

# The Transition from Hospital to Home in Parents of Pediatric Solid Organ Transplant Recipients

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THE TRANSITION FROM HOSPITAL TO HOME IN PARENTS OF PEDIATRIC  
SOLID ORGAN TRANSPLANT RECIPIENTS

by

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## ABSTRACT

### THE TRANSITION FROM HOSPITAL TO HOME IN PARENTS OF PEDIATRIC SOLID ORGAN TRANSPLANT RECIPIENTS

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Marquette University, 2010

Readiness for hospital discharge is an under-investigated topic in pediatric solid organ transplant. The immediate post-operative period and first few weeks after transplant are a critical time period where patients are at high risk for transplant-related complications.

A correlation design framed by Meleis' Transitions Theory were used to determine; (1) the influences of discharge teaching and care coordination on parent readiness for hospital discharge among parents of children who have experienced solid organ transplantation; and (2) the relationship of parent readiness for hospital discharge with coping, adherence difficulty, utilization of healthcare resources, and family impact in the first three weeks following discharge from the hospital. Qualitative data were used to supplement quantitative findings.

Thirty seven parents from three pediatric transplant centers participated. Participants completed questionnaires on the day of hospital discharge and three weeks following hospital discharge. Regression analysis for quantitative data and content analysis for qualitative data were used to identify significant relationships and themes. Results contribute to the understanding of important issues surrounding the discharge transition in a specific pediatric chronic illness population. Care coordination was associated with readiness for hospital discharge. Readiness for hospital discharge was subsequently associated with post-discharge coping difficulty, adherence difficulty with medical follow-up and family impact.

Implications for nursing practice, nursing education and nursing research are identified. Identifying parents who are not ready to go home from the hospital following their child's solid organ transplant provides an opportunity to offer additional transitional services so parents can effectively manage their child's recovery and continuing care at home. Transitions theory provides a useful framework for conceptualizing and investigating the discharge transition of parents of children experiencing solid organ transplant. Results fill the current gap in knowledge and contribute to the advancement of nursing science.

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## CHAPTER ONE

### Introduction

Solid organ transplantation, formerly an experimental option for terminally ill children, has now become the treatment of choice for a number of serious conditions resulting in end stage organ failure. The United Network for Organ Sharing (UNOS) reported that 1,796 pediatric heart, kidney, and liver transplants took place in 2009 (United Network for Organ Sharing, 2010). Children, defined as less than 18 years of age, account for approximately 9% of all solid organ transplants in the United States (United Network for Organ Sharing, 2010). Even though the annual number of pediatric transplantation procedures remains relatively constant, the population of long-term survivors of transplantation has grown dramatically with improved long term survival. The advent of safer and more effective immunosuppression medications has been the main factor responsible for improved survival.

Pediatric heart, kidney, and liver transplant recipients have unique characteristics dependent on the epidemiology of disorders leading to end-organ failure. Renal failure is more common in older children thus the majority of pediatric kidney transplant recipients are adolescents (Fine, Webber, Olthoff, Kelly, & Harmon, 2007). Specifically, 62% of kidney transplants in 2007 were in the adolescent age group (United Network for Organ Sharing, 2008). Also, living donors are the predominant source of organs for children receiving their first kidney transplant, accounting for 57% of all pediatric renal transplants in 2002 (Magee et al., 2004). Therefore, over half of pediatric kidney transplants are planned or scheduled. Biliary atresia affects infants and is the most common disorder leading to liver failure in children. Therefore, 70% of pediatric liver

transplants are comprised of recipients less than five years of age (United Network for Organ Sharing, 2008). Living donation is an option for liver transplant, although less common than in kidney transplant. Only 10% of pediatric liver transplants in 2007 were from live donors (United Network for Organ Sharing, 2008). Pediatric heart transplant recipients comprise of infants, older children and adolescents. Infants, newborn to 12 months of age, account for approximately 25% of heart transplants performed each year. The remaining 75% of heart transplants are older children and adolescents (Fine et al., 2007). Unlike kidney and liver transplant, live donation is not an option for pediatric heart transplant recipients.

Kidney transplantation survival rates have increased to 97% one-year survival and to 96% five-year survival (United Network for Organ Sharing, 2010). Liver transplant patients have a 5 year survival ranging from 79 to 87% and heart transplant patients have a one-year survival of 70 to 80% (Sweet et al., 2006). The population of long-term survivors of liver transplantation alone was 10-fold greater than the number of transplantations carried out each year (Bucuvalas & Ryckman, 2002).

As pediatric transplant recipients enjoy long-term survival, it is important to not only manage the medical complications but also ensure adjustment of management strategies for pediatric patients and families. The transplant experience challenges the child and family to transition from the management of acute life threatening illness related to end stage organ failure to chronic illness management following solid organ transplantation (Shemesh, 2008; Stuber, 1993).

The pre-transplant diagnosis of end stage organ failure and the life saving transplant operation can be emotionally traumatic for family caregivers of heart

transplant recipients (Stukas et al., 1999), parents of transplant recipients (Fredericks et al., 2008; Green, McSweeney, Ainley & Bryant, 2008; Shemesh, 2008), pediatric liver transplant recipients (Shemesh et al., 2000) and pediatric transplant candidates in general (Simons, Ingerski, & Janicke, 2007). In fact, the emotional and psychological distress of parents after transplant was consistent with the diagnosis of post-traumatic stress disorder and was relatively common in parents of pediatric transplant recipients (Young et al., 2003). The time immediately following transplant is a crucial transition for children and families as they face the new challenges of managing the child's continued recovery following surgery and the emotional shift to managing a chronic illness condition.

The transition from hospital to home is the first experience that parents have in caring for the child independently following the transplant operation. Management at home following the transplant is extremely complex. The home regimen includes precise administration of multiple medications, wound care, central line care, and a complex outpatient schedule for laboratory and clinic follow-up. In addition to these tasks, the family must be well versed in the complications of transplant such as rejection and infection.

The transition from hospital to home and the discharge needs of children and families following pediatric solid organ transplant have not been studied. According to the Joint Commission on Accreditation of Health Care Organizations, it is required that discharge planning be provided to all patients (The Joint Commission, 2010). Discharge planning is seen as the primary strategy for ensuring that patients' needs will be met post-discharge in order for patients to function at optimal levels upon return home from the hospital (Coleman et al., 2004).

For all types of hospitalizations, there has been a movement toward shorter lengths of stay to reduce health care costs. Reduced length of stay results in patients being discharged home in increasingly shorter periods of time (Heine, Koch, & Goldie, 2004; Weiss et al., 2007) and in intermediate rather than later stages of recovery (Kortilla, 1991). The consequence of shorter hospitalizations is less time to educate patients and family members and to coordinate home and community services. Ultimately, many patients and families are discharged with unmet home care needs and at increased risk for complications and hospital readmissions (Titler & Pettit, 1995).

A patient's level of readiness for hospital discharge is associated with hospital readmission rate in studies of hospitalized adults. Decreased readiness for discharge scores in adults with diabetes and heart failure correlated with increased risk for readmission (Ashton, Kuykendall, Johnson, Wray, & Wu, 1995) while high readiness for discharge was predictive of fewer readmissions (Weiss et al., 2007). Mamon et al. (1992) reported that adult patients who identified inadequate support before hospital discharge had higher rates of post-hospitalization complications and readmission than those who reported that their post-discharge needs were sufficiently met. Readiness for discharge is a crucial intermediate outcome in the transition from hospital to home based care. The identification of predictors for readiness of hospital discharge is necessary for determining the appropriate timing of discharge and subsequent post-discharge needs.

The literature regarding discharge from the hospital in pediatric solid organ transplant is limited to a report on the importance of discharge education in preparing parents of heart transplant recipients (Higgins, 2000). There is no literature describing the relationship of discharge readiness and post-discharge outcomes such as coping



difficulty, family impact, utilization of healthcare resources and adherence. Literature on adult solid organ transplant recipients does not substantively add to the body of knowledge on discharge readiness. The adult recipient literature is limited to highlighting the importance of a primary caregiver (Bohachick, Reeder, Taylor & Anton, 2001; Dew et al., 1994; Kurz, 2002; Steinberg, Diercks, & Millspaugh, 1996).

The transition from hospital to home has been studied in a number of pediatric populations including high risk infants (Affleck, Tennen, Rowe, Roscher, & Walker, 1989; Baker, 1991; Bissell & Long, 2003; Sheikh, O'Brien, & McCluskey-Fawcett, 1993; Smith, Young, Pursley, McCormick, & Zupancic, 2009; Sneath, 2009), children in the pediatric intensive care unit (Bent, Keeling, & Routson, 1996), children with special health care needs (Kirk, 1999), children with asthma (Wesseldine, McCarthy, & Silverman, 1999) and more generally in hospitalized children (Melnyk, 1994; Smith & Daughtrey, 2000; Snowdon & Kane, 1995; Suderman, Deatrich, Johnson, & Sawatzky-Dickson, 2000; Weiss et al., 2008). The pediatric studies aimed to identify areas to improve the discharge transition so parents make the transition to home with confidence and continue care in the home environment. The concept of discharge readiness can also be found in the obstetrical literature (Bernstein et al., 2002; Bernstein et al., 2007; Weiss & Lokken, 2009; Weiss, Ryan, & Lokken, 2006; Weiss, Ryan, Lokken, & Nelson, 2004) and adult medical-surgical literature (Anthony & Hudson-Barr, 2004; Artinian, 1993; Ashton et al., 1995; Bobay, Jerofke, Weiss, & Yakusheva, 2010; Bull, 1992; Clark, Steinberg, & Bischoff, 1994; Congdon, 1994; Weiss & Piacentine, 2006; Weiss et al., 2007; Weiss, Yakusheva, & Bobay, 2010).

Nursing care, specifically discharge education, promotes discharge readiness in the pediatric population (Weiss et al., 2008). A discrepancy between parent and nursing perception of discharge education (Sheikh et al., 1993) draws attention to the importance of communication with parents in preparing for hospital discharge.

The transition from hospital to home following solid organ transplant involves a deeper understanding of the challenges families face before, during and after transplant. Meeting the patient and family needs through every stage of the transplant process is critical to long term success. This research will add an important dimension to the current body of knowledge on pediatric discharge readiness and the impact nurses have with families as they face this important transition.

#### *Statement of the Problem*

Readiness for hospital discharge is an under-investigated topic in pediatric solid organ transplant. Research exploring the transition from hospital to home in parents following his or her child's solid organ transplant is indicated in order to not only explain the family experience but also describe the role that nurses play in this crucial time period. Nursing care of the child and family following transplant will impact outcomes immediately following discharge as well as long term outcomes of the child and family.

#### *Purpose of the Study*

The purpose of the study is to investigate the impact of hospital based nursing practice on the transition from hospital to home for parents following their child's solid organ transplant procedure. There are two specific aims to accomplish the aforementioned purpose.

The first aim is to determine the relationships of the nursing processes of discharge teaching and care coordination on the readiness for discharge among parents of children who have experienced solid organ transplantation. The second aim is to determine the relationship of parent readiness for hospital discharge with coping difficulty, utilization of healthcare resources, family impact and adherence to the medical regimen following hospital discharge.

#### *Significance to Nursing*

Nurses play an integral role in the healthcare team in preparing children and families for hospital discharge. Nurses have both an opportunity and responsibility to impact quality patient care in preparation for hospital discharge with discharge education and assistance with successful coping strategies in dealing with the chronic illness aspect of solid organ transplant. Additionally, nurses have close contact with patients and families and have an opportunity to provide support and enhance the functioning of each family unit.

Knowledge of trends in this population will guide nurses to plan targeted interventions. Recognizing the individual concerns of parents before discharge will promote quality parent care and discharge planning. Meaningful interactions with patients and families will foster confidence in the family unit to manage the child's needs in the home environment (Lerret, 2009). Nursing interventions surrounding the discharge period have implications for parent readiness and success once in the home environment.

#### *Significance to Nursing Education*

Nurses are expected to practice in an evidence-based manner. Evidence-based practice in nursing involves applying the best research-based evidence to a specific

clinical question or situation (Melnik, Fineout-Overholt, Stone, & Ackerman, 2000).

Evidence-based practice refers to a decision-making approach based on integrating clinical expertise with the best available evidence from systematic research (Kim, 2000).

This research contributes to decreasing the knowledge gap of factors related to discharge readiness in parents of solid organ transplant recipients.

Nursing students traditionally practiced according to knowledge acquired in theory courses and made modifications based on experience acquired through interactions with their patients. Now, nurse educators are encouraged to facilitate critical thinking by supporting practice with evidence (Ferguson & Day, 2005). Undergraduate and graduate nursing education must include research-based evidence to teach nursing students how to best prepare patients for hospital discharge. Nurse educators must include evidence to support practice in the course curriculum.

The results of this study bring evidence-based knowledge to the practicing nurse on factors related to discharge readiness. The relationship of care coordination and discharge teaching with parent readiness for hospital discharge will support the importance of nurses engaging, planning, and making joint decisions with families in discharge preparation and the impact of discharge teaching. Nurses that use evidence based practice can have confidence that the best outcomes are achieved from the nursing care patients and families receive (Melnik & Fineout-Overholt, 2005).

#### *Significance to Nursing Research*

The goal of nursing research is to yield important knowledge relevant to the nursing profession (Polit & Beck, 2008). Furthermore, there is a need for nursing

specific knowledge in order to advance the science of nursing (Melnyk & Fineout-Overholt, 2005).

The findings of this study contribute to the body of nursing knowledge regarding factors related to discharge readiness in parents of children that have received a solid organ transplant. The results of the study give nurses that care for transplant patients research-based knowledge on essential areas to address with parents as they prepare to take their child home from the hospital. Although the study population is unique, parents of pediatric transplant recipients, the results may be extrapolated to parents of other chronic illness populations.

This dissertation research is a beginning exploration of the concepts of interest in this study population. The results provide evidence to support care practices, but will also identify areas of need for further study in designs of larger scale. Furthermore, the results may identify areas for development and testing of nursing interventions for use with parents of hospitalized children.

#### *Significance to Vulnerable Populations*

The definition of vulnerability stems from its Latin roots meaning ‘to wound’. Vulnerability is interpreted to mean susceptibility to harm, neglect, or health problems. Therefore, vulnerable populations are at risk for poor physical, psychological and/or social health (Aday, 1993).

Vulnerability is an important concept for nurses because it is a crucial component of health and health problems. In general, chronically ill pediatric patients are a vulnerable group of persons. Pediatric solid organ transplant recipients are a vulnerable population due to two determinant characteristics, age and chronic illness. Infants and

children are considered vulnerable because of age and the associated age-related developmental factors. Specifically, infants and children are dependent on others for their care and unable to communicate their own needs (Rogers, 1997). On the other hand, adolescents have a level of independence and can speak to their needs, but remain at risk because of risk-taking behavior based on their developmental stage (Rogers, 1997). Chronic illness is the second major determinant of vulnerability for this particular population. The chronicity and severity of complications following transplant can create a vulnerable situation for the patient and family.

The transition to home following liver transplant is a vulnerable time as families are faced with managing chronic illness. In the immediate post-transplant period the number of potential complications is high. Therefore, the child is expected to return to the hospital multiple times per week for laboratory and clinic follow-up to allow for close monitoring of the newly transplanted organ.

Managing the post-transplant regimen may challenge family dynamics. Each age places different demands on parents and families based on the age-specific developmental needs. For example, an infant will be completely dependent on the parent for all medication administration and transportation to the hospital in order to adhere to the rigorous outpatient monitoring required while the school age and adolescent children will be more active in medication administration. Parents and families will be faced with unique challenges at each developmental stage.

The concept of transition from hospital to home following pediatric solid organ transplant is absent in the literature. The only transition that has been described is in relation to transferring care of an adolescent to an adult transplant center. Transitioning

from a pediatric to an adult transplant center can be a difficult and traumatic experience (McCurdy et al., 2006). Transition to an adult center is associated with poor medication adherence (Annunziato et al., 2007), which may put a patient at increased risk for rejection and other transplant-related complications (Chaturvedi, Jones, Walker, & Sawyer, 2009; Watson, 2000). The goal for pediatric to adult transition is to ensure that developmentally appropriate healthcare is coordinated, uninterrupted, and comprehensive for adolescents and young adults (Blum et al., 1993). Similarly, this same goal must be sought in the child's transition from hospital to home after transplantation.

There is limited research exploring the concept of vulnerability and solid organ transplantation. The current literature related to vulnerability and solid organ transplant refers to the heart transplant (Bohachick et al, 2001; Dew et al, 1994) and lung transplant (Kurz, 2002) population. Care-giving in adult lung transplant and heart transplant creates a situation of vulnerability that can result in increased mortality and morbidity for illness and emotional stress (Bohachick et al., 2001; Dew et al., 1994; Kurz, 2002). These studies highlight the important role that health care providers have in assessing the entire family throughout the transplant process.

Vulnerability is a concept that is applicable to all pediatric chronic illness populations. Parents that respond to their child's chronic illness by changing parenting practice or exhibiting excessive concern may unintentionally communicate to their child that he/she is vulnerable and influence the adjustment of the chronically ill child (Mullins et al., 2007). Perceptions of child vulnerability should be addressed with individual family units through education and access to resources to reassure families (Anthony, Gil, & Schanberg, 2003). Family Stress Theory emphasizes that the role of nurses is to not

only promote family members' health and recovery from illness, but to also support and enhance family strengths to assist families in the process of adaptation (McCubbin, 1993). The family and the home environment are important in the care of children with health problems. Family-centered care is a core concept in pediatric nursing (Ball, Bindler, & Cowen, 2010), emphasizing the important relationship nurses have with pediatric patients and families.

The proposed research on the transition from hospital to home relates to vulnerability of parents of pediatric solid organ transplant recipients because parents of children with chronic illness generally have increased perceptions of child vulnerability (Anthony et al., 2003).

### *Conclusion*

The transition to home following inpatient hospitalization is a critical time period. This study addresses a gap in literature and makes a significant contribution to nursing by highlighting the important role that nursing processes have with a parent's readiness for hospital discharge. The dissertation extends nursing research in the area of discharge readiness into a specific chronic illness population. Although the research results are not directly generalizable to all other pediatric chronic illness populations, the research may provide a framework for further research in the area of discharge readiness in chronic illness.

Pediatric and adult solid organ transplantation is not the same. The pediatric transplant recipient has a distinct set of challenges to overcome including but not limited to growth, cognitive and emotional development, and striving for social acceptance. Research studies have concluded that caregivers are essential components to the recovery



process with adult recipients (Bohachick et al., 2001; Dew et al., 1994; Kurz, 2002), which does not directly correlate but points to the need to investigate the experience of parent as caregiver during the discharge transition.

An awareness of the sources of vulnerability may assist nurses to provide more holistic, comprehensive care to their clients (Rogers, 1997). Nurses play an important role in helping families meet the challenges of caring for a child with a chronic illness. This research provides important information that will improve nursing care of children with solid organ transplant and their families.

## CHAPTER TWO

### Review of the Literature

Chapter two includes the review of the literature relevant to the discharge transition of parents of children experiencing solid organ transplant. The review of literature was conducted first as a concept analysis of discharge transition and the resultant manuscript (Lerret, 2009) is presented in Appendix A. The focus of the published review was factors that influence discharge readiness, including patient, parent, and provider factors. This review includes substantive discussion of discharge teaching and care coordination as factors that influence discharge readiness and the links between discharge teaching and care coordination with discharge readiness.

To complete a thorough presentation of the review of the literature related to discharge readiness, Chapter 2 contains a summary of relevant research on the concepts of parental coping following pediatric hospitalization, impact that chronic illness has on the family, and post-discharge utilization of health care services in acute recovery and chronic illness and the relationships with discharge readiness. Chapter 2 also contains commentary on the philosophic stances relevant to the investigation of the discharge transition that guided the selection of the conceptual-theoretical-empirical structure for the study.

#### *Discharge Readiness*

The comprehensive review and critical analysis of pertinent literature related to discharge readiness including recent and classic works is attached as Appendix A. Appendix A is the manuscript “Discharge readiness: An integrative review focusing on

discharge following pediatric hospitalization” (Lerret, 2009). The four concepts or themes related to parent readiness for discharge following pediatric solid organ transplant that emerged from the critical literature review include communication and coordination, education, identification of individual needs, and support. From these four themes two new concepts were developed in regard to discharge readiness, meaningful interactions and confidence building. These two concepts encompassed the four themes that emerged from the literature in regard to discharge readiness (Lerret, 2009).

The manuscript includes relevant literature related to the relationships between discharge teaching and care coordination with discharge readiness. Further explication of discharge teaching and care coordination are presented to provide an in depth review of the concepts. The components of the conceptual framework that are not well developed in the manuscript include post-discharge coping difficulty, family impact, utilization of healthcare resources, and adherence to the medical regimen. These concepts will be explored in more detail below.

### *Discharge Teaching*

The nurse plays an essential role in preparing the family for hospital discharge throughout the inpatient hospitalization in planning, preparing, and coordinating for a successful transition to home. One of the key elements in preparing for discharge from the hospital is discharge teaching (Maloney & Weiss, 2008; Weiss & Lokken, 2009). Patients and caregivers have a strong desire for information including education on illness and recovery, what to expect, management strategies, when and how to call for help, counseling, continuity of care, and for involvement in the discharge process (Clark et al., 2005).

Time for discharge preparation is limited due to numerous factors including the current nursing shortage and high patient acuity (Maloney & Weiss, 2008). Despite the time restrictions, nurses are charged with the responsibility of thoroughly assessing the individual needs of patients and families to ensure useful and appropriate discharge teaching (Smith & Liles, 2007)

Discharge teaching is related to readiness for hospital discharge in parents of hospitalized children (Weiss et al., 2008). Patient education is a fundamental area of nursing practice (Smith & Liles, 2007). Discharge teaching will be measured in this study because it may be related to the level of discharge readiness in this specific patient population and to the post-discharge outcomes of coping, family impact, adherence, and utilization of healthcare resources. The concept of discharge teaching in preparing for hospital discharge is reviewed extensively in the education section of the manuscript “Discharge readiness: An integrative review focusing on discharge following pediatric hospitalization” (Lerret, 2009) and can be seen as Appendix A.

#### *Care Coordination*

The Institute of Medicine report ‘*Crossing the quality chasm: A new health system for the 21st century*’ (2001) called attention to the importance of care coordination with the statement, “Care for the chronically ill needs to be a collaborative, multidisciplinary process. Effective methods of communication, both among caregivers and between caregivers and patients, are critical to providing high-quality care” (p. 27). The transition from hospital to home is an opportunity for a collaborative, multidisciplinary process (American Geriatrics Society, 2007). This transition and the crucial role of care coordination have been reported in the elderly (Coleman et al., 2004;

Naylor et al., 2007; Naylor, Kurtzman, & Pauly, 2009) and adult populations (Coleman, Mahoney, & Parry, 2005; Greenwald & Jack, 2009; Snow et al., 2009).

Care coordination has been described as inadequate because healthcare is delivered by individual specialists and practitioners who rarely communicate with one another (Coleman et al., 2004). The lack of coordination in the transition from hospital to home can result in fragmented care which leads to patient complications (Coleman et al., 2002). There is a clear need to reduce fragmented care and to assist patients and families in making smooth transitions (Coleman et al., 2004). The addition of advanced practice nurses who intensively manage patients during the transition from hospital to home in patients hospitalized with congestive heart failure (McCauley, Bixby, & Naylor, 2006; Stewart, Pearson, & Horowitz, 2000) and medically complex elderly patients (Einstadter, Cebul, & Franta, 1996; Naylor, Bowles, & Brooten, 2000; Naylor et al., 1994; Naylor et al., 1999; Naylor et al., 2004) has demonstrated a reduction in later utilization of healthcare resources. A decrease in hospital readmission rates and cost of care was similarly reported when there was a focus on careful discharge transition (Greenwald & Jack, 2009; Jack et al., 2009; MacKinney-Smith, 2010).

Care coordination at a time of transition, transitional care, is defined as, “a set of actions designed to ensure the coordination and continuity for health care as patients transfer between different locations” (American Geriatrics Society, 2007, p. 30).

Although the definition for transitional care and the aforementioned intervention studies to reduce fragmentation at the time of hospital discharge are provided in the context of the elderly, the concept remains important and applicable in chronic illness populations.

The state of knowledge on care coordination in the pediatric solid organ transplant population is scarce and does not mirror the extent of research in the elderly and adult population. Nonetheless, care coordination is an essential component of medical care and is needed by children with special health care needs (Stille & Antonelli, 2004) and pediatric transplant recipients (Shemesh, 2007). The concept of coordination and communication in preparing for hospital discharge is reviewed extensively in the manuscript “Discharge readiness: An integrative review focusing on discharge following pediatric hospitalization” (Lerret, 2009) and can be seen as Appendix A.

#### *Post-Discharge Coping Difficulty*

Coping is a life-long process that occurs with both individuals and families (Jackson Allen, Vessey, & Schapiro, 2010) and the coping mechanisms parents use to manage stress can have a significant effect on how they experience the child’s chronic illness (Zelikovsky, Schast & Jean-Francois, 2007). Coping can serve as a potential risk or protective factor across pediatric chronic illness by moderating the relationship between the experience of medical stress and psychological outcomes for parents and children (Wallander, Thompson, & Alriksson-Schmidt, 2003).

Transplantation is a process with various phases that require the family to cope with both short-term crises and long-term chronic illness (LoBiondo-Wood, Williams, Kouzekanani, & McGhee, 2000). Parents experience stress throughout the transplant process beginning at the pre-transplant phase when the child is placed on the national transplant waiting list (Suddaby, Flattery, & Luna, 1997). Family caregivers of patients on the transplant list are under considerable stress and at risk for deterioration in physical

and mental health (Bolden & Wicks, 2008; Maloney, Clay & Robinson, 2005; Zelikovsky et al., 2007).

The challenges parents face continue after transplantation as parents transition from the care of an acutely ill child to the care of a child with a chronic illness and its associated uncertainties for potential transplant complications (Shemesh, 2007; Stuber, 1993). Parent stress has also been documented among parents of children who have received an organ transplant (Simons et al., 2007; Young et al., 2003). Parents of adolescent kidney and liver transplant recipients reported significantly more emotional distress and disruption of family activities in comparison to parents of healthy children (Sundaram, Landgraf, Neighbors, Cohn, & Alonso, 2007). If parents are not able to successfully manage this stressful transition, their child is at higher risk of suffering post-operative complications which are burdensome to the family and the health care system (Shemesh, 2007).

Parents experience stress during their child's chronic illness and treatment, and the way in which families cope with the stress can have an impact on the child (Douglas, Hulson, & Trompeter, 1998). A significant amount of nursing literature focuses on the area of family coping with illness. Specifically, The Family Crisis Oriented Personal Scales or F-COPES, has been used to identify problem solving and behavioral strategies employed by families when faced with problems or crises that describes a variety of coping behaviors used in times of stress or crisis (McCubbin, Olson, & Larsen, 1991). The F-COPES scale was used with parents of kidney transplant recipients and the findings indicate that parents of kidney transplant recipients use a variety of coping strategies. Most parents used the 'passive appraisal' coping strategy, meaning that

parents are more reliant on the medical team for managing the child's illness (Douglas et al., 1998).

Although the F-COPES has been used to assess family coping at a specific time point (Douglas et al., 1998), the measure was developed to assess family coping over the life cycle (Olson et al., 1983). The F-COPES measures strategies used for coping and does not identify the difficulty experienced by parents.

Discharge after transplant is frightening for families because the family develops a strong dependence on the hospital during the peri-operative time period (Gold, Kirkpatrick, Fricker, & Zitelli, 1986). Quantitative research exploring discharge readiness of 135 parents of hospitalized children found that the quality of discharge teaching was associated with increased parental readiness for discharge and was ultimately associated with less coping difficulty, as measured by the Post Discharge Coping Difficulty Scale (PDCDS), during the first three weeks following discharge from the hospital (Weiss et al., 2008). This study did not specifically explore this relationship in a chronic illness population and is not generalizable to the solid organ transplant population.

Some parents cope better than others with the challenges associated with their child's chronic condition, highlighting that it is critical for healthcare to address the needs of children and their families (Simons et al., 2008). A parent's ability to cope with the transition from acute to chronic illness and the transition from hospital to home is an important factor for nurses to assess and target interventions. Nurses can ensure parents feel ready to go home and ultimately decrease the level of stress at the time of hospital discharge. The psychosocial adjustment starts immediately following the solid organ



transplant procedure where individualized support, education, and open communication can enhance parental coping skills for the stress associated with transplant. The psychosocial factors associated with transplant must be considered in order to identify ways for nurses to support the parent's coping ability and ensure successful post-transplant outcomes (Uzark, 1992). The concept for this study is coping difficulty in order to identify potential areas for nursing to intervene and help families cope with life after their child's transplant.

#### *Family Impact*

Caregivers of chronically ill children face a variety of psychosocial stresses and are at risk for psychological adjustment problems. There are a number of stressors that parents of a child with a chronic illness may experience including financial stress, role strain, adjustment to the medical system, change in daily routines and plans for the future, and questions in regard to the child's prognosis (Brown et al., 2008; Coffey, 2006; Wang & Barnard, 2004).

The family impact of a chronic illness is scarcely documented in the pediatric solid organ transplant literature. Parents of pediatric transplant recipients face considerable psychological stress after the transplant related to the child's future, social isolation, and role strain (LoBiondo-Wood, Williams, & McGhee, 2004; Shemesh, 2008; Uzark & Crowley, 1989; Young et al., 2003;). Transplant parents live under the constant threat of rejection or other transplant-related complications (Green, Meaux, Huett, & Ainley, 2009; Shemesh, 2008). Similarly, uncertainty and stress related to the transition home was reported in parents of children being discharged from the pediatric intensive

care unit (Bent et al., 1996), in parents of hospitalized children (Snowdon & Kane, 1995), and parents of premature infants (Baker, 1991).

The daily tasks of caring for a chronically ill child, that include performing medical tasks, administering medications, managing insurance, attending clinic visits, obtaining laboratory tests, and unforeseen hospitalizations, place stress on the parents and family (Gavin & Wysocki, 2006). Organizing care of a chronically ill child into the family schedule poses difficulties in maintaining normal family function and a sense of routine (Jerrett, 1994; Fredericks et al., 2008). The subsequent needs of the child after transplant involve similar changes in family routines and present additional challenges to the family unit.

These challenges may lead to anxiety, depression, posttraumatic stress, hopelessness, and a loss of control (Brown et al., 2008). A pediatric critical illness or injury is stressful for the whole family and responses to traumatic events that occur at diagnosis and treatment often mirror posttraumatic stress disorder (Shudy et al., 2006). Posttraumatic stress symptoms in parents of children with chronic conditions have been studied in a number of different populations. Parents of pediatric cancer survivors (Kazak et al., 1997; Pelcovitz, 1996), severe burn injuries (Fukunishi, 1998), and diabetes (Landolt et al., 2002) all report significant levels of traumatic stress symptoms.

The existing body of literature describes an impact, both positive and negative, of pediatric illness on family dynamics (Brown et al., 2008). In families with children who survived a traumatic brain injury, more than one-third were impacted in a moderate to profoundly negative way, 30% reported deterioration in finances, and 16% reported a worsening of adult relationships (Montgomery, Oliver, Reisner, & Fallat, 2002).

On the other hand, families as a whole function well when there is strong adaptability and cohesion utilizing a variety of positive coping mechanisms (Philichi, 1989). Mothers of children with a chronic illness including sickle cell disease, cystic fibrosis, diabetes mellitus, and asthma were asked to identify the positive impact their child's chronic illness had on the family (Chernoff, List, DeVet, & Ireys, 2001) Mothers stated they felt better about themselves by learning to manage their child's chronic condition and that their family was stronger and had benefited in some way from having a child with a chronic illness. This study underscores the importance of teaching and coordination by nurses and the transplant team in helping families face the continued challenges of raising a child with a chronic illness (Chernoff et al., 2001).

A reciprocal relationship exists between chronic illness and parental adaptation, where the child's illness impacts the parents' functioning and parental functioning subsequently influences child adaptation (Brown et al., 2008). This reciprocal relationship was seen in a study of adolescent solid organ transplant recipients and their families (Simons et al., 2008). The adolescent's perceived frequency of transplant medication side-effects and family conflict significantly contributed to adolescent physical functioning and mental health outcomes. Family environment significantly impacted physical and mental health outcomes in adolescent transplant recipients (Simons et al., 2008).

A child's diagnosis of chronic illness impacts the entire family unit and families differ in their adaptation to chronic illness. Many families of children with a chronic illness develop a balance in family functioning and provide adequate medical care, while

other families do not achieve a balance and ultimately provide inadequate medical care in the home environment (Rosman, 1988).

