Institute for Clinical Social Work

An Examination of Adult Attachment and Liver Transplant Success

A Dissertation Submitted to the Faculty of the

Institute for Clinical Social Work in Partial Fulfillment

for the Degree of Doctor of Philosophy

By

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February 2017

Abstract

The purpose of this retrospective, quantitative, secondary data analysis pilot study was to examine if a relationship exists between adult attachment and liver transplant outcomes. A medical record review with a sample size of 20 was utilized for a period of six months post-transplant to analyze relationship occurrences among pre-transplant psychosocial evaluation, pre-transplant attachment scale scores and post-transplant outcomes. As an exploratory study with a small sample size, it is unsurprising that the analysis did not reveal any statistical significance, but the results suggest some possible trends that would be interesting to explore further with a larger sample size. The results support three findings: (a) All patients transplanted had scores that supported secure attachment. (b) Patients transplanted in 2015-2016, fared better overall after transplant than the patients transplanted in 2013-2014. (c) Negative outcome markers experienced post-transplant by the patients in this study were relatively short-lived and manageable and did not have a long-term negative impact on the patient's health and recovery. The discussion addresses how secure attachment may have contributed to better outcomes and how these outcomes may be attributed to a brief disruption in secure attachment during the most difficult time of transplant recovery, followed by a return to a more secure attachment as a patient's body and psyche heals and recovers.

For Hahnemann University Hospital Transplant Center

Acknowledgments

I would like to thank my dissertation committee members: first and foremost, my chair, Denise Duval-Tsioles, PhD, for her constant support, priceless input and advice, unwavering guidance, tireless availability and reassuring encouragement; Michael Casali, PhD, for helping me conceive this research idea during my first independent study and providing counsel throughout the process; Joan DiLeonadi, PhD, for her patience and commitment in helping me make sense of and analyze the data; James Lampe, PhD, for his valuable contribution to the structure of my discussion section; Kevin McMahon, MSW, for his influence with regards to theory. I want to thank my transplant program, especially the medical director, David Reich, MD, for his leadership and support; Faith Michie, LCSW, for her professional counsel and input in the development of this research as well as her friendship; Hahnemann University Hospital and Drexel University College of Medicine for assistance and collaboration with this dissertation.

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List of Abbreviations

HE	Hepatic Encephalopathy
MRR	Medical Record Review
OLT	Orthotopic liver transplantation
PLOS	Prolonged Length of Stay
SIPAT	Stanford Integrated Psychosocial Assessment for Transplantation

Chapter I

Introduction

General Statement of Purpose

The purpose of this retrospective, secondary data analysis pilot study was to see if a relationship exists between adult attachment (as theorized by John Bowlby and Mary Ainsworth) and liver transplant outcomes for patients at a liver transplant center in a major urban city in Pennsylvania. A patient's capacity to successfully recover from transplant surgery was generally defined as the patient's ability to comply with medical treatment (including post-surgery clinic visits, medication adherence and other medical recommendations), appropriately utilize support (including their primary support person and team of transplant professionals), avoid significant psychiatric symptoms, avoid substance use and avoid rejection of the transplanted liver (Maldonado, Dubois, David, Sher, Lolak, Dyal, & Witten, 2012).

Significance of the Study for Clinical Social Work

Because social workers are at the forefront of psychosocial evaluations for organ transplantation candidacy, physicians and other transplant professionals rightly consult with social workers when a post-transplant patient does not psychosocially thrive after

surgery. Prior to listing for transplant, a patient must be cleared from a psychosocial standpoint. Most transplant centers rely on social workers to conduct evaluations that assess for candidacy including support persons willing to assist with the emotional and physical stress following transplant surgery. Despite thorough psychosocial evaluations, there are instances where patients, unexpectedly, do not thrive and struggle to adhere to a medical regimen post-transplant. These patients often struggle with motivation needed for post-surgery medical adherence as well as psychiatric symptoms. Many such patients also struggle with receiving/accepting help and assistance from their support person(s) and their transplant team (including doctors, nurses, social workers and other providers).

"Over the past 25 years, attachment research has extended beyond infant-parent bonds to examine dyadic relationships in children, adolescents and adults. Attachment has been shown to influence a wide variety of biopsychosocial phenomena, including social functioning, coping, stress response, psychological well-being, health behavior, and morbidity, and has thus emerged as an important focus of psychosomatic research" (Ravitz, Maunder, Hunter, Sthankiya & Lancee, 2010). However, specific research has not yet been conducted to see if a relationship exists between adult attachment and transplant outcomes. It is possible that a patient's lack of motivation, struggle with adherence and/or experience of psychiatric symptoms post-transplant could be (at least in part) a manifestation of insecure adult attachment. Research has shown that people who show a tendency for insecurity on an adult attachment scale have been more likely to have links to depressive and anxiety symptoms, negative affectivity, and periods of distress (Ravitz, et al., 2007).

Although pioneered by a psychiatrist named John Bowlby, attachment theory has historical roots connected to social work. Sable (2011) states that Bowlby credits social workers as the professionals who "introduced him to the idea that unresolved problems from a parent's childhood could be related to a current problem in their children" (p. 18). During a presentation to the Social Work Continuation Group in London in 1987, Bowlby continued to credit the development of his theories to the profession of social work (Sable, 2011). "In a video of that presentation he told the group that he 'owed social workers a great deal of debt and gratitude' and that he 'learned everything from social workers,' such as their emphasis on 'actual experiences' over fantasy'" (Sable, 2011, p. 18; Bowlby, 1987).

