioning. Pediatric rehabilitation psychology is a small, but similarly growing field devoted to promoting adjustment and resilience throughout the rehabilitation process, promoting effective communication between families and the medical teams, and helping families adjust to the implications of long-term disability and/or complicated medical regimens (Wade & Walz, 2010).

Though the field of pediatric rehabilitation psychology is still quite limited in terms of both research and available work-force, extant research and clinical practice draws heavily from the larger body of resources that exist within the two areas of pediatric psychology and adult rehabilitation psychology (Wagner, Hommel, Mullins, & Chaney, 2010). More specifically, pediatric rehabilitation psychologists often draw from the pediatric psychology literature to understand the unique clinical needs of children and families affected by medical conditions, as well as literature from rehabilitation psychology to understand the challenges of adjusting to disability and lost function.

However, there are a number of factors unique to pediatric rehabilitation that can make generalization from these bodies of literature challenging. For instance, primary goals and the context of care in pediatric rehabilitation differ greatly from the acute and tertiary care settings that are commonly addressed by pediatric psychologists. In the context of rehabilitation, children's goals are to maximize gains in physical and cognitive functioning. This can be a lengthy process. Because of this, children often are admitted for weeks to months, which can complicate family dynamics and parental stress. These goals also change the dynamics of care, as children are being seen daily by not only the medical team, but also a large team of rehabilitation therapists, including physical therapy, occupational therapy, speech therapy, among others. Such a setting is drastically different as compared to typical acute care settings in which pediatric psychologists work. Thus, there is considerable need for continued research in the pediatric rehabilitation context to better understand and address the needs of this unique population.

Children and Families in the Pediatric Rehabilitation Context

Children admitted for medical rehabilitation have unusually complex medical needs that typically require daily therapies and care, including physical therapy, occupational therapy, speech therapy, among many others (Wade & Walz, 2010). Children are often admitted to inpatient rehabilitation after an initial hospitalization for life-threatening illness or injury. Among the most common injuries resulting in inpatient rehabilitation are brain injuries and spinal cord injuries (SCIs; Matthews & Alexander, 2015). Other medical conditions that can necessitate inpatient rehabilitation include orthopedic injuries, cerebrovascular accidents or strokes, spina bifida, and deconditioning due to conditions such as cancer (Matthews & Alexander, 2015). Children are typically admitted for rehabilitation for between two weeks to two months to facilitate recovery of essential and critical functions such as mobility functioning and speech. Although some children achieve significant recovery during inpatient rehabilitation, for many families the rehabilitation process is a time of adjusting to their child's continued disability and increased caregiving demands (Wade & Walz, 2010).

Types of Injuries

Brain Injuries. Brain injuries are a heterogeneous group of disorders. In the pediatric inpatient rehabilitation setting, brain injuries can include both various types of traumatic brain injuries (TBIs) and anoxic brain injuries. TBIs are the result of external mechanical force to the brain; it is estimated that nearly half a million children per year suffer from TBIs (Faul, Xu, Wald, & Coronado, 2010; Wade, Bolger, & Kurowski, 2017). TBIs are most commonly caused by falls, and the highest rates of these falls occur in children aged 0-4 years (Faul & Coronado, 2015). Child abuse is most commonly a cause of TBIs among infants (Faul & Coronado, 2015). In adolescence, motor vehicle collisions/crashes and assault are the most common causes of injury (Faul & Coronado, 2015). Anoxic brain injuries similarly involve damage to the brain, but due to lack of oxygen; they are often the result of near drowning episodes (Matthews & Alexander, 2015). Among the many medical complications that may occur include seizures, hydrocephalus, intracranial infections, pain, coordination and gait impairments, and endocrine changes. Importantly, brain injuries often result in long term impairment in cognitive and socioemotional functioning. Regarding cognitive functioning, children are clearly at increased risk for attentional, learning, and intellectual difficulties following the injury, often presenting similar to children with ADHD, learning disorders, and/or intellectual disability (Taylor et al., 2002). Regarding socioemotional functioning, these children often have deficits in social information-processing and social skills, and are at advanced risk for personality changes, blunted affect, and anxiety, in particular (Anderson, Brown, Newitt, & Hoile, 2011; Schwartz et al., 2003; Yeates et al., 2005). Thus, not only are the causes of brain injuries often psychologically traumatic in nature, which provides its own risks, but these children are at risk for many long-term deficits that broadly affect medical, cognitive, and socioemotional domains. Additionally, the prognosis for rehabilitation of cognitive, physical, and socio-emotional deficits related to brain injuries is often unclear, and the length of recovery is often extended (Matthews & Alexander, 2015).

Spinal Cord Injuries. SCIs are conditions that result from acute trauma to the spine. Youth with SCIs are at risk for tetraplegia or paraplegia, decreased life-span, and reliance on long-term assisted care (Wade et al., 2017). Typically, SCIs are the result of traumatic, and often life threatening, events (Saunders, Selassie, Cao, Zebracki, & Vogel, 2015). The mechanisms for sustaining a SCI vary by age, but the most recent data suggests that motor vehicle collisions or crashes are the most common across all age groups, accounting for roughly 34.4% of all SCIs in youth (Selvarajah et al., 2014). The remainder include falls (19%), being struck by others or objects (15.1%), firearms (8.3%), sports (6.4%), and others (16.1%). Medical complications that can arise from an SCI include difficulties with breathing, pneumonia, thrombosis, pain, continence issues, sexual dysfunction, autonomic dysreflexia, pressure ulcers, osteoporosis, high cholesterol, and obesity (Budd, Hough, Wegener, & Stiers, 2017). Further, youth with SCI may become dependent on ventilators, and often must follow protocols for continence and avoiding pressure sores, which can impose upon their quality of life and independence (Wade et al., 2017). Notably, although improvements have been made in predicting long-term functional outcome following an SCI, the prognosis often remains ambiguous, and rehabilitation is typically lengthy (Marino & Graves, 2004). Thus, this population is likely confronted with a great deal of uncertainty about the future, particularly as it pertains to length of treatment and anticipated future functioning or limitations due to disability. Further, 90.3% of youth SCIs are incomplete injuries, which means that it is possible, but not guaranteed, that some functioning can be regained (Selvarajah et al., 2014).