Hymovich developed the Contingency Model of Long-Term Care and has used the model with families of children with chronic conditions. The model was developed to organize knowledge about chronic illness and provide nursing with a way to assess and intervene with families that have a child with a chronic condition (Hymovich & Hagopian, 1992). The five major dimensions of the model include: systems (family, community, and society), time, contingency variables (orientation to life, stressors, coping, strengths, and needs), level of functioning and adaptation to chronic illness, and nursing care (Hymovich & Hagopian, 1992). The model highlights the role of nursing assessment and intervention activities to enhance family function (Hymovich & Hagopian, 1992), a component particularly applicable in parents of pediatric solid organ transplant recipients. The dimensions of Hymovich's model are relevant to the pediatric solid organ transplant population because families (systems) adapt to transplant (a chronic illness) differently based on the stressors, coping, strengths and needs of each individual family unit (Hymovich & Hagopian, 1992).

The nurse should be aware of all the possible responses of a parent in order to enhance the positive responses and minimize the negative. An important component of family impact is psychosocial adjustment. Family impact is an important concept to measure because positive parent and child psychosocial adjustment following transplant is important to ensure adherence to the medical recommendations, ultimately resulting in graft and patient survival (Rianthavorn, Ettenger, Malekzadeh, Marik, & Stuber, 2004). In this study, this concept is measured three weeks following discharge from the hospital

because it is in this time frame that parents are dealing with the responsibilities of caring for the child in the home environment when the experience is new. The initial coping patterns and family impact will set the stage for long-term management of the solid organ transplant child and the chronicity of the post-transplant period.

The impact of disease and treatment on family functioning can be assessed by using the PedsQL™ Family Impact Module (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). The Family Impact Module was developed to assess the impact of chronic medical conditions on the quality of life of parents and family functioning (Scarpelli et al., 2008). The six dimensions of the instrument include parent self-report measurement of the following: physical function, emotional function, social function, cognitive functioning, communication, and worry (Scarpelli et al., 2008). Two additional subscales measure family functioning with daily activities and family relationships (Scarpelli et al., 2008). The six dimensions and two subscales measured in the Family Impact Module are relevant to the investigation of family functioning following the child's solid organ transplant operation because parents of children that have received a solid organ transplant are at risk for psychological stress (Brown et al., 2008; Uzark & Crowley, 1989; Young et al., 2003). In pediatric chronic health conditions, the impact of disease on family functioning is a salient concern given the essential role of the family in child adaptation to disease (Varni et al., 2004). With pediatric solid organ transplant, parents and children are adapting to recovery from extensive acute treatment followed by long-term chronic illness management.

### *Adherence*

The transplant recipient faces life-threatening situations as a routine part of the post-transplant course, most commonly related to rejection and infection. The transplant recipient and family must adjust to the limitations and consequences of living with a chronic medical condition, which includes the need for lifelong daily immunosuppression medications. A positive psychosocial adjustment to the post-transplant chronic medical condition is extremely important to ensure adherence to medical recommendations, improved quality of life and family adjustment, and long-term patient and graft survival (Rianthavorn et al., 2004).

A transplant offers a better prognosis and quality of life in comparison to acute illness associated with end stage organ failure. The overall success of pediatric kidney, heart and liver transplantation is often compromised by non-adherence (Kahana, Frazier, & Drotar, 2008). The rate of medication non-adherence resulting in late graft failure in adolescent kidney transplant recipients was reported at 12%, a rate that is four times greater than the adult population (Cecka, Gjertson, & Terasaki, 1997). A systematic review of 36 papers found that non-adherence in adult and pediatric kidney transplant resulted in 44% of all graft losses and 23% of late acute rejection episodes and were related to family conflict, symptoms of depression, number of medications, knowledge, and poor communication with the transplant team (Dobbels et al., 2010). Non-adherence is an important consideration in the post-transplant period because non-adherence is one of the leading causes of organ rejection resulting in hospital admission or even death (Butler, Roderick, Mullee, Mason, & Peveler, 2004; Rianthavorn et al., 2004; Ringewald et al., 2001; Shemesh et al., 2008).

Measuring adherence to the medication regimen has a number of challenges because there is no tool that has been validated to measure adherence in the transplant population (Shemesh, 2004; Stuber et al., 2008). Non-adherence is dynamic, fluctuating at different points in time. Adherence has been studied in the transplant population by a number of different measures.

Self-report (Berquist, et al., 2008; Shemesh et al., 2004) has been used as a means to measure adherence but is limited because patients may offer socially appropriate responses. Clinician assessment (Berquist et al., 2008; Shemesh et al., 2000; Shemesh et al., 2004) has also been used and has not been effective in identifying recipients who are or at risk for non-adherence (Stuber, 2010). Electronic event monitoring devices (which are pill boxes with electronic caps that register each opening of the device) (Shellmer & Zelikovsky, 2007) are limited because they cannot be used with patients who use suspensions. Medication blood levels (Fredericks et al., 2008; Shemesh et al., 2000; Shemesh et al., 2008; Simons, McCormick, Mee, & Blount, 2009; Stuber et al., 2008) are an objective measurement of adherence and have successfully differentiated between patients that have organ rejection (Stuber et al., 2008).

Adherence not only applies to medication administration but also to recommended follow-up for laboratory and clinic appointments, nutrition, and other lifestyle factors. Non-adherence to clinic appointments associated with post-transplant care was prevalent in 20% of adolescent liver (Berquist et al., 2008) and 67% of adolescent and young adult heart transplant patients (Stilley et al., 2006). Adherence to medications and other forms of post-transplant care including routine clinic and laboratory appointments has important clinical implications related to both assessment

and intervention. Identification of predictors for post-transplant adherence will lead to potential treatments to not only improve adherence but overall post-transplant outcomes. Non-adherence following pediatric solid organ transplantation has been identified as a national priority for research in this unique patient population (Bartosh et al., 2008).

### *Utilization*

The post-transplant regimen presents different challenges for individual patients and families in regard to the number and severity of medical complications. Healthcare utilization following transplant includes both planned and unplanned visits to the clinic and hospital. The parent receives education about the expected or planned utilization of healthcare resources (routine laboratory and clinic appointments) and unplanned utilization (contacting the transplant team for signs of infection, rejection, or medication related side-effects resulting in an unscheduled clinic visit, emergency department visit or readmission to the hospital) during the transplant hospitalization. Literature on the relationship between readiness for discharge and utilization of healthcare resources following hospitalization is scarce in both adult and pediatric populations. The frequency of unplanned utilization of healthcare resources, specifically readmission to the hospital, has been associated with a patient's readiness for hospital discharge in studies of hospitalized adults. Decreased readiness for discharge scores in adults with diabetes and heart failure correlated with increased risk for readmission (Ashton et al., 1995) while high readiness for discharge was predictive of fewer readmissions in an adult medical surgical (Weiss et al., 2007) and older adult population (Bobay et al., 2010). In contrast, the relationship between readiness for hospital discharge and utilization of healthcare



resources was not seen in a parallel study with postpartum mothers (Weiss & Lokken, 2009) or parents of hospitalized children (Weiss et al., 2008).

The relationship between readiness for discharge and utilization will be investigated in this study despite the fact that Weiss (2008) did not find a relationship between parent readiness for hospital discharge and utilization of healthcare resources. This relationship may not have been significant because the sample of hospitalized children was heterogeneous (Weiss et al., 2008). A significant relationship may be seen when studied in a chronic illness population such as pediatric solid organ transplant recipients. This population has complex medical needs following hospital discharge that may result in a higher rate of healthcare utilization and one that is more sensitive to variations in discharge preparation and parental readiness for discharge.

A parent's level of readiness at the time of hospital discharge following the child's solid organ transplant may affect the utilization of healthcare resources after discharge from the hospital. In the adult transplant population, it is essential for a transplant recipient to have a primary caregiver if they are to be successful in managing their post-discharge care regimen effectively (Bohachick et al., 2001; Dew et al., 1994; Kurz, 2002). A primary caregiver's understanding of discharge teaching is essential for adherence to the medication regimen and follow-up care required after transplant (Steinberg et al., 1996) because inaccurate medication administration and lack of close follow-up with the transplant team will result in the use of healthcare resources ranging from emergency department visits to inpatient hospitalizations. Evidence from adult studies underscore the important role of a parent's level of readiness at the time of

hospital discharge following the child's solid organ transplant and how it may affect the utilization of healthcare resources after discharge from the hospital.

Specific pediatric literature provides insight for other factors to consider. A decrease in healthcare utilization was seen after a structured education program for children with asthma (Wesseldine et al., 1999) while higher utilization was described with parental difficulty coping after hospital discharge (Weiss et al., 2008) and with self-reported lower family functioning in families of children with sickle cell disease (Barakat et al., 2007).

The samples of hospitalized children (Weiss et al., 2008), children with sickle cell disease (Barakat et al., 2007), and children with asthma (Wesseldine, 1999) have limited generalizability to the pediatric solid organ transplant population. The findings presented in this pediatric literature highlight the importance of assessing the level of parent coping after discharge (Weiss et al., 2008), providing structured education (Wesseldine et al., 1999), and assessing family function (Barakat et al., 2007). Identifying predictors of readiness, or lack of readiness, is essential for determining appropriate timing of discharge and subsequent post-discharge follow-up needs (Weiss et al., 2007).

Utilization of healthcare resources is an important concept to measure in this study because the identification of factors that influence an increase in utilization may lead to interventions that ultimately decrease unplanned utilization. The level of unplanned utilization of healthcare resources may relate to other factors being measured including coping and family impact. Identifying risks for unplanned utilization of

healthcare resources could provide an opportunity to implement more specific interventions to reduce this risk.

### *Gaps in the Literature*

For hospital-based nurses, preparing patients and families for the transition from hospital to home is a daily occurrence. This transition has a variety of implications for patients and families depending upon the reason for hospital admission and complexity of care necessary to continue the recovery process within the home environment. Pediatric solid organ transplant recipients are a unique population of patients experiencing the transition from hospital to home.

Patient readiness for discharge has been described as, “a complex multidimensional, multiphase phenomenon that provides an estimate of a person’s ability to leave the hospital” (Anthony & Hudson-Barr, 1998, pg. 119) and “a multifaceted concept and best arrived at through inter-professional discussion and decision” (Fenwick, 1979, pg. 14). Discharge readiness encompasses physiologic, functional, cognitive, affective, psychological abilities and limitations, stability, competency of the patient and family, perceived self efficacy, availability of social support, and access to the health care system and community resources (Fenwick, 1979; Titler & Pettit, 1995).

Readiness for discharge is a crucial topic in relation to pediatric chronic illness, including pediatric solid organ transplant recipients and their families. There are few studies that report the needs of patients and families that have experienced a pediatric solid organ transplant.

There is also limited research that identifies the needs of a primary caregiver following transplant. The psychosocial needs of families following organ transplant has

been well documented (Benning & Smith, 1994; Gold et al., 1986; Uzark & Crowley, 1989; Young et al., 2003) but has not specifically described family needs during the transplant discharge experience. Currently, no research has been conducted related to readiness for hospital discharge of a parent as the primary caregiver for a child with solid organ transplant. The proposed research will fill this gap in the knowledge needed for care of solid organ transplant children and parents and underscores the importance for transplant professionals to partner with parents in the transition from hospital to home following transplantation in order to improve post-discharge outcomes.

Knowledge of the factors that contribute to a smooth transition from hospital to home following pediatric solid organ transplant is needed by pediatric clinicians. Nurses have a singular opportunity and responsibility to impact quality patient care upon hospital discharge. The results of this study will provide information for a future intervention-based study investigating the ability to improve the transition from hospital to home following pediatric solid organ transplantation. This research study makes an original contribution to nursing and health care because there is no literature regarding the discharge experience following pediatric solid organ transplant. Furthermore, the results may not be directly generalizable to other pediatric chronic illness, but may provide a framework within which to consider other chronic illness populations.

### *Research Questions*

The purposes of this study are to: (1) determine the relationship of discharge teaching and care coordination to parent readiness for hospital discharge in the transition from hospital to home for parents of children who have received a solid organ transplant; and (2) to determine the relationship of parent readiness for hospital discharge to parent

coping difficulty, family impact, adherence, and utilization of healthcare resources following discharge from the hospital. Specific research questions to address the study purposes are:

Q1: What is the relationship between care coordination and readiness for hospital discharge among parents of children who experience a solid organ transplant?

Q2: What is the relationship between discharge teaching and readiness for hospital discharge among parents of children who experience a solid organ transplant?

Q3: What is the relationship between parent readiness for hospital discharge and parent coping difficulty after discharge following pediatric solid organ transplant?

Q4: What is the relationship between parent readiness for hospital discharge and family impact after discharge following pediatric solid organ transplant?

Q5: What is the relationship between parent readiness for hospital discharge and adherence to medical treatment and follow-up care after discharge following pediatric solid organ transplant?

Q6: What is the relationship between parent readiness for hospital discharge and utilization of healthcare resources after discharge following pediatric solid organ transplant?

#### *Philosophical Underpinnings for the Study of the Discharge Transition*

All nursing theory and research is derived from the underlying relationship with philosophy (Silva, 1977). The research process allows for an investigation of the relationships among philosophy, science, and theory. The connection between philosophy, science and theory is arrived at differently by individual researchers resulting in unique perspectives, ultimately providing a deeper contribution to the advancement of

nursing knowledge (Silva, 1977). Philosophy of science provides a useful frame of reference in which to appreciate the advancement of nursing knowledge through research and scholarly thinking.

The main philosophical underpinning that supports this proposed research project is post-positivism. However, a singular perspective is insufficient to adequately understand the human experience. Constructivism provides a different and supplementary lens for considering this investigation of the discharge experience. A brief review of positivism will provide history for how post-positivism emerged and explanations for why it is the main philosophical underpinning for researching the discharge transition. Constructivism will also be reviewed in order to explain how this philosophical perspective fits with the study.

Positivist philosophy began in the 18<sup>th</sup> and 19<sup>th</sup> century with roots in the writings of John Locke and David Hume and placed an emphasis on observation and experience. In the early 20<sup>th</sup> century philosophers known as the Vienna Circle placed importance on establishing laws. Most recently in the 1960's, positivism focused on reasoning and the development of a logical conclusion through deductive thinking (Allmark, 2003; Crossan, 2003). The ontology of positivism is that a knowable reality exists for all to access, measure, and comprehend in a concrete, reproducible form and is driven by laws that are not changeable (Guba, 1990). The aim of science according to positivism is to predict and control natural phenomena (Guba, 1990). Historically, nursing embraced positivism under the influence of medicine (McEwen & Willis, 2007)

Post-positivism emerged to challenge traditional positivism as a number of disciplines became frustrated with the reductionist view of reality within the positivistic

approach. Within the nursing discipline, the frustration with positivism stemmed from the fact that it did not seem to reflect core values and beliefs of the discipline including holism, person-centered, care, and understanding the myriad of human experiences in health and disease (Guba, 1990). Post-positivists identified imbalances of positivism and adapted them to the post-positivist paradigm that both valued and extended the positivist perspective (Guba, 1990; Monti & Tingen, 1999). The main imbalances of positivism are the reliance on objectivity, control, and dehumanization. Positivist reliance on objectivity and control was thought to create an artificial reality, ultimately resulting in findings that are not generalizable (Monti & Tingen, 1999). The excessive control was also considered dehumanizing because the participant is viewed as responding to environment inputs in a mechanistic manner rather than interacting with the environment (Monti & Tingen, 1999). The positivist does not see value in data that pertain to indirectly observable phenomena such as perceptions or feelings, but rather believes that these components distort knowledge (Whall, 1989).

Constructivism extended the notion of multiple contributing factors to one's reality, the dominant perspective in post-positivism, to the perspective that individuals have unique experiences that are constructed by their own unique interpretation of their reality. Constructivism is a philosophy based on the premise that individuals construct knowledge through interaction with the environment (Appleton & King, 1997). Many philosophers have contributed to constructivist thinking. Immanuel Kant was the first to suggest that human beings perceive experiences, and subsequently acquire knowledge in unique ways or categories of the mind (McErlean, 2000).

### *Ontology, Epistemology and Methodology*

Post-positivism and constructivism will be described in regard to ontology, epistemology, and methodology. Ontology describes the nature of reality (Guba, 1990; Polit & Beck, 2008). The ontology of post-positivism is that reality exists but cannot ever be fully explained or understood because reality is constantly changing and evolving. Reality can never be fully explained or understood because it is impossible for humans to see and experience the world perfectly (Guba, 1990). There are multiple dimensions to reality, suggesting that researchers need to explore the phenomena of interest through multiple approaches. In this perspective, multi-trait multi-method investigations provide insights that support understanding within this philosophic perspective.

The ontology of constructivism is that reality is a mental construction that is different every time because it is socially and experientially based. Reality is perceived by the knower and based on their situation, making it a unique experience for each individual (Guba, 1990).

The proposed research to explore the multiple factors that contribute to and result from discharge readiness has primarily post-positivist foundations. The contributing factors include discharge teaching and care coordination, the four dimensions of discharge readiness (child and parent personal status, knowledge, coping ability, and expected support), and the multiple outcomes include coping, family impact, adherence, and utilization.

A parent's level of discharge readiness following his/her child's solid organ transplant is unique for every parent and every family based on their own reality. Each patient and family has a unique reality that may vary with social support, education,



financial support, or family structure. It is crucial to recognize the entire family in order to provide appropriate support to the family, as discharge to home is a critical transition. The proposed research is also underpinned by the ontology of constructivism by recognizing that each person has a unique construction of his/her own reality and is defined by the individual (Appleton & King, 1997). Transition is an experience, and is therefore subject to individual perception and interpretations with many influencing factors.

Epistemology describes the nature of the relationship between the participant and the researcher (Guba, 1990; Polit & Beck, 2008). The epistemology of post-positivism is “modified objectivist” (Guba, 1990, pg. 23). The post-positivist would argue that objectivity in research is the goal, but that it is impossible to achieve because a researcher cannot be without bias (Guba, 1990). The bias of the researcher in this study is that there is a relationship between discharge teaching and coordination of care with a parent’s readiness for discharge from the hospital. The researcher also believes that there is a relationship between parent’s readiness for hospital discharge and post-discharge outcomes of coping, family impact, adherence, and utilization of healthcare resources. Thus, the researcher’s bias is evident in the types of research questions generated for the study.

The epistemology of the post-positive paradigm fits most closely with this study. The post-positivist is a modified realist that objectifies reality by reducing phenomena to discrete elements that can be verified or refuted by others. The modified realist recognizes the fault of looking at a single reality and therefore looks at multiple ways of observing (Guba, 1990). This study incorporates a post-positivism perspective by

investigating multiple factors that relate to discharge readiness and post-discharge outcomes. There are multiple measures of factors related to discharge readiness (coordination of care and discharge teaching) and multiple measures of the parent's post-discharge experience (coping, family impact, adherence, and utilization of healthcare resources).

The epistemology of constructivism is that knowledge emerges as a process of creation and that the participant and observer are co-creators (Guba, 1990). This perspective would be evident in a study using qualitative methods where the researcher speaks with the family about their experience of discharge readiness. The small qualitative component of this research design will allow the researcher to gain a deeper understanding of the discharge transition. The dissertation research uses mainly quantitative method and therefore does not fully meet the epistemology of constructivism (Appleton & King, 1997) because constructivists describe and interpret phenomena in an iterative, interactive, and co-creation process with study participants. In this study, qualitative data were collected at a single point in time with retrospective reflection across the post-discharge transitional period.

Methodology describes how the researcher obtains knowledge (Guba, 1990; Polit & Beck, 2008). The methodology of post-positivism is mixed-method as both quantitative and qualitative methods are used to collect data in natural settings (Guba, 1990). In this study, the relationship between discrete variables is studied in a longitudinal frame of reference which links closely with the changing realities of the discharge transition.

The dissertation research addresses questions about the relationships of discharge teaching and care coordination to discharge readiness and subsequently discharge readiness to utilization of healthcare resources, family impact, adherence, and coping following hospital discharge. In this regard, the study design fits within the post-positivist paradigm (Guba, 1990; Polit & Beck, 2008). The study aim is to determine factors associated with discharge readiness. These concepts will be measured quantitatively and undergo statistical analysis with the goal of generalizing results to pediatric solid organ transplant recipients (Polit & Beck, 2008).

The methodology of constructivism is that individual constructions are elicited and compared and contrasted with the aim of generating one or more constructions on which there is substantial consensus (Guba, 1990). This approach fits most closely with qualitative research (Appleton & King, 1997). Qualitative data was collected to assist with interpretation of the meaning of quantitative responses. The qualitative responses provide insight into the meaning constructed by forced quantitative ratings.

Constructivism and post-positivism are competing philosophic perspectives. Each perspective has strengths that fit with the research purpose and design to explore factors related to discharge readiness, recognizing that each patient and family has a unique experience.

The constructivist ontology links most closely with the goal of learning about the individual experiences of the discharge transition, while post-positivism epistemology and methodology fit well with the design to study factors related to discharge readiness. Post-positivist methodology allows for quantitative and qualitative data collection, consistent with the data collection methods selected for the study. Post-positivism is a

good fit for nursing knowledge development because the paradigm allows for recognition of the intricate relationship between behavior, attitudes, and socio-cultural, and economic issues (Crossan, 2003; Newman, 1992; Rodgers, 2005). Two philosophic perspectives are used because each has components that contribute to the study. “Ignoring the complexity of nursing phenomena and ascribing to only one view will likely lead to an incomplete nursing science” (Whall & Hicks, 2002, p. 75).

The philosophic assumptions underlying the study of discharge transitions are that of linear movement in time and trajectory from hospital discharge to home. Within this trajectory from hospital to home the response patterns that patients have to chronic illness and medical management may be time sensitive. The post-discharge follow-up data collection time, three weeks following hospital discharge, measures a point in time for each individual family and may not reflect a consistent response pattern among families. Transition is an experience, and is therefore subject to interpretation and many influencing factors.

#### *Statement of Assumptions*

The following assumptions are derived from the researcher’s view of the ontology of the phenomenon of interest for this investigation, transition from hospital to home in parents of pediatric solid organ transplant recipients:

1. Children have a primary caregiver who is invested in the care of the child following transplant.
2. The home environment is conducive to and supportive of recovery from surgery.

3. Parents and children perceive the transition from life threatening to chronic illness. There is also an assumption that there is a period of time that parents transition from caring for an acutely ill child in the pre-transplant time period to caring for a child with a chronic illness in the post-transplant time period.
4. There is a continuum of care and the care has relevance to parents and providers.
5. Nursing care and communication can impact parents and families. The study design functions under the assumption that there is value in meaningful interactions and confidence building with the parent to help in a smooth and supported transition from hospital to home.
6. Children are either completely dependent (infancy) or somewhat dependent (school age to adolescent) on the parent following the transplant operation for a smooth transition to the home environment. The parent has different needs at the time of discharge which is influenced by many factors, one of which is the child's age. The developmental needs of the child affect the home environment and adherence to the post-transplant medical regimen.
7. Patient and family needs at the time of transition from hospital to home are complex and would benefit from nursing research.
8. Nursing has an integral role in communication and coordination, education, and assessing for the individual needs of parents and families.
9. The care provided to parents and families is provided by a multidisciplinary team within the hospital setting and into the post-discharge period.

### *Conceptual- Theoretical-Empirical Structure*

Every conceptual-theoretical-empirical structure includes the following components: a conceptual model, a theory, and empirical research methods (Fawcett, 1999). Research starts with the general conceptual model which provides a frame of reference for theory development or testing by means of empirical research. Every study needs to link to extant nursing theoretical work that can be expanded, refuted, and modified by the new investigation (Fawcett, 1999).

### *Theoretical Thinking in Nursing*

“Theoretical thinking in nursing uses concepts and their relationships to organize and critique existing knowledge and guide new discoveries to advance practice” (Higgins & Moore, 2000, p. 179). The four levels of theoretical thinking in nursing include: meta-theory, grand theory, middle-range, theory, and micro-range theory (Higgins, & Moore, 2000). Meta-theory is the most abstract of the four levels and is critical to nursing research and practice (Higgins & Moore, 2000). Fawcett describes a metaparadigm for nursing that contains four essential concepts: person, environment, health, and nursing (Fawcett, 1980). This metaparadigm can be viewed as an umbrella for nursing theories.

Under the umbrella of metaparadigm or meta-theory is grand theory, middle-range theory, and micro-range theory. Grand theory is abstract in nature and provides broad explanations for an understanding of nursing. Grand theories are not specific enough for empirical testing and ultimately have little predictive capability (Higgins & Moore, 2000). Although grand theories are too abstract for empirical testing, they have been invaluable in advancing nursing knowledge development (Higgins & Moore, 2000). Middle range theory is more specific than grand theory in that it can guide research and

practice while also crossing multiple clinical populations (Higgins & Moore, 2000). Micro-range theory is thus the least formal of theoretical levels, most restrictive, and ultimately very applicable to nursing practice (Higgins & Moore, 2000).

A middle-range theory describes, explains, or predicts phenomena (Fawcett, 1999) but may limit the description, explanation, and understanding of the diversities in patient experiences and responses to specific phenomenon (Im & Meleis, 1999). Situation specific theories, a form of micro-range theory, focus on specific nursing phenomena that reflect clinical practice in a particular population and are developed to explain a specific situation (Im & Meleis, 1999). The proposed research study uses Meleis' middle range theory on transitions (Meleis, Sawyer, Im, Messias, & Schumacher, 2000) in a specific situation of the transition from hospital to home in parents of pediatric solid organ transplant recipients.

#### *Conceptual Framework*

Concepts are the basic building blocks of theory. Situation specific theory allows the researcher to analyze concepts for a specific patient population in a specific situation from the nursing perspective (Im & Meleis, 1999). The nursing perspective for this study is to better understand the impact that nurses have on parent's readiness to go home from the hospital and on post-discharge outcomes.

A conceptual model or framework is defined as "a set of relatively abstract and general concepts and the propositions that describe or link those concepts" (Fawcett, 1999, p. 3). Figure 1 is the theoretical framework at the situation specific theory level for the dissertation.

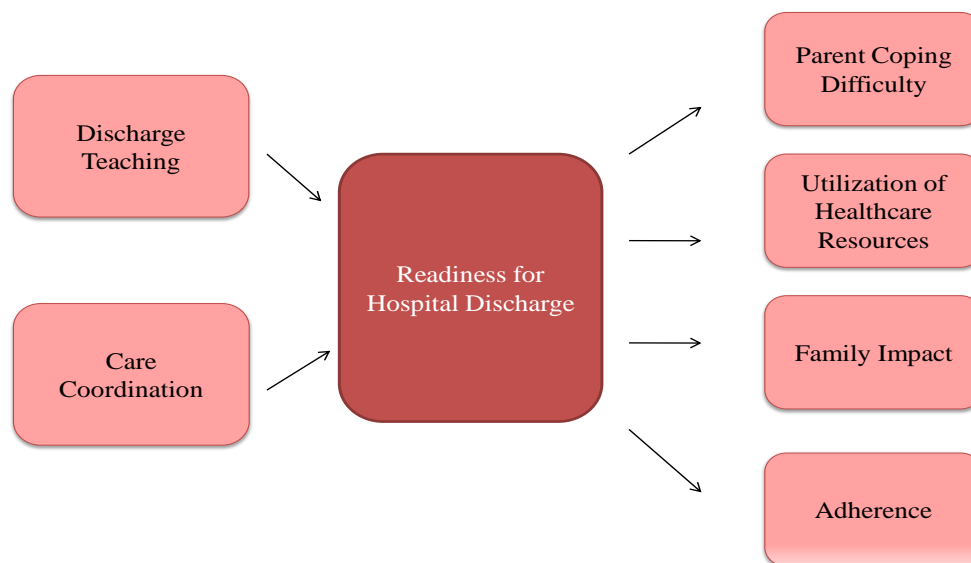


Figure 1. Theoretical Framework

### *Middle Range Theory*

The middle-range theory, Meleis' Transitions theory, provides an organizing framework for conceptualizing the transition from hospital to home. In Meleis' transitions theory, transition is a change in health and illness that tends to create a period of vulnerability (Meleis et al., 2000). Transition is both a process and outcome of complex interactions that occur over time (Meleis & Trangenstein, 1994). There are four major components of transition: nature of transition, transition conditions, nursing therapeutics and patterns of response (Meleis et al., 2000).

Each of Meleis' four transitions theory concepts (Meleis et al., 2000) is represented by the study variables. The first component, Nature of the Transition, is defined as the descriptor of the type, pattern, and property of a transition and is



operationalized as hospitalization characteristics in this study. The second component, Transition Conditions, is the personal or environmental conditions that facilitate or hinder progress toward achieving a healthy transition. Transition Conditions are operationalized as parent and child characteristics. The third component, Nursing Therapeutics, focuses on the prevention of unhealthy transitions, promoting perceived well-being, and dealing with the experience of transitions. Nursing therapeutics, the critical role played by nurses in preparing families for transition, is operationalized as the discharge teaching and care coordination study variables. The fourth component, Patterns of Response, attempts to understand how patients manage the diagnosis, treatment, and recovery. Patterns of Response have four major components: feeling connected, interacting, location and being situated, and developing confidence and coping (Meleis et al., 2000).

Two of the four dimensions from Patterns of Response (feeling connected and developing confidence and coping) are important outcomes measured in this research. Feeling connected to the health care team means that patients are comfortable calling the health care team in order to answer questions. The connection to the health care team is an important indicator of a positive transition experience (Meleis et al., 2000). Developing confidence and coping is another component that reflects the nature of the transition process and is manifested by mastery of treatment and recovery, level of resource utilization, and strategies for managing the illness over time (Meleis et al., 2000).

Patterns of Response are measured in both the immediate and short term time period. The immediate time period of hospital discharge is operationalized as readiness for hospital discharge and the short term, three weeks following hospital discharge, is

operationalized as coping, utilization of healthcare resource, reported medication adherence, and family impact. The association between each of Meleis' Transitions concepts, study variables, and study measures is seen in Table 1. Table 1 is the conceptual-theoretical-empirical structure where conceptual is the middle range theory level using Meleis' Transitions theory, theoretical is the situation specific theory level shown as the study variables, and empirical is the measurement level which is shown as the study measure.

Meleis' Transition Theory	Study Variable	Study Measures
Nature of the Transition	1) Hospitalization characteristics	1) Type of transplant, return to OR, rejection, infection, length of hospitalization, number of medications, additional nursing care at discharge
Transition Conditions	1) Parent characteristics 2) Child characteristics	1) Age, race, gender, marital status, number of children and adults at home 2) Age, race, gender
Nursing Therapeutics	1) Discharge teaching 2) Care coordination	1) QDTS 2) Care Transition Model
Patterns of Response	1) Readiness for hospital discharge 2) Post discharge coping 3) Utilization of healthcare resources 4) Adherence 5) Parent adjustment	1) RHDS 2) PDCDS 3) Utilization of: calls to provider, calls to hospital, unscheduled clinic visit, urgent care or emergency department visit, hospital readmission 4) Self report of adherence to the medical regimen 5) PedsQL Family impact module

Notes. Quality of Discharge Teaching Scale (QDTS), Readiness for Hospital Discharge Scale (RHDS), Post Discharge Coping Difficulty Scale (PDCDS)

Table 1. Conceptual-Theoretical-Empirical Structure

The nurse's goal for transition is to enhance well-being (Meleis & Trangenstein, 1994). Meleis' Transitions Theory provides a framework for nurses to support parent well-being in the transition from hospital to home in a longitudinal and multidimensional approach (Meleis & Trangenstein, 1994).

*Summary*

This chapter has provided an extensive review of the literature of each concept included in the proposed dissertation research on factors related to discharge readiness. Relationships between the concepts were highlighted in each section of the review. There is a clear gap in the literature on the concept of parent readiness for discharge following a child's solid organ transplant. A combination of post-positivism and constructivism is the philosophic stance of the researcher for exploring the concept of discharge readiness in parents of pediatric solid organ transplant recipients. The conceptual-theoretical-empirical framework outlines how Meleis' Transitions Theory is connected to the study variables and measurement tools. The dissertation research is guided by theory and examines the impact of nursing care on parents of pediatric solid organ transplant recipients during the transplant hospitalization and at home.

## CHAPTER THREE

### Research Design and Methods

This chapter provides a detailed review of the research design and methods to address the research questions for the dissertation. The research sample, data collection methods, variables being measured, and the planned statistical analyses are outlined in this chapter. Rationale for the research design and methods are reviewed to justify decisions made.

#### *Research Design*

The goal of nursing research is to answer questions relevant to the nursing profession through systematic inquiry in order to advance the science of nursing (Polit & Beck, 2008). There are two methodological approaches to nursing research, quantitative and qualitative research methods. The quantitative approach is rooted in objective reality and emphasizes empirical evidence as the basis for knowledge. The philosophical underpinning of quantitative research is the positivist paradigm (Polit & Beck, 2008). Alternatively, the qualitative approach emphasizes an understanding of the human experience as it is lived and produces exploratory and descriptive knowledge (Hesse-Biber & Leavy, 2006) with the naturalistic paradigm as the philosophical underpinning (Polit & Beck, 2008). Both quantitative and qualitative research adds to the body of nursing science and represents different perspectives from which to understand nursing phenomena (Polit & Beck, 2008).

The purpose of this study aligns with quantitative methodology. The variables chosen to measure the discharge transition are expressed as instrument scores which fit with quantitative research design (Orcher, 2005). The purpose of this study was

addressed using a prospective, correlational, longitudinal design. Data were collected prospectively because the anticipated causes of discharge teaching and care coordination affect a parent's readiness for hospital discharge. It is further presumed that a parent's level of readiness for discharge affects the post-discharge outcomes including coping, family impact, adherence, and utilization of healthcare resources. The correlational design was employed because the aims of this study are to understand the sequential relationship of nursing care to parent outcomes in the specific situation of parents of solid organ transplant children as they experience the discharge transition. The study design was chosen in order to investigate the transition in a manner that is consistent with the longitudinal nature of the experience of transitioning from hospital to home following solid organ transplant from the parent's perspective.

The quantitative research design is enhanced with the addition of a qualitative component. The qualitative component allows for a fuller understanding of the research problem, specifically in the area of discharge teaching education and the overall transition experience. The quantitative design is the primary research method with qualitative research as secondary. This design is used to provide clarification or depth to the quantitative research findings (Hesse-Biber & Leavy, 2006).

The parent perspective on transition of the child from hospital to home is the chosen perspective on transition for the purpose of this research study. The primary quantitative and secondary qualitative components allow the parents to respond to questionnaires and open-ended questions about the transition experience. The concept of patient-centered care fits well with the need to consider the parent perspective in this critical transition. The Institute of Medicine listed patient-centered care as a quality aim

in the 2001 report (Institute of Medicine, 2001). Patient-centered care is defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001).

The parent and family is the focus for patient or family-centered care in pediatric nursing. The pediatric patient must be viewed within the context of the family in order for nurses to build a partnership with families and promote healthy outcomes (Wertlieb, 2003). Parents of children with special health care needs report that collaborative relationships with health care providers are a key component of family-centered care (MacKean, Thurston, & Scott, 2005). Nurses who integrate patient-centered care can positively impact the patient’s perception of quality and satisfaction with the care received (Wolf, Lehmann, Quinlin, Zullo, & Hoffman, 2008). A focus on the parent perspective is a means to highlight patient-centered care and will provide meaningful research conclusions to advance nursing science.

### *Research Questions*

Q1: What is the relationship between care coordination and readiness for hospital discharge among parents of children who experience a solid organ transplant?

Q2: What is the relationship between discharge teaching and readiness for hospital discharge among parents of children who experience a solid organ transplant?

Q3: What is the relationship between parent readiness for hospital discharge and parent coping difficulty after discharge following pediatric solid organ transplant?

Q4: What is the relationship between parent readiness for hospital discharge and family impact after discharge following pediatric solid organ transplant?

Q5: What is the relationship between parent readiness for hospital discharge and medication adherence and adherence difficulty after discharge following pediatric solid organ transplant?

Q6: What is the relationship between parent readiness for hospital discharge and utilization of healthcare resources after discharge following pediatric solid organ transplant?

### *Research Methods*

#### *Setting*

Three major pediatric transplant centers located in the Midwest and Southeast United States were chosen as study sites in order to achieve the minimum sample size requirements. Children's Hospital of Wisconsin in Milwaukee (CHW) was chosen as the first site for data collection because it is the major pediatric transplant center in the state of Wisconsin. CHW is a 210 bed free-standing Children's Hospital with a full service transplant center including bone marrow transplant (not included in the study), liver transplant, kidney transplant, and heart transplant. CHW performs approximately 25 heart, kidney, and liver transplants annually. The principal investigator has access to the solid organ transplant programs at Children's Hospital of Wisconsin based on employment as liver transplant coordinator and working relationship with the heart and kidney transplant programs.

Children's Memorial Hospital in Chicago (CMH) was chosen as the second study site because it is the largest solid organ transplant center in the state of Illinois. CMH is a 270 bed free-standing children's hospital performing approximately 50 solid organ transplants every year.

Levine Children's Hospital (LCH) in North Carolina was chosen as a third study site. LCH is a 234 bed pediatric hospital located on the campus of Carolinas Medical Center in Charlotte, North Carolina. The hospital performs approximately 20 heart, kidney and liver transplants on an annual basis.

Enrollment at all three centers allows for attrition and refusal of parents to participate in the study. The three sites are large pediatric solid organ transplant centers making it feasible to meet the minimum sample requirement to complete analyses.

#### *Selection of Sample Participants*

Participants were identified as parents of children being treated within the heart, kidney, and liver transplant clinic at one of the three major pediatric transplant centers listed above. A sample of eligible parents self-identified as the primary caregiver of patients who receive a solid organ transplant during the study period were approached for voluntary participation.

Power analysis for testing the relationship of quality of discharge teaching and care coordination to readiness for hospital discharge was completed. A power analysis performed with G-Power 3 software indicated that a total sample size of 36 was needed to ensure adequate power to detect correlations for two independent/predictor variables with a single dependent/outcome variable with a moderate effect size ( $r = .30$ ) with beta set at .20 (Faul, Erdfelder, Lang, & Buchner, 2007). The sample size provided sufficient power for investigating relationships for both one independent variable and two independent variables with a single dependent variable. All eligible parents were contacted to discuss voluntary participation.



The parent self-identified as the primary caregiver was eligible for participation upon meeting the following inclusion criteria: (1) Parents of children who have undergone a heart, kidney, or liver transplant and are being discharged to home from the hospital after the transplant procedure; (2) Parents must be English speaking since the tools being used for the study have been validated for English participants only; (3) Parents are 18 years of age or older; and 4) Have a telephone in order to complete the three week post-discharge interview. Exclusion criteria: (1) Presence of significant communication or cognitive impairment on the part of the parent that would preclude completion of questionnaires based on self-report; (2) Parent whose child is receiving a second or third organ transplant and has already experienced the transition from hospital to home; (3) Patients with extreme co-morbid conditions including tracheostomy and/or ventilator dependence. A child who received a second or third transplant due to technical complications of organ transplant that require immediate re-transplantation was not excluded from the study as long as the child had not been discharged from the hospital in between the time of the subsequent transplant operation.

#### *Study Variables and Instruments*

The study involved completion of multiple surveys which have been used in previous studies where they demonstrated adequate reliability and validity. The reliability and validity of each instrument are discussed in detail below. The completion of questionnaires allows the researcher to quantitatively measure predictors and outcomes of parental readiness for hospital discharge.

### *Instruments*

*(1) A Discharge Survey was used to collect the following data within four hours of hospital discharge:*

*(a) Parent and Child Characteristics (Appendix B).* Parents provided information about parent and child characteristics. Parent characteristics include age, race, gender, marital status, and number of adults and children living in the home. Child characteristics include age, race, and gender. The parent and child characteristics were used to describe the sample and were not included in subsequent analyses to respond to the research questions.

*(b) Hospitalization Characteristics (Appendix B).* Patient medical chart reviews were conducted to record type of organ transplant, unplanned returns to the operating room during transplant hospitalization, transplant-related complications including rejection or infection, length of transplant hospitalization, number and type of medications at time of discharge, and home medical care needs at time of discharge (including central line care, wound care, supplemental tube feedings, or other medical related care). The purpose of collecting hospitalization characteristics was to describe the sample.

*(c) Parents' Readiness for Hospital Discharge (Appendix B).* The parent form of the Readiness for Hospital Discharge Scale (RHDS) is a 29-item tool that was used to assess parents' perceptions of readiness for discharge. The parent form is comprised of the original RHDS tool (21 items) used with a variety of patient populations (Weiss & Piacentine, 2006) and an additional eight items particularly addressing the parent (Weiss et al, 2008). The parent form of the RHDS measures the parents' perceptions of

readiness for discharge and is composed of five subscales (parent's personal status, child's personal status, knowledge, coping ability, and expected support). The parent's self-report requires the parent to answer each question on a scale from '0' (indicating 'not at all') to '10' (indicating 'totally'). Higher total scores are interpreted as greater readiness for hospital discharge. The total scale reliability estimates are high, with Cronbach's alpha ranging from .84 to .90 in various populations including adult medical-surgical patients, older adults, and parents of hospitalized children (Bobay et al., 2010, Weiss et al., 2008; Weiss & Piacentine, 2006; Weiss et al., 2010). The Cronbach's alpha reliability for the individual five subscales of the parent form were acceptable, ranging from .70 to .86 (Weiss et al., 2008). Construct validity was supported with factor analysis. Predictive validity was supported as readiness for hospital discharge was associated with post-discharge coping difficulty (Weiss & Piacentine, 2006, Weiss et al., 2007; Weiss et al., 2008; Weiss & Lokken, 2009).

Two qualitative questions were added to this instrument, "What were the most important topics for you to learn about in preparing to go home?" and "What helped or interfered with you feeling confident to care for your child after discharge?" These questions provided specific information about what parents need when preparing for hospital discharge and add depth to the quantitative responses stating parents did or did not feel ready to go home. These questions answered the question why parents did or did not feel ready to go home.

*(d) Quality of Discharge Teaching Scale (Appendix B).* The Quality of Discharge Teaching Scale (QDTS) was used to measure the parent's perspective of educational preparation for discharge. The 18-item QDTS tool consists of two subscales, content

received (6 items) and delivery (12 items). The content subscale included six paired items, needed and received. The content needed and content received focus on the child's care, medical care, knowledge on when and how to call the provider, parents' feelings, and information for family members. The delivery subscale asks the parent about the ability of the nurse to educate the family on discharge teaching. The tool asks parents to rate the teaching received from the nursing staff on a scale from '0' (indicating 'none or not at all') to '10' (indicating 'a great deal, always or extremely'). The total scale score is calculated by adding the two subscale (content received and delivery) scores. The content needed is not included in the total scale score but will be used for comparison with the parent's report of content needed.

The Cronbach's alpha reliability of the QDTS in a sample of parents of hospitalized children was high at .88. The two subscales had high Cronbach's alpha reliability, content received .78 and delivery .88 (Weiss et al., 2008). The QDTS has been used with adults and older adults, with Cronbach's alpha ranging from .88 to .93 (Bobay et al., 2010; Weiss et al., 2007). Construct validity was supported with principal components exploratory factor analysis (Weiss et al., 2007). Predictive validity was supported as QDTS was associated with readiness for hospital discharge (Weiss et al., 2008).

Two qualitative questions were asked in connection with two of the questions in the Quality of Discharge Teaching Scale in order to provide descriptive content from the unique perspective of pediatric solid organ transplant recipient parents. The two additional open-ended questions offer detail about the nature of the content needed.

The first of two additional qualitative questions was added following question number three which asks the parent to rate on a scale of zero to ten “How much information did you need from your child’s nurses about your child’s medical needs or treatments (for example, caring for a wound, breathing using equipment, or taking your medications in the correct amounts and at the correct time) after you go home?” (Weiss et al., 2008). The qualitative question asked in conjunction with this question is, “What were the most important topics for you to learn about in preparing to go home?”

The second qualitative question coincides with question number eighteen which asks the family to rate on a scale of zero to ten (with anchoring words of ‘Not at all’ and ‘A great deal’), “Did the information your child’s nurses provided about your child’s care at home decrease your anxiety about going home?” The narrative question that was asked is, “What helped or interfered with you feeling confident to care for your child after discharge?” Both of the qualitative questions were open-ended for the parent to complete. These narrative responses provide depth to the quantitative data being collected that is specific to the pediatric solid organ transplant population.

*(e) Care Coordination (Appendix B).* Care coordination was defined as the parent’s perception of the healthcare provider actions to ensure coordination and continuity of healthcare in preparation for hospital discharge. The Care Transition Measure (CTM) was used to measure the extent to which parents are prepared to participate in care following hospital discharge (Coleman et al., 2002). The CTM was developed and validated in a sample of older patients (65 years and older) who were recently discharged from the hospital and received subsequent skilled nursing care either in a facility or at home (Coleman et al., 2002). Respondents use a four point Likert scale

with scores 1 (strongly disagree) to 4 (strongly agree). The mean score for each respondent is linearly transformed to a 0-100 scale. The total score represents the overall quality of the care transition. Lower total scale scores are indicative of a poorer quality transition where higher scores indicate a better transition (Coleman, 2007).

The CTM was modified as discussed below in order to capture parent perception of care coordination in preparation for discharge from the hospital at the time of hospital discharge. Currently, there are no tools available that accurately assess parent's perception of coordination of care in preparation for hospital discharge. The CTM was developed and validated with older adult patients who required skilled nursing care at discharge and their caregivers. The tool is applicable to parents of solid organ transplant recipients because parents are the caregivers and solid organ transplant recipients require continued medical care at the time of discharge from the hospital. The tool was designed to ask about the transition after discharge (Coleman et al., 2002). The CTM was used in this study to measure parent's perception of care coordination at the time of hospital discharge. The questions are relevant to the time of discharge and each question was slightly modified to address this time point.

There are four key domains measured in the CTM: transfer of information, preparation of the patient and caregiver, self management support, and empowerment to address preferences. Psychometric testing of the CTM included content validity, construct validity, floor and ceiling effects, and intra-item variation. Construct validity was obtained by comparing specific items of the CTM to similar items of an existing measure developed by Hendriks and colleagues (2001) to measure the quality of hospital discharge from the perspective of the patient (Coleman et al., 2002). The CTM has

reasonable construct validity based on inter-item correlation with Hendriks and colleagues measure (Coleman et al., 2002). The tool has a Cronbach's alpha of .93 and was shown to successfully discriminate between patients discharged from the hospital that did and did not have a subsequent emergency department visit or re-hospitalization (Coleman, Mahoney, & Parry, 2005). The CTM maintained a high internal consistency when used with diverse populations with a Cronbach's alpha coefficient ranging from .93 to .96 in African Americans, Hispanic Americans, and rural dwelling participants. Similarly high levels of reliability ranging from .93 to .95 were reported for patients grouped by age, gender, educational status, and self-reported health status (Parry, Mahoney, Chalmers, & Coleman, 2008).

The CTM is a fifteen item measure of the quality of preparation for care transitions, and for the purpose of this study, was completed at the time of hospital discharge. Since the original tool was developed for the older adult population, the questions are phrased in the first person. In order to use the CTM for this study, the questions were changed slightly to reflect the parent's perception based on their child's health condition and to reflect completion at the time of discharge from the hospital. For example: Question 1 on the original CTM reads, "Before I left the hospital, the staff and I agreed about clear health goals for me and how these would be reached". In order to fit with this study the question was modified to say, "At the time of hospital discharge, the staff and I agreed about clear health goals for my child and how these would be reached". Each of the fifteen questions was slightly modified to ensure that the parent was answering the question based on the time of hospital discharge and coordination of their child's health condition, solid organ transplant recipient. The tool was completed within

four hours of hospital discharge. The results provide information on how well parents feel the discharge process was coordinated on the day of hospital discharge. Cronbach's alpha reliability coefficient was calculated for the modified scale to evaluate the use of the scale in this study population.

*(f) Family Impact (Appendix B).* Parents completed the PedsQL Family Impact Module (Varni et al., 2004), a 36-item measure comprised of eight dimensions of parent and family functioning including: parent physical, emotional, social, and cognitive functioning, communication, worry, daily activities, and family relationships. Parents rate the degree that each topic has been a problem for the parent/the family as a result of their child's health in the last 30 days. Parents rate each topic on a 5-point scale ranging from 0 'Never' to 4 'Almost Always'. The resultant raw scores are reverse coded and linearly transformed to a 0-100 scale. Higher scores indicate better parent or family functioning. A total score and two summary scores, a Parent Health Related Quality of Life (HRQOL) Summary Score and a Family Functioning Summary Score, can be computed. This is a well validated instrument with excellent psychometric properties: total scale score ( $\alpha = 0.97$ ), parent health-related quality of life summary score ( $\alpha = 0.96$ ), and the family functioning summary score ( $\alpha = 0.90$ ).

The PedsQL Family Impact Module was considered both reliable and valid for assessing the impact of a chronic health condition in a population of pediatric hematology and oncology patients in Brazil (Scarpelli et al., 2008). The PedsQL Family Impact Module distinguished between families with children in a long-term care facility and families whose children resided at home (Varni et al., 2004). For this study, the PedsQL was administered in person within four hours before discharge on the day of hospital



discharge and by telephone interview three weeks following hospital discharge. Both modes of administration result in similar interpretations of the tool (Varni, Limbers, & Newman, 2009).

The tool was completed on the day of hospital discharge in order to measure the relationship of readiness for discharge with family responses to the post-transplant experience. The pre-transplant phase poses significant stressors for the family (Bolden & Wicks, 2008; Suddaby et al., 1997; Zelikovsky et al., 2007). The completion of the tool at hospital discharge will allow the researcher to identify the parent perspective four weeks (30 days) before hospital discharge, a time period which included the transplant hospitalization and the immediate period prior to the hospital stay.

*(2) A post-discharge telephone or in-person interview at a hospital clinic was used to collect the following data at 3 weeks post-discharge:*

*(a) Post Discharge Coping Difficulty Scale (Appendix B).* The Post Discharge Coping Difficulty Scale (PDCDS) is a 10-item scale that measures the parent's perception of stress, recovery, self care and management, support, confidence in care provided, and child's adjustment after discharge from the hospital. The tool asks parents to rate the responses on a scale of '0' (indicating 'not at all, none at all, or not ready') to '10' (indicating 'a great deal, extremely, completely, or totally ready'). Included with the quantitative scale are follow-up probing questions asking the parent for more detail in a qualitative form on 'what has been stressful or difficult?' Overall, higher scores mean the parent is experiencing more difficulty coping (Weiss et al., 2008). In a study exploring readiness for discharge in parents of hospitalized children, a Cronbach's alpha reliability coefficient was high at .84. Construct validity was verified with factor analysis

as having a single factor structure accounting for 39% of scale variance. Predictive validity of the instrument was supported because higher scores of PDCDS were related to a higher utilization of healthcare resources (Weiss et al., 2008).

The PDCDS was used in this study because it was developed to measure of coping at a specific time point, following hospital discharge (Weiss et al., 2008). The PDCDS is the best fit for this study because the relationship between readiness for hospital discharge and parent coping is being measured three weeks after hospital discharge.

Parents were also asked an open-ended question to address whether there are events that affected the ability to cope since hospital discharge. The open-ended question states, “What positively or negatively affected your ability to cope in the last three weeks following hospital discharge?” The answer to this question provided specific detail about what may be contributing to parent coping after hospital discharge and may provide insight for future intervention research.

*(b) Post-discharge Utilization of Healthcare Services (Appendix B).* Utilization of healthcare services was assessed during a post-discharge interview. Occurrences of self-reported utilization activities were recorded in dichotomous format (yes/no) and clarified with brief response questions to provide further detail (Weiss et al., 2008).

The following questions were used to identify utilization of healthcare resources:

- 1) Calls or a visit to the health care provider was asked in a dichotomous format.

If a parent responds ‘yes’, clarification was completed by asking the type of visit (scheduled or unscheduled) and the number of scheduled or unscheduled

visits. If the visit to the doctor was unscheduled, parents were asked to clarify the reason for the unscheduled visit.

- 2) Calls to the hospital were asked in a dichotomous format. If a parent responded 'yes', clarification was requested by asking who at the hospital was called and for what reason.
- 3) Visits to an urgent care or emergency room since discharge was asked in a dichotomous format. If a parent responds 'yes', clarification was requested by asking reason for the visit to an urgent care or emergency department and coded as transplant or not transplant-related.
- 4) Readmissions to the hospital were asked in a dichotomous format. If a parent responded 'yes', clarification was requested by asking the reason for hospital readmission in order to assess whether the admission is transplant or non transplant-related.

The parent was also asked to describe their transition experience by answering two open-ended questions, "What do you know now that you would like to have known before your child's discharge?" and "What positively or negatively affected your ability to cope in the last three weeks following hospital discharge?" Responses to these questions provided detail about what parents need in order to be successful in the home environment.

*(c) Adherence (Appendix B).* Adherence was measured by parent self-report of adherence difficulty and medication discrepancy. Self-report was used to assess the parent's perception of adherence difficulty to the medical regimen. The Medication Event Monitoring System (MEMS) was not used as a means to assess adherence due to the cost

of the MEMS system and the difficulty in tracking adherence with younger age groups that utilize liquid medications (Shellmer & Zelikovsky, 2007). The measurement of medication levels were not used in this study because of the short time interval following hospital discharge that levels would be measured. The use of standard deviations in measuring drug levels has been used as a measure of adherence to immunosuppressive medications over a time period of one year (Fredericks et al., 2008; Shemesh et al., 2004; Shemesh et al., 2008). Medication levels tend to fluctuate following the transplant operation and over time, the three week time interval is not a sufficient period of time to measure the standard deviation of drug levels. The clinician assessment was not used because the purpose is to determine the parent's perception of adherence to the medical regimen and not the clinician's perception of adherence.

Adherence was assessed using both quantitative and qualitative data. The parent was asked to answer the questions, 1) "How difficult has it been to administer the medications as prescribed at the time of hospital discharge?" and 2) "How difficult has it been to attend the laboratory and clinic follow-up since going home from the hospital?" The self-report scale asked the parent to answer each question on a scale from '0' (indicating 'not at all') to '10' (indicating 'totally'). This format was chosen because it is similar formatting to the other scales used in the study. Youngblut and Casper (1993) pointed out that single-item indicators asking study participants for a global rating of a concept are consistent with nursing's focus on holistic phenomena and individualized care, and the reliability and validity of single-item indicators have been supported (Sagrestano et al., 2002; Youngblut & Casper, 1993).

Adherence was also measured by identifying medication list discrepancies through medication reconciliation (Appendix B). Parents and transplant coordinators separately listed current patient medications. The transplant center was asked to provide a medication list from the exact date of the parent's response in order to ensure an accurate assessment of medication adherence. Specifically, the medication list consists of the following information: name of medication, dose of medication in milligrams (and milliliters if the dose is a suspension), and times each medication is given. The parent list of medications was compared to the medication list that was provided by the transplant center in order to assess accuracy of medication administration and adherence to the prescribed medication regimen.

A small portion of this study was qualitative in nature in order to provide depth to the quantitative responses not allowed for in the survey format. The pediatric solid organ transplant population is unique and the qualitative responses from parents will allow for clarification and elaboration of concepts specific to the population.

Qualitative open-ended questions provided depth and clarification to the quantitative response. The parent was asked the following questions: 1) "Tell me about the challenges, if any, you have had with medication administration", 2) "What, if anything, would help you to better or more easily manage your child's medications?", 3) "Tell me about the challenges, if any, you have had following up with clinic appointments and laboratory appointments?" Answers to these questions give insight to the challenges families have managing the complex medical needs of the child once in the home environment.

*(d) Family Impact (Appendix B).* Parents completed the PedsQL Family Impact Module (Varni et al., 2004). The tool dimensions and psychometrics are described above in the discharge survey section.

Currently, the PedsQL form asks parents to respond to the questions as he/she reflects on the last 30 days. This was modified when administering the questionnaire in the post-discharge survey to say, “Since hospital discharge” so the parent is assessing the family functioning in the last 3 weeks following hospital discharge and does not include the time period while the child is recovering in the hospital after the transplant operation. The parent completed this tool in both the hospital discharge survey packet and post-discharge survey packet to allow for comparative analysis and evaluation of family impact has changed significantly since hospital discharge.

Level of data measurement for the tools is provided in the Table 2.

Research Question	Measure or Questionnaire	Level of Measurement	Type of Variable
What is the relationship between care coordination and readiness for discharge among parents of children who experience a solid organ transplant?	Care Transition Measure	Interval	Independent variable
	RHDS	Interval	Dependent variable
What is the relationship between discharge teaching and readiness for discharge among parents of children who experience a solid organ transplant?	QDTS	Interval	Independent variable
	RHDS	Interval	Dependent variable
What is the relationship between parent readiness for hospital discharge and parent coping difficulty after discharge?	RHDS	Interval	Independent variable
	PDCDS	Interval	Dependent variable
What is the relationship between parent readiness for hospital discharge and family impact after discharge?	RHDS	Interval	Independent variable
	PedsQL	Interval	Dependent variable
What is the relationship between parent readiness for hospital discharge and adherence following hospital discharge transplant?	RHDS	Interval	Independent variable
	Adherence Difficulty Items	Interval	Dependent variable
	Medication Discrepancy	Nominal	Dependent variable
What is the relationship between parent readiness for hospital discharge and parent utilization of healthcare resources after discharge?	RHDS	Interval	Independent variable
	Utilization of Healthcare Resources	Nominal	Dependent variables
	RHDS	Interval	Independent variable
	Utilization "Total use" variable	Count	Dependent variable

Table 2. Relationship of Research Question and Measurement

### *Data Collection Methods*

Data collection took place at Children's Hospital of Wisconsin (CHW) in Milwaukee, Wisconsin, Children's Memorial Hospital (CMH) in Chicago, Illinois, and Levine Children's Hospital in North Carolina (LCH). Prior to study initiation, research assistants and transplant coordinators involved with the study were trained in the study procedures, Health Insurance Portability and Accountability Act compliance, principles of informed consent, recruitment techniques, and telephone interviewing by the principal investigator.

Within two days prior to the anticipated discharge date, as identified by the transplant team or transplant coordinator, the principal investigator, transplant coordinator or research staff confirmed eligibility from inpatient hospital records of parents by ensuring that the child would be discharged from the hospital with a primary diagnosis of status-post heart, kidney, or liver transplantation. The research team (principal investigator, transplant coordinator, or research staff) then described the study to the potential participant, obtained informed consent, and abstracted required data elements from the medical record. The required data elements included completion of the hospitalization characteristics form.

Data collection took place on the inpatient units of each of the three participating pediatric transplant centers. Within four hours prior to discharge, the parent received a discharge survey containing the parent and child demographic form, Readiness for Hospital Discharge Scale, Quality of Discharge Teaching Scale, Care Transition Measure, and PedsQL Family Impact Module. The discharge survey forms took approximately 40 minutes to complete (5 minutes to complete the parent and child



demographic form, 10 minutes to complete the Readiness for Hospital Discharge Scale, 10 minutes to complete the Quality of Discharge Teaching Scale, 5 minutes to complete the Care Transition Measure, and 10 minutes to complete the PedsQL Family Impact Module). The parent completed the study forms prior to hospital discharge, placed the completed forms in a sealed envelope, and returned the envelope to a member of the research team.

At three weeks post-discharge, parents completed the post-discharge interview survey. Data collection took place as a telephone survey. A small number of patients completed a face-to-face interview in the outpatient follow-up clinic setting at CHW because they could not be contacted by telephone. The post-discharge survey consisted of the Post Discharge Coping Difficulty Scale and post-discharge utilization of healthcare form, PedsQL Family Impact Module, and questions regarding adherence to the medical regimen. The post-discharge forms took approximately 30 minutes to complete (10 minutes to complete the Post Discharge Coping Difficulty Scale and utilization of healthcare resources form, 10 minutes to complete the PedsQL Family Impact Module, and 10 minutes to complete the questions regarding adherence). The transplant center portion of the adherence form was completed by the transplant center coordinator by responding to an email sent by the principal investigator or research assistant.

Since data collection took place at three different institutions it was crucial for the principal investigator to achieve consistency of data collection. Each of the transplant coordinators and research assistants involved in patient consent or data collection were thoroughly trained in the accurate implementation of study questionnaires. The individuals collecting the data were trained thoroughly and had protocols to follow to

enhance accurate implementation. The principal investigator travelled to CMH to ensure complete understanding of the study design and implementation and completed a study orientation over the phone for LCH.

The principal investigator maintained all records at CHW. The data from CMH and LCH was sent to the principal investigator at CHW in a pre-stamped and pre-addressed envelope. Data from CMH and LCH included identifying information in order for the principal investigator and/or research staff at CHW to complete the post-discharge survey at three weeks following hospital discharge. Each parent received a total of \$20.00 in the form of a gift certificate for participation in the research study. The parent received \$10.00 upon completion of the hospital discharge survey packet and the remaining \$10.00 upon completion of the post-discharge survey packet three weeks following hospital discharge.

#### *Research Procedures*

The time frame of three weeks following hospital discharge to complete the post-discharge surveys was selected in order to allow parents to develop a routine for the child in the home environment. A one or two week time period following hospital discharge may be too soon to assess the level of coping, family impact, adherence, and utilization of healthcare services. Three weeks provided time for the parent and family to develop a routine and organize care that worked best for each individual family. The rationale for choosing this time period was to capture the impact of readiness on the early post-hospital period, when families are beginning to develop patterns of functioning. The study findings may indicate the need for future research at three weeks post-discharge if families are not coping, the child's illness has a negative impact on the family, adherence

to the medical regimen is compromised, or there is a significant use of healthcare resources.

### *Methodological Rigor*

Methodological rigor of the research study was addressed by consideration of potential threats to internal and external validity and selection of research methods. Internal validity assesses whether the results of a study can be attributed to the independent variables or must be explained by other extraneous factors (Orcher, 2005; Polit & Beck, 2008). True experiments have a high degree of internal validity because of the control that randomization purports over the data, enabling the researcher to rule out most alternative explanations for the results (Polit & Beck, 2008). This study design may be affected by a number of threats to internal validity because it is a non-experimental design.

A major threat to internal validity for this research project is sample size. The sample size of 36 is sufficient to analyze each individual research questions as a preliminary investigation but is not sufficient for complex modeling of inter-relationships among variables or mediating and moderating effects. The population of interest (pediatric heart, kidney, and liver transplant recipients) is limited due to the relatively rare occurrence of pediatric solid organ transplants. The United Network for Organ Sharing (UNOS) reported that only 1,796 pediatric heart, kidney, and liver transplants took place in the United States in 2009 (United Network for Organ Sharing, 2010). These transplants take place in nearly all 50 states in the United States which limits the ability of researchers to directly access this population. The study sample accesses

parents from three major pediatric solid organ transplant centers in Wisconsin, Illinois and North Carolina.

Despite the fact that the sample size is small, it is a strength that the study sample includes parents from three different institutions. Accessing parents from more than one institution allows the researcher to capture a broader range of the hospital discharge experiences because each institution has different transplant coordination processes and services for transplant recipients.

Another potential threat to internal validity is maturation. Maturation is the effect that naturally occurring processes (based on time) have on participants and ultimately on the study results (Polit & Beck, 2008). Maturation can pose a threat to internal validity with research in the pediatric population based on the various developmental stages that children experience (Orcher, 2005). The current research design does not pose a significant threat to maturation because the time period of three weeks that is given for the completion of the hospital discharge survey and post-discharge survey is short. A time period of three weeks does not allow a child to move from one developmental stage to another, such as childhood to adolescence. Furthermore, the focus of the study is to examine the experience of families over time and is not based on a particular intervention that could be affected by maturation.

History is another important threat to internal validity to consider. History refers to an event that occurs outside of the study that might have caused the observed change in parent behavior (Orcher, 2005). A number of life events may take place during the three week post-discharge time period that may positively or negatively impact the parent responses to the three week questionnaires. This may include a significant family event

such as death of a family member or patient readmission to the hospital. This potential threat was assessed in the post-discharge survey by asking an open-ended question about things that positively or negatively affected their ability to cope in the last three weeks.

Testing is the threat to internal validity that results from learning how to answer survey questions based on the response to the first survey questions. Testing is not a significant threat in this study design because only one instrument, the PedsQL Family Impact Module will be utilized twice (at the time of hospital discharge and at the three week post-discharge follow-up). Although there are two time points for data collection, this is not a pre- and post-test design (Orcher, 2005). Knowledge of the questions could potentially impact parent responses, but is not anticipated because the life events are markedly different.

In longitudinal studies attrition can cause potential problems with completion of study requirements (Polit & Beck, 2008). Mortality is an unlikely threat to internal validity because attrition will be limited due to the intense follow-up required for transplant recipients (Polit & Beck, 2008). It is difficult for a pediatric solid organ transplant recipient to be lost to follow-up in the first three weeks following hospital discharge because laboratory and clinic follow-up is frequent and expected. The study process ensures that the parents can be contacted by telephone for the three week follow-up survey. If a parent cannot be contacted by phone the follow-up questionnaires may also be completed at a follow-up clinic appointment as a face-to-face interview. The only mortality or loss of participants would be related to death after transplant, which is also limited albeit a possibility. The most recent transplant statistics reported for pediatric transplants between 2004 and 2005 report the following three month survival rates: heart

91%, deceased donor liver 89%, live donor liver 88%, deceased donor kidney 97%, and liver donor kidney 91% (Health Resources and Service Administration, 2007).