Youth with SCI are clearly at risk for psychosocial distress, including depression, anxiety, and PTSD (Kelly & Vogel, 2013; Klaas, Kelly, Anderson, & Vogel, 2014; Le & Dorstyn, 2016). Given the acute trauma that precedes SCIs, PTSD is a particularly relevant concern, with estimates being that roughly 25% of youth experience PTSD following a SCI (Boyer, Knolls, Kafkalas, Tollen, & Swartz, 2000). Female youth, and older adolescents with SCI are most at risk for depression and anxiety. Similar to other injuries and illnesses, both pre-trauma and peri-truama factors affect the risk of resulting PTSD. Pre-trauma factors can include a history of psychosocial or behavioral concerns such as depression and anxiety, the experience of adverse life events, and female gender all relating to increased posttraumatic stress (Boyer et al., 2000; Pollock, Dorstyn, Butt, & Prentice, 2017). For SCI specifically, peri-trauma risk factors include having a complete SCI and experiencing tetraplegia. As children with SCI age into adulthood, they are less likely than peers to be married, have children, live independently, or be employed (Anderson, Vogel, Betz, & Willis, 2004). Further, they report less community participation, lower life satisfaction, and lower perceived physical health than peers (Anderson et al., 2004). Thus, youth affected by SCIs are at risk for impaired social functioning, reduced quality of life, functional limitations, and disability that provide challenges to psychosocial adjustment.

Other Pediatric Medical Conditions

Other medical conditions that may necessitate pediatric inpatient rehabilitation include cancer, epileptic conditions, rheumatic diseases, diseases of the central nervous system, among others. The reasons for needing rehabilitation may vary for these children, but typically involve improving conditioning and functional abilities, including activities of daily living (e.g., dressing, bathing, feeding). In general, children with pediatric medical conditions, including those who might be admitted for inpatient rehabilitation, evidence increased rates of internalizing, externalizing, and posttraumatic stress symptoms (Pinquart, 2018; Pinquart & Shen, 2011a, 2011b, 2011c). Children with pediatric medical conditions also evidence poorer health-related quality of life, experience more pain, have higher rates of familial dysfunction, and are more likely to come from socially-disadvantaged backgrounds, as compared to non-affected peers (Lescano & Rahill, 2017; Pai et al., 2007; Varni, Limbers, & Burwinkle, 2007). Further, many pediatric medical conditions require extensive and invasive medical regimes, for which adherence can be challenging (Hommel, Ramsey, Rick, & Ryan, 2017). Thus, regardless of type of medical condition or injury, children and families admitted for inpatient rehabilitation are at increased risk for problems in psychosocial adjustment as compared to non-affected peers.

Parent Adjustment to Child Illness and Injury

It is well-demonstrated that parents of children with chronic medical conditions are also at an increased risk for negative psychosocial outcomes, including depression, anxiety, and posttraumatic stress, and that these parents evidence higher levels of parenting stress as compared to peers (e.g., Cousino & Hazen, 2013; Pai et al., 2007; Patenaude & Kupst, 2005; Pinquart, 2017). Importantly, only a small minority of this research has been conducted with parents of children with conditions commonly seen in rehabilitation settings, and no previous studies have assessed parent psychosocial adjustment during the inpatient rehabilitation process. The small literature that does exist on rehabilitation populations has indeed demonstrated patterns of poorer parent adjustment in parents of children with SCI, TBI, spina bifida, cancer, and orthopedic injuries (Boyer et al., 2000; Holmbeck & Devine, 2010; Kelly et al., 2012; Narad, Yeates, Taylor, Stancin, & Wade, 2016; Vermaes, Janssens, Bosman, & Gerris, 2005).

A number of theoretical models have been proposed to attempt to understand parental adjustment to having a child diagnosed with a chronic medical illness or injury, with the most notable being the transactional stress and coping model of adjustment to chronic illness, the social-ecological model, and the pediatric medical traumatic stress model (Kazak, 1989; Kazak et al., 2006; Thompson & Gustafson, 1996). Notably, the transactional stress and coping model may be considered the broadest model, incorporating the social-ecological model in the context of stress and coping. The transactional stress and coping model applies to numerous domains of parent adjustment, including depressive, anxious, and posttraumatic stress symptoms, making it a more inclusive model for understanding distress outcomes as compared to the pediatric medical traumatic stress model. In understanding parent adjustment, the transactional stress and coping model posits that there are both illness- and injury-related factors that affect a parent's coping and serve as a precipitating event for maladaptive adjustment. Further, there are several systemic and pre-existing factors that influence adjustment, such as socio-economic status, cognitive processes, such as cognitive appraisals, coping approaches, family functioning, and child functioning. An exemplar of how this theory may apply to parent adjustment in the rehabilitation context can be demonstrated by focusing on parental posttraumatic stress in the context of pediatric rehabilitation. A new medical diagnosis, or an injury resulting in a medical condition, is considered a potentially traumatic event. This event is then subjectively evaluated by the parent through cognitive appraisals, which are influenced by available coping strategies, systemic factors such as social support, functioning within the family, and socioeconomic status. See Figure 1 for a depiction of this model in the rehabilitation context.