External validity must be considered in addition to internal validity. The external validity of a study is the extent to which the research findings are generalizable to other individuals and other settings (Orcher, 2005; Polit & Beck, 2008). Selection bias, any bias that might have occurred in the selection of study participants, is certainly a threat to external validity in this research design. The parent identified as the primary caregiver for this study was selected based on the fact that his/her child had received a heart, kidney, or liver transplant at one of three transplant centers in the United States. As mentioned above, accessing parents from more than one institution allowed the researcher to capture a broader range of the hospital discharge experience based on the variation in transplant coordination processes and services for transplant recipients. The homogeneity of the study population may improve the overall internal threats to validity, but the results are generalizable to a very narrow population of patients based on the rare health condition that is required for inclusion in the study. The results specifically provide insight on the transition from acute to chronic illness which may be generalizable to other pediatric chronic illness populations. This study is the first to investigate the parental discharge readiness in this population and will begin the construction of a body of knowledge specific to solid organ transplant parents while contributing to the overall body of knowledge about transitions to chronic illness.

Several limitations are present in this preliminary study of this topic and patient population. The study design is not experimental research and ultimately poses a number

of threats to both internal and external validity detailed above. Random sampling would help to minimize these threats although it was not possible in this research design.

Oversight by the principal investigator and existing relationships with transplant coordinators at all sites reduced limitations associated with the difficulty that data collection at multiple sites may pose. These challenges were addressed by the principal investigator providing an on-site review of the study procedures for data collection at CHW and CMH and a telephone orientation at LCH. The principal investigator and trained research assistant pre-assembled parent packets to minimize error at the data collection points. The principal investigator was available by phone, email and pager to answer any questions that arose during data collection.

The small sample size is a limitation to the study because it does not lend itself to a full path analysis of the relationships in the model. Therefore, the results of this study provide preliminary data for development of larger scale investigations in the future.

Despite the aforementioned limitation, this study contributes to the advancement of nursing knowledge because the results provide valuable information to nurses as they care for a unique and vulnerable population, pediatric solid organ transplant recipients. Although the small sample size poses limitations to the study, the population is one of a rare and infrequent chronic illness. The research fills a gap in the body of literature related to parental discharge readiness following the child's solid organ transplant procedure.

#### *Statistical Procedures and Rationale*

All analyses were conducted with the Statistical Package for the Social Sciences, Version 17.0 (SPSS, Inc.). Probability levels of  $p < .05$  were used for determining

statistical significance in all analyses. Descriptive analyses were conducted to examine normality of distribution. In addition, descriptive analyses provided summary information about participant characteristics including child, parent, and hospital factors at the time of hospital discharge. The plan for data analyses for each research question is listed below.

For Research Questions 1 and 2, the predictor variables, Care Transition Measure and Quality of Discharge Teaching Scale, were entered simultaneously into a multiple regression equation with Readiness for Hospital Discharge Scale as the dependent variable. Multiple regression analyses was first conducted using the total scale score for Quality of Discharge Teaching Scale, the total scale score for care coordination, and the total score for Readiness for Hospital Discharge Scale.

Further regression analyses explored the same relationships using Quality of Discharge Teaching Scale and Readiness for Hospital Discharge Scale subscale scores. The two subscales of the Quality of Discharge Teaching Scale (content received, and delivery) were run as separate regression analyses with the Readiness for Hospital Discharge Scale subscales (parent's personal status, child's personal status, knowledge, coping ability, and expected support). The additional analyses to explore the relationship between the subscales will increase the family wise error rate (Tabachnick & Fidell, 2007). This study has a small sample size and exploratory analyses were run recognizing the family wise error rate.

Overall, six regression analyses were completed for the purpose of answering these two research questions: 1) Quality of Discharge Teaching Scale and Care Transition Measure with Readiness for Hospital Discharge Scale total scores; 2) Quality of



Discharge Teaching Scale subscales (content received and delivery) with Readiness for Hospital Discharge Scale subscale parent's personal status; 3) Quality of Discharge Teaching Scale subscales (content received and delivery) with Readiness for Hospital Discharge Scale subscale child's personal status; 4) Quality of Discharge Teaching Scale subscales (content received and delivery) with Readiness for Hospital Discharge Scale subscale knowledge; 5) Quality of Discharge Teaching Scale subscales (content received and delivery) with Readiness for Hospital Discharge Scale subscale coping ability; and 6) Quality of Discharge Teaching Scale subscales (content received and delivery) with Readiness for Hospital Discharge Scale subscale expected support.

Multiple regression techniques were applied to these two research questions due to the fact that there are two independent variables and one dependent variable (Tabachnick & Fidell, 2007). There were number of issues addressed before performing multiple regression in order to ensure appropriate and accurate analysis of data. The ratio of cases to independent variables was addressed by ensuring appropriate sample size of 36 as indicated by G Power analysis.

The assumptions for multiple regression were addressed by analyzing the sample for normality, linearity, and homoscedasticity (Tabachnick & Fidell, 2007). The assumptions were addressed through analysis of the residuals or differences between the obtained and predicted dependent variable scores (Tabachnick & Fidell, 2007). Residual scatterplots were run in SPSS.

The assumption of normality revealed that errors of prediction are normally distributed around each score of the predicted variable (Tabachnick & Fidell, 2007). Based on the nature of the Quality of Discharge Teaching Scale and Readiness for

Hospital Discharge Scale and published research on the use of these tools, there is an assumption that the data may be negatively skewed (Weiss et al., 2008). Linearity of relationships was assessed between the predicted and dependent variable scores. If non-linearity was present, transformation of the independent or dependent variable would have been performed in order to meet this assumption for multiple regression because failure to meet linearity in regression would weaken the relationship under investigation (Tabachnick & Fidell, 2007).

The assumption of homoscedasticity states that the standard deviations of errors of prediction are approximately equal for all predicted dependent variable scores. If this assumption was not met, transformation of the variables would have been attempted to reduce heteroscedasticity. Failure to meet the assumption of homoscedasticity will weaken the relationship under investigation (Tabachnick & Fidell, 2007). Outliers in the sample were examined individually to see if they were extreme cases or actual outliers; inclusion of these potential data points will be addressed. Multicollinearity and singularity were addressed. Multicollinearity occurs when variables are too highly correlated and singularity occurs when variables are redundant or measuring the same concept (Howell, 2007). Multicollinearity and singularity create problems with the correlation matrix (Howell, 2007).

For Research Questions 3, 4, and 5 separate linear regression analyses were used for Readiness for Hospital Discharge Scale as the predictor variable with Post Discharge Coping Difficulty Scale, responses to the adherence difficulty with medication and adherence difficulty with clinic and lab follow-up, and the PedsQL Family Impact Module as the dependent variable. Assumptions for linear regression were similar to

those for multiple regression and were addressed in the same manner as discussed for research questions 1 and 2. Logistic regression was used for Readiness for Hospital Discharge Scale as the predictor variable with medication discrepancy.

A paired samples t-test was used to assess whether there was a significant change in parent report of family impact before and after transplant. A paired samples t-test was used because data on family impact is collected on two different occasions from the same parents. The variables were entered in a paired format. The paired samples t-test were used to identify whether there is a statistically significant ( $p < .05$ ) difference in the mean scores of family impact before and after transplant.

The following assumptions were assessed to assure for appropriate use of the paired t-test: random sampling, independence of observations, normal distribution, and homogeneity of variance (Pallant, 2007). The small sample size may impact the incidence for making a Type 1 or Type 2 error and will be assessed during data analysis (Pallant, 2007).

For Question 6, separate logistic regression analyses was used to determine the relationship of Readiness for Hospital Discharge Scale, an interval level variable, with each type of utilization (calls to provider, calls to the hospital, unscheduled office visits, emergency use, and readmission), which are each categorical level data (yes/no). The urgent care or emergency room visits were further broken down into transplant-related versus non-transplant-related visits for analyses in order to determine the type of services needed.

In addition to logistic regression analysis, a total utilization score was computed in order to measure the total use of healthcare resources after hospital discharge. A new

variable was labeled as the “total use” variable. The “total use variable” was a sum of the total number of unscheduled visits to the emergency room or urgent care visits and readmissions to the hospital. The “total use” variable was used in Poisson regression analysis because the dependent variable is a count variable. In the regression analysis, Readiness for Hospital Discharge Scale was the independent variable and the “total use” variable measuring the unscheduled healthcare visits was the dependent variable.

Logistic regression does not require assumptions about the distributions of the predictor variables including normal distribution, linear relationship, or equal variance within each group (Tabachnick & Fidell, 2007). Issues that were assessed for logistic regression include ratio of cases to variables, missing data, outliers, and multicollinearity (Tabachnick & Fidell, 2007).

As noted above, the individual relationships specified in the aforementioned research questions were analyzed for the purpose of this study. There are not enough subjects for a full path analysis of the relationships in the model.

Content analysis of the qualitative data is used to determine themes from the interpretation and categorization of the data (Elo & Kyngas, 2008; Polit & Beck, 2008). Content analysis is a systematic means of describing phenomena of interest allowing the researcher to enhance understanding of the data (Elo & Kyngas, 2008). The questions being posed to the participant are specific in order to provide more detail in regard to particular content areas including readiness for hospital discharge, coping, utilization of healthcare resources, and adherence to the medical regimen. The qualitative content was transcribed verbatim and subsequently categorized through consensus by two independent reviewers. Qualitative analysis is an iterative process where the resultant

themes reflect the area of interest in a reliable manner (Elo & Kyngas, 2008). Content analysis for each qualitative question included the generation of initial themes, re-analysis of data, and resultant final themes (Hesse-Biber & Leavy, 2006). The qualitative data is meaningful and important for this study because it gives insight and detail to the quantitative responses and may provide nursing with more specific interventions for this unique population of patients and parents.

#### *Human Subjects Protection*

Protection of human subjects was addressed by facility Institutional Review Board approval before beginning the research project. Institutional Review Board approval by expedited review at the CHW, CMH, LCH and Marquette University Institutional Review Board was completed before study recruitment and data collection began.

There was minimal risk to the participant as this was not an intervention study. Consent was voluntary and participants were aware of their right to withdraw from the study at anytime. All participants were reminded that withdrawal from the study may take place at anytime and would in no way affect the care of the child and family.

Strict confidentiality was maintained throughout the duration of the study. Participant confidentiality was addressed through the assignment of a unique identifying number which was used throughout the study. Original data forms were kept in a locked office accessible only by authorized research staff. De-identified data were entered into a database in a protected folder, configured to allow access only to the principal investigator. The principal investigator monitored adherence to the protocol and supervised all research staff that assisted to collect and code data.

CMH and LCH sent data in two separate envelopes: the study identification number was sent in one envelope and the identifier data with contact information was sent in a second envelope. Both envelopes from CMH and LCH were sent to the principal investigator via a pre-addressed and pre-stamped envelope marked “confidential”. CMH and LCH also maintained a copy of the study data locked at their facility until the principal investigator received the data or according to their hospital specific Institutional Review Board guidelines.

### *Summary*

This chapter provided a detailed description of the research design and methods to answer each of the six research questions for the dissertation research. The research methods outlined the study setting and how participants were recruited. The study variables and instruments were described in detail providing rationale for use and reliability and validity when indicated. The statistical procedures and rationale were described according to each of the six research questions. Protection of human subjects was described.

## CHAPTER FOUR

### Results

Chapter Four includes sample characteristics, descriptive statistics for study measures, and results of data analysis for each of the six research questions listed in Chapter Three. The major findings of the study are presented in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D) are not duplicated in this section. Additional analyses presented below include: (1) demographic and scale characteristics not presented in the major study findings manuscript and (2) additional detail on findings for each research question along with qualitative analyses for corresponding open-ended questions. Content analysis was used to analyze each of the qualitative responses.

#### *Demographics*

Demographic and hospitalization characteristics of the sample are presented in the manuscript Appendix D. Demographics not listed in appendix D indicate that many parent respondents had other children in the home (average of 2.1 [s.d 1.1] total children in the home [range 1-5]). The transplant-related care needs following discharge from the hospital included 14 patients who had 1 additional need, 6 patients with 2 additional needs, 1 patient with 3 additional needs, and 1 patient with 4 additional needs.

#### *Scale Statistics*

Scale statistics are reported in the manuscript. Two scale statistics not reported in the manuscript are the Quality of Discharge Teaching Scale (QDTS) content needed subscale and the PedsQL Family Impact subscales. The QDTS content needed subscale

has 6 items. The item mean was 6.0 (s.d. 1.4) and item mean range was 4.0-7.3 with a Cronbach's Alpha = .70. Parents reported a low to moderate amount of content needed on the six subscale questions (mean range 4.0-7.3, s.d. range 2.8-3.5 on a scale of 0 to 10) and a moderate to high amount of content received on the six subscale items (mean range 4.8-8.9, s.d. range 1.8-3.7 on a scale of 0 to 10). The mean amount of content received was higher than the mean amount of content needed when comparing the parallel items.

The PedsQL family impact scale contains eight subscales: physical functioning, emotional functioning, social functioning, cognitive functioning, communication, worry, daily activities, and family relationships. The means and standard deviations for each of the eight subscales are presented in Table 1.

PedsQL Family Impact Subscale	Mean (s.d.)
Physical functioning	72.8 (18.2)
Emotional functioning	81.7 (14.1)
Social functioning	75.0 (21.3)
Cognitive functioning	81.8 (17.7)
Communication	81.8 (21.7)
Worry	47.9 (18.2)
Daily activities	62.6 (28.2)
Family relationships	81.4 (19.5)

Table 1. Subscale Scores for Family Impact Module

### *Research Question 1*

#### **What is the relationship between care coordination and readiness for discharge among parents of children who experience a solid organ transplant?**

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were no extreme cases or significant outliers.



The results are in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D).

*Research Question 2*

**What is the relationship between discharge teaching and readiness for discharge among parents of children who experience a solid organ transplant?**

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were no extreme cases or significant outliers.

The majority of results are listed in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D). The relationship between RHDS and QDTS was also analyzed with multiple regression. Multiple regression was used to explore the relationship between the QDTS subscales (content received and delivery) and RHDS total scale as well as with each of the five RHDS subscales (Table 2). No significant relationships were identified between any total scale or subscale measures of QDTS and RHDS.

Independent Variable	Dependent Variable	Model Statistics	B	SE B	Stand $\beta$	t	p
QDTS - Content received -Delivery	RHDS total scale	F(2,34) = .51, p = .61, R <sup>2</sup> = .03	.01	.58	.00	0.2	.98
			.42	.50	.17	.84	.41
QDTS  -Content received -Delivery  -Content received -Delivery  -Content received -Delivery  -Content received -Delivery  -Content received -Delivery	RHDS subscales						
	<i>Parent Personal Status</i>	F(2,34) = .25, p = .78, R <sup>2</sup> = -.04	-.08	.19	-.09	-.43	.67
			.11	.16	.14	.71	.48
	<i>Child Personal Status</i>	F(2,34) = .34, p = .72, R <sup>2</sup> = -.04	.12	.16	.15	.73	.47
			-.10	.14	-.15	-.72	.48
	<i>Knowledge</i>	F(2,34) = 1.70, p = .20, R <sup>2</sup> = .04	-.04	.14	-.06	-.29	.77
.20			.12	.33	1.69	.10	
<i>Coping</i>	F(2,34) = .33, p = .72, R <sup>2</sup> = -.04	-.02	.06	-.07	-.37	.72	
		.04	.05	.16	.81	.42	
<i>Support</i>	F(2,34) = 1.03, p = .37, R <sup>2</sup> = .00	.04	.18	.04	.21	.83	
		.16	.15	.21	1.08	.29	

Quality of Discharge Teaching (QDTS), Readiness for Hospital Discharge Scale (RHDS)

Table 2. Quality of Discharge Teaching and Readiness for Hospital Discharge

Analysis was combined in order to explore the relationship between both QDTS and CTM with RHDS. Both the QDTS and CTM were predictor variables in a multiple regression equation (Table 3). Similar to results of separate linear regression, CTM was the only significant predictor of RHDS. The p values are slightly different than those

presented in the paper because both CTM and QDTS were entered simultaneously into the regression equation.

Independent Variable	Model Statistics	B	SE B	Standardized $\beta$	t	p
CTM and QDTS	F(2,34) = 3.64, p = .04, R <sup>2</sup> = .13					
CTM		1.25	.44	.44	2.51	<b>.02</b>
QDTS		-.06	.26	-.04	-.23	.82

Care Transition Measure (CTM); Quality of Discharge Teaching (QDTS)

Table 3. Care Transition and Discharge Teaching with Readiness for Hospital Discharge

The QDTS was enhanced with two additional qualitative questions to gain insight to the teaching experience. These were written responses completed on the day of hospital discharge. Analyses of each of the qualitative responses were conducted by the principal investigator and another transplant nurse practitioner with 7 years of transplant experience at Children’s Hospital of Wisconsin. Consensus was subsequently reached by discussion and themes for each of the questions were identified.

The first QDTS open-ended qualitative question was, “What were the most important topics for you to learn about in preparing to go home?” Content analysis of the data resulted in three themes: (1) Medications, (2) Restrictions and (3) Warning signs. The ‘Medications’ theme was the most common as parents were most interested in learning about medication side effects and proper medication administration. The ‘Restrictions’ theme represents parents concerns for what their child can and cannot do in the home environment. The third and final theme was ‘Warning signs’ and captured parents concerns for knowing exactly who and when to call with questions or concerns after hospital discharge.

The three themes that emerged from the qualitative responses related to three quantitative items on the QDTS; information needed to care for the child, information needed about medical needs and treatments, and information needed about who and when to call with problems. The three quantitative items were rated high (mean range 6.8 to 7.3 out of 10) and the parallel items for content received were rated higher indicating that at the time of hospital discharge parents felt they received more information than they needed about how to care for the child, care for the medical needs, and who to call with problems.

The second QDTS open-ended qualitative question was, “What helped or interfered with you feeling confident to care for your child after discharge?” Content analysis was completed for both “helped” and “interfered” components of the question. The responses to “helped to feel more confident to care for your child after discharge” resulted in two themes: (1) Education and (2) Support. ‘Education’ was helpful when it was consistent, from knowledgeable staff, repetitive, and offered hands on experience. The comments from parents highlight specific components of education that build confidence including education from staff that is knowledgeable about the post-transplant regimen. Parents also benefited from learning about medications or post-transplant complications on more than one occasion. ‘Support’ from nurses and family were also identified as helpful. The hospital associated home away from home or “Kohl’s house” provided support to parents who lived far from the transplant hospital. Education and support are important concepts for the transplant team to address before hospital discharge in order to assure parents are confident to successfully care for the child in the home environment.

Three themes emerged for “interfered with feeling confident to care for your child after discharge”: (1) Amount of education, (2) The unknown and (3) Lack of support. The ‘Amount of education’ needed during the transplant hospitalization was identified as interfering with parents ability to feel confident to continue care at home. Transplant families receive education including but not limited to medication administration, medication side effects, and signs of rejection or infection. The amount of education may be overwhelming but is critical in order to ensure accurate medication administration and ability to know when to call the transplant team. Parents reported ‘The unknown’ interfered with their ability to feel confident. Transplant parents felt that having to be prepared for what could happen interfered with their confidence level. The post-transplant period may involve complications resulting in emergency department visits or re-hospitalizations and parents are challenged by not knowing when or if these potential complications may occur for their child. Finally, ‘Lack of support’ from family or the transplant team was listed as the third theme for interfering with a parent’s confidence to take their child home from the hospital. One parent described this lack of support by writing, “I feel confident, I just feel they [the hospital staff] need to feel more confident in us”. Parents look to the transplant team for guidance and support. The transplant team plays an important role in building parent’s confidence to continue care at home after hospital discharge.

### *Research Question 3*

**What is the relationship between parent readiness for hospital discharge and parent coping after discharge?**

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were no extreme cases or significant outliers.

The results are in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D). The relationship between RHDS and PDCDS was analyzed using linear regression (Table 4). RHDS was predictive of PDCDS.

Independent Variable	Dependent Variable	Model Statistics	B	SE B	Standardized $\beta$	t	p
RHDS	PDCDS	F(1,35) = 28.52, p <.001 R <sup>2</sup> = .45	-.26	.05	-.67	-5.34	<.001

Readiness for Hospital Discharge Scale (RHDS), Post Discharge Coping Difficulty Scale (PDCDS)

Table 4. Linear Regression for Readiness for Hospital Discharge and Post Discharge Coping Difficulty

The PDCDS asked seven qualitative questions to provide insight to the challenges parents experience in the first three weeks following hospital discharge. Five of the qualitative questions were in the original scale and two additional items were added for this study.

The first qualitative question asked, “What has been stressful?” The two themes that emerged from this question were: (1) Getting into a family routine and (2) Worry. The first theme was common and thread through nearly each of the parent responses. ‘Getting into a family routine’ meant juggling other children, getting to and from hospital for clinic and lab appointments, ensuring accurate medication administration, and getting back to work or school. Families appear to be trying to figure it all out during the first

three weeks and get into a rhythm or pattern of fitting it all in so that the child is receiving the best care possible at home. The second theme was 'Worry'. Parents are worried because they are watching for signs and symptoms of complications, concerned for rejection, and worried about good immunosuppression drug levels. Parents are not only managing the daily needs of the transplanted child but also managing day-to-day life. The families are trying to create a new normal that not only incorporates the daily tasks that need to be completed related to post-transplant care but also includes dealing with the associated worry for unknown complications that may occur.

The next three qualitative questions focus on difficulties parents face caring for the transplanted child. Parents were specifically asked to discuss difficulties regarding their child's recovery, caring for their child, and managing their child's medical condition.

The second qualitative question asked in the PDCDS was, "What has been difficult about your child's recovery?" Four themes resulted from this question: (1) Medications, (2) Daily living or routines (3) Complications or medical issues and (4) The unknown. Parents reported that a difficult part of the child's recovery at home was 'Medications'. Accurate medication administration was challenging for parents because it was difficult to remember to give medications at the right time. 'Daily living or routines' was the second theme that emerged. Parents specifically described concerns for picking up their child the correct way so they did not hurt their child. Parents also described that it was difficult to explain how life is different to the child. Other daily lifestyle changes reported include drinking more water and restrictions on the child's activity. The third theme is 'Complications or medical issues'. Parents reported

concerns for managing other medical related care such as a gastrostomy tubes, incisions, and infections. The final theme for this question is 'The unknown'. Parents reported difficulty not knowing what is going to happen after transplant in regard to possible complications or hospital readmissions. Another component of this theme is the parent having to watch their child go through everything related to the transplant such as laboratory draws, clinic appointments, and other transplant related procedures. Parents are not only faced with wondering about possible post-transplant complications but also their child's reaction to the diagnosis and treatment for the particular complication.

The third qualitative question asked, "What has been difficult in caring for your child?" There were three themes similar to the above themes: (1) Medications, (2) Daily living or routines and (3) Complications or medical issues. Parents described accurate medication administration as one of the difficulties caring for the child in the first three weeks following hospital discharge. The second theme that emerged from this question was 'Daily living or routines'. The post-transplant regimen is time consuming as parents are trying to put it all together with laboratory follow-up, clinic follow-up and other therapies for some transplant recipients. Parents describe trying to find a routine at home and are challenged by trying to lead a normal life within the context of potential transplant-related restrictions. The transplanted child is also trying to get back into a routine. One parent reported how difficult it was for her school aged child who wanted to return to school and see her friends. 'Complications and medical care' was the final theme that emerged from this question. The difficult part in caring for the transplanted child included readmissions to the hospital for complications that arose and other medical related care such as packing and treating incisions. There were two additional statements



from parents that did not fall into one of the aforementioned categories but captured important insight into this stage of recovery, “I was expecting much worse” and “Gets better as time progresses”. Parents face numerous stressors and challenges when they take their transplanted child home from the hospital, but are optimistic and resilient.

The fourth question asked of parents in the PDCDS was “What has been difficult about managing your child’s medical condition?” Three themes emerged: (1) Medications, (2) Daily living or routines and (3) Complications or medical issues. Parents reported that the difficulties surrounding ‘Medications’ included timing of medication administration. One of the parents stated, “Before transplant I did not worry about the timing of medications, and now it matters”. Other parents struggled with getting their child to take medications by mouth as opposed to using a nasogastric or gastrostomy tube. The second theme that emerged from this question was ‘Daily living or routines’. Driving back and forth to the hospital for frequent clinic and laboratory appointments created challenges for the family routine. Parents also described developing a new routine for sanitizing everything and felt it was difficult to go out in public because of their concern for sanitation. The third theme was ‘Complications or medical issues’. The medical issues were related to additional medical care transplant recipients required such as gastrostomy tube management.

The three aforementioned questions focusing on difficulties parents have caring for the transplanted child generated similar themes. Parents receive education in the hospital from the transplant team regarding the importance of medications. More specifically, parents are taught that the immunosuppression medications must be administered at specific times in order to be therapeutic and therefore minimize the risk

of rejection. Parents reported that medication administration was a difficult component to caring for their transplanted child in each of the three above mentioned questions. Transplant providers also monitor the immunosuppression medication levels closely which results in frequent timed laboratory appointments. Parents reported difficulty developing a routine that allows for frequent laboratory appointments in order to monitor the immunosuppression medications. Parents consistently described their concern for complications throughout the three questions. The potential risk for complications, including rejection of the transplanted organ or development of a new infection, is a documented concern for parents in this study. Parents are constantly thinking about what complication may develop and assert whatever control they have over minimizing the risk for complications through diligent medication administration and the desire to sanitize everything.

The fifth qualitative question was, “What has been difficult for your family members or other close persons?” There were four themes that emerged from this question: (1) Siblings, (2) The Unknown, (3) Getting into a family routine, and (4) Isolation. For the first time in this study, parents are talking about siblings and how they may be affected by the transplant. Parents reported difficulties having to manage the other children. The siblings have their own schedules too and it is challenging to meet coordinate the needs of siblings and the transplanted child. Siblings have a difficult time when parents are not around due to dealing with medical issues for the transplanted child. One of the parents reported an interesting finding, “The brother’s teacher states he is doing better since sibling has had the transplant”. Siblings are a part of the entire family and have particular needs from the parents once the transplanted child is discharged home

from the hospital. The second theme that emerged from this question was ‘The unknown’. The comments comprising this theme are similar to the themes above describing what has been difficult caring the child but now focus on how the unknown is difficult for family members. Parents are not the only ones that have a difficult time watching the transplant child deal with post-transplant regimen and worry about the unknown including potential transplant-related complications; these affect the entire family. One of the parents reported that not knowing what the future holds is emotionally hard for the family. The third theme that emerged was ‘Getting back into a family routine’. Routine was a theme that was also seen above when parents were asked to describe what has been difficult caring for the child. The responses for this question are again similar but focus on the family unit. One of the parents described that her husband was having a hard time because he had to go back to work and could not be at clinic appointments, making him feel helpless. Other parents reported that relatives helped with other things (not the transplant child) in order for the family to get into a routine and set up a schedule. One parent reported that the family had to “learn patience” while they were all trying to figure out a routine. The final category is ‘Isolation’. Parents felt isolated from other family when they lived far away from relatives. Other parents reported isolation due to the transplant by stating, “Cannot be too close to other family members for parties or gatherings because of transplant precautions”.

The PDCDS also had two additional open-ended qualitative questions that were added specifically for this study in order to provide specific detail about what may be contributing to parent coping after hospital discharge. One question was, “What positively or negatively affected your ability to cope in the last three weeks following

hospital discharge?” Table 5 outlines the themes that emerged from parent’s responses to this qualitative question.

<b>THEMES</b>	
<b>Positive Influence on Parent Coping</b>	<b>Negative Influence on Parent Coping</b>
<p><b>Community Support:</b> Stay at Kohl’s house, Support from family and friends, Community support, Support from blog, Support from school</p>	<p><b>Lifestyle:</b> Can’t just get up and leave because everything is much more scheduled, Dealing and juggling gets hard, Everybody who was helping when we were in the hospital now wants our time that we are now home, Juggling other kids</p>
<p><b>Medical Support:</b> Support from coordinators physicians and social workers, Coordinators answer questions, Talking to transplant team, Calling coordinators with questions, Physicians sitting down to explain things, Nurses always available, Fantastic hospital, Amazing hospital people, Nurses always available to explain everything</p>	<p><b>Hospital systems:</b> Too much paperwork at discharge, Recommend streamlining discharge process, Redundancy between different floors, 2 sets of discharge papers, Miscommunication between team members leaving it confusing and wondering who was in charge, Overbearing staff, Different or younger doctors who do not know patient well results in more tests, Inpatient is an emotional rollercoaster</p>
<p><b>Discharge Teaching and Preparation:</b> Preparation and organization, Knowing that something bad could happen, Education/information provided, Information, Nurses gave me [mom] tools to know what to do and be confident in providing care to patient, Education, Consistent and good education, Education regarding medications, 24 hour preparation test in the hospital, They (the hospital) did everything they could do to prepare us</p>	
<p><b>Being normal:</b> Watching child feel better, Seeing child improved physically, Seeing child be feel and having fun with life, Coming home in general and trying to be normal</p>	

Table 5. Qualitative Results for Coping Ability

The resultant themes were consistent with the quantitative data collected.

‘Community support’ reflects the quantitative data collected from coping and family impact tools while ‘Medical support’ reflects the quantitative data collected in the Care Transition Measure. The ‘Discharge teaching and preparation’ theme gives depth to the answers provided in the QDTS. ‘Being normal’ and ‘Lifestyle’ highlight the responses in the PedsQL Family Impact. The ‘Lifestyle’ theme also reflects the responses in the PDCDS. ‘Hospital systems’ offers insight to the quantitative responses provided in the Care Transition Measure.

Two parents specifically reported that there was nothing affecting their ability to cope after hospital discharge because life after transplant is easier than life before transplant. One parent stated, “Easier now compared to before transplant” which gives perspective or relative difference between pre and post-transplant management.

Two statements did not fall into one of the aforementioned themes, but rather summarized the discharge experience. One of the parents summarized the discharge experience with the following statement, “Going home from the hospital is a big deal, it is life changing”. Another parent summarized the discharge experience with the following statement, “In the first 12 hours I wanted to rush back to the hospital, but then at 24 hours I knew I could do it”. These statements emphasize that the discharge transition is a significant event for parents and families.

A second open-ended qualitative question that was asked of families during the 3-week post-discharge interview was, “What do you know now that you would have liked to have known before your child’s discharge from the hospital?” A majority of parents (70%, n=26) stated that they did not need to know anything more before leaving the

hospital because they felt very well prepared. Table 6 lists what parents would have liked to have known before discharge from the hospital.

Reflections on hospital discharge education
1. Education regarding dehydration and why after kidney transplant need to drink so much water
2. How much more different my child was going to be with activities such as eating and smiling
3. Bag to put medications in on the long ride home to keep cold
4. More education about medications
5. Highlight medication times with different colors
6. Better stethoscope to take vitals
7. Need more supplies at discharge for wound care
8. More information about the home away from home (Kohl's house) in regard to supplies needed and rules
9. Insurance issues for medications and requirement to use specialty pharmacy

Table 6. Reflections on Hospital Discharge Education

A majority of the parent responses regarding reflection on hospital discharge education were patient specific and may not benefit every parent. The specific suggestions included the need for supplies, better understanding for the importance of hydration after kidney transplant, and better preparation for what to expect at the home away from home (Kohl's house). Other parent responses were related to medications. One of the parents wanted to know that certain medications needed to be kept cold on the ride home from the hospital while another parent described a way to organize the medication list. The more general reflections on hospital discharge may benefit all parents and included a desire for a better explanation of insurance issues and a discussion regarding what to expect from the transplant child once at home.

*Research Question 4*

***What is the relationship between parent readiness for hospital discharge and parent and family impact after discharge?***

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity. There were no extreme cases or significant outliers.

RHDS and family impact was analyzed using linear regression. Results of the relationship of RHDS with total PedsQL at 3 weeks post-discharge and change in PedsQL between hospitalization and 3 weeks is presented in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D). In addition, the family impact subscales, health-related quality of life (HRQOL) and family functioning, were analyzed individually (Table 7). Readiness for hospital discharge was associated with both the family impact HRQOL and family functioning raw score subscales but was not associated with the change scores.

Dependent Variable	Model Statistics	B	SE B	Standardized $\beta$	t	p
PedsQL Family Impact Module*	F(1, 35) = 11.07, p = .002, R <sup>2</sup> = .24	.22	.07	.49	3.33	<b>.002</b>
HRQOL*	F(1, 35) = 8.21, p = .007, R <sup>2</sup> = .19	.19	.07	.44	2.87	<b>.007</b>
Family functioning*	F(1, 35) = 8.86, p = .005, R <sup>2</sup> = .20	.28	.09	.45	2.98	<b>.005</b>
PedsQL Family Impact Module**	F(1, 35) = 2.31, p = .14, R <sup>2</sup> = .04	-.08	.06	-.25	-1.52	.14
HRQOL**	F(1, 35) = 17, p = .68, R <sup>2</sup> = .01	-.04	.09	-.07	.42	.68
Family functioning**	F(1, 35) = 8.21, p = .29, R <sup>2</sup> = .00	-.07	.07	-.18	-1.07	.29

\*Family impact is time 2 and defined as 3 weeks after hospital discharge, Health related quality of life (HRQOL), \*\*Family impact change score

Table 7. Readiness for Hospital Discharge and Parent and Family Impact

#### *Research Question 5*

### **What is the relationship between parent readiness for hospital discharge and adherence following hospital discharge for heart, kidney or liver transplant?**

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, multicollinearity, and homoscedasticity for linear regression. There were no extreme cases or significant outliers. Logistic regression assumptions were met as there were no missing data, multicollinearity, or major outliers.

The results are in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D). The Adherence form was enhanced with qualitative questions. Open-ended questions asked about adherence difficulty with the medication regimen and



follow-up laboratory and clinic appointments in order to provide depth to the two single item questions about adherence difficulty.

The first qualitative question asked, “Tell me about the challenges, if any, you have with medication administration?” Fifty-four percent of parents (n=20) stated that there were no challenges with medication administration. Parents stated that medication administration was not challenging because the child was older and used to taking medications before transplant. The remaining 46% (n=17) parents reported that the challenges with medication administration were related to timing, number of medications, storing medications, route of administration, and drug levels (Table 8).

Challenges with medication administration
1. Timing of administration a. Hospital is 8am and 8pm so it was hard when we got home because we needed to changed the medication timing to fit our schedule b. Intravenous medications every 6 hours in addition to other medications so I am giving medications 7 different times during the day. I don't want to be late. c. Making sure he is awake to get all the medications on time d. The hours are random e. Getting the schedule is the hardest part f. Trying to get into the habit of when to take what pill
2. Number of medications
3. Storing medications
4. Route of administration a. Magnesium oxide is the most difficult because it has a bad taste and does not dissolve all the way b. Medication pills are small and [patient] has backwashed pills when using a bottle c. She does not like swallowing the bigger pills, she is just trying to deal with it d. Trying to transition to all orally, some of the medications are given by g-tube
5. Medication levels a. Frustrating trying to get therapeutic immunosuppression drug levels

Table 8. Challenges with medication administration

The challenges reported with medication administration are similar to the difficulties parents reported caring for the child with respect to ‘Medications’ and ‘Daily

routines'. The timing of medication administration can pose significant challenges because there are numerous medications that must be administered at specific times. Medication administration and obtaining therapeutic drug levels with multiple lab draws presents difficulties as families are trying to develop a routine.

The second qualitative question asked, "What, if anything, would help you to better or more easily manage your child's medications?" The majority of parents (62%, n=23) stated that there was nothing that would help them to better manage the medications. One of the parents responded, "It is just difficult, there is nothing else to do."

Parents provided a number of suggestions as to what would help to more easily manage the medications at home. Some of the parents reported it would be helpful to schedule medication administration and talk about when to give medications before leaving the hospital. One of the parents stated that a beeper or alarm would be helpful to make sure that medications are always given on time. Another parent expressed the desire for help by stating, "Have my husband do some of the medication administration because he doesn't know how to administer". Other tips were not necessarily related to the actual medication administration but rather to timing of refills, "Getting refills done on time is important because liquid medications need time for compounding."

The precise timing that is required with administration of the immunosuppression medication was a struggle verbalized by parents throughout many of the qualitative questions. Parents reported that it is hard to give medications while juggling other responsibilities knowing that immunosuppression drug levels are timed. Immunosuppression drug levels are monitored by a test requiring a laboratory visit which

parents reported as a challenge, “All the blood draws are hard” and “You have to come to the hospital in the morning for lab draws.”

Some of the parents did not report challenges, but rather provided words of wisdom for other parents including: have a tote with times and medications, purchase plastic pencil totes for dosing of medication so you have one for each medication time, and use the medication calendar from the pharmacist.

The adherence form also asked parents about the difficulty they have had with adhering to the medical follow-up including laboratory and clinic appointments. The qualitative question that was asked alongside this question was, “Tell me about the challenges, if any, you have had following up with clinic appointments and laboratory appointments?” The two themes that resulted were ‘Getting into a routine’ and ‘Siblings’. ‘Getting into a routine’ was difficult for parents because parents reported having to figure out the commute in the early morning to get to the hospital for timed lab draw, getting through traffic, and coordinating work. ‘Siblings’ was the other theme because parents had challenges coordinating child care for the other children, rearranging to get the other children to school on time, and arranging babysitters for other children. The themes are again similar to those reported when asking parents what is difficult caring for their child and what is difficult for the family after going home from the hospital.

#### *Research Question 6*

**What is the relationship between parent readiness for hospital discharge and parent utilization of healthcare resources after discharge?**

All patients returned to the transplant center for a clinic appointment at least once in the first 3 weeks after hospital discharge. Overall, there were 203 routine clinic appointments and 10 non-routine clinic appointments reported. Patients went to an urgent care or emergency department for the following reasons: crying, tight abdomen, feeding tube issue, pain, fever, and peripherally inserted central catheter (PICC) line flushing. Readmission reasons included high glucose, low oxygen, plasmapheresis, fever, antibiotics, biopsy, tear in kidney, and medication related (immunosuppression drug levels).

More calls were made to the hospital staff (59.5%) than calls to family for support (10.8%). More than three-quarters (82%) of the calls made to the hospital were made to the transplant nurse or coordinator.

The relationship between RHDS and each utilization category was analyzed separately using logistic regression. Preliminary analyses were conducted to ensure no violation of the assumptions including missing data, multicollinearity, or major outliers. The results are presented in the manuscript (Appendix D) without a supporting table. Table 9 included the results of the statistical analysis.

Independent Variable	Dependent Variable	B	S.E.	Wald	df	p	Odds Ratio	95% C.I.
RHDS	Calls to family	-.01	.02	.71	1	.40	.99	.96-1.02
RHDS	Calls to hospital	.01	.01	.56	1	.46	1.01	.99-1.03
RHDS	Readmission	-.02	.01	3.34	1	<b>0.07</b>	.98	.95-1.00
RHDS	ER	.01	.02	.18	1	.67	1.01	.97-1.04

Readiness for hospital discharge scale (RHDS)

Table 9. Predictors of Post-Discharge Utilization

In addition to logistic regression analysis, a total utilization score was computed in order to measure the use of healthcare resources after hospital discharge. Poisson regression was used to separately examine the relationship between RHDS with emergency department visits and readmissions. The regression indicated a statistically significant relationship with number of visits to emergency department ( $p < .0005$ ) and readmissions ( $p < .0005$ ). However, these findings were not reported in the manuscript in Appendix D because two major violations for the assumptions of Poisson regression analysis were identified. Poisson regression results can be influenced by a small sample size and zero inflation due to a large number of zeros which indicates non-utilization. Small sample size was a factor seen with this sample size of 37. The results were also influenced by the zero inflated Poisson regression because the number of zero's for this particular analysis was high; a zero indicated that there was no hospital readmission (73.0%) and no visit to the emergency department (89.2%).

Parents were asked whether or not they called family or friends for advice or support in the first three weeks following hospital discharge. If a parent responded "yes", they were then asked the reason for the call. The parents reported needing the following advice or support from family or friends: support with other children, money, help with bringing things the child needed, and reminders to give medications on time.

Parents were also asked whether or not they called the nurse or physician at the hospital in the first three weeks following hospital discharge. If a parent responded "yes", they were asked the reason for the call. The most frequent reason for phone calls to the hospital was about various symptoms the patient was demonstrating including: cough, pain, fever, wound care and healing, vomiting, feeding, headache or peripherally

inserted central catheter line function. Parents also called with questions regarding medications. The final reason for phone calls was for reassurance that the parent was doing everything correctly.

#### *Additional Analyses*

Although the results of linear regression analyses for each of the post-discharge outcomes are in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D), the results are also presented in table format (Table 10).

Independent Variable	Dependent Variable	Model Statistics	B	SE B	Standardized $\beta$	T	p
RHDS	PDCDS	F(1,35) = 28.52, p < .001, R <sup>2</sup> = .45	-.26	.05	-.67	-5.34	<b>&lt;.001</b>
RHDS	PedsQL Family Impact Module (Post-discharge Raw Score)	F(1, 35) = 11.07, p = .002, R <sup>2</sup> = .24	.22	.07	.49	3.33	<b>.002</b>
RHDS	PedsQL Family Impact Module (Change Score)	F(1, 35) = 2.31, p = .14, R <sup>2</sup> = .06	-.08	.06	-.25	-1.52	.14
RHDS	Adherence Difficulty Medications	F(1, 35) = 2.88, p = .10, R <sup>2</sup> = .08	-.02	.01	-.28	-1.70	.10
RHDS	Adherence Difficulty Follow-up	F(1, 35) = 10.13, p = .003, R <sup>2</sup> = .22	-.05	.02	-.47	-3.18	<b>.003</b>

RHDS = Readiness for Hospital Discharge Scale, PDCDS = Post Discharge Coping Difficulty Scale

Table 10. Linear Regression Analyses for Post-Discharge Outcomes

Additional analyses were performed to explore relationships not specified in the original study model. As a primary study finding, care coordination was associated with the intermediate variable readiness for hospital discharge. Further exploration of the data included identifying direct relationships between care coordination measured by the Care Transition Measure (CTM) and post-discharge outcomes including post-discharge coping difficulty, family impact, and adherence difficulty with medications and follow-up (Table 11). Care coordination was predictive of post-discharge coping and was not predictive of any other post-discharge outcome.

Independent Variable	Dependent Variable	Model Statistics	B	SE B	Stand $\beta$	T	p
CTM	PDCDS	F(1,35) = 5.00, $p = .03$ , Adjusted $R^2 = .10$	-0.40	0.18	-0.35	-2.24	<b>0.03</b>
CTM	Family Impact Total	F(1,35) = 1.66, $p = .21$ , Adjusted $R^2 = .02$	0.27	0.21	0.21	1.29	0.21
CTM	Adherence Difficulty with Medications	F(1,35) = 0.30, $p = .59$ , $R^2 = -0.02$	0.02	0.04	0.09	0.55	0.59
CTM	Adherence Difficulty with Follow-up	F(1,35) = 2.42, $p = .13$ , $R^2 = .04$	-0.07	0.05	-0.25	-1.55	0.13

Care Transition Measure (CTM), Post Discharge Coping Difficulty Scale (PDCDS)

Table 11. Care Coordination and Post-Discharge Outcomes

Post-discharge coping difficulty was also further analyzed with the utilization categories and medication discrepancy. Table 12 displays the results of logistic regression for Post Discharge Coping Difficulty Scale (PDCDS) with four separate

measurements of utilization and medication discrepancy. PDCDS was not significantly related to any of the four separate measurements of utilization or medication discrepancy.

Independent Variable	Dependent Variable	B	S.E.	Wald	df	P	Odds Ratio	95% C.I.
PDCDS	Calls to family	.02	.04	.26	1	.61	1.02	.94-1.11
PDCDS	Calls to hospital	-.04	.03	1.76	1	.19	.96	.91-1.02
PDCDS	Readmission	.02	.03	.57	1	.45	1.02	.97-1.08
PDCDS	ER visit	-.02	1.02	2.61	1	.11	.19	.90-1.07
PDCDS	Medication Discrepancy	-.04	.03	1.22	1	.27	.96	.90-1.03

Post-discharge coping difficulty scale (PDCDS), Emergency room (ER)

Table 12. Logistic Regression for Post-Discharge Coping Difficulty

Family impact after hospital discharge raw score was not associated with medication list discrepancy ( $p = .17$ ), calls made to family or friends for support ( $p = .99$ ), emergency department visits ( $p = .65$ ), readmission to the hospital, ( $p = .60$ ), difficulty with medication administration ( $p = .66$ ) or difficulty with laboratory and clinic follow-up ( $p = .09$ ).

Logistic regression analyses were used to examine the relationship between adherence difficulty (medication and follow-up) and utilization. Adherence difficulty with medications was not associated with calls to family or friends for support ( $p = .42$ ), calls to the hospital ( $p = .79$ ), emergency department visits ( $p = .42$ ), or readmissions ( $p = .84$ ). Similarly, adherence difficulty with laboratory and clinic follow-up was not associated with calls to family or friends for support ( $p = 0.51$ ), calls to the hospital ( $p = .63$ ), emergency department visits ( $p = .66$ ), or hospital readmission ( $p = .63$ ).



*Study Site and Organ Type Analyses*

Differences in main study variables were assessed by site. Two of the three sites were included for analysis as the majority of the sample was collected from two of the three pediatric transplant centers (18 at CHW and 18 at CMH). Independent samples t-tests were conducted to compare the total scale scores for Care Transition Measure ( $t = -1.59, p = .12$ ), Quality of Discharge Teaching Scale ( $t = -.18, p = .86$ ), Readiness for Hospital Discharge Scale ( $t = -.49, p = .63$ ), Post Discharge Coping Difficulty Scale ( $t = .32, p = .75$ ), Peds QL Family Impact Time 1 ( $t = -.10, p = .93$ ), Peds QL Family Impact Time 2 ( $t = .08, p = .94$ ), and adherence difficulty administering medications ( $t = -.21, p = .84$ ) or attending laboratory and clinic follow-up ( $t = .52, p = .61$ ). There was no significant difference in scores for participants at CHW and CMH.

Differences in main study variables were also assessed by type of organ transplant (heart, kidney, or liver). A one-way between-groups analysis of variance was conducted to explore the impact of organ type on the main study variables. The three different organ type groups did not differ significantly for Care Transition Measure ( $F(2, 34) = .23, p = .79$ ), Quality of Discharge Teaching Scale ( $F(2, 34) = .41, p = .67$ ), Readiness for Hospital Discharge Scale ( $F(2, 34) = 1.20, p = .32$ ), Post Discharge Coping Difficulty Scale ( $F(2, 34) = 1.11, p = .34$ ), Peds QL Family Impact Time 1 ( $F(2, 34) = .11, p = .90$ ), Peds QL Family Impact Time 2 ( $F(2, 34) = .74, p = .49$ ), and adherence difficulty administering medications ( $F(2, 34) = .39, p = .68$ ) or attending laboratory and clinic follow-up ( $F(2, 34) = 1.44, p = .25$ ).

*Summary*

This chapter provides a detailed description of the quantitative and qualitative results for each of the six research questions. Results from additional relationships not specified in the original six research questions were reviewed.

## CHAPTER FIVE

### Discussion

Chapter five includes the interpretation of findings and discussion of the results. The majority of relevant discussion is included in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D). The discussion in this chapter focuses on the qualitative results and their relationship to quantitative findings. Each of the results will be discussed according to the six individual research questions.

#### *Interpretation and Discussion of Findings*

##### *Research Question 1*

The interpretation and discussion for the first research question is described in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D).

##### *Research Question 2*

The interpretation and discussion for the second research question is described in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D). Additional analyses involved exploring the relationship of the QDTS subscales (content received and delivery) with RHDS total scale score and RHDS subscale scores (parent personal status, child personal status, knowledge, coping and support). None of the relationships were significant indicating that QDTS subscales were not associated with RHDS or the individual subscales. The manuscript (Appendix D) provides an explanation for why QDTS and RHDS may not have resulted in significant relationship.

The QDTS includes two subscales, ‘content needed’ and ‘content received’. Parents of this study indicated that they received more content than they needed. In the qualitative responses, parents reported that the most important concepts to learn during the transplant hospitalization were medications, restrictions, and warning signs for complications. These three topics are part of routine post-transplant education at transplant centers, but transplant teams should not assume that the education provided is sufficient.

Parents must receive adequate information in order to build confidence for a successful transition from hospital to home (Lerret, 2009). Transplant teams should communicate with parents about the amount of education and what additional information might be necessary. In addition, the education provided to families should be consistent in order to build parent confidence. Transplant teams can promote confidence by communicating as a team in order to provide consistent information and education to families.

### *Research Question 3*

The interpretation and discussion for the third research question is described in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D).

Overall, parents reported relatively low post-discharge coping difficulty (mean 2.0 on a 0-10 scale) but expressed many themes related to stresses of the post-discharge period in the qualitative analyses. Parents indicated that worry about the future was a major stressor in the first three weeks following hospital discharge. Uncertainty of the child’s future health and well-being has been reported as a source of family stress for

families of pediatric transplant recipients (Gold et al., 1986; Uzark & Crowley, 1989; Uzark 1992). The uncertainties for medical complications including rejection, infection, and medication side effects are stressful and may diminish over time but likely never disappear (Anthony et al., 2010).

Although parents reported a number of challenges, they also described what positively affected their ability to cope in the first three weeks following hospital discharge. The community support from family and friends, school, and social networking including blogging were described as positive. This highlights the importance of encouraging parents to reach out to the community for support. Parents who feel isolated, especially geographically isolated, may consider blogging or using online support groups.

Support from the transplant team and discharge teaching were also described as positively affecting parent's ability to cope after discharge from the hospital. Trust between the family and the medical team is crucial to assure that the transplanted child is receiving the appropriate care (Lerret, 2009). Parents also stated that the discharge teaching positively affected their ability to cope. Parents were comforted by knowing the potential complications and felt that the nurses gave them the tools to know what to do and be confident in providing care to their child.

Most importantly, parents were positively affected by watching their child feel better and seeing them physically improve. Parents were happy to see the child have fun and to be coming home to resume some sort of normalcy. The importance of normality after transplant has been described by parents (Uzark, 1992; Green et al., 2008) and pediatric liver transplant recipients (Wise, 2002).

Transplant centers also can consider areas for improvement based on parent responses for what negatively affected parent's ability to cope in the first three weeks following hospital discharge. Parents had concerns regarding the hospital system for discharge. The most common recommendation for improvement was in regard to the discharge process. Parents reported that there was too much paperwork at the time of discharge and the process should be streamlined. Parents also found it difficult when there was miscommunication between team members stating that it caused them to feel confused and wondering who was really in charge of their child's care. This is certainly an area for improvement as parents need to not only be involved in the discharge process but also receive consistent information from all members of the transplant team. The recommendations for improvements to the discharge process by parents of transplant recipients resonate in other discharge transition literature emphasizing the importance of a comprehensive and coordinated discharge from the hospital (Naylor et al., 1999; Coleman et al., 2004; Naylor et al., 2004; Jack et al., 2009).

#### *Research Question 4*

Both family impact subscales, parent health-related quality of life and family functioning, were also analyzed for their potential relationship with RHDS. RHDS was significantly associated with parent health-related quality of life and family functioning meaning that the more parents were ready to leave the hospital, the higher the 3-week post-discharge quality of life and family functioning.

Despite high parent health-related quality of life and family functioning, the lowest subscale scores were for both 'worry' and 'daily activities'. The 'worry' subscale asked parents how worried they were about whether medical treatments were working,

side effects of the medications and medical treatments, how their child's illness affects other family members, and how worried they were about their child's future. Worry is a constant burden that parents carry when they have a child that received a solid organ transplant. Parents of pediatric kidney transplant recipients reported worry six years following transplant using the same PedsQL Family Impact Module (Anthony et al., 2010). The low scores reported for daily activities indicated that parents had a difficult time with daily activities taking more time and effort and difficulty finding time to finish household tasks. Qualitative responses in this study mirror this finding as parents consistently report the challenges posed by getting into a routine after hospital discharge.

Identifying families who are not functioning well after transplant is crucial to the health of the transplanted child (Fredericks, Lopez, Magee, Shieck, Opiari-Arrigan, 2007). The ability of the family to function once in the home environment is critical to ensuring that the transplant patient is receiving all of the necessary treatment, medications, and follow-up for continued recovery in the home environment. Parent perception of readiness to leave the hospital after transplant does not explain all of the family's health-related quality of life and functioning but certainly does play a role (nearly 25% of explained variance). The transplant team can help to minimize impact on family by asking parents how they are coping and expect to cope at home, support persons that may be available to help, and how the transplant team members can facilitate the parent's care of the child (Shemesh, 2008). Parents who are functioning well and have a good reported quality of life may be able to better manage all of the post-transplant needs of their transplanted child. Non-ready and lower functioning families

may need additional support and service coordination for the post-discharge transitional period.

*Research Question 5*

The quantitative results for adherence are discussed in the manuscript (Appendix D). Qualitative results regarding adherence provide insight to both medication and follow-up related difficulties after hospital discharge. A little over half of the parents stated they did not have any challenges with medication administration because they were accustomed to administering medications before transplant. Parents who did report challenges with medication administration stated their challenges were related to medication timing, number of medications, route of administration, and drug levels. The transplant coordinator or pharmacist can provide assistance with medication planning to minimize this stress once at home. Inpatient education should include a specific medication schedule that fits the family routine. Families can discuss their home routine with the transplant team so the medication schedule can be tailored to meet each individual family's needs.

The struggle of getting into a routine and managing other children continued as a theme when parents were asked about the challenges they have had with following up for laboratory and clinic appointments. Laboratory appointments are complicated by the fact that they are timed in order to accurately monitor the amount of medication being administered. Parents were confronted with “getting through traffic”, “coordinating work”, and “managing the other children” in order to get to the hospital multiple times each week for timed laboratory draws and scheduled clinic appointments. The quantitative results have similar findings by indicating that a lack of readiness was



associated with adherence difficulty for laboratory and clinic follow-up. A component of discharge teaching may need to include planning for multiple returns to the hospital and fitting transplant-related management in with normal family related daily activities.

Parents must create a new family routine when they are discharged from the hospital and indicated that getting into this new routine was a major stressor. The stressor of post-transplant management is also seen in parents of pediatric bone marrow recipients (Packman, Weber, Wallace, & Bugescu, 2010). The meetings with families may also need to include discussion on how going home will impact the family structure and organization once in the home environment.

Siblings are a part of the family routine posing unique challenges to the family unit in the first three weeks following hospital discharge. Parents were consistently stating that the other children had needs as well including getting to school or other events. Parents who have other children are faced with finding babysitters or other support persons in order to bring the transplanted child to clinic and laboratory draws. Families may benefit from discussion with the transplant team or post-transplant families on how to manage the day to day family activities in addition to caring for the transplanted child.

#### *Research Question 6*

The transplant team received more calls for support than family and friends, indicating that the support needed by families in the first three weeks after hospital discharge is mainly related to patient medical needs. The transplant team is a lifeline for patients and families after hospital discharge. Families of medically complex children want a single point of contact to address their medical concerns (Balling & McCubbin,

2001). An overwhelming majority of the calls made to the transplant team were directed to the transplant nurse or coordinator, highlighting the critical role that transplant coordinators play in the post-transplant care of families.

Transplant coordinators are a consistent and accessible part of the transplant team, and serve as a single point of entry to the hospital system. The communication between the transplant coordinator and family is meaningful and helps families to feel connected to the healthcare system (Lerret, 2009). Some parents reported the reason for a phone call to the transplant coordinator was for reassurance that everything was being done correctly. A phone conversation between the transplant coordinator and family can continue to provide reassurance and build parent confidence (Lerret, 2009). Transplant providers who develop a meaningful connection with patients and families encourage families to actively participate in the post-transplant care which is essential to successful outcomes (Wise, 2002).

Although phone calls to family and friends were not as frequent as those to the medical team, the reason for calls provides insight for additional services that can be provided to families. Parents reached out to family or friends for support with their other children by asking them to babysit so that the transplanted child could get to a clinic or laboratory appointment.

Some of the parents were geographically isolated from family and friends because they had travelled to a hospital to have the transplant procedure performed. Families that are geographically separated after transplant may have greater stress or strain because they have limited support. The transplant social worker may be of assistance in these particular situations.

Even if parents are close to home, they may feel isolated from family members and friends because of transplant precautions and concerns for complications. Social isolation has been reported in a previous descriptive study of parents of pediatric transplant recipients (Uzark, 1992) and parents of pediatric heart transplant recipients may place unnecessary restrictions on their transplanted children due to fear of infectious diseases (Green, McSweeney, Ainley, & Bryant, 2008).

Parent dyads were not interviewed for the purpose of this study, but future studies may reveal that fathers have feelings of isolation as well. Mothers stated that their husbands felt helpless and were having a difficult time because they had to go back to work and could not be at clinic appointments.

Parents also called family or friends for financial support. The financial burden of pediatric transplantation has been identified as a stressor in previous descriptive studies and can lead to family stress (Gold, Kirkpatrick, Fricker, & Zitelli, 1986; Zitelli et al., 1987; Uzark & Crowley, 1989; Uzark 1992). The insurance co-payments for physician visits, laboratory tests, and medications can put burden and stress on the family. The transplant social worker can assess the financial concerns of families and identify sources of potential financial support. Addressing the family's financial concerns may help the family's ability to cope and ultimately affect the child's outcome.

#### *Convergence of Quantitative and Qualitative Findings*

Both quantitative and qualitative research adds to the body of nursing science and represents different perspectives from which to understand nursing phenomena (Polit & Beck, 2008). The qualitative responses generated similar themes regarding the obstacles parents were facing in the home environment including 'Getting into a family routine'

meaning juggling other children, getting to and from hospital for clinic and lab appointments, ensuring accurate medication administration, and getting back to work or school. Parents also had concerns related to medications, medical complications, and worry or uncertainty for what the future may hold. Families appear to be trying to figure it all out during the first three weeks and get into a rhythm or pattern of how to fit it all in so that the child is receiving the best care possible at home.

The quantitative tools that had additional qualitative questions provided more information and detail than the quantitative results alone. The qualitative results provided depth and insight to the quantitative results and offered more detail as to what parents are actually experiencing during the discharge transition. The qualitative data were limited to single open ended questions and did not generate lengthy responses from parents.

The demographic results were used for descriptive purposes only and not used in regression analyses due to power constraints. One of the important demographic findings is that parents reported an average of two children in the home. Although alone this finding may not be meaningful, it is important when linked with the qualitative result that families with other children reported difficulty getting into a routine. Parents specified that juggling other children was difficult in the first three weeks after hospital discharge. The preparation for hospital discharge and post-discharge management may be improved by tailoring the education based on family dynamics.

Readiness for hospital discharge was negatively associated with adherence difficulty for laboratory and clinic follow-up. Care coordination is another component of discharge preparation but was not associated with adherence difficulty for laboratory or

clinic follow-up. This study identified the significant relationship for care coordination in helping families feel ready for hospital discharge and suggests that a lack of coordination has potential consequences.

Worry was a common theme that emerged from the qualitative questions and was also the lowest subscale in the PedsQL Family Impact Module. Transplant teams can talk to families about what they are worried about to help them cope. Ongoing education throughout the transplant experience may help to minimize the profound worry parents' experience.

The qualitative themes and parent comments complemented the quantitative findings by explaining what was challenging, what was positive, and what the transplant team can do to improve the discharge transition process. Parents are living their lives within the context of having a transplanted child. This study captures the parent experiences of putting disease and life together in the first three weeks following hospital discharge after a life changing event, transplant.

#### *Clinical significance of the findings*

This is the first study to explore parent perceptions of the transition from hospital to home with both quantitative and qualitative data. In addition to educating parents on medications and complications, parents also have a need for emotional support and guidance in parenting the child with a transplant (Weichler & Hakos, 1989). Some parents cope better than others with the challenges associated with their child's chronic condition, highlighting that it is critical for healthcare to address the needs of children and their families (Simons et al., 2008).

The qualitative results of this study highlight what positively affected parents' ability to cope after discharge from the hospital. These included support from both the community and transplant team, discharge teaching and preparation, and watching their child feel better. Parents were negatively affected by the change in lifestyle after transplant. Transplant teams are able to successfully educate parents about transplant medications and complications with many handouts and other educational materials. The transplant team may consider adding an additional dimension to education which focuses on managing day-to-day life after transplant.

If parents are not able to successfully manage this stressful transition, their child is likely at higher risk of suffering post-operative complications which are burdensome to the family and the health care system (Shemesh, 2007). Understanding the parent experience and how parents adapt to this stressful life experience may have important implications for both short and long term patient survival.

#### *Relationship to Theoretical Framework*

Meleis' Transitions Theory provided a useful framework to evaluate the multiple factors contributing to the transition from hospital to home (Meleis et al., 2000). The hospital discharge was viewed as a transition process because it is a passage from one life phase or condition to another where changes in health and illness create or period of vulnerability (Meleis et al., 2000; Meleis & Trangenstein, 1994).

Each of Meleis' four transition theory concepts (Meleis et al., 2000) were represented by the study variables. The nursing therapeutics (discharge teaching and care coordination) and patterns of response (readiness for hospital discharge and post-discharge outcomes) theory concepts represent the important relationship between the

nurse and parent. Two of the four major components in Patterns of Response are feeling connected and developing confidence and coping. Parents identified the important role of the transplant nurse coordinator as a consistent and trusted member of the transplant team to not only call with questions or concerns but to also call for reassurance and support.

The study findings support the propositions of Meleis' Transitions Theory by addressing a change in health status during a period of vulnerability, discharge to home. The theory incorporates both the nurse's role in discharge preparation and parent's experience in the discharge transition.

#### *Implications for Nursing Practice*

The study results highlight the important role that nurses play in the discharge process for transplant families. Parents reported that the quality of discharge teaching was high on the Quality of Discharge Teaching Scale and also qualitatively reported how the education from nurses positively helped them to cope in the first three weeks following hospital discharge. Nurses have close contact with families and are building confidence in parents with each encounter they have with families (Lerret, 2009).

Assessments of parents and how the illness impacts the family structure and ability of the family to support the transplanted child (Shemesh, 2008) are extremely important because families that are not functioning well put the transplanted child at substantial risk (Fredericks et al., 2007). Non-adherence to the transplant regimen puts the child at risk for post-transplant complications. Parents in this study reported difficulty adhering to the laboratory and clinic follow-up due frequency of appointments and management of other family members or activities.

An assessment can be as simple as asking families how they are coping and may result in a referral for the family to meet with a pediatric psychologist (Shemesh, 2008). Nurses and other members of the transplant team can assess the impact of transplant and offer support and encouragement to transplant families to promote strong functioning families during the transplant hospitalization, discharge and throughout the transplant trajectory.

#### *Implications for Nursing Education*

The results of this study bring evidence-based knowledge to the practicing nurse and transplant team members regarding factors related to discharge readiness. The relationship of care coordination and readiness for hospital discharge with post-discharge outcomes supports the important role that a nurse plays in planning and making joint decisions with families in discharge preparation. A discharge readiness assessment may outline challenges the family faces to provide continued care at home or additional education needed before hospital discharge.

The study findings inform nurse educators regarding necessary content to include in courses for pre-licensure and graduate student nurses. Additionally, post-licensure nurses practicing at various pediatric institutions can benefit from the study results through basic orientation and continuing staff nurse education. The study results highlight the important role that nurses play in the discharge transition including the role of care coordination in a parent's readiness to leave the hospital and the subsequent post-discharge experience of parents in this specific patient population

Nurses who use evidence based practice can have confidence that the best outcomes are achieved from the nursing care patients and families receive (Melnik &



Fineout-Overholt, 2005). Nurses play an important role in the discharge period and this study underscores the impact of nursing care during hospitalization and on outcomes beyond hospitalization.

### *Significance to Nursing Research*

The results from this preliminary study generated questions for future research in the transition from hospital to home for parents of pediatric solid organ transplant recipients. Future research with a larger sample size would allow for more complex analyses with additional predictor variables and a full path analysis of the transition from hospital to home model. The addition of demographic variables such as marital status or other children living in the home may more fully explain variation in readiness for hospital discharge or post-discharge outcomes including coping difficulty, family impact, and utilization.

The first three weeks following hospital discharge are one of the most complicated times after transplant due to the frequency of lab and clinic appointments necessary to assure that the child is medically stable. The results of this study are important and describe the experience of parents in the acute or initial post-transplant time period. There is a compelling need for a longitudinal study of this population because outcomes after transplant are not static. Future research may include interviews at longer time intervals such as 6-months post-transplant where there are routinely less medications and less medical follow-up including lab and clinic appointments. Extended follow-up is necessary to determine whether coping and family impact change over time and how nurses can facilitate the coping process and getting life back to normal within the context of a having a child with a chronic illness.

Life after transplantation in children is complex and requires the expertise of a dedicated multidisciplinary team to ensure optimal care. These results help uncover the important issues for further study and may allow members of the transplant team to plan for intervention strategies where ultimately both pediatric transplant recipients and their parents will benefit. More sophisticated measures of adherence are indicated to further identify how nurses can support families as they manage the transplant-related medical needs at home.

Future research efforts with this population must involve multiple transplant centers because there are limited numbers of pediatric transplant patients in any one pediatric program. Collaboration between transplant centers across the country will result in generalizable results for more transplant programs to improve the discharge transition.

The findings of this study contribute to the body of nursing knowledge regarding factors related to discharge readiness in parents of children that have received a solid organ transplant. Although not directly generalizable, the results of this study provide the framework to consider in other pediatric chronic illness populations. The results provide evidence to support care practices and advance the science of nursing.