Multiple stressors that arise following a new illness or injury may add to parental stress, and serve as precipitating events that may lead to poor parental adjustment, as described by the transactional stress and coping model. Parents of children with special healthcare needs also must balance typical parenting responsibilities, while providing care for their children's medical needs. This can include doctor visits, medications, medical regimens, and providing assistance in activities of daily living (Cousino & Hazen, 2013; Wade et al., 1998). Research on parent functioning during the critical illness phase, which often predates the inpatient rehabilitation phase, indicates that parents often experience impaired physical and mental well-being, increased stress, and express that their nutrition, rest, and communication needs are unmet (Shudy et al., 2006). Further, extant research has demonstrated the long-term increased financial strain, family and marital conflict, and changing roles that can accompany the presence of a chronic medical condition (Cousino & Hazen, 2013; Shudy et al., 2006; Wade & Walz, 2010). To complicate matters, for parents of children with brain injuries, these children evidence impulsive, emotionally volatile, non-compliant, or "acting out behaviors." It has been speculated that parents may have a difficult time distinguishing between these behaviors being secondary to the injury as compared to being a learned behavior of the child, which can add to parenting stress (Wade & Walz, 2010). Such ambiguity in symptom presentation can also add to parenting stress and even damage the parent-child relationship if the parent over-attributes the agency of the child in these behaviors. Thus, there are many stressful events that may occur for parents of children in the context of inpatient rehabilitation.

In considering the numerous adjustment difficulties experienced by parents of children with chronic medical conditions and debilitating injuries, it certainly seems pertinent to address and understand the pathways by which adjustment occurs in these parents. It is additionally important to understand the nature of parent adjustment, as there is considerable evidence to suggest that there is a link between parent and child adjustment (Bemis et al., 2015; Clawson, Jurbergs, Lindwall, & Phipps, 2013). Indeed, there is literature to support this relationship in TBI populations (Taylor et al., 2001). Thus, parents who experience more negative psychosocial outcomes (e.g., depression, anxiety, posttraumatic stress) have children who are more likely to also experience these outcomes (e.g., Clawson et al., 2013). Therefore, understanding risk factors for poor parent psychosocial adjustment is pertinent to improving outcomes for these children, as supporting parents may allow for a reduced transmission of stress and maladaptive adjustment between parent and child.

Unfortunately, the current literature addressing predictors of parent adjustment in the rehabilitation context is quite limited. Much of the available research on parent adjustment following pediatric brain injury, SCI, and other rehabilitation-oriented research has assessed for the presence of poor psychosocial adjustment and family functioning (Dreer, Elliot, Shewchuk, Berry, & Rivara, 2007; Wade et al., 2003; Yeates et al., 2002). The existing literature has addressed the relationship between injury-related factors (e.g., severity of injury) and demographic factors to parental adjustment (Yeates et al., 2002). However, little research has sought to understand potentially modifiable factors among these parents, such as the cognitive processes and coping approaches outlined in the transactional stress and coping model. In other pediatric populations, such as pediatric cancer, cognitive appraisals mechanisms have received significant attention, and have been found to be strongly linked to parental adjustment (e.g., Tackett et al., 2015). Within the rehabilitation context, cognitive appraisals seem particularly relevant, as there are many new and challenging events that occur throughout the rehabilitation process, and how a parent appraises this situation shapes how they adjust to operating in the rehabilitation setting. Illness uncertainty, a well-established predictor of parent distress, is a cognitive appraisal that has demonstrated particular utility in predicting parental distress (Mullins et al., 2012; Szulczewski, Mullins, Bidwell, Eddington, & Pai, 2017). In addition, illness uncertainty may be highly relevant in a population with such high levels of uncertainty related to prognosis. Thus, the present study will seek to assess this particular cognitive process in the context of the transactional stress and coping model.

When considering the environmental context of parents of children in the rehabilitation setting, it is often seen that parents of children admitted for inpatient rehabilitation will stay in the hospital with their child, or spend a significant amount of their time in the rehabilitation hospital with their child. Thus, there is a significant disruption to a parent’s typical support system and routines. In accordance with the transactional stress and coping model, parents adjust to the onset of a new illness or injury through various coping approaches, which can include both instrumental and palliative coping approaches. The use of these approaches may help to alleviate stress related to this new associated with cognitive appraisals related to the situation. Thus, it is pertinent to understand how well parents are able to cope with the stress of the rehabilitation process in the context of this new system, and to understand how well they are able to use instrumental coping approaches such as advocating for their needs, seeking social support, and taking care of their physical health needs. Additionally, it is important to understand parents' palliative coping in this context, or the extent to which they cope with their emotional needs, as this may also play a vital role in how they navigate coping in this new setting. Such coping approaches have been found to be highly important in understanding parent adjustment among both pediatric rehabilitation populations and other pediatric illness populations (e.g., Narad et al., 2016; Peer, 2011; Trask et al., 2003), however no such studies have assessed coping during the rehabilitation process. Therefore, this study will also assess *parent's self-care*, a specific type of coping approach, which may be particularly important to understand in the context of inpatient rehabilitation. Self-care is a broad construct that involves highly practical skills for coping through seeking support from the environment, and engaging in both instrumental and palliative coping strategies. In the following sections, further information will be discussed about the literature on illness uncertainty and self-care and how these variables may play particularly important roles in the parent adjustment process during pediatric inpatient rehabilitation.