#### *Implications for Vulnerable Populations*

The severity of complications following solid organ transplant creates a vulnerable situation as parents worry about their child's future and possible complications, and try to develop a new routine in order to meet the needs of every member of the family. Parents in this study had a particularly difficult time managing laboratory and clinic follow-up. Many challenging factors were listed including work

schedules, timing of laboratory draws, and other children. Laboratory and clinic follow-up are crucial means of monitoring for post-transplant complications and non-adherence to the medical follow-up places the transplant child at increased risk for complications resulting in emergency department visits and hospital readmission.

At the time of hospital discharge, parents are also learning to manage a new chronic illness (Gold et al., 1986; Uzark, 1992). Parents reported feeling isolated from family and friends due to risk for infection. Nurses can assess the individual support systems for families and suggest alternative forms of support including online support groups or talking with other transplant families to give parents a feeling of connectedness and support with individuals outside of the transplant team.

The family and home environment are important in the care of children with chronic illness and nurses can support and enhance family strengths to support families in the transition from hospital to home (McCubbin, 1993). Nurses not only promote family members' health and recovery from illness, but also support and enhance family strengths to assist each individual family in the process of adaptation (McCubbin, 1993). Members of the transplant team must continually assess the needs of families throughout the entire transplant process to assure families are supported as they are needed.

### *Strengths and Limitations*

The major study limitations are discussed in the manuscript "How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant" (Appendix D). Additional discussion of strengths and limitations is presented in this section.

The study is based on a theoretical framework, Meleis' Transitions theory. The findings of this study, although based on a small population, suggest issues that are important in caring for parents of pediatric transplant recipients. The qualitative responses provide insight as to the specific stressors and concern that parents are faced with when their child is discharged from the hospital after solid organ transplant.

The qualitative component of this study is limited because telephone interviews asked parents brief open-ended questions to enhance or provide depth to specific quantitative questions. This format offered parents an opportunity to briefly respond versus more extensive responses that may have been elicited by in-depth interviews. Future studies allowing parents to discuss more freely and openly about the transplant discharge experience may illuminate more specific barriers or strengths to the discharge process.

The study was also limited by interviewing one parent, self identified as the primary caregiver for the transplanted child. Interviewing parent dyads may provide better insight as to how to support the family as a whole. Each parent has a unique role and may need to be supported in different ways in order to assure that the best care is being given to the transplanted child.

Parental characteristics were not explored due to power limitations. Age and marital status were collected but not used in the regression analysis to identify potential significant relationships with RHDS. The age and marital status of the parent may play a role in a parent's ability to feel ready to leave the hospital. More specifically, young single parents with minimal support may indicate lower readiness for hospital discharge than middle-aged married parents that have support in the home environment. The

education level of parents was not measured in this study but could impact readiness for hospital discharge and should be considered in future research studies with this population.

### *Summary*

This chapter provides a detailed discussion of the additional quantitative results not already discussed in the manuscript “How ready are they? Parents of pediatric solid organ transplant recipients and the transition from hospital to home following transplant” (Appendix D) and qualitative results. Implications for nursing practice, education, and research were discussed.

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## Appendix A: Manuscript

*Lerret, S. (2009). Discharge readiness: An integrative review focusing on discharge following pediatric hospitalization.*

*Journal for Specialists in Pediatric Nursing, 14(4), 245-255.*

Preparing patients and families for the transition from hospital to home is an everyday occurrence for hospital-based nurses. This transition has a variety of implications for patients and families depending upon the reason for hospital admission and complexity of care necessary to continue the recovery process at home. Pediatric solid organ transplant (SOT) recipients are a unique population of patients experiencing the transition from hospital to home. According to the United Network for Organ Sharing, there were 1,957 pediatric solid organ transplants (a recipient less than 18 years of age that has received a kidney, liver, pancreas, heart, lung, or intestinal transplant) performed in 2007 (United Network for Organ Sharing, 2008).

While the psychosocial, emotional, and medical benefits of organ transplantation are substantial, organ transplantation is best viewed as trading a life-threatening pre-transplant medical illness with a post-transplant chronic medical condition (Stuber, 1993). Pediatric SOT recipients experience lengthy hospitalizations due to the complexity of the procedure and potential life-threatening post-operative complications. Management at home following SOT is complex as care includes but is not limited to: precise administration of multiple medications, wound care, central line care, and a time-consuming outpatient schedule for laboratory and clinic follow-up. In addition to these tasks, the family must be well versed in the complications of transplant such as rejection and infection.



Pediatric transplant recipients are dependent on their parent(s) who assist them in meeting the immediate post-transplant needs. Studies of the adult transplant experience provide insight about the essential role of the primary caregivers in the recovery process with adult recipients (Dew et al., 1994; Bohachick et al., 2001; Kurz, 2002). The parental relationship provides the same essential role for the child with SOT.

Symptoms of emotional trauma have been documented in parents of children who had a transplant (Stuber, Shemesh, & Saxe, 2003; Young et al., 2003). The parents' needs must be met for the parent to provide adequate support and care to the child in the immediate post-operative period and time following discharge from the hospital to ensure optimal outcomes for the patient. The nurse is essential in preparing the family for hospital discharge through the nursing role in planning, preparing, and coordinating for a successful transition to home.

For all types of hospitalizations, there has been a movement toward shorter lengths of stay to reduce health care costs that results in patients being discharged home in increasingly shorter periods of time (Heine, Koch, & Goldie, 2004; Weiss et al., 2007) and in intermediate rather than later stages of recovery (Kortilla, 1991). The consequence of shorter hospitalizations is less time to educate patients and family members and to coordinate home and community services. Ultimately, many patients and families are discharged with unmet home care needs and at increased risk for complications and hospital readmissions (Titler & Pettit, 1995).

A patient's level of readiness for hospital discharge is associated with hospital readmission rate in studies of hospitalized adults. Decreased readiness for discharge scores in adults with diabetes and heart failure correlated with increased risk for

readmission (Ashton, Kuykendall, Johnson, Wray, & Wu, 1995) while high readiness for discharge was predictive of fewer readmissions (Weiss et al., 2007). Readiness for discharge is a crucial intermediate outcome in the transition from hospital to home based care. Patient readiness for discharge has been described as, “a complex multidimensional, multiphase phenomenon that provides an estimate of a person’s ability to leave the hospital” (Anthony & Hudson-Barr, 2004, pg. 119) and “a multifaceted concept and best arrived at through inter-professional discussion and decision” (Fenwick, 1979, pg. 14). Discharge readiness encompasses physiologic, functional, cognitive, affective, psychological abilities and limitations, stability, competency of the patient and family, perceived self efficacy, availability of social support, and access to the health care system and community resources (Fenwick, 1979; Titler & Pettit, 1995).

Meleis’ transitions theory provides an organizing framework for conceptualizing the transition from hospital to home. Transition is a change in health and illness that tend to create a period of vulnerability (Meleis et al., 2000). There are four major components of transition: nature of transition, transition conditions, nursing therapeutics and patterns of response (Meleis et al., 2000). Transition experiences involve critical life events such as a child receiving a solid organ transplant, each of which is differentiated by a sense of stabilization in new routines and skills (Meleis et al., 2000). These periods of uncertainty parallel the transplant population because parents must learn to create a new schedule accommodating the administration of timed medications and going to frequent lab and clinic appointments, learn new skills including knowledge of rejection and infection as well as wound care or central line cares.

Research has explored the psychosocial needs of families following liver transplant in adult patients (Benning & Smith, 1994) but have not specifically described family needs during the transplant discharge experience. There is no research literature describing the transition from hospital to home following pediatric SOT or pediatric chronic illness. This is a unique and vulnerable population of patients with a higher risk of life-threatening complications. Research aimed at understanding the discharge readiness of parents following their child's solid organ transplant will help to define the diversity and complexity in transition experiences and provide further insight to the patterns of transition, and uncover opportunities for clinical practice modifications to improve SOT parent and child readiness for the discharge transition.

#### Purpose of the Integrative Review

The aim of this integrative review is to identify factors associated with discharge readiness and propose opportunities for extending research in the field. The original interest for this integrative review stems from the author's questions on how to best prepare a parent and child to go home following pediatric SOT. The research question is, "What influences readiness to go home after hospitalization for pediatric SOT?" A focused literature review revealed that there was no research or practice-based articles that address this topic. The scope of the review was expanded to inquire about the discharge readiness of parents after hospitalization of their child and of family caregivers of adult patients with the intent of applying this knowledge to the pediatric transplant situation.

#### Methods

The integrative review was completed using the 5 stages in Cooper's (1982) framework: problem formulation, data collection, evaluation of data points, data analysis and interpretation, and presentation of results (Cooper, 1982).

### *Search Method*

Multiple words were used to search for research and clinical practice references to literature on discharge readiness to ensure a robust and definitive conclusion (Cooper, 1982). The following words were placed in the online indexes individually and in combination with one another: "discharge readiness," "discharge," "patient discharge education," "patient discharge," "discharge planning," "early patient discharge," "pediatric," and "transition". The inclusion criteria were: (1) a focus of family and health team factors that influence readiness for hospital discharge, and (2) publication in the English language. Obstetrical sources were included in the pediatrics category because they discussed the maternal perceptions of mother-infant readiness to go home. The search was further expanded to include relevant key sources related to discharge transitions of adults and their caregivers or support persons.

### *Search Results*

A search for healthcare sources in CINAHL 1982 to 2008 and Medline 1966 to 2008 was completed. An initial search using the term discharge further truncated as patient discharge education, patient discharge, discharge planning, early patient discharge or transfer resulted in 8,833 papers. Additional search strategies were employed by combining the aforementioned results with the following terms, "discharge readiness", "transfer", "pediatric", and "transition", resulting in 432 papers. All abstracts were retrieved and their relevance to the study questions was assessed. Articles were excluded

if the focus was on pediatric to adult transition, wound discharge, and long term care/nursing. The social science databases, Proquest psychology, and EBSCO electronic database of social work were excluded due to their attention to discharge from a treatment center or inmates with HIV from prison to a community. During the final phase of the literature search, a computer search of dissertations was conducted using Proquest and did not yield additional articles. Ultimately, 38 publications were identified as the basis of this integrative review.

Appraisal of the literature to be included in the analysis is essential to assure validity (Cooper, 1982). The studies were evaluated using the Melnyk & Fineout-Overholt (2005) hierarchy of evidence. The seven levels from the highest to lowest include evidence from: a systematic review or meta-analysis or randomized controlled trials (RCT), a minimum of one RCT, controlled trials without randomization, case-control and cohort studies, systematic reviews of qualitative and descriptive studies, a single descriptive or qualitative study, and the opinion of authorities or expert committees (Melnyk & Fineout-Overholt, 2005).

### Findings

38 articles were included in the analysis of factors influencing discharge readiness: 14 pediatric research, nine pediatric and adult clinical practice, four obstetrical research, and 11 adult research articles. Table 1 summarizes the results of the relevant sources obtained during the literature search and facilitates the synthesis of the studies included for analysis.

### *Themes*

Four major concepts emerged from analysis of retrieved documents as influencing discharge readiness: support, identification of individual needs, education, and communication and coordination. All themes relate to the role of the nurse and interdisciplinary team in planning and preparing the parent and child for the discharge transition.

### *Support*

Support is instrumental to feeling ready to go home in both parents of hospitalized children (Snowdon & Kane, 1995) and family caregivers of adult patients (Artinian, 1993; Congdon, 1994), including feeling comfortable in the home environment (Bent, Keeling, & Routson, 1996). The level of perceived support is different for each parent and may be related to the parent's level of health and available social support available (Affleck, Tennen, Rowe, Roscher, & Walker, 1989). The level of support a parent requires may not necessarily correlate with the child's level of illness. Specifically, the capability of the caregiver in the household environment may be an issue especially so for the chronic and more medically dependent child with multiple medical conditions (Domanski, Jackson, Miller, & Jeffrey, 2003). Each parent and family is different and will require various levels of support (Wong, 1991). Therefore, support must be available for both the child (patient) and the parent (caregiver). The parent's social environment may provide a network of support and resources for the parents, thus enhancing their capabilities for providing support to the child. Bronfenbrenner's Ecological Systems Theory provides a useful framework for conceptualizing the surrounding structure of the environment that affects a child's development. Bronfenbrenner suggests that there is a reciprocal relationship between the immediate

and larger environment described as the micro-, meso-, exo-, and macrosystems (Bronfenbrenner & Morris, 1998). For a child, the microenvironment is the parents, mesoenvironment is the immediate family, exoenvironment is the family social network, and the macroenvironment is the broad societal system.

The transition to home involves support of the parent and child before, during, and after discharge. In planning for discharge, parents must receive adequate time for informational support to care for children at home (Committee on Fetus and Newborn, 1998). Parents also require support throughout the transitional period (Snowdon et al., 1995). Post-discharge support at home in the form of a home visit (Snowdon et al., 1995), follow-up call by the nurse (Bent, et al., 1996), or post-discharge teaching (Reiley, Iezzoni, Davis, Tuchin, & Calkins, 1996) were identified as helpful.

#### *Identification of individual parent needs*

Each individual family will have unique and varying stressors that will influence discharge readiness: financial stressors (Snowdon et al., 1995), ambivalence before discharge stemming from hesitation of removing the child from the hospital's care (Baker, 1991; Smith & Daughtrey, 2000), adjustment needed to incorporate an infant into the family unit (Baker, 1991; Snowdon et al., 1995; Bissell & Long, 2003), parental competence (Baker, 1991), and perceived vulnerability and fear of death (Baker, 1991; Bent et al., 1996). Addressing the individual needs of families may provide a unique opportunity to strengthen parental coping (Snowdon et al., 1995; Bissell & Long, 2003; Bernstein et al., 2007). The American Academy of Pediatrics reports that individualized needs of families require individualized discharge planning (Committee on Fetus and Newborn, 1998) in order for care services to match parent needs (Bernstein et al., 2002).

A patient-centered model of care that is driven by patient [or parent] views may be instrumental in facilitating readiness for discharge and decreasing complications and readmissions (Anthony & Hudson-Barr, 2004).

### *Education*

Parents must acquire sufficient knowledge about the illness or disease process, treatment, self-management, potential complications, and recovery. A solid knowledge base is of primary concern for parents at the time of discharge to ensure parents understand the illness and treatments to prevent further problems or complications (Snowdon et al., 1995; Bent et al., 1996). Parents express anxiety about their need for education, expectations of recovery (Smith & Daughtrey, 2000), and child's future life course (Firth, Grimes, Poppleton, Hall, & Richold, 2000). Furthermore, the personal, family, work-life disruptions, and financial concerns related to medical care costs or work may affect a parents' ability to learn how to care for their recovering child and their readiness to assume care responsibilities at home (Melnyk & Alpert-Gillis, 1998; Snowdon & Kane, 1995; Suderman, Deatrich, Johnson, & Sawatzky-Dickson, 2000).

Teaching is the primary mechanism used by nurses in preparation for parents to successfully continue care within the home environment. Focused discharge education was reported to decrease readmission rate in both a pediatric asthma (Wesseldine, McCarthy, & Silverman, 1999) and an adult diabetes and heart failure population (Ashton, Kuykendall, Johnson, Wray, & Wu, 1995). Readmission to the hospital may represent a failure of pre-discharge anticipatory planning and interventions.

The teaching that parents receive must provide adequate information, be individualized, caregiver driven, and build confidence in the parent in order to be



successful. Individual parent assessments should guide the delivery of teaching, ensuring that parents gain the necessary knowledge to be successful at home (Suderman et al., 2000; Baker, Kuhlmann, Magliaro, 1989). Nurses can improve teaching by assessing parents' educational and motivational needs through communication (Shiekh, O'Brien, & McCluskey-Fawcett, 1993; Hamilton & Vessey, 1992).

Parents are often faced with performing complex nursing skills in the home environment to continue the treatment and recovery process. Parents have reported that they do not remember learning the information that nurses identified as important (Shiekh et al., 1993). This may be related to the fact that nurses often incorporate teaching into other patient care activities and therefore, parents may not recognize it as teaching (Weiss et al., 2008). The skills of nurses in delivering discharge teaching content are important to patient and parent perceptions of discharge readiness. The quality of the delivery of discharge teaching was the strongest predictor of perceived readiness for hospital discharge in parents of hospitalized children and adult medical surgical patients (Weiss et al., 2007; Weiss et al., 2008). Nurses may need to improve how patients are educated for discharge (Reiley et al., 1996) as patient and parent education is a crucial component to the discharge process.

Knowing what to expect is important to feeling prepared (Artinian, 1993; Melnyk, 1994). In addition to disease-specific education, parent education should be directed toward building parental confidence, coping skills, realistic expectations for being at home, and strategies for connecting with community resources and supports in order to further discharge readiness and a positive transition home (Worthington, 1995; Boonmee & Pickler, 2005).

*Communication and coordination*

Communication and coordination is essential between family members and the health care team. Communication helps to avoid confusion (Suderman et al., 2000; Stephens, 2005) and may be enhanced between the health care team and the parents by involving parents in the planning for discharge (Steele & Sterling, 1992; Congdon, 1994; Smith & Daughtrey, 2000; Wong, 1991; Bernstein et al., 2007). Inviting parents to take part in specific interdisciplinary discharge planning rounds (Bent et al., 1996) allows a forum for parents to ask the health care team questions. Establishing parent-professional partnerships, with open and honest communication (Boonmee & Pickler, 2005), is crucial to providing family support that empowers family members, particularly parents, to assume the responsibilities of caring for their child (Wong, 1991) and supports a successful discharge transition. Active participation in the patient/family-provider partnership (Anthony & Hudson-Barr, 2004) facilitates early recognition of concerns prior to discharge and promotes discharge planning that is more acceptable to patients and carers (Heine et al., 2004).

Communication is emphasized because if discharge is planned in partnership (Smith & Daughtrey, 2000) and begun early such as at the time of admission (Baker et al., 1989; Wong, 1991) parents experience less anxiety and feelings of being left to cope alone at home. In a study of abrupt discharge to home from the Pediatric Intensive Care Unit, parents experienced frustration over the difficulties they experienced with regard to communication and coordination of services (Bent et al., 1996). Channels for communication across the discharge transition are important to reduce parent stress and

anxiety, provide continuity of care, and foster a continuing collaborative relationship (Wong, 1991).

The varying perceptions of readiness for discharge between healthcare providers and patients/families underscore the importance of communication and coordination. Different perceptions of readiness exist between the patient, family members, and nurses (Congdon, 1994). Comparisons of adult medical surgical patients and their nurses' revealed that nurses' perceived patients to be more knowledgeable than patients reported (Reiley et al., 1996).

In addition to collaborating with parents, professionals must also work in partnership with other professionals and/or organizations to deliver coordinated and integrated services (Kirk, 1999; Anthony & Hudson-Barr, 1998) especially in the discharge process (Smith & Daughtrey, 2000). Appropriate referrals should be addressed and made before hospital discharge (Clark, Steinberg, & Bischoff, 1997) to avoid confusion. More specifically, a multi-disciplinary team approach is helpful (Congdon, 1994) as long as each team member has a clear understanding of their individual roles and responsibilities (Stephens, 2005) to avoid duplications or conflicting communications.

Transitional care is defined as "actions designed to ensure the coordination and continuity of health care as patients transfer between different locations or different levels of care in the same location" (Coleman & Berenson, 2004, pg. 533). The Care Transitions model was developed by Coleman and colleagues to improve the discharge transition for elderly patients. Despite the fact that the elderly population is strikingly different than a pediatric transplant population, there are indeed similarities that highlight the important

components to positively enhance a patient's perception of discharge readiness. Communication and collaboration between families and health care professionals is essential for effective transitions to address the multiple and complex factors that affect quality of discharge (Coleman & Berenson, 2004). Furthermore, supporting patients and caregivers to actively participate in transition may reduce readmission rates (Coleman et al., 2004).

### Integration and Synthesis of Themes

The concepts of support, individuality, education, and communication are familiar within nursing. These four themes emerging from the review of the selected literature are not mutually exclusive but are rather recursive as one impacts the other. From the convergence of these four concepts emerge two overarching concepts related to discharge readiness: meaningful interactions and confidence building (Figure 1).

The term 'meaningful interactions' emphasizes the significance of each time period, brief or long, that is spent with parents and families. All interactions with patients must convey reassurance of support and knowledge of what to do, so parents feel prepared, confident, and connected. The education that parents receive will be meaningful if it is distinctive to each parent's educational and motivational needs. Open communication and coordination with parents as partners in the discharge process are meaningful interactions between parents and nurses. This is especially important for parents of children with a chronic illness such as pediatric SOT recipients.

Meaningful interactions will leave the patient and family feeling connected to the health care system. This connection extends beyond the hospitalization, knowing that the health care team is within reach and available. Parents must feel comfortable sharing

their needs and concerns in order for nurses to provide individualized support to patients and parents. The meaningful interaction that nurses have with their patients underscores the important partnership of family and nurse to reach a common goal.

Confidence building also incorporates the four themes reviewed in the findings. Parents are confident in their skill and ability to take care of a child at home following hospital discharge if they have received education, had an opportunity to review their thoughts, concerns, and questions with the nurses, and have support systems in place at the time of discharge. Confidence building empowers parents to be successful in providing care upon arrival home and offers a safety net for easy connection with the health care team if necessary. If not confident in the management of their health condition, they will seek reassurance from health care providers (Bernstein et al., 2002; Smith & Daughtrey, 2000; Henderson & Zernike, 2001) or family members (Weiss & Piacentine, 2006).

### Conclusions and Implications

The goal of this integrative review was to generate insights about the role nurses play in discharge readiness of a unique population, pediatric SOT recipients. Because no reports about discharge readiness of parents for children with SOT or other rare diseases were identified in initial literature searching, relevant materials about discharge readiness of parents of hospitalized children and other family caregivers were reviewed. Meaningful interactions and confidence building are the overarching concepts related to discharge readiness that resulted from this integrative review. These two concepts integrate the four core contributors to parental discharge readiness: support, individuality, education, and communication and coordination. The findings outline a

framework of essential components of discharge readiness that can be applied specifically for the families of pediatric transplant recipients and more generally for parents of hospitalized children.

Additional research is needed to verify the applicability of the themes to the SOT population and other patients experiencing hospital discharge, and to identify additional factors that can be modified by nursing interventions. Research is particularly needed to evaluate the stresses related to hospital discharge following transplant to identify effective methods to ensure a safe and smooth transition home, ultimately promoting adaptation for these children and their families.

Meleis' Transitions Theory (Meleis et al., 2000) provides a useful framework for practice and research in the area of discharge transitions. The themes discovered in this integrative review of parental discharge readiness are situation-specific examples of Meleis' Transitions theory concepts. The 'nature of the discharge transition' is influenced by the personal (patient and parent characteristics) or environmental 'conditions' (factors associated with the hospitalization) that facilitate or hinder progress toward achieving a healthy transition outcome. Assessing and meeting the individual needs of patients and families to plan for delivering sufficient education, ensuring support, and promoting seamless communication and coordination are critical nursing processes in preparing for discharge. These 'nursing therapeutics' focus on the prevention of unhealthy transitions and promoting perceived well-being and is enhanced by confidence building and meaningful interactions. 'Patterns of response' reveal the outcome of the discharge transition. Feeling confident and connected to the supportive networks including the health care system are key response patterns (Meleis &

Trangenstein, 1994) and evidence of successful transition. Nursing therapeutics in the discharge preparatory period and the continuation of the meaningful interactions and confidence building in post-discharge contacts with the family will promote and reinforce the parent in stabilizing the new routine of continuing care in the home environment.

#### How Do I Apply This Evidence to Nursing Practice?

As time with patients and families is limited due to multiple demands placed on nurses, this review underscores the importance of the relationships nurses have with patients. Nurses have close contact and develop strong relationships with their patients (Bent et al., 1996), providing opportunities to address factors related to discharge readiness. The four resultant themes and two overarching concepts connect to Meleis' transitions theory, emphasizing the vital link of nursing theory to practice.

Strategies for nurses to engage in meaningful interactions and confidence building stem from incorporating each of the four factors related to discharge readiness: support, individuality, education, and communication and coordination. Education is not content delivery alone, but rather an opportunity to provide individual education specific to parent strengths, is supportive as parents are encouraged and rewarded, and occurs as open communication. The combination of these four factors will provide for a meaningful interaction between parent and nurse as well as build confidence in the parent's ability to continue care within the home and reach out to the medical team for additional support when necessary.

Nurses are crucial to the successful implementation of the discharge transition as families face new challenges (Worthington, 1995). Every contact that a nurse has with parents is an opportunity to prepare parents to take their recovering child home (Smith &

Daughtrey, 2000). The individual parent perspective must be considered in order to positively impact the parent's experience (Bissell & Long, 2003) and ultimately promote a successful transition from hospital to home (Suderman et al., 2000).



Table 1. Summary of articles included in integrative review

Author/Year	Sample	LOE	Conclusion
Summary of Pediatric Research Studies			
Affleck et al. (1989)	94 moms of NICU infants	II	Scarce professional resources should be allocated according to the mothers that report needing the most support during the transition home.
Baker (1991)	16 parents of infants < 36 weeks	IV	The transition home for parents of premature infants poses unique needs and concerns.
Steele et al. (1992)	1, single case study	VI	Patients and their home caregivers are involved in discharge preparation as planners and as learners.
Sheikh et al. (1993)	34 NICU nurses, 45 moms of infants	VI	Staff and parents did not agree on topics discussed as part of standard discharge teaching.
Melnyk (1994)	108 mothers	IV	Information alone improves outcomes for families experiencing unplanned childhood hospitalization.
Snowdon et al. (1995)	16 families	VI	Importance of supporting parental roles in the discharge phase of a child's illness and hospitalization.
Bent et al. (1996)	20 parents	VI	Suggest that parents are uncertain, stressed, and unprepared for the realities of caring for their children at home.
Kirk (1999)	24 parents, 4 children, and 38 professionals	VI	The care for people with specialized health needs in the community presents challenges for the primary care sector of the health service.
Wesseldine et al. (1999)	160 children	II	Delivering a brief, individual, and simple education and support during a child's stay in hospital decreased readmissions over a six month period.
Smith et al. (2000)	164 survey, 20 interviews	VI	If discharge is planned and negotiated with parents they experience less anxiety and feelings of being left to cope alone at home.
Suderman et al. (2000)	20 interviews	VI	Need to recognize the individual needs of parents as learners.
Bissell et al. (2003)	10 parents of infants	VI	Intervention on parent needs positively impact parental experiences.
Domanski et al. (2003)	219	IV	Discharge risk factors for objective illness and treatment criteria were the most reliable predictors of need for social work discharge

			planning.
Weiss et al. (2008)	119 parents of hospitalized children	IV	The “delivery” of discharge teaching by the nurses was the only significant predictor of parental readiness for hospital discharge.
<b>Summary of Obstetric Research Studies</b>			
Bernstein et al. (2002)	55 mothers	VI	Individualized approach ensures quality care and follow-up services.
Weiss et al. (2004)	1,192 mothers	IV	Patient, provider, and payer factors influence discharge timing.
Weiss et al. (2006)	1462 mothers	IV	Mom perception of readiness for discharge identifies at risk mothers.
Bernstein et al. (2007)	4300 mothers	IV	Mothers and health care team perceptions of readiness often differ.
<b>Summary of Adult Research Studies</b>			
Artinian. (1993)	67 participants	VI	There are clinical implications for discharge planning and teaching.
Congdon. (1994)	24 participants	VI	Varying perception of readiness with patients, families and nurses.
Ashton et al. (1995)	2513 men with chronic illness	IV	Patients with decreased readiness for discharge adherence scores correlated with increased risk for readmission.
Reiley et al. (1996)	97 nurse-patient pairs	VI	High disparity between what nurses thought patients understood and what patients actually said they understood.
Clark et al. (1997)	71 elderly patients 52 caregivers	VI	Problem areas for older patients being discharged home are not referred to rehabilitative type services.
Anthony et al. (1998)	28 participants	VI	Identification and evaluation of system, patients, and caregiver issues with implementation of strategies for successful discharge.
Henderson et al. (2001)	158 participants	VI	Patients discharged with little or no information may not be confident in the management at home and access a health facility.
Anthony et al. (2004)	44 participants	VI	Nurse and patient need for information was different.
Heine et al. (2004)	5 participants	VI	Three categories: confidence, family and friends, and feeling safe.
Weiss et al. (2006)	356 adults and children	IV	Reliable and valid measure of perception of readiness for discharge.
Weiss et al. (2007)	147 adult patients	IV	High readiness for discharge was predictive of fewer readmissions.

Summary of Clinical Practice Literature – Level VII			
Author/Year	Focus of Paper	Population	Conclusion
Baker et al. (1989)	Transition to home and discharge teaching in newborns with special needs.	Pediatrics	Successful parent education is via an accurate and thorough family assessment.
Wong et al. (1991)	Discusses components of successful home care.	Pediatrics	Nurses are crucial to the successful transition from hospital to home.
Hamilton et al. (1992)	Pediatric discharge planning process.	Pediatrics	Nurses must assess the educational and motivational level of families.
Worthington. (1995)	Managing the transition from hospital to home.	Pediatrics	Nurses help families learn to meet the challenges of transition to home.
Committee on Fetus and Newborn. (1988)	American Academy of Pediatrics statement on hospital discharge of high risk neonate.	Pediatrics	The need for individualized planning is emphasized.
American Academy of Pediatrics. (1998)	The discharge plan should include six key components.	Pediatrics	Readiness must be considered when discharging high-risk infants to home.
Boonmee et al. (2005)	Addresses parent needs of preterm infants ready for discharge from the hospital.	Pediatrics	Importance of meeting the informational needs of the parent and instill confidence.
Stephens. (2005)	Framework for a smooth transition to home for children with complex needs.	Pediatrics	Collaboration to meet needs of parents and communication to boost confidence.
Titler et al. (1995)	Importance of a discharge readiness assessment with patients and families.	Adult	Discharge assessment evaluates family needs and risk for complications.

Appendix B  
Study Forms and Instruments

**TO BE COMPLETED AT DISCHARGE  
TO BE COMPLETED BY PARENT/GUARDIAN**

Who completed form (please circle)?                      Mom                      Dad                      Guardian

**Study ID:** \_\_\_\_\_

**Parent and Child Characteristics**

Parent Characteristics

Please circle the following responses:

**Ethnicity (circle one):**      Hispanic or Latino                      Not Hispanic or Latino

**Race (circle all that apply):** Asian              Black or African American                      White or Caucasian

Native Hawaiian or other Pacific Islander                      Native Alaskan/American Indian

**Gender:**              Male                      Female

**Marital Status:** Single                      Married                      Divorced                      Widowed

Please fill in the following responses

**Age:** \_\_\_\_\_

**Number of adults (age 18 and older) living in home:** \_\_\_\_\_

**Number of children (age newborn to 17) living in home:** \_\_\_\_\_

Child Characteristics

Please fill in the following response:

**Date of Birth:** \_\_\_\_/\_\_\_\_/\_\_\_\_ (mm/dd/yyyy)

**Age:** \_\_\_\_\_ years (**or** \_\_\_\_\_ months if less than 24 months)

Please circle the following responses:

**Ethnicity (circle one):**      Hispanic or Latino                      Not Hispanic or Latino

**Race (circle all that apply):** Asian              Black or African American                      White or Caucasian

Native Hawaiian or other Pacific Islander                      Native Alaskan/American Indian

**Gender:**              Male                      Female

**TO BE COMPLETED AT DISCHARGE  
TO BE COMPLETED BY NURSE/RESEARCH STAFF**

Who completed form (please circle)?                      Mom                      Dad                      Guardian

**Study ID:** \_\_\_\_\_

**Hospitalization Characteristics**

Type of organ transplant(s):     Liver             Heart             Kidney

Date of organ transplant: \_\_\_\_/\_\_\_\_/\_\_\_\_ (mm/dd/yyyy)

Number of **unplanned** trips to the operating room during transplant hospitalization:

none             one             two             three or more

Transplant-related complications:

- |               |     |    |
|---------------|-----|----|
| • Infections? | YES | NO |
| • Rejection?  | YES | NO |

Date of hospital discharge: \_\_\_\_/\_\_\_\_/\_\_\_\_ (mm/dd/yyyy)

Number of medications at discharge: \_\_\_\_\_

Additional medical needs at time of discharge:

- |                               |     |    |
|-------------------------------|-----|----|
| • Central line care?          | YES | NO |
| • Wound care?                 | YES | NO |
| • Supplemental tube feedings? | YES | NO |
| • Drainage tubes in place?    | YES | NO |
| • Other: _____                | YES | NO |
| • Other: _____                | YES | NO |
| • Other: _____                | YES | NO |

Readiness for Hospital Discharge Scale Parent Form

Copyrighted Questionnaire

Used with Permission from Dr. Marianne Weiss

Weiss, M. E., & Piacentine, L. B. (2006). Psychometric properties of the readiness for hospital discharge scale. *Journal of Nursing Measurement, 14*(3), 163-180.

Weiss, M., Johnson, N. L., Malin, S., Jerofke, T., Lang, C., & Sherburne, E. (2008). Readiness for discharge in parents of hospitalized children. *Journal of Pediatric Nursing, 23*(4), 282-295.