Parent Perceptions of Uncertainty in Illness

Injuries and illnesses seen in the context of pediatric rehabilitation typically have objectively uncertain prognoses. For brain injuries, prognoses are often unclear in terms of amount of cognitive gains that can be made through rehabilitation, and how long recovery will take. Although neuropsychological testing can help generally predict a range of gains that are possible through therapies, there is no way to predict with certainty how much functioning a child will recover (Matthews & Alexander, 2015). Additionally, brain injuries will most often result in at least some level of impairment, even if significant recovery is attained (Schwartz et al., 2003; Yeates et al., 2005). For spinal cord injuries, neurological testing and imaging reports can help predict functional gains, however, there is yet again a wide range of variability in recovery of function, even among individuals with comparable imaging and neurological testing results (Marino & Graves, 2004; Matthews & Alexander, 2015). Functions such as use of extremities, control over breathing, walking, bowel and bladder control, and sensation can all be impaired, and may or may not be regained as part of rehabilitation (Matthews & Alexander, 2015). Thus, both brain injuries and SCIs have incredibly ambiguous prognoses, which can be challenging for parents and children. Further, ongoing medical complications are common with both conditions, leading functioning to be intermittently impaired, which can result in uncertainty about day-to-day functioning and symptoms management needs. Children with other illnesses and injuries can also present with similarly unclear and uncertain prognoses. As such, it seems there is reason to suspect that uncertainty may be a common experience for parents of children admitted for pediatric medical rehabilitation, especially in relation to their child's prognosis, length of recovery, disability status, and day-to-day functioning.

Illness uncertainty as a construct is defined as perceived uncertainty, ambiguity, unpredictability, lack of information, or difficulty identifying meaning in events related to a medical condition (Mishel, 1988). This can involve uncertainties in day-to-day functioning, prognosis, and treatment. In the pediatric psychology literature, illness uncertainty has been found to be an especially important predictor of psychosocial distress in children and parents, and is consistently identified in a subset of families affected by pediatric medical conditions. Indeed, a recent meta-analysis identified over 58 studies evaluating illness uncertainty or parental perceptions of uncertainty in pediatric medical condition populations (Szulczewski et al., 2017). Studies that have examined parental perceptions of illness uncertainty, or the extent to which parents perceive uncertainty about their child's condition, have found strong relationships between parental uncertainty and parent depression, anxiety, and posttraumatic stress (Mishel, 1983; Szulczewski et al., 2017).

The theoretical model for illness uncertainty proposed by Mishel in 1988 posits that illness uncertainty is a cognitive appraisal variable in which an uncertain illness-related event occurs, and the individual appraises the event as either a danger or an opportunity. If the event is appraised as a danger, this leads to difficulties with coping and is a risk factor for poor adjustment. This theory fits well within both the transactional model of stress and coping, as it posits that cognitive appraisals of events shape the interactions between and individual and their environment, and translate into adjustment outcomes (Thompson & Gustafson, 1996). As such, it is likely that illness uncertainty will indeed be relevant to pediatric rehabilitation populations.

Few studies have investigated illness uncertainty as a construct in populations often seen in pediatric rehabilitation settings. Much of this research has taken place in the context of juvenile rheumatic diseases, a constellation of conditions that can necessitate rehabilitation. This research has demonstrated that the uncertainty experienced by both children and their parents indeed affects adjustment outcomes (Chaney et al., 2016; Fedele et al., 2011). Similarly, research on families of youth with pediatric cancer has identified illness uncertainty as a strong predictor of parent and child adjustment (Szulczewski et al., 2017). To date, no studies have evaluated illness uncertainty among children and their families affected by brain injuries or SCIs. However, it can be speculated that illness uncertainty would be a particularly prevalent experience among parents of children with brain injuries and SCIs, as well as many other conditions seen in a pediatric rehabilitation context. Additionally, in the adult rehabilitation literature, illness uncertainty has been identified as a highly relevant construct in understanding coping and adjustment among adults with SCI and multiple sclerosis (Wineman, Durand, & Steiner, 1994). Thus, it seems that perceived uncertainty may indeed be of notable importance in the context of pediatric rehabilitation. Additionally, given the pronounced impact of illness uncertainty, it is clearly important to also understand those coping approaches that may alleviate it’s effects, such as self-care.

Parent Self-Care

Self-care is a form of coping that includes prioritizing one’s emotional and physical health, which can include actions such as seeking social support, dealing with difficult emotions, engaging in appropriate levels of sleep and exercise, and maintaining close relationships (Barnett, Baker, Elman, & Schoener, 2007). Self-care fits well within the transactional stress and coping model, as coping can involve instrumental and palliative coping as mentioned previously.

Instrumental coping, defined as altering the environment or one's self may include aspects of self-care in which an individual seeks out social support, or pleasurable activities. Palliative coping, defined as regulating emotional states may involve coping through the process of addressing difficult emotions and prioritizing healthy diet, sleep, and exercise routines. Limited research has centered on the importance of self-care, as it relates to caregivers, despite increasing attention to clinician self-care in the burnout prevention literature (Shapiro, Brown, & Biegel, 2007). Upon exhaustive searches of the literature, no articles were identified directly assessing the construct of self-care in parents. However, a small number of studies were found evaluating self-care among familial caregivers of adults with chronic illness or disability. These studies found that caregivers who reported lower levels of self-care experienced greater caregiving stress and burden, and evidenced poorer well-being (Acton, 2002; Gallant & Connell, 1997; Lu & Wykle, 2007; Merluzzi, Philip, Vachon, & Heitzmann, 2011).

Stress associated with parenting a child with a chronic or life-threatening medical condition, and strains that parents experience in domains such as financial, family, and marital stability have been well-documented (Cousino & Hazen, 2013; Shudy et al., 2006; Wade & Walz, 2010). Thus, challenges in prioritizing personal emotional and physical well-being seem likely in the context of inpatient rehabilitation. To underscore this potential for reduced self-care and well-being, a recent study of caregivers of adults with terminal illnesses found that caregivers reported significantly higher confidence in caring for their care-recipient than caring for themselves, and in managing their own difficult emotions (Merluzzi et al., 2011). Additionally, caregivers who expressed poorer confidence in their ability to care for themselves, and to manage their own difficult emotions, experienced increased rates of stress and caregiver burden. Therefore, improvements in coping, specifically through self-care, may be highly useful in addressing this need as it is composed of practical skills, which can be easily taught and defined (Barnett et al., 2007).

In regard to the emotional- or palliative-focused aspects of self-care, a great deal of research has identified the negative effects of denial or disengagement coping strategies in parents of children with chronic medical conditions (e.g., Goldbeck, 2001; Greening & Stoppelbein, 2007; Grootenhuis & Last, 1997). However, few of these studies have been done in pediatric rehabilitation populations. One investigation recently conducted assessed coping styles among parents of children with orthopedic injuries and TBI. It was discovered that parents who avoided coping with emotional concerns were more likely to evidence poor psychosocial adjustment (Narad et al., 2016). As may be expected, parent use of denial coping varied based on demographic variables, such as parent sex. However, there were also key differences in denial coping strategy use across time since injury and injury group, indicating that coping approaches are malleable, and not static traits. Thus, it is important to understand as modifiable factors that may affect parent adjustment.

On the other hand, instrumental coping approaches include a variety of strategies that seek to modify one's environment. This includes seeking out social support and engaging in pleasurable experiences, which are of great importance in the pediatric rehabilitation setting, given the disruption that occurs in a parents' support system and daily routines. Multiple studies have demonstrated the importance of social support in adjustment to parenting a child with a new-onset of illness or disability (e.g., Trask et al., 2003). Parent self-care also includes coping aspects such as addressing basic health needs, which is essential due to the influence of physical health on emotional well-being (Borrell-Carrió, Suchman, & Epstein, 2004). Indeed, deficits in sleep, healthy diet, and proper exercise routines are all associated with poorer mental health-related quality of life, and poorer psychosocial adjustment (Barbour, Edenfield, & Blumenthal, 2007; Franzen & Buysse, 2008; Rao, Asha, Ramesh, & Rao, 2008). For parents who are staying in the hospital with their child, parents' typical routines and supports are especially disrupted. Thus, a parent may be less likely to see or spend time with individuals in their social network, or may have compromised diet and exercise routines. Parents may also be sleeping poorly if they are staying in the hospital, as they are often awakened throughout the night to attend to their child, or due to medical staff being in the room for care. As such, the practical coping approaches that comprise self-care may be of particular relevance for parents of children admitted for inpatient rehabilitation, given the separation of these parents from their typical routines and social groups.

Summary

In sum, parents of children admitted for inpatient rehabilitation are at increased risk for negative psychosocial adjustment, including depressive, anxious, and posttraumatic stress symptoms. However, limited literature exists to document distress in parents of children with conditions typically seen in rehabilitation settings, such as traumatic brain injuries and spinal cord injuries. Further, there is no prior literature assessing parent adjustment during a stay in a rehabilitation hospital. Thus, there is a clear need to better understand these parents' adjustment outcomes, as well as the unique risk and resilience factors related to parent adjustment in this context. According to the transactional stress and coping model, cognitive processes and coping approaches may play particularly important roles in parent adjustment related to their child's medical condition. Illness uncertainty appears to be a cognitive process that is of particular importance in the context of pediatric rehabilitation. As illness uncertainty is ultimately an appraisal of illness-related events, it is potentially modifiable through cognitive restructuring interventions, and thus is of high clinical relevance to pediatric psychologists working with families in inpatient rehabilitation settings. Parent self-care also appears to be particularly important in protecting against depressive, anxious, and posttraumatic stress symptoms. Future research is needed to confirm these findings, better understand how these factors change across time, and evaluate the effectiveness of interventions that target uncertainty and self-care in clinical practice with parents of children admitted for inpatient rehabilitation.

CHAPTER III

METHODOLOGY

Procedures

The present study included 30 parents of children admitted to a pediatric rehabilitation hospital in a Midwestern city serving both urban and rural populations. Eligible parents were a primary caregiver of a child admitted for pediatric medical rehabilitation. Parents were required to be over the age of 18 years and be proficient English to participate. Parents were not eligible if they were being treated for a serious psychiatric disorder or had a documented intellectual disability. Parent eligibility was determined by the unit pediatric psychologist based on family history and consultation with the medical team. Parents of children newly admitted to the PMRU were recruited between 4-10 days following admission. Parents were consented to the study and signed a HIPAA release form allowing access to the child's basic medical information. Child medical information, such as medical diagnoses, was gathered from chart review. Parents were monetarily compensated at completion of the study. A total of 36 parents were approached for the study, with a consent rate of 88%, resulting in 32 total parents consented for the present study. However, one family withdrew from study participation and the study materials were unable to be obtained from one parent.

Measures

Demographic characteristics. Demographic information collected included parents' age, ethnicity, marital status, medical and mental health history, trauma history, education level, number of children, employment status, and income. Child's age, gender, and ethnicity was also collected.

Parent Perception of Uncertainty Scale (PPUS). The PPUS is a 31-item, self-report measure of perceived uncertainty regarding a child's illness/condition (Mishel, 1983). Items were rated on a 5-point Likert scale ranging from "Strongly Agree" to "Strongly Disagree." Items on the scale evaluated uncertainty within four domains: ambiguity (e.g., "The doctors say things to me that could have many meanings"), lack of clarity (e.g., "My child's treatment is too complex to figure out"), lack of information (e.g., "The explanations they give about my child seem hazy to me"), and unpredictability (e.g., "My child's symptoms continue to change unpredictably"). The measure demonstrated acceptable internal consistency in the present study ($\alpha = .75$), which is slightly lower than that observed in previous studies ($\alpha = .85$-.91; Chaney et al., 2016).