Quality of Discharge Teaching Scale Parent Form

Copyrighted Questionnaire

Used with Permission from Dr. Marianne Weiss

Weiss, M., Johnson, N. L., Malin, S., Jerofke, T., Lang, C., & Sherburne, E. (2008).  
Readiness for discharge in parents of hospitalized children.  
*Journal of Pediatric Nursing, 23*(4), 282-295.



## CARE TRANSITION MEASURE (CTM-15)

Copyrighted Questionnaire

Modified and Used with Permission from Dr. Coleman

Coleman, E. A., Smith, J. D., Frank, J. C., Eilertsen, T. B., Thiare, J. N., & Kramer, A. M. (2002). Development and testing of a measure designed to assess the quality of care transitions. *International Journal of Integrated Care*, 2(1), 1-9.

PedsQL™ Family Impact Module

Copyrighted Questionnaire

Used with Permission from Dr. J. Varni

Post Discharge Coping Difficulty Scale and Utilization of Healthcare Resources

Copyrighted Questionnaire

Used with Permission from Dr. Marianne Weiss

Weiss, M., Johnson, N. L., Malin, S., Jerofke, T., Lang, C., & Sherburne, E. (2008).  
Readiness for discharge in parents of hospitalized children.  
*Journal of Pediatric Nursing, 23*(4), 282-295.  
(Used with permission)





Appendix C  
Institutional Review Board

**CHILDREN'S HOSPITAL OF WISCONSIN  
HUMAN RESEARCH REVIEW BOARD  
STATEMENT OF VOLUNTEER CONSENT FOR RESEARCH STUDY**

**TITLE OF STUDY:** The Transition from Hospital to Home in Parents of Pediatric Solid Organ Transplant Recipients

**PRINCIPAL INVESTIGATOR:** Stacey Lerret, CPNP **EMAIL:** slerret@chw.org

**PHONE NUMBER:** 414-266-3944

**FULL STREET ADDRESS:** Children's Hospital of Wisconsin  
9000 W. Wisconsin Avenue  
P O Box 1997  
Milwaukee, WI 53201

**CO-INVESTIGATORS:**

Brian Shames, MD	414-456-6920
Estella Alonso, MD	773-880-6328
Marianne Weiss, DNSc, RN	414-288-3855
Julie Banda, CPNP	414-266-3874
Jenni Axelson, RN	414-266-3090
Shelley Chapman, RN	414-266-2894
Grzegorz Telega, MD	414-266-3690
Kathryn Tillman, CPNP	414-266-4752
Gail Stendahl, CPNP	414-266-3874
Katie Neighbors, MPH	773-880-6328
Joan Lokar, CPNP	773-880-6328
Stephanie Nottling, BS	414-266-3194
Kerry Lazewski, CPNP	773-880-3049

**NAME OF SUBJECT:** \_\_\_\_\_ **MR NUMBER :** \_\_\_\_\_

**WE INVITE YOU TO TAKE PART IN THIS RESEARCH STUDY. TAKING PART IN THIS RESEARCH STUDY IS YOUR CHOICE. YOU DO NOT NEED TO PARTICIPATE. YOU MAY LEAVE THIS RESEARCH STUDY AT ANY TIME. IF YOU LEAVE THIS RESEARCH STUDY, YOU WILL NOT BE PENALIZED. YOU WILL STILL GET ANY TREATMENTS OR BENEFITS COMING TO YOU. THIS FORM TELLS YOU WHAT WILL HAPPEN IN THE RESEARCH STUDY. THIS FORM ALSO TELLS YOU ABOUT THE RISKS, DISCOMFORTS AND OTHER INFORMATION ABOUT THE RESEARCH STUDY. MEDICAL LANGUAGE MAY BE HARD TO UNDERSTAND. IF THERE IS ANYTHING THAT YOU DO NOT UNDERSTAND, PLEASE ASK QUESTIONS.**

**A. WHAT IS THE PROBLEM?**

You are being asked to take part in this study because you have a child who has been listed for a heart, kidney, or liver transplant and you have agreed for you and/or your child to participate in a research study.

There are very few studies that look at the factors affecting a parent's readiness for hospital discharge after the child has received an organ transplant. Little information is available on how parents adapt to going home after their child has received an organ transplant. The goal of this study is to provide us with an improved understanding of parent and child perceptions of factors affecting the transition from hospital to home following their child's solid organ transplant.

**B. WHAT IS THE PURPOSE OF THIS RESEARCH STUDY?**

The purpose of this study is to look at how ready parents are to take their child home after receiving an organ transplant. The information we receive will help guide us with future interventions and ways to support our organ transplant families.

We are planning to enroll up to 75 families into the study.

**C. WHAT IS INVOLVED IN THE RESEARCH STUDY?**

Parents that have a child waiting for or who have just received a heart, kidney, or liver transplant will be asked to participate. If you choose to take part in this study, the study coordinator or investigator will ask you to provide written consent at the bottom of this form. If you take part in this study, you will be asked to complete 8 questionnaires in total. These questionnaires will ask about your readiness for hospital discharge, wellness and concerns. All of the information you provide will be confidential and will be associated only with your unique study identification number, not with you personally.

The first 5 forms you will complete at the time of hospital discharge. These forms will include questions about the following: 1) your readiness to take your child home from the hospital; 2) characteristics about you and your child including you and your child's age and who lives in the home; 3) teaching you received in order to take your child home from the hospital; 4) coordination of care between you and the hospital; and 5) the impact or effect that transplantation has on your family. These forms will take approximately 40 minutes to complete and will be done in the hospital before discharge from the hospital.

The last forms will be completed 3 weeks after discharge from the hospital. They will be completed either during a follow-up transplant clinic appointment or over the phone. These questionnaires will ask about: 1) your coping after hospital discharge; 2) providing medical care such as giving medications and following up in the hospital; and 3) the impact or effect that transplantation has on your family (this form was also completed at the time of hospital discharge). It is estimated that these forms will take about 30 minutes to complete.



It is important that the study surveys be done independently and completely. Study surveys can only be taken home to be completed with the permission of the investigator. Study coordinators will be available to assist you if you have questions about the surveys.

Parents of organ transplant patients will complete the questionnaires. While the patients themselves will not be asked to complete questionnaires for this study, their medical information will be collected by the research team for the purpose of this study.

#### **D. WHAT ARE THE RISKS OF THE RESEARCH STUDY?**

The potential risks of participating in this study include a feeling of loss of privacy or emotional upset due to the personal nature of the questions. Completion of the study instruments may also cause families to identify problems in family functioning that they may not have been aware of. If you experience these concerns, the study coordinators at each participating center will help you to access social work or psychological support services as resources.

#### **E. WHAT IF PROBLEMS OCCUR DURING THE STUDY OR WITH TREATMENT?**

Your health is more important than following the research plan. If you feel you are injured or have concerns as a result of the experimental parts of this research study, you should immediately contact Stacey Lerret, the Principal Investigator at 414-266-3944. You may also call the Chairperson of the hospital committee that reviewed the research study at 414-266-2986.

The researcher may decide to take you off this study if the study is ended before enrollment is complete, if funding to support the study is not adequate or if new information becomes available to answer the study questions.

You do not waive any legal rights by participating in this study or by signing this form.

#### **F. WHAT ARE THE POSSIBLE BENEFITS?**

The information which is obtained may be useful to the medical community and other parents. This study may provide us with an improved understanding of parent needs as they prepare to take their child home the hospital after organ transplant. Some parents of children have reported that the opportunity to think and talk about their concerns has been helpful, but this is not guaranteed.

#### **G. WHAT ARE THE FINANCIAL RISKS?**

There are no costs to you associated with participating in this study.

#### **H. WILL YOU BE PAID FOR TAKING PART IN THE RESEARCH STUDY?**

You will receive a total of a \$20 gift card upon completion of the study. After completion of the questionnaires at the time of hospital discharge, you will receive a \$10 gift card. After you complete the 3-week follow-up questionnaires you will then receive an additional \$10 gift card.

**I. DO YOU HAVE TO PARTICIPATE IN THIS RESEARCH STUDY?**

You do not have to participate in this study. You are free to withdraw at any time. Your decision to withdraw will not change the quality of care that you or your child receives from the Medical Staff. However, if you decide to stop participating in the study, we encourage you to talk to the researcher or study coordinator first.

**J. WHAT IF YOU HAVE MORE QUESTIONS?**

For questions about the study or a research-related concern, contact the principal investigator, Stacey Lerret, at 414-266-2000. The principal investigator or one of the co-investigators will be available 24 hours a day, 7 days a week at 414-266-2000. Also, the research study has been reviewed and approved by the Human Research Review Board, whose purpose is to see that the rights and welfare of research participants are adequately protected, and that risks are balanced by potential benefits. A member of this committee is available to speak to you if you have any questions or complaints at 414-266-2986.

You will get a copy of this form. A copy of the signed consent, assent (if applicable) and HIPAA Authorization will be kept in your medical record.

**K. WILL INFORMATION BE CONFIDENTIAL?**

To minimize potential risks to confidentiality, all study data will be recorded by an assigned study identification number. Data will be housed in a secure database created and maintained at the Children's Hospital of Wisconsin. Every attempt will be made to insure ongoing confidentiality and security of the data obtained. Access to the data will be limited to the research team and the entities defined within the informed consent and HIPAA authorization signed by participants.

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Also, scientific data from this study may be presented at meetings and published so that it may be useful to others, as long as it is not identifiable with you. Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as: Medical College of Wisconsin's Human Research Review Committee and Children's Hospital of Wisconsin Institutional Review Board (IRB).

**L. PERMISSION TO PROCEED**

**The signing of this consent does not absolve your doctors from responsibility for your proper medical care at all times.**

**The proposed research study and consent has been explained to you by:**

\_\_\_\_\_  
**Name of Principal Investigator or  
 Designee**

\_\_\_\_\_  
**Signature of Principal Investigator or  
 Designee**

\_\_\_\_\_  
**Date**

**When you sign this form, you agree that you have read the above description of this research. You also agree that your questions have been answered, and that you want to take part in this research.**

\_\_\_\_\_  
**Signature of Subject or Authorized  
 Representative**

\_\_\_\_\_  
**Date**

\_\_\_\_\_  
**Signature of Subject or Authorized  
 Representative**

\_\_\_\_\_  
**Date**

**ASSENT OF MINOR:**

**The study procedure has been explained to me and I agree to participate-**

\_\_\_\_\_  
**Signature of Minor**

\_\_\_\_\_  
**Date**

**WAIVER OF MINOR'S ASSENT:**

**In my opinion, this child is not capable of assent because *(add reason and what you are basing your decision:***

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

\_\_\_\_\_  
**Signature of Principal Investigator  
 or Research Team Designee**

\_\_\_\_\_  
**Date**

**HUMAN RESEARCH REVIEW BOARD  
ASSENT**

---

**STUDY TITLE:** The Transition from Hospital to Home in Parents of Pediatric Solid Organ Transplant Recipients

**INVESTIGATORS:** Stacey Lerret, CPNP; Brian Shames, MD; Estella Alonso, MD; Marianne Weiss, DNSc, RN; Julie Banda, CPNP; Jenni Axelson, RN; Shelley Chapman, RN; Grzegorz Telega, MD; Katie Tillman, CPNP, Gail Stendahl, CPNP; Joan Lokar, CPNP; Katie Neighbors, MPH; Stephanie Nottling, BS; Kerry Lazeswki, CPNP

**PHONE NUMBER:** Children's Hospital of Wisconsin 414-266-2000

*Complete or attach patient's label to top of assent:*

**NAME OF SUBJECT:** \_\_\_\_\_ **MEDICAL RECORD NUMBER:** \_\_\_\_\_

**A. WHAT IS THE PROBLEM?**

You are being invited to take part in this study because you need or have already received a heart, liver, or kidney transplant.

**B. WHAT IS THE PURPOSE OF THIS RESEARCH STUDY?**

The purpose of this study is to look at how ready your parents are to take you home once you leave the hospital after your organ transplant surgery. There is a lot to learn after surgery and hopefully this study will allow us to help your parents and other parents more in the future.

**C. WHAT IS INVOLVED IN THE RESEARCH STUDY?**

If you want to be in the research study, your parent will need to fill out a total of 8 forms. They will fill out five of these forms before you leave the hospital and three of the forms will be completed after you have been home for three weeks. One of the forms they complete will be done before you leave the hospital and again when you have been home for three weeks. You will not be asked to fill out any questionnaires. We will be collecting some of your medical information for research purposes in this study. Only people working on this research study will collect your information.

**D. WHAT ARE THE RISKS TO YOU IN THIS RESEARCH STUDY?**

The only risk to you in this study is the risk of privacy. We protect your privacy by using a code number for all of your information instead of your name. This means your personal information will stay locked up and private.

**E. WHAT ARE THE POSSIBLE BENEFITS TO YOU IN THIS RESEARCH STUDY?**

We hope that this study will help doctors and nurses better understand what your parents need to prepare to take you home after your organ transplant surgery. These benefits are not promised, but we hope that the results will help patients in the future.

**F. WILL YOU BE PAID FOR TAKING PART IN THE RESEARCH STUDY?**

Your parent will receive a total of a \$20 gift card for finishing this study. Your parent will get a \$10 gift card after they fill out the forms before you leave the hospital. Then, your parent will receive another \$10 gift card after filling out forms once you have been home from the hospital for three weeks.

**G. DO YOU HAVE TO PARTICIPATE IN THIS RESEARCH STUDY?**

You do not have to be in this study, and if you are in it you can stop at any time. If you have any questions please ask your doctor.

**H. PERMISSION TO PROCEED**

Your parents / guardian will receive a copy of this form. A copy of the signed consent, assent and HIPAA Authorization will be kept in your medical record.

If you agree to participate in this study, please sign below:

\_\_\_\_\_

Childs Name

\_\_\_\_\_

Child's Signature

\_\_\_\_\_

Date

Assent Form administered and explained in person by:

\_\_\_\_\_  
Principal Investigator or Designee

\_\_\_\_\_  
Date

**MARQUETTE**  
UNIVERSITY

February 4, 2009

Ms. Stacey Lerret  
Nursing

Dear Ms. Lerret:

Your protocol number HR-1774, titled, "*The Transition from Hospital to Home in Parents of Pediatric Solid Organ Transplant Recipients*" was expedited on February 4, 2009, by a member of the Marquette University Institutional Review Board.

This approval is contingent upon receipt by the Office of Research Compliance of the IRB approval letter and approved consent/HIPAA documents from Children's Memorial Hospital.

You are approved to recruit a total of 45 individual parents. Any changes to your protocol must be requested in writing by submitting an IRB Protocol Amendment Form, which can be found at: <http://www.marquette.edu/researchcompliance/research/irbforms.shtml>. All changes must receive IRB review before being initiated, except when necessary to eliminate apparent immediate hazards to the human subjects. Any public advertising of this project requires prior IRB approval. If there are any adverse events, please notify the Marquette University IRB immediately.

Please provide copies of any IRB continuing review approval letters, amendment approval letters, consent forms if any revisions are made, and any other approval letters or revised documentation from Children's Hospital of Wisconsin and Children's Memorial Hospital to the Marquette Office of Research Compliance on a timely basis.

Your approval is valid until February 3, 2010. Prior to this date, you will be contacted regarding continuing IRB review.

If you have any questions or concerns, please do not hesitate to contact me. Thank you for your time and cooperation.

**IRB APPROVAL / EXPEDITED**

January 26, 2009

Stacey Lerret, BS, MSN  
B610

Dear Ms. Lerret:

Please be advised that your protocol entitled **The Transition From Hospital To Home In Parents Of Pediatric Solid Organ Transplant Recipients** was given expedited approval on **January 26, 2009** for Children's Hospital of Wisconsin (CHW).

For purposes of identification, this research has been assigned the following numbers: **CHW 09/10, GC 811**. *All CHW protocols are also assigned a Grants and Contracts Office (GC) number by the Medical College of Wisconsin.*

The Consent, Assent and HIPAA Forms approved **January 26, 2009** must be used from this date forward.

**This protocol is approved for 1-year from the date of the Board meeting and a continuing review is scheduled for January 25, 2010. A Continuing Review Form will be forwarded three months prior to this review date. Failure to submit the Continuing Review Form in a timely manner may result in the termination of your research approval.**

Any changes to this study and any serious adverse reactions, or death, must be reported immediately to the Children's Hospital of Wisconsin's Human Research Review Board.

Federal regulations require that if any advertising is involved in the initiation of this protocol, prior approval must be obtained from Children's Hospital's HRRB.

If this is a sponsored research project, it is incumbent upon the Principal Investigator to be aware of the Quality Assurance requirements of the sponsor and to carry out the project accordingly.

When the above work is completed or discontinued, the Board must be notified in order to maintain an accurate record of all current projects.

If you leave the staff of the hospital, you are expected to notify the Board in writing to whom the protocol should be transferred; otherwise, the protocol will be terminated.



## ***EXPEDITED APPROVAL NOTICE***

TO: **Estella Alonso, MD**  
Gastroenterology/Hepatology/Nutrition, Box#57

RE: **The Transition from Hospital to Home in Parents of Pediatric Solid Organ Transplant Recipients**

IRB #: **2009-13873**

APPROVED: **June 9, 2009 – Expedited Review**

EXPIRATION OF  
IRB APPROVAL: **June 8, 2010**

*This protocol was approved under the following risk/benefit determination as described in CFR 45 Part 46, Subpart D:*

**45 CFR §46.404                      *Research not involving greater than minimal risk.***

The Institutional Review Board (IRB) reviewed and approved, via expedited procedure as authorized by 45 CFR 46.110 and 21 CFR 56.110, the above-named protocol which will involve human subjects.

**This research was reviewed under expedited review category #5:** “Research involving materials (data, documents, records, or specimens) that have been collected, or will be collected solely for non-research purposes (such as medical treatment or diagnosis).”

**This research was reviewed under expedited review category #7:** “Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.”

The IRB would like to call your attention to some of your obligations as principal investigator. Prior IRB review and approval is required before any change in the protocol, or in its procedures, may be implemented. A change in the principal investigator or any significant adverse effects or injury to subjects must be reported to the IRB immediately.

Please note that if this study is a sponsored study, you may NOT begin work on this study including subject enrollment until your contract/award is fully executed. Please contact Kristine Martens at (773) 755-6561 or [kmartens@childrensmemorial.org](mailto:kmartens@childrensmemorial.org) for industry sponsored clinical trial contracts.. For non-industry sponsored studies (Federal, subcontracts, foundations, etc) please contact your appropriate OSP delegate.

Federal regulations require that an IRB conduct continuing review of research not less than once per year, regardless of whether initial approval was via full board or expedited procedures. Please note the expiration date for your current IRB approval and be aware that you must submit a progress report for IRB review prior to the expiration in order to obtain IRB approval for the next approval period. If the current approval expires and you do not obtain approval for another approval period, research on this study, including subject enrollment, must cease until you regain approval. If you have questions about your obligations as principal investigator, please contact the IRB Office at 773-755-6305.

Best wishes for a successful study.

Sincerely,

---

Adrienne Prestridge, MD, Acting Chair  
Institutional Review Board  
Children's Memorial Hospital



## Carolinah HealthCare System

James E.S. Hynes  
Chairman

Michael C. Tarwater, FACHE  
Chief Executive Officer

Joseph G. Piemont  
President & COO

December 2, 2009

Vani Gopalareddy, MD  
Carolinah Medical Center  
1001 Blythe Blvd., Suite 200  
Charlotte, NC 28203

### RESEARCH PROTOCOL APPROVAL, IRB File # 12-09-12E

On December 2, 2009, the Institutional Review Board reviewed your research request:

*The Transition from Hospital to Home in Parents of Pediatric Solid Organ Transplant Recipients*

Your Protocol, dated 01/07/2008 (Version 1), Consent Form and Assent Form, both dated December 2, 2009 (expiration date December 1, 2010) were approved for a period of one year for use within the facilities of Carolinah HealthCare System. The HIPAA Authorization included within the consent form was approved. The Board determined your study poses minimal risk to subjects and meets criteria for Expedited review under 45 CFR 46.110, Category 7. If you plan to use the protocol in institutions outside of this facility, you must submit it to the IRB at that institution for approval.

**Enclosed, please find a copy of the consent form(s) stamped by the IRB. This copy should be used when obtaining the participant's signature. You will need three (3) copies of the Informed Consent: one for the patient, one for the patient's chart, and one for your records.** The FDA requires that advertisements for recruiting subjects be reviewed and approved by the IRB before publication.

We will contact you in approximately 10 months to schedule an annual update and review of these projects. If you complete a study prior to receiving the form, please notify the IRB Office. You are required to report any changes to the research study to the IRB for approval prior to implementation. If we can be of any further assistance, do not hesitate to contact us. **Please use the IRB File # for reference.**

## Appendix D: Manuscript II

*Lerret, S. M. & Weiss, M. E. (In Review)*

*How Ready Are They? Parents of Pediatric solid Organ Transplant Recipients and the  
Transition from Hospital to Home Following Transplant*

**Title Page**

**Title:** How Ready Are They? Parents of Pediatric Solid Organ Transplant Recipients and  
the Transition from Hospital to Home Following Transplant

**Authors:** Stacey M Lerret<sup>1,2</sup> and Marianne E Weiss<sup>3</sup>

Medical College of Wisconsin<sup>1</sup>

Children's Hospital of Wisconsin<sup>2</sup>

Marquette University<sup>3</sup>

**Running Head:** Transplant and Transition to Home

**Abstract Page**

**Author Surname and Initials:** S. M. Lerret, PhD, RN, CPNP and M. E. Weiss, DNSc, RN

**Title of Manuscript:** How Ready Are They? Parents of Pediatric Solid Organ Transplant Recipients and the Transition from Hospital to Home Following Transplant

**Title of Journal:** Pediatric Transplantation, Pediatric Transplantation

**Abstract:** Poor discharge transition is evidence of a gap between evidence-based practices and current health care delivery. Pediatric solid organ transplant recipients are a vulnerable population at risk for complications during the discharge transition. The aim of this study was to investigate factors associated with the transition care from hospital to home. We studied the transition experience of parents of heart, liver, or kidney recipients in order to identify opportunities for improvement in discharge and post-discharge care processes and outcomes. Thirty-seven parents from three different pediatric transplant centers completed questionnaires on the day of hospital discharge and three weeks following hospital discharge. Care coordination was associated with readiness for hospital discharge. Readiness for hospital discharge was subsequently associated with post-discharge coping difficulty, adherence with medical follow-up, and family impact. Identifying parents who are not ready to go home provides an opportunity to offer additional support services so parents can effectively manage their child's recovery and continuing care at home.

**Key Words:** pediatric, solid organ transplant, discharge transition

**Corresponding Author:** Stacey Lerret

Children's Hospital of Wisconsin, 9000 West Wisconsin Avenue MS B610,  
Milwaukee, WI 53226

## Introduction

The Institute of Medicine (IOM) published a landmark report in 2001, *Crossing the Quality Chasm: A New Health System for the 21<sup>st</sup> Century*, highlighting the gap between evidence-based practices and current health care delivery. Poor quality discharge transitions are evidence of this gap and improvement of the quality of discharge transitions is a current national research and practice priority. The National Coalition on Care Coordination (2008) has proposed an agenda to promote and implement care coordination services that enhance the discharge process resulting in improved patient care, increased quality of life, and reduction of stress on family caregivers. Although the National Coalition on Care Coordination focuses on the older adult population, there are certainly other high-risk populations that would also benefit from improved discharge transition. Pediatric transplant recipients are an extremely vulnerable population at high risk for complications who can experience significant consequences, including death, from a poor discharge transition.

Efforts to date to improve the discharge transition have focused on the elderly (Coleman et al, 2004; Coleman, Mahoney, & Parry, 2005; Naylor, Bowles, & Brooten, 2000; Naylor et al., 1999) and other high risk populations such as patients with heart failure (McCauley, Bixby, & Naylor, 2006; Naylor et al., 2004; Stewart, Pearson, & Horowitz, 2000). Studies have highlighted problems with the discharge process (LaMantia, Scheunemann, Viera, Busby-Whitehead, & Hanson, 2010; Mistiaen, Francke, & Poot, 2007), post-discharge medication errors (Moore et al., 2003; Forster et al., 2004), and adverse events within one month of hospital discharge (Forster et al., 2003) leading to unnecessary and preventable readmissions (Goldfield, 2010; Jack et al., 2009;

Greenwald & Jack, 2009). A decrease in hospital readmission rates and cost of care is seen when there is a focus on careful discharge transition (Jack et al., 2009; Naylor et al., 1999; Naylor & McCauley, 1999; Naylor et al., 2004).

The state of knowledge on discharge transition in the pediatric patients in general and the pediatric transplant population, specifically, is scarce and does not mirror the extent of research in the elderly and adult population. Discharge preparation and coordination processes are essential components of care for families of hospitalized children, for example, medically complex children (Klitzner, Rabbitt, & Chang, 2010; Wong, 1991), and infants being discharged from the neonatal intensive care unit (Affleck, Tennen, Rowe, Roscher, & Walker, 1989; Baker, 1991; Kenner & Lott, 1990; Shiekh, O'Brien, & McCluskey-Fawcett, 1993; Smith, Young, Pursley, McCormick, & Zupancic, 2009; Sneath, 2009).

Pediatric transplantation has seen significant medical, surgical, and medication advancements in the last 3 decades making solid organ transplant (SOT) the treatment of choice for end stage organ disease (Fine et al., 2007). However, little is known about the hospital discharge experience for parents of pediatric SOT recipients aside from the fact that emotional and psychological distress is common (Young et al., 2003). An integrative literature review of discharge readiness focusing on pediatric transplant recipients concluded that meaningful interactions and confidence building with families might enhance the discharge transition process (Lerret, 2009).

Transplant providers have an opportunity to align with the national agenda to improve the discharge transition process. As with other complex patient populations, a collaborative, multidisciplinary process among providers will benefit pediatric transplant



recipients and families through consistently addressing quality and cost outcomes in the care delivery provided by integrated health systems (IOM, 2001). Research exploring the transition from hospital to home after pediatric SOT is warranted not only to determine care processes that affect the patient and family discharge experience, but also to provide direction for improving outcomes, utilization of healthcare services, and overall cost of care for these families.

### ***Aims***

The purpose of this study was to investigate factors associated with the transition from hospital to home of parents of SOT (heart, liver, or kidney) recipients in order to identify opportunities for improvement in discharge and post-discharge care processes and outcomes. The specific aims were to determine the relationships of: 1) pre-discharge care processes of discharge teaching and care coordination with parent perception of readiness for hospital discharge and 2) parent readiness for hospital discharge with post-discharge coping difficulty, family impact, adherence, and utilization of healthcare resources within the three weeks following hospital discharge.

## **Methods**

### ***Design***

Meleis' Transitions theory provided an organizing framework for conceptualizing the transition from hospital to home in the specific situation of parents of pediatric SOT recipients. The four major components of transition are Nature of the Transition, Transition Conditions, Nursing Therapeutics, and Patterns of Response (Meleis et al., 2000). Each of these transitions theory concepts is represented by the study variables. The prospective, correlational design examined the sequential relationships among pre-

and post-discharge variables including the evaluation of relationships of discharge teaching and care coordination (Nursing Therapeutics) with readiness for hospital discharge, post-discharge coping difficulty, family impact, adherence, and utilization of healthcare resources (Patterns of Response). The hospitalization factors and parent/child characteristics were collected for descriptive purposes and represent the Nature of the Transition and Transition Conditions components of Transitions Theory.

### ***Sample***

A sample of 37 parents self-identified as the primary caregiver of children who received a heart, kidney, or liver transplant at three major pediatric transplant centers was obtained between May 2009 and May 2010. Inclusion criteria consisted of the following: parents 18 years of age or older, English speaking, and a telephone to complete the post-discharge interview. Parents were excluded if the child had a previous transplant or extreme co-morbid conditions requiring significant skilled nursing care in the home such as tracheostomy or ventilator dependence. All eligible parents were approached to participate in the study and seven parents refused.

### ***Data Collection Procedures***

Following Institutional Review Board approvals at all study sites, eligible parents were identified and contacted by their transplant coordinator to request voluntary participation and obtain informed consent. Parents completed written questionnaires on the day of hospital discharge and completed a second set of questionnaires by a phone interview three weeks post-discharge. Parents were given \$10 gift cards for completion of each portion of the study (discharge and post-discharge).

The discharge survey packet consisted of 5 questionnaires including Parent and Child Characteristics form, Quality of Discharge Teaching Scale (Weiss et al., 2008), Care Transition Measure (Coleman, Mahoney, & Parry, 2005), Parent Readiness for Hospital Discharge Scale (Weiss & Piacentine, 2006), and PedsQL Family Impact Module (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). The transplant coordinator completed a hospitalization characteristics form at the time of hospital discharge.

The post-discharge survey packet consisted of 4 questionnaires including: Post Discharge Coping Difficulty Scale (Weiss et al., 2008), Utilization of Healthcare Resources form, PedsQL Family Impact Module (Varni et al., 2004), and Adherence form. Parents and transplant coordinators also provided a current medication list.

### ***Study Measures***

*Parent and Child Characteristics:* Parent and child characteristics included age, race, and gender. Parental marital status was also obtained.

*Hospitalization Characteristics:* Patient medical chart reviews were conducted to record type of organ transplant, unplanned returns to the operating room, transplant-related complications including rejection or infection, length of transplant hospitalization, and number of medications and home medical care needs at the time of discharge.

*Quality of Discharge Teaching Scale (QDTS):* The QDTS was used to measure the parent's perspective of the quality of discharge teaching provided by nurses throughout the hospitalization. The 18-item QDTS tool consists of two subscales, content received and delivery. The content received subscale focuses on discharge education content including taking care of the child at home, information about medical

care, knowledge about when and how to call the provider, and parents' feelings. The delivery subscale assesses the skill of the child's nurses in providing discharge education to the parent. Parents rate the discharge education content and delivery of teaching received from the nursing staff on a scale of '0' (none or not at all) to '10' (a great deal or always) with higher scores indicating higher quality of teaching. The Cronbach's alpha reliability has ranged from .88 to .92 in samples of parents of hospitalized children, adults, and older adults .88 to .93 (Weiss et al., 2007; Weiss et al., 2008; Bobay et al., 2010). Construct validity was supported with principal components exploratory factor analysis (Weiss et al., 2007).

*Care Transition Measure (CTM)*: Care coordination was defined for the study as parent perception of the healthcare team actions to ensure patient-centered comprehensive planning and continuity of healthcare for the child and family in preparation for hospital discharge (National Coalition on Care Coordination, 2008). The CTM is a 15-item measure with four domains: transfer of information, preparation of patient/caregiver, self management support, and empowerment to assert preferences (Coleman et al., 2002). Respondents use a four point Likert scale with scores '1' (strongly disagree) to '4' (strongly agree). The mean score for each respondent is linearly transformed to a 0-100 scale. Lower total scores are indicative of poorer quality care transition and higher scores indicate better transitional care coordination (Coleman et al, 2002).

The CTM was developed and validated in a sample of adult patients aged 65 years and older who experienced the transition from hospital to home, hospital to skilled nursing facility, or skilled nursing facility to home (Coleman et al., 2002). Cronbach's

alpha of .93 was reported in a sample of adult patients 18 years and older discharged from hospital to home or a skilled nursing facility and was shown to successfully discriminate between patients discharged from the hospital who did and did not have a subsequent emergency department visit or re-hospitalization (Coleman, Mahoney, & Parry, 2005).

Although the CTM has not been used in the pediatric population, the discharge experience and implications for post-discharge outcomes are similar to the older adult population. Both pediatric and older adult populations have a need for a primary caregiver and must integrate complex medical condition management with the stresses of home life. For this study, the wording of CTM items was modified with permission for the parent as respondent, in order to capture the parent perception of care coordination in preparation for discharge from the hospital. The CTM is typically administered between 3 and 12 weeks after hospital discharge (Coleman et al., 2004; Coleman, Mahoney & Parry, 2005). The parent CTM was administered to identify the parent perception of care coordination on the day of hospital discharge rather than the usual post-discharge administration that asked participants to retrospectively recall their hospital discharge experience.

*Readiness for Hospital Discharge Scale (RHDS):* The RHDS is a 29-item tool that was used to assess parents' perceptions of readiness for discharge. The RHDS is composed of five subscales: parent's personal status, child's personal status, knowledge, coping ability, and expected support. The parent answers each item on a scale from '0' (not at all) to '10' (totally) where higher total scores are interpreted as greater readiness for hospital discharge. Cronbach's alpha reliability estimates are high ranging from .84

to .90 in various population groups including adult medical surgical patients, older adults, and parents of hospitalized children (Bobay, Jerofke, Weiss & Yakusheva, 2010; Weiss et al., 2008; Weiss & Piacentine, 2006; Weiss, Yakusheva & Bobay, 2010). Construct validity was supported with confirmatory factor analysis and group comparisons. Predictive validity was supported as readiness for hospital discharge was associated with post-discharge difficulty coping (Weiss & Piacentine, 2006).