Caregiver Inventory-Revised (CGI-R). The CGI-R is a 21-item, self-report measure of parent self-care and caregiving actions for the child (Merluzzi, Philip, Vachon, & Heitzmann, 2011). The scale assesses caregivers' perceived success in managing medical information (e.g., "Asking physician and nurses questions"), caring for their child (e.g., "Providing emotional support for my child"), caring for themselves (e.g., "Continuing to engage in personal activities that I like to do"), and managing difficult interactions and emotions (e.g., "Talking openly and honestly with my child"). The measure was initially developed to assess parent self-efficacy in the above-mentioned areas. For the purpose of this study, the measure was modified such that parents rated the extent to which they felt they were presently successful in engaging in behaviors in these areas. Thus, items are rated on a 9-point Likert scale ranging from "Not at All Successful" to "Totally Successful." The measure was also developed and normed on caregivers of adults, and thus items were modified to state "my child" rather than "the person." One item of the scale was modified from "talking about death and dying" to "talking about my child's potential long-term impairments or difficulties" given the non-terminal nature of the patient population assessed in this study. The measure demonstrated good internal consistency in the present study ($\alpha = .89$), which is consistent with levels reported in previous studies ($\alpha = .91$; Merluzzi et al., 2011).

Patient Health Questionnaire-9 (PHQ-9). The PHQ-9 is a 9-item self-report measure of depressive symptoms (Kroenke, Spitzer, & Williams, 2001). Items included both cognitive and somatic symptoms of depression, and were rated on a 4-point Likert scale ranging from "Not at All" to "Nearly Every day." The items were summed to create a total score, with scores of 10 or more indicating probable depression (Manea, Gilbody, & McMillan, 2012). The measure demonstrated excellent internal consistency in the present study ($\alpha = .90$), which is consistent with previously reported levels ($\alpha = .86$-$.89$; Kroenke et al., 2001).

Generalized Anxiety Disorder-7 (GAD-7). The GAD-7 is a 7-item self-report measure of anxious symptoms (Spitzer, Kroenke, Williams, & Löwe, 2006). Items included both cognitive and somatic symptoms of anxiety, and were rated on a 4-point Likert scale ranging from "Not at All" to "Nearly Every day." The items were summed to create a total score, with scores of 5-9 indicating mild anxiety, 10-14 indicating moderate anxiety, and scores of 15 and above indicating severe anxiety (Spitzer et al., 2006). The measure demonstrated excellent internal consistency in the present study ($\alpha = .92$), which is consistent with previously reported levels ($\alpha = .92$; Spitzer et al., 2006).

Impact of Events Scale-Revised (IES-R). The IES-R is a 22-item self-report measure of posttraumatic stress symptoms (Creamer, Bell, & Failla, 2003). Items assessed the three domains of posttraumatic stress, including intrusion, avoidance, and hyperarousal using a 4-point Likert scale ranging from "Not at All" to "Extremely." The items were summed to create a total score, with scores of 33 or more indicating clinically significant posttraumatic stress (Creamer et al., 2003). The measure demonstrated excellent internal consistency in the present study ($\alpha = .95$), which is consistent with previously reported levels ($\alpha = .87$-$.92$; Creamer et al., 2003).

Overview of Analyses

Data was analyzed using SPSS Version 25. For descriptive purposes, analyses were conducted to assess rates of depressive, anxious, and posttraumatic symptoms in parents, and these rates were compared with national normative data. Rates of parental perceptions of illness uncertainty were compared to uncertainty rates observed in other pediatric illness populations. A series of bivariate correlations were then used to identify relationships between demographic and illness variables and psychosocial adjustment outcomes. All variables with significant relationships to the outcome variables were included as covariates in subsequent analyses.

In order to evaluate relationships between illness uncertainty and psychosocial adjustment outcomes, and caregiver self-care and psychosocial adjustment outcomes, hierarchical regressions were conducted. Next, the Hayes Process macro (Hayes, 2017) was used to assess self-care as a moderator in the relationship between illness uncertainty and parent adjustment. Given the exploratory nature of the study, a sample of 30 was determined to provide sufficient power to evaluate these relationships.

CHAPTER IV

FINDINGS

Parents included in the study were predominantly Caucasian (60%) and female (83.33%), and their child had been admitted for an average of 6.43 days on the day of their study participation. On average, parents were 39.6 years of age and their children were 10.63 years of age. Children of the parents enrolled had a wide range of medical conditions, including brain injuries (*n* = 14), developmental disabilities (*n* = 6), orthopedic injuries (*n* = 5), diseases or infections affecting the central nervous system (*n* = 4), and spinal cord injuries (*n* = 1). Additionally, one third (33.3%) of the parents in the study reported personally experiencing a previous traumatic event (e.g., experiencing or witnessing an event that involved significant harm or threat of harm). See Table 1 for all demographic details.

Notably, parents reported substantial levels of psychosocial distress, with 36% reporting depressive symptoms above the clinically concerning cut-off, 44.8% reporting anxious symptoms above the clinically concerning cut-off, and 41.4% reporting posttraumatic stress symptoms above the clinical cut-off. Across the sample, 57% of parents reported clinically concerning symptoms in at least one area of distress (i.e., depressive, anxious, or posttraumatic stress symptoms). Means and standard deviations of variables of interest can be found in Table 2.

In order to better characterize the current sample, we compared the current rates of distress to parents of youth with other medical conditions. Compared to parents of children with a wide range of other medical conditions, parents in this sample appear to exhibit higher rates of psychosocial distress (Pai et al., 2007; Pinquart, 2019). However, when compared specifically to parents of children newly diagnosed with cancer, parents in the present sample appeared to have comparable rates of distress (Dolgin et al., 2007). Compared to parents of children with cancer, parents in the present study also appeared to report comparable levels of uncertainty (e.g., Mullins et al., 2016). When comparing parents in the present sample to caregivers of adults in hospice, the current parents appeared to report comparable levels of caring for themselves (Merluzzi et al., 2011).

Preliminary Analyses

Bivariate correlations revealed a significant relationship between income and parental perceptions of uncertainty ($r = -.48$, $p < .05$). No other demographic or illness variables were significantly correlated to variables of interest and ANOVAs evaluating the relationships between ethnicity and variables of interest did not yield significant results. The full correlation matrix can be found in Table 3.

Hierarchical Regressions

Hierarchical multiple regressions, with income included as a covariate, revealed that parental perceptions of uncertainty were significantly related to parents' posttraumatic stress symptoms ($\beta = .43$, $p < .05$), but not anxious symptoms ($\beta = .25$, $p > .05$) or depressive symptoms ($\beta = .26$, $p > .05$). Uncertainty accounted for 18% of the variance in parent posttraumatic stress symptoms ($F(1, 28) = 7.06$, $p < .05$). Hierarchical multiple regressions, with income included as a covariate, revealed that parent self-care was significantly related to parents' depressive symptoms ($\beta = -.43$, $p < .05$) and posttraumatic stress symptoms ($\beta = -.47$, $p < .01$), but not anxious symptoms ($\beta = -.35$, $p > .05$). Self-care accounted for 18% of the variance in parent depressive symptoms ($F(1, 28) = 4.71$, $p < .05$) and 22% of the variance in parent posttraumatic stress symptoms ($F(1, 28) = 4.6$, $p < .05$). Given that both uncertainty and self-care were significantly related to posttraumatic stress symptoms, an additional regression model was run evaluating both variables together. The model accounted for 34% of the variance in posttraumatic stress symptoms.

Exploratory Analyses

As an exploratory analysis, parent self-care was evaluated as a moderator of the relationship between parental uncertainty and parent adjustment outcomes. Parent self-care was not found to be a significant moderator of the relationship between uncertainty and depressive, anxious, or posttraumatic stress symptoms (*p*s > .05).

CHAPTER V

CONCLUSIONS

The aims of the present study were to better understand parent adjustment in the context of inpatient pediatric rehabilitation, and to understand modifiable factors that may impact risk for poor psychosocial adjustment. Notably, this study is among the first to document parental distress shortly after their child is admitted for inpatient rehabilitation. Parents in this sample reported rates of depressive, anxious, and posttraumatic stress symptoms that are substantially higher than rates observed in the general population, and are most consistent with rates observed by parents of children with a new diagnosis of pediatric cancer (Dolgin et al., 2007). Given the limited research on pediatric rehabilitation populations, the characterization of parent adjustment in this setting is essential, and has multiple important implications. These data shed light on the high risk that these families have for psychosocial adjustment difficulties during the early phase of the pediatric rehabilitation process. Notably, research conducted in other pediatric populations has demonstrated that parent distress does indeed subside over time (Doglin et al., 2007). However, a recent study of parents of pre-school children with brain injuries and orthopedic injuries found that between 17-34% of parents continued to endorse clinically significant rates of distress even six years following onset of the injury (Narad et al., 2016). Thus, examination of the trajectory of parent distress in the context of pediatric rehabilitation is clearly needed to better understand if and when these symptoms are likely to subside.

The present study was also the first to assess illness uncertainty in the context of pediatric rehabilitation, and to evaluate its importance in understanding parent adjustment. Parent perceptions of illness uncertainty have a well-documented relationship with parent distress in other pediatric populations (Szulczewski et al., 2017). It was hypothesized to be especially salient for parents of children admitted for inpatient rehabilitation, given the complexity of recovery from these conditions. In the present sample, illness uncertainty was associated with posttraumatic stress symptoms, but not anxious or depressive symptoms. Thus, illness uncertainty appears to similarly play a role in adjustment among parents of children in pediatric rehabilitation settings. It is notable, however, that no relationship was found between illness uncertainty and other adjustment outcomes. First, it should be taken into account that this lack of relationship may be due to the small sample size, as it may be that there was too much variability in this small sample to observe this effect. Alternatively, it may be that illness uncertainty has a more immediate impact on posttraumatic stress symptoms, as they are directly linked to the illness and a parent's appraisal of the illness and its meaning. However, it may take more time for illness uncertainty to have a direct association with depressive or anxious symptoms. Regardless, these results demonstrate the importance of evaluating perceptions of illness uncertainty in pediatric rehabilitation populations and demonstrate the applicability of this measure to this population. Further, given the paucity of data on clinical interventions in pediatric rehabilitation populations, the applicability of illness uncertainty to this population also suggests that uncertainty-based clinical interventions may be beneficial (e.g., Hoff, Mullins, Gillaspy, Page, Van Pelt, & Chaney, 2005; Mullins et al., 2012).

Parent self-care, which has not previously been evaluated among parents of children with complex medical conditions, was also determined to be an especially salient variable in understanding parent adjustment in the context of inpatient rehabilitation. On average, parents reported being moderately successful at engaging in self-care activities, though over a third of parents reported being "not at all" to "mildly" successful at engaging in self-care, such as continuing to engage in activities they enjoy or caring for themselves through activities like sleep or exercise. Further, parent self-care was related to parent depressive and posttraumatic stress symptoms, but not anxious symptoms. Again, these findings provide preliminary support for the potential impact of parents being able to engage in successful self-care throughout a child's hospital admission. Although speculative, these results underscore the value of having conversations with parents about how they are engaging in self-care to help themselves cope with their child's medical condition and hospital admission. Clinically, self-care is also likely to be a teachable skill and may be encouraged by pediatric psychologists in inpatient rehabilitation settings.