*Post Discharge Coping Difficulty Scale (PDCDS):* The PDCDS is a 10-item scale used to measure the degree of parental difficulty in coping with stress, recovery, self care and management, support, confidence, and child's adjustment after hospital discharge (Weiss et al., 2008). Parents rate the individual items on a scale of '0' (not at all) to '10' (extremely, completely or a great deal) where higher scores indicate the parent is experiencing more difficulty coping. In a sample of parents of hospitalized children, the Cronbach's alpha reliability coefficient was .84. Construct validity was supported through factor analysis and the association of higher scores of PDCDS related to a higher post-discharge utilization provided evidence in support of predictive validity (Weiss et al., 2008).

*Utilization of Healthcare Resources Form:* Utilization of healthcare resources post-discharge was obtained through parent report and validated by medical record review. Occurrences of calls to providers, scheduled and unscheduled office or clinic visits, urgent care or emergency department visits and hospital readmissions were recorded in a dichotomous format (yes/no).

*PedsQL Family Impact Module:* The PedsQL Family Impact Module is a 36-item measure comprised of eight dimensions of parent and family functioning including:

parent physical, emotional, social, cognitive functioning, communication, worry, daily activities, and family relationships (Varni, Sherman, Burwinkle, Dickinson, & Dixon, 2004). Parents rate the degree each item has been a problem as a result of the child's health in the last 30 days on a 5-point scale ranging from '0' (never) to '4' (almost always). The resultant raw scores are reverse coded and linearly transformed to a 0-100 scale where higher scores indicate better parent or family functioning. The PedsQL Family Impact Module is able to distinguish between families with children in a long-term care facility versus those that reside at home and has a high Cronbach's alpha of .97 (Varni et al., 2004).

Parents completed the PedsQL Family Impact Module on two occasions, the day of hospital discharge and three weeks following discharge from the hospital. Completion of this form on the day of hospital discharge captured parent responses of the four weeks before the date of hospital discharge, a period which included the transplant hospitalization and the immediate period prior to the hospital stay. Parents completed this form at a second time point, three weeks following hospital discharge, capturing parent responses in the time since discharge from the hospital following transplant. The form was reworded for data collection at the second time point stating, "In the last 3 weeks or since the date you were discharged from the hospital". A change score was calculated to measure the difference between the two scores (change score = post-discharge raw score minus raw score at discharge).

*Adherence:* Adherence was measured by both parent report of adherence difficulty and medication list reconciliation. Difficulty with adherence to the medication and medical follow-up regimens was assessed with single item questions. The parent

answered each item on a scale from '0' (not at all difficult) to '10' (totally difficult) with higher scores indicating more difficulty with the regimen. The reliability and validity of single item indicators have been supported (Sagrestano et al., 2002; Youngblut & Casper, 1993). Adherence was also measured as a criterion variable by identifying medication list discrepancies (yes/no) through medication reconciliation. Parents and transplant coordinators individually listed the current medications. To minimize error, coordinators were given the date and time that the parent provided the medication list in order to control for dosing and frequency changes that may occur over time.

### ***Data Analysis***

Analyses were conducted using SPSS version 17.0 (SPSS, Inc.). Descriptive analyses were conducted to provide summary information regarding participant characteristics including child, parent, and hospital factors at the time of hospital discharge.

Zero order correlations were calculated for the primary study variables measured at an interval level. Linear regression was used to measure the relationship between readiness for hospital discharge with predictors (QDTS and CTM) and outcomes (Adherence, PDCDS, PedsQL Family Impact) that were measured at the interval level. The relationship of readiness for hospital discharge and PedsQL Family Impact was analyzed with both the 3-week post-discharge raw score and the hospital to post-discharge change score. Logistic regression was utilized to examine the relationship between readiness for hospital discharge and utilization of healthcare resources and medication adherence. The PedsQL Family Impact scores were further analyzed with a paired *t* test to compare family impact four weeks before hospital discharge and three



weeks after hospital discharge. Probability levels of  $p < .05$  were used for determining statistical significance in all analyses.

## **Results**

A majority of the 37 parents were enrolled at two of the three pediatric transplant centers (Hospital A = 18, Hospital B = 18, and Hospital C = 1). Approximately half of the sample were parents of children that received a heart transplant ( $n=18$ ), while the remaining received a kidney ( $n=10$ ) or liver ( $n=9$ ) transplant.

### ***Sample Description***

Table 1 summarizes the sample characteristics. Parents were mostly Caucasian, married and female. The mean age was  $38.9 \pm 9$  years (range 22-55). The mean age of the transplanted patients was  $7.9 \pm 6.0$  years (range 3 months to 18 years).

There were 14 individual patients (38%) with one or more complication defined as an unplanned return to the operating room (OR), infection, and/or rejection. Patients were discharged from the hospital with a mean of  $11.4 \pm 3.3$  medications (range 5-18). Half of the patients had one or more additional post-discharge medical care needs, defined as skilled care tasks including central line care, wound care, or enteral tube feeding (Table 2).

### ***Descriptive Statistics***

Parents reported moderate levels of care transition coordination (CTM mean 3.7, [s.d. 0.9] out of 5) in preparing for the transition to home as well as high quality discharge teaching (QDTS) (Table 3). The highest QDTS items asked parents about the skill of their nurses to educate the family: 'teaching was understandable' (mean 9.4, [s.d. 1.1] out of 10), 'nurses listened to concerns' (mean 9.3, [s.d. 1.1] out of 10), and 'nurses

checked to ensure understanding' (mean 9.3, [s.d. 1.4] out of 10). The lowest scoring QDTS item was information parents received about the patient's emotions after going home from the hospital (mean 4.8, [s.d. 3.7] out of 10).

Parents reported a high level of readiness for hospital discharge (RHDS) (mean 8.3, [s.d. 0.9] out of 10), indicating they felt reasonably ready to leave the hospital on the day of discharge. Knowledge and Coping subscales of the RHDS were the two subscales with the highest scores. The item with the highest score was part of the Knowledge subscale and asked the parent's knowledge on who to call with problems (mean 9.5, [s.d. 0.7] out of 10). The two lowest scoring subscales for the RHDS were Child Personal Status and Expected Support. The lowest scoring items (indicating relative lack of readiness) were parent stress on the day of discharge (mean 6.3, [s.d. 2.1] out of 10) and parent knowledge of services and support (mean 7.0, [s.d. 2.6] out of 10).

Parents had relatively little difficulty coping after hospital discharge with a PDCDS item mean of 2.0 (s.d. 1.4) out of a score of 10. The least amount of difficulty was in caring for their child's medical needs (mean 0.3, [s.d. 0.7] out of 10). In contrast, the highest rated item on the PDCDS was how stressful life has been after discharge (mean 4.7, [s.d. 2.7] out of 10).

A little over half of the parents (54%) had a different medication list than that reported in the medical record. The most common discrepancy was related to dose and frequency of medication administration. Reported difficulty with adherence to attending lab and clinic follow-up (mean 2.6, [s.d. 3.2] out of 10) was higher than for medication administration (mean 1.4, [s.d. 2.3] out of 10). There was no significant difference in adherence difficulty scores for parents with no medication discrepancy ( $M = 1.25$ ,  $SD =$

2.15) compared to parents with medication discrepancy ( $M = 1.05$ ,  $SD = 1.61$ ),  $t(34) = .32$ ,  $p = .50$ .

Utilization of healthcare resources in the first three weeks following hospital discharge was obtained by parent report (Table 4). More calls were made to the hospital staff (59.5%) than to family for support (10.8%) and more than three quarters (82%) of the calls to the hospital was made to the transplant nurse or coordinator. Four patients (10.8%) were seen in the emergency department for fever, pain, crying, feeding tube or central line problems. Twenty-seven percent ( $n=10$ ) of patients were re-admitted to the hospital for the following reasons: hyperglycemia, infection, fever, antibiotics, biopsy, or medication related complications.

#### ***Care Process Associations with Readiness for Hospital Discharge***

Zero order correlations were significant for CTM with RHDS ( $r = .42$ ,  $p < .01$ ) but not for QDTS with RHDS ( $r = .15$ ,  $p > .05$ ) (Table 5). CTM and QDTS were also correlated ( $r = .44$ ,  $p < .01$ ). Likewise when entered together in a linear regression equation, QDTS total score was not predictive of RHDS ( $F(1,35) = .85$ ,  $p = .36$ ,  $R^2 = .02$ ). However, CTM was significantly associated with RHDS ( $F(1,35) = 7.44$ ,  $p = .01$ ) explaining 15% ( $R^2 = .15$ ) of the variance in parents' perception of discharge readiness.

#### ***Readiness for Hospital Discharge and Post Discharge Outcomes***

Zero order correlations for post-discharge coping difficulty, family impact, adherence, and utilization of healthcare resources are displayed in Table 5. Separate linear regressions were also computed. Readiness for hospital discharge was associated with post-discharge coping difficulty ( $F(1,35) = 28.52$ ,  $p < .001$ ,  $R^2 = .45$ ), family impact raw score ( $F(1,35) = 11.07$ ,  $p = .002$ ,  $R^2 = .24$ ), and adherence difficulty with lab and

clinic follow-up ( $F(1,35) = 2.88, p = .003, R^2 = .22$ ). RHDS was not associated with parent report for adherence difficulty with medication regimen ( $F(1,35) = 2.88, p = .10, R^2 = .08$ ) or family impact change score ( $F(1,35) = 2.31, p = .14, R^2 = .06$ ).

RHDS was not predictive of the post-discharge utilization categories including calls to the hospital ( $p=.46$ ), calls to family or friends ( $p=.40$ ), emergency department visits ( $p=.67$ ), or hospital readmission ( $p=.07$ ). RHDS was not associated with medication discrepancy ( $p=.67$ ).

Family functioning, measured by the PedsQL Family Impact Module, improved after transplant. There was an increase in family impact scores for perceptions of family impact pre-discharge ( $M = 63.98, SD = 16.59$ ) to three weeks post-discharge ( $M = 74.38, SD = 14.34$ ),  $t(36) = 5.79, p < .0005$ . The mean increase in scores was 10.4 (95% confidence interval = 6.75 to 14.04). The eta squared statistic (.48) indicates a large effect size.

### ***Additional Analyses***

Additional analyses were performed to explore relationships not specified in the original study model. Separate linear regressions were used to analyze the relationships between quality of discharge teaching and care coordination with post-discharge outcomes (coping difficulty, family impact, and adherence difficulty). QDTS was not directly predictive of any of the post-discharge outcomes. Care coordination was not directly associated with family impact after hospital discharge ( $p = .21$ ) or adherence difficulty with medications ( $p = .59$ ) and follow-up ( $p = .13$ ). Care coordination was associated with post-discharge coping difficulty ( $F(1,35) = 5.0, p = .03$ ) explaining 16% ( $R^2 = .16$ ) of its variance, similar to the explained variance between CTM and RHDS

(15%). Because CTM and RHDS were independently associated with PDCDS, both were entered together as independent variables in a regression equation of PDCDS. The resultant model was significant ( $F(2,34) = 14.2, p < .001$ ) explaining 42% ( $R^2 = .42$ ) of PDCDS variance, but RHDS was the only significant predictor ( $\beta = -.63, p < .001$ ). The results indicate that the direct path from CTM to PDCDS does not add any explanatory power beyond that provided by RHDS. The resultant significant paths from CTM to RHDS to PDCDS suggest the mediation role of RHDS in the impact on care coordination on post-discharge coping difficulty.

The relationships among the post-discharge outcomes were analyzed using linear and logistic regressions as appropriate to the level of measurement. Two significant associations were identified. PDCDS was associated with parent report for difficulty with lab and clinic follow-up ( $F(1,35) = 4.8, p = .04$ ) explaining 10% ( $R^2 = .10$ ) of its variance. Family impact after discharge was associated with calls to the hospital,  $\chi^2(1, N = 37) = 4.48, p = .03$  indicating that the model was able to distinguish between individuals who did and did not call the hospital after discharge. The model as a whole explained between 11.7% (Cox and Snell  $R^2$ ) and 15.9% (Nagelkerke  $R^2$ ) of the variance and correctly classified 61.1% of cases.

The final model of the significant relationships between study variables is presented in Figure 2.

## Discussion

Collectively, the results of the study provide preliminary evidence that readiness for hospital discharge of SOT parents is influenced by care team process and associated with subsequent post-discharge outcomes. The first aim of this study examined the

relationship between pre-discharge care processes (discharge teaching and care coordination) and parent perception of readiness for hospital discharge. Care coordination, but not quality of discharge teaching, was significantly associated with readiness for hospital discharge explaining a small but meaningful portion of the variance (15%). Care coordination is an essential component for safe transitions, especially with a complex patient population (Lerret, 2009; Liptak, Burns, Davidson, McAnarney, 1998). The result emphasizes the important role of coordination of the transition home in this population. All aspects of the discharge transition must be well coordinated from the parent's perspective to successfully implement a complex post-discharge medical regimen and optimize continued recovery at home.

Despite the fact that discharge teaching was not associated with parent perception of discharge readiness, parents did indicate high quality discharge teaching on the QDTS. In addition, knowledge was the highest scored subscale of the RHDS. Patient education is a fundamental area of nursing practice (Smith & Liles, 2007) and an essential component to being successful once in the home environment (Maloney & Weiss, 2008; Clark et al., 2005). Parents of pediatric SOT recipients receive a significant amount of education during a stressful hospitalization in order to continue care at home. The education itself may be anxiety-provoking for transplant parents.

A previous study of parents of children hospitalized for a variety of admission diagnoses (emergent, chronic illness, neonatal intensive care unit or planned short stay) did report a significant relationship between QDTS and RHDS (Weiss et al., 2008). However, education of transplant parents such as those in this study is considerably different because transplant parents have a protocol-derived educational experience

throughout the transplant hospitalization to master concepts of rejection and infection, medication administration, and other skilled care activities. Transplant families also experience an extended hospitalization allowing for repeated educational sessions and reinforcement from a consistent educator, the transplant coordinator.

Quality of teaching may be less of a driver of readiness for hospital discharge than care coordination in care situations with a long hospital length of stay and uncertain complex post-discharge courses. In this study, QDTS and CTM were correlated. The tools have some redundancy in the content of questions regarding information needed for medication administration and who to call with questions after hospital discharge. Both tools focus conceptually on preparation for hospital discharge. The QDTS specifically measures teaching by nurses and whether education meets the parent's needs in regard to methods used for discharge teaching and the amount of content. The CTM is reflective of the transplant team with a focus on the parent's perception of ability to manage the medical regimen and if a written plan was provided at the time of discharge.

The transplant team consists of surgeons, physicians, pharmacists, nurses, transplant coordinators, and social workers who are all working toward a common goal, discharge from the hospital. The reality is that not every team member relays the same information to families. Coordinated preparation with consistent communication with parents and between providers will enhance parents' feelings of confidence or readiness to go home from the hospital. The study results highlight the importance for coordination of the transition as a whole rather than discharge teaching specifically in promoting parental feelings of being ready and prepared to be discharged from the hospital.

The second aim of the study addresses the relationship between parent readiness for discharge and post-discharge outcomes; a critical time interval because transplant patients are at high risk for complications in the first months after transplant (Fine et al., 2007). Although parent level of stress was the item of lowest perceived readiness on the RHDS, the mean was above the mid-point of the scale. Being ready to go home clearly contributes to a parent's ability to cope after discharge from the hospital in this specific patient population. Previous studies provided insight into the importance of helping families cope. Caregivers of organ transplant candidates were reported to be under considerable stress and at risk for deterioration in both physical and mental health (Bolden & Wicks, 2008; Maloney, Clay, & Robinson, 2005; Zelikovsky et al., 2007). A parent that is not physically or mentally available to care for the transplanted child may put the child at increased risk for complications. Transplant teams that focus on preparing parents for hospital discharge are in turn helping parents cope and provide the necessary care at home.

Readiness for hospital discharge also contributed to family impact and parent report of adherence difficulty to the medical regimen for lab and clinic follow-up. The relationship between RHDS and the PedsQL Family Impact Module was measured with both the 3-week post-discharge family impact raw score and the family impact change score. A change score was calculated because there was a statistically significant difference between the two time points (date of hospital discharge and 3-weeks post-discharge). The only significant relationship was with RHDS and family impact post-discharge raw score. The amount of change from pre-discharge to post-discharge was not associated with RHDS, but the association of readiness for discharge with adjustment



following discharge was evident. The pre-discharge family impact score likely incorporates the trauma and uncertainty of the transplant and hospitalization, while post-discharge adjustment may be more indicative of family adjustment and stabilization. The RHDS was also related to parents reported difficulty with adherence to lab and clinic follow-up, explaining 22% of the variance. Feeling ready to leave the hospital resulted in less adherence difficulty with the medical regimen follow-up for lab and clinic appointments. The relationship between readiness and adherence is critical because the overall success of pediatric transplant is often compromised by non-adherence (Kahana, Frazier, & Drotar, 2008).

Non-adherence is the leading cause of organ rejection resulting in hospital admission or even death (Butler, Roderick, Mullee, Mason, & Preveler, 2004; Rianthavorn, Ettenger, Malekzadeh, Marik, & Stuber, 2004; Ringewald et al., 2001). Parental readiness for hospital discharge and post-discharge coping difficulty were both independently related to adherence difficulty with lab and clinic follow-up. Identifying parents who are struggling to cope after discharge may at the same time determine parents who are having difficulty adhering to the follow-up regimen and could benefit from additional support services available through the transplant social worker. Parents rated knowledge of services and support on the RHDS form completed on the day of hospital discharge the lowest, indicating that additional social work services may benefit families starting at the time of discharge.

Although RHDS and PDCDS were significantly associated with adherence difficulty for lab and clinic follow-up, this was not the case for adherence difficulty with medications. The study results did indicate that patients were discharged on numerous

medications and approximately half of the parents may not have been administering the correct medication dose or frequency. Medication-related complications were identified as a reason for hospital readmission and adherence to the medication regimen may have been a contributing factor. More frequent medication reconciliation with transplant coordinators or pharmacists may benefit families in this immediate post-transplant period when the number of medications is typically the highest.

Medications, frequent lab and clinic follow-up, and other medical care necessary after hospital discharge can be overwhelming for transplant families (Stuber, 1993). Stress after hospital discharge was the highest rated item on the PDCDS and may not be related to the child's medical needs, the lowest rated item on the PDCDS. Although the source of stress was not identified in this study, parents of children with a chronic illness may experience financial stress, role strain, and questions about the future (Brown et al., 2008; Coffey, 2006; Wang & Barnard, 2004). Transplantation is a process that challenges parents to manage demanding follow-up and the underlying threat for potential transplant complications (Shemesh, 2007). The stressors may lead to anxiety, depression, post-traumatic stress and a loss of control (Brown et al., 2008). Post-traumatic stress symptoms have been reported in parents of pediatric cancer survivors (Kazak et al., 1997; Pelcovitz et al., 1996), and children with diabetes (Landolt et al., 2002).

Organizing the care of a chronically ill child into the family schedule poses difficulties in maintaining normal family function and a sense of routine (Jerrett, 1994). Studies have demonstrated the efficacy of care coordination on post-discharge outcomes including improving medical outcomes, reducing medical resource use, and improving

parent satisfaction for children with complex medical conditions (Liptak, Burns, Davidson, & McAnarney, 1998; American Academy of Pediatrics, 2005; Gordon, Colby, Bartelt, Jablonski, Krauthoefer, & Havens, 2007; Klitzner, Rabbitt, & Chang, 2010). The trajectory of influence from care coordination through readiness for discharge to post-discharge coping difficulty was evident in the study results. There is some degree of overlap of concepts within the CTM and RHDS tools (e.g. ability to provide medical care and knowing who to call after hospital discharge). CTM did not add any additional explained variance over RHDS in the association with PDCDS but did offer some explanatory relationship with RHDS, supporting the influence of care process on patient outcome at discharge.

RHDS was not associated with any of the post-discharge utilization categories including calls to family or friends, calls to the hospital, emergency department visits, or readmission. Although RHDS and readmission was not statistically associated ( $p = .07$ ), the result suggested further study with a larger sample size is warranted to determine if discharge transition efforts are associated with decreased hospital readmission rates, as they are in other populations (Naylor et al., 1999; Naylor & McCauley, 1999; Naylor, Brooten, Campbell, Maislin, McCauley, & Schwartz, 2004; Gordon et al., 2007).

Although the PDCDS was not associated with utilization of healthcare resources in this study, it was predictive of more calls for support to family and friends in adult medical surgical patients (Weiss et al., 2007) and predictive of calls to family and friends for support, calls to the hospital, unscheduled office visits, emergency visit use, and readmission in a study of hospitalized children (Weiss et al., 2008). The studies by Weiss involved larger samples, so further research with larger samples in this specialized

population may uncover significant relationships. In addition, a three-week post-discharge interval may be too short to detect the full impact of discharge coordination. A longer follow-up period in the transplant population may be necessary given the complexity of the recovery process.

### ***Limitations and Strengths***

Strengths of this study include a multi-center design, linking hospital process with outcomes after discharge, and investigating the caregiver experience in the transition from acute post-surgical care to management of post-transplant care. Accessing parents from more than one institution and multiple SOT types captured a broad range of the post-transplant post-discharge experiences.

Care transition was measured with the CTM, a national quality measure. Although the tool was developed and tested in the older adult population, the concept remains important and applicable in other chronic illness populations. While the modified CTM had acceptable reliability estimates and was predictive of parent readiness for hospital discharge, it has not yet been subjected to comprehensive testing in the pediatric parent population.

The small sample size restricted the number of variables that could be included in regression analyses and did not lend itself to a full path analysis of the relationships in this research model. In regressions of RHDS on predictor variables, only 2 predictors were included. In regressions of post-discharge outcomes, single predictor variables were included. The possibility of false positive associations between variables resulting from numerous analyses is recognized.

Timing of data collection is a limitation that precludes inference of prediction and causality. The QDTS is a summary measure of all the teaching received throughout the transplant hospitalization. The statistical test for this study used QDTS as a predictor variable and RHDS as the outcome variable despite the fact that the data were completed at the same time. The interpretation must therefore be association, and not prediction.

Measurement of adherence difficulty and adherence is also a limitation of this study. There is no standard measurement for adherence. In the transplant population, adherence to medications has been measured by self-report (Berquist et al., 2008; Shemesh et al., 2004), electronic event monitoring devices (Shellmer & Zelikovsky, 2007), medication blood levels (Shemesh et al., 2000), and clinician assessment (Berquist et al., 2008; Shemesh et al., 2004). For the purpose of this study, adherence difficulty was measured by parent report as the perception of difficulty with medication administration and medical follow-up using single item questions. Adherence was measured by comparison of parent and hospital medication list to identify discrepancies, most of which were dose and frequency differences. Future research with this population should include more direct methods of adherence measurement.

This study focuses on the parent perception of discharge readiness and does not measure the health care team perception of parent readiness. A recent study of nurse and patient perspectives in an adult population reported that nurses' ratings were both higher than patients themselves and more strongly associated with post-discharge utilization of healthcare services (Weiss, Yakusheva, & Bobay, 2010). The transplant team may have a different perception of parent readiness and their perspectives should be considered in future research studies with this patient population.

Despite the limitations, this preliminary investigation provides insights into this complex discharge transition and direction for future research. Future research with larger samples will allow for further exploration of potentially significant relationships indicated in this study sample and permit investigation of the combined effects of multiple predictors on post-discharge outcomes in a full path analysis. The relationship between readiness for discharge and post-discharge outcomes should be studied longitudinally to determine if the results are sustainable over a longer period of time and to identify areas for long-term impact.

### ***Implications for Practice***

Transplant teams may consider implementing a readiness for hospital discharge assessment as standard practice before hospital discharge. The RHDS could serve as a screen to assist with identification of parents at risk for adverse post-discharge outcomes. Parents who self-identify themselves as not ready to leave the hospital could subsequently receive additional care coordination or support services while in the hospital environment and through the immediate transition to home-based care.

Transplant centers should concentrate on optimizing multidisciplinary care coordination by ensuring patient-centered comprehensive discharge transition plans are in place at the time of hospital discharge (National Coalition on Care Coordination, 2008). Care coordination is an important first step in setting the stage not only for discharge from the hospital, but successful transition to continued recovery at home

Transplant patients and families are faced with a staggering amount of education during the transplant hospitalization in order to understand complex medication regimens, medication side effects, rejection, infection, and other post-transplant

complications. At the three study centers, parents reported quality discharge education. Dissemination of current transplant education practices may provide tips for other transplant centers to improve their center-specific education process.

Stress reduction through better preparation for going home should be considered. This can begin in the pre-transplant evaluation with the aid of the psychosocial assessment (Annunziato, Fisher, Jerson, Bochkanova, & Shaw, 2010). Educational sessions during the transplant hospitalization could include potential scenarios the parent may need to work through once at home. For example, parents could explain how they would manage the family schedule to accommodate the transplanted child laboratory appointment and sibling's school schedule. Scenarios may provide insight for the juggling that takes place once in the home environment and allow parents to identify support persons before leaving the hospital. Discharge planning may need not only to include treatment related education but also include identification of a support network in order to decrease the stress parents are feeling once in the home environment.

### **Conclusion**

Readiness for hospital discharge has been an under-investigated topic in the pediatric SOT population. The immediate post-operative period and first few weeks after transplant are a critical time period where patients are at high risk for complications. Findings of this preliminary study contribute to the understanding of important issues surrounding the discharge transition. Care coordination positively influenced discharge readiness which in turn influenced the post-discharge outcomes of coping difficulty, adherence with medical follow-up, and family impact. The use of Meleis' Transitions Theory provided a framework for the multidisciplinary transplant team to focus on

preparation for discharge and outcomes of the discharge transition. The results of the study, while not directly generalizable to other pediatric patient populations, provide insights about the discharge transition of patients with complex post-discharge regimens. In line with the national agenda, the results set the stage for continuing efforts in research and clinical practice to improve the discharge transition process and outcomes for pediatric SOT families.



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Figure 1. Conceptual model of relationships between study variables with results

Note: n.s = not significant, \* denotes Beta value

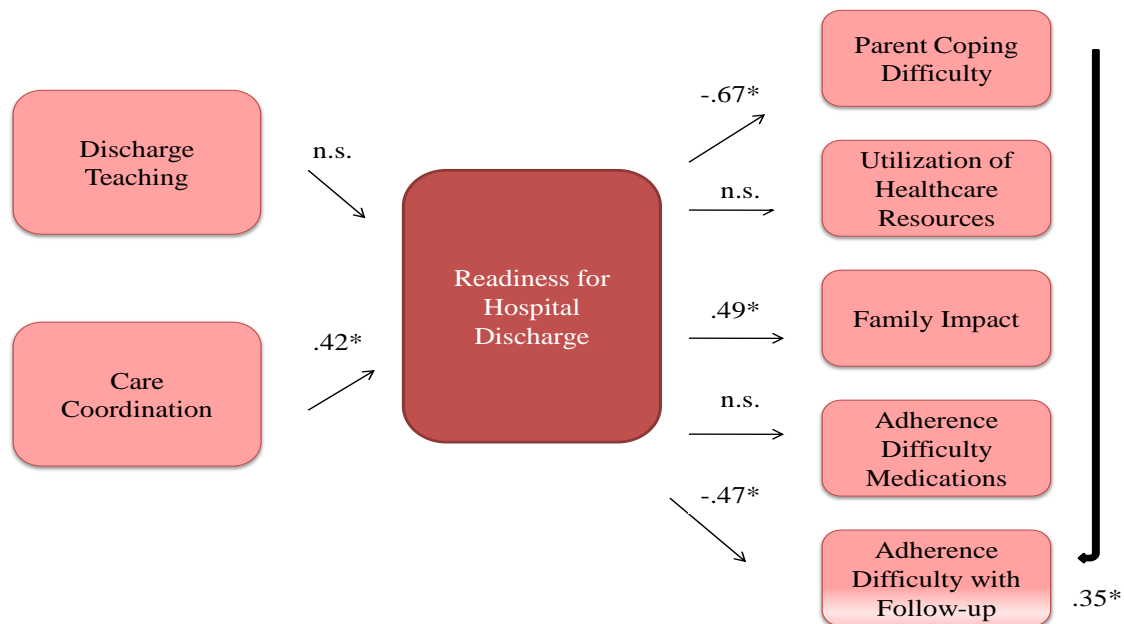




Table 1. Parent and child demographics

Demographics	
Parent Gender	Male = 10 (27%) Female = 27 (73%)
Parent Age	Mean 38.9 years (range 22-55, s.d. 9.0 years)
Parent and Child Race	Asian = 1 (2.7%) Alaskan or American Indian = 1 (2.7%) Did not answer = 3 (8.1%) Black = 7 (18.9%) White = 25 (67.6%)
Parent marital status	Divorced = 3 (8.1%) Single = 6 (16.2%) Married = 28 (75.7%)
Child Gender	Female = 16 (43.2%) Male = 21 (56.8%)
Child Age	Mean 95.2 months or 7.9 years (range 3 months to 18 years, s.d. 71.5 months)

Table 2. Hospitalization characteristics and post-discharge characteristics

Hospitalization Complications	
Inpatient number of days	Mean 19.5 (s.d. 15.5)
Unplanned return to the OR	7 (18.9%)
	5 (13.5%) with one return to the OR 2 (5.4%) with two returns to the OR
Hospitalization infection	7 (18.9%) individual patients
Hospitalization rejection	5 (13.5%) individual patients
Post-Discharge Characteristics	
Number of medications at discharge	Mean 11.4 (s.d. 3.3) Range 5-18
Discharge with enteral tube feeding	12 (32.4%)
Discharge with wound care	11 (29.7%)
Discharge with central line care	7 (18.9%)
Discharge with drainage tube	1 (2.7%)
Discharge with oxygen supplementation	1 (2.7%)

Table 3. Scale statistics

Scale	Number of Items	Item Mean (SD)	Item Mean Range (Min-Max)	Cronbach's Alpha
Readiness for Hospital Discharge	29	8.3 (0.9)	6.3-9.5	$\alpha = .92$
Parent personal status	7	8.3 (1.0)	6.3-9.3	$\alpha = .85$
Child personal status	6	7.8 (0.7)	7.2-9.0	$\alpha = .77$
Knowledge	9	8.9 (0.7)	7.0-9.6	$\alpha = .80$
Coping	3	9.1 (0.5)	8.3-9.3	$\alpha = .75$
Expected support	4	7.6 (0.7)	7.0-8.8	$\alpha = .86$
Quality of Discharge Teaching	18	8.4 (1.2)	4.8-9.4	$\alpha = .86$
Content received	6	7.4 (1.5)	4.7-8.8	$\alpha = .72$
Delivery	12	8.9 (0.5)	7.7-9.4	$\alpha = .86$
PedsQL Family Impact				
Time 1 (Day of Discharge)	36	64.0 (13.2)	33.7-85.1	$\alpha = .95$
Time 2 (3 week follow-up)	36	74.4 (14.3)	39.2-95.9	$\alpha = .93$
Care Transition Measure	15	3.7 (.09)	3.6-3.9	$\alpha = .90$
Post Discharge Coping Difficulty Scale	11	2.0 (1.4)	0.3-4.7	$\alpha = .76$

Table 4. Post-Discharge Utilization

Utilization Type	N	Percent
Call or visit MD	37	100%
Call hospital for medical problem	22	59.5%
<i>Transplant Nurse/Coordinator</i>	18	48.6%
<i>Transplant Nurse and Physician</i>	2	5.4%
<i>Transplant Physician</i>	1	2.7%
<i>Other</i>	1	2.7%
Hospital Readmission	10	27.0%
Calls to family or friends for support	4	10.8%
Use of Emergency Department	4	10.8%

Table 5. Correlation matrix for study variables

	QDTS	CTM	RHDS	PDCDS	Family Impact <sup>†</sup>	Difficulty administering medications	Difficulty with lab and clinic follow-up
QDTS		.44**	.15	-.16	.16	-.17	-.07
CTM	.44**	---	.42**	-.35*	.21	.09	-.25
RHDS	.15	.42**	---	-.67**	.49**	-.28	-.47**
PDCDS	-.16	-.35*	-.67**	---	-.71**	.22	.35*
Family Impact <sup>†</sup>	.16	.21	.49**	-.71**	---	-.07	-.28
Difficulty administering medications	-.17	.09	-.28	.22	-.07	---	.31
Difficulty with lab and clinic follow-up	-.07	-.25	-.47**	.35*	-.28	.31	---

Notes: QDTS = Quality of Discharge Teaching Scale, CTM = Care Transition Measure, RHDS = Readiness for Hospital Discharge Scale, PDCDS = Post-Discharge Coping Difficulty Scale,

<sup>†</sup> = 3 week post-discharge raw score, \* =  $p < 0.05$ , \*\* =  $p < .01$