Summary

The area of pediatric rehabilitation has received limited attention in the literature, despite it being an especially vulnerable population (Wade, Bolger, & Kurowski, 2017; Wade & Walz, 2010). The present findings highlight multiple factors to consider in future research and clinical practice within pediatric rehabilitation populations. Specifically, the high rates of parent distress, especially early on in the rehabilitation process, as well as the potential impact of illness uncertainty and self-care on parents' adjustment processes, should continue to be studied. It is likely that there are many additional risk factors that have yet to be explored in the context of pediatric rehabilitation. Future research should seek to not only assess how parent distress changes across time, but also how other cognitive processes, as well as environmental and family factors influence the parent adjustment process. Finally, given the demonstrated association between parent and child adjustment (e.g., Bakula et al., 2019, Bemis et al., 2015; Taylor et al., 2001), further research is needed to understand the impact that this heightened parental distress may have on children who undergo inpatient rehabilitation. Specifically, intervening to prevent and reduce parental distress may allow for a reduced transmission of stress and maladaptive adjustment between parent and child, increasing the need for investigating parent adjustment in pediatric rehabilitation populations.

Limitations and Future Directions

The findings of the present study need to be interpreted in light of a number of limitations. First, this study is cross-sectional in nature and relies on parent self-report. As such, causal inferences cannot be made based on the results of these data and it is possible that findings could be impacted by shared method variance. Second, the sample was primarily Caucasian and female, which limits our ability to generalize the findings to ethnically diverse populations and to male caregivers. Additionally, due to the diversity of reasons for admission and small sample size, we were unable to control for reason for admission (i.e., diagnosis) in understanding parent adjustment outcomes. Therefore, further research is needed to understand how severity of illness or injury, as well as types of illnesses or injuries may differentially impact parent outcomes. Additionally, more specific research is needed to identify how specific aspects of self-care relate to psychosocial. Finally, given the novel nature of the present study, and the small sample size, the findings here are meant to be provide a preliminary exploration of these variables in a pediatric rehabilitation setting, and further research is necessary to confirm these findings. However, despite these limitations, it is believed that the results of this study are highly important to our understanding of parent psychosocial adjustment in the context of pediatric rehabilitation.

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APPENDICES

Table 1. Demographic Characteristics (N = 30)

Characteristic	*N* (%)
Ethnicity	
Caucasian	18 (60)
African American	1 (3.33)
Hispanic	5 (16.67)
Native American	4 (13.33)
Multi-Racial	2 (6.67)
Age – Mean (SD)	39.6 (11.22)
Sex (%)	
Female	83.33

Table 2. Descriptive Characteristics (N = 30)

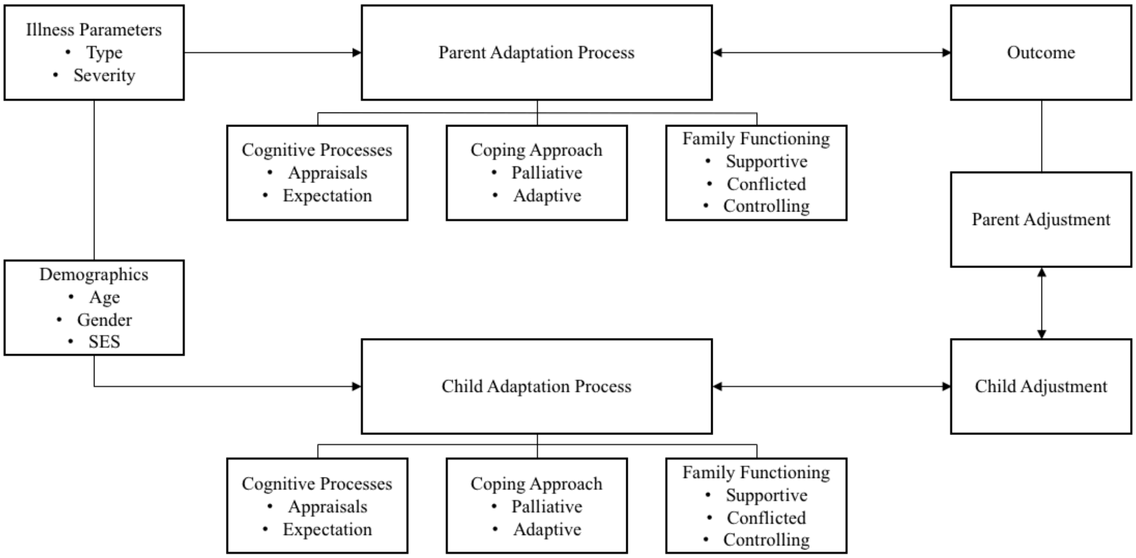
Characteristic	M (SD)
Depressive Symptoms (PHQ-9)	8.46 (6.42)
Anxious Symptoms (GAD-7)	9.45 (6.02)
Posttraumatic Stress Symptoms (IES-R)	29.75 (21.35)
Parent Perceptions of Uncertainty in Illness (PPUS)	73.86 (19.00)
Self-Care (CGI-Self-Care)	5.48 (2.09)

Table 3. Correlation Matrix

Variables	1	2	3	4	5
1. PPUS	-				
2. CGI Self-Care	-.17	-			
3. PHQ-9	.22	-.43*	-		
4. GAD-7	.20	-.34	.72**	-	
5. IES-R	.43*	-.47*	.70**	.65**	-
6. Age	-.27	.17	-.19	-.29	-.21
7. Sex	.09	-.16	.16	.03	.05
8. Income	-.48*	-.23	.03	.04	-.13

Note: **p* < .05, ***p* < .01, ****p* < .001

Figure 1. Transactional Stress and Coping Model.



Note. Adapted from Thompson, Gustafson, George, and Spock (1994).

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