"Attachment behaviour is any form of behaviour that results in a person attaining or maintaining proximity to some other clearly identified individual who is conceived as better able to cope with the world. It is most obvious whenever the person is frightened, fatigued, or sick, and is assuaged by comforting and caregiving" (Bowlby, 1988, p. 26-27). Transplant patients are often frightened, fatigued and sick in varying levels, making attachment styles relevant when looking at ability to thrive and be supported by others during the course of their disease and recovery from transplant surgery. When a patient receives a liver transplant, it is very likely that the security of a bond to a significant other (primary support person as well as the patient's medical team members) may feel threatened. A post-transplant patient has survived a surgery that carries the risk of death. Recovery can be painful and laborious. Medication regimens can be tedious and wrought with significant side effects. If immunosuppressant medications are not taken as directed,

the transplanted organ is at risk for rejection. A patient's mortality is dependent on adherence to post-transplant medical protocol; this emphasis on mortality often has an impact on a patient's emotional state. All these factors may trigger an unconscious response based on early attachment patterns.

De Geest, Burkhalter, Berben, Bogert, Denhaerynck, Glass, Goetzmann, Kirsch, Kiss, Koller, Piot-Ziegler, and Schmidt-Trucksass (2013) state "a number of studies have shown that patients with higher levels of trust in their health care provider are more likely to adhere to recommended health behaviors such as medication adherence" (p 237). Although this does not specifically speak to attachment theory and transplant outcomes, it is an important concept because trust is typically a component of secure attachment. On the contrary, patients with anxious or avoidant attachment may struggle with trust. It is possible that patients without secure attachment have a greater struggle trusting their transplant providers, thus struggling more with treatment adherence, leading to poorer transplant outcomes.

A post-transplant patient often feels a multitude of feelings after surgery that range from relief and gratitude to guilt, depression and anxiety. A patient who receives an organ transplant may be vulnerable in new way. They need to be able to trust and rely on their personal support and medical team as they work together to recover from surgery keep the new organ alive. A patient may also feel some burden since they received a life-saving organ (an organ that could have saved someone else if not given to them; an organ that came at the expense of the death of a stranger). What the literature acknowledges as symptoms of depression or anxiety post-transplant may be a manifestation of the

vulnerability and distress a patient with insecure attachment feels after a transplant. A transplant is likely to trigger attachment responses which could cause a person with an insecure attachment to pull-away instead of feeling comfortable receiving help in their time of need.

In such cases, a patient usually has a support person (be it a spouse, an adult child, as parents, a sibling, a friend, etc.) who has been very involved in their care prior to transplant. This support person meets with the social worker and is typically deemed to be a strong, capable, reliable support person. However, it is the ability of the patient to feel comfortable and attached while vulnerable post-transplant that this study attempted to further explore. The relationship with the support person may appear stable, but the patient's ability to adequately utilize the support of others and feel securely attached may interfere with the patient's ability to thrive and allow for assistance post-transplant. A person without a secure attachment may struggle feeling or appearing weak in front of their loved ones. They may consciously or unconsciously fear they will lose their relationship with that person(s) if they are weak and need to depend on them. This idea is separate from the perspective of their loved-ones. The loved-ones may not view the patient as weak and the patient may have no logical reason to fear this from the actual relationship with the loved-one(s). However, the patient's own personal history (starting in the pre-verbal, infancy stage of life) has a profound impact on adult attachment. If attachment is insecure, a patient may not utilize the support that seems so readily available by loved-one(s).

Attachment style has been shown to have an impact on individual self-regulation and ability to achieve goals. Secure attachment has been associated with better self-control and more effective behavioral regulation. Research has shown that patients with insecure attachment will have greater struggle with behaviors related to supporting better health (Pietromonaco, DeVito, Ge, & Lembke, 2015). Multiple studies have shown that insecure attachment is correlated with a variety of physical symptoms that lead to poor health outcomes including poor sleep quality, higher tendency to contract a cold, cardiovascular disease, high blood pressure, and a lower threshold to tolerate pain and recovery (Pietromonaco et al, 2015). Unfortunately, there are no existing studies that explore a relationship between adult attachment and the liver (or any organ) transplant experience. It is probable that similar finding may exist when looking at attachment and liver transplant patients.

Although past relationship dynamics are assessed during most transplant centers' psychosocial evaluations, specific adult attachment styles (secure vs. insecure) are not typically evaluated. This pilot study attempted to see if a relationship exists between attachment and ability to thrive post-transplant. Use of a standardized attachment scale during the psychosocial evaluation was examined and analyzed to determine if a relationship occurs between adult attachment and transplant outcomes. It was thought that such research could be the groundwork for more consideration of adult attachment as a valuable part of the psychosocial evaluation. By identifying patients with obstacles to secure attachment, transplant centers could include interventions to assist patients achieve better outcomes and avoid some of the post-transplant obstacles. It was also thought that

a study of adult attachment in post-transplant patients could offer insight regarding the difficulty some patients may have in relying on, trusting, reaching out to and receiving help not only from primary support systems but from the medical team that cares for them as well.

The literature review documents the lack of psychodynamic research as it pertains to liver and other solid organ transplantation. A quantitative study examining attachment styles of liver transplant patients was a unique opportunity to research a psychodynamic understanding of human behavior as it pertains to liver transplant and transplant outcomes. Furthermore, clinicians conducting psychosocial assessments for transplant have varying degrees of knowledge and understanding of psychodynamic theory. It was believed that the implementation of an attachment scale as part of the psychosocial assessment may prove useful in having a more psychodyamically oriented understanding of a patient through use of a reliable, valid scale that can be administered by social workers and mental health clinicians, independent of their level of understanding of or familiarity with psychodynamic theory. Furthermore, attachment categories can "aid clinicians in tailoring interventions based on an understanding of individuals' differences. In medicine, categorization allows for rapid diagnosis and clinical decision making" Ravitz at al., 2010). It was thought that knowledge of attachment style can be useful for the social worker and transplant committee in making decisions about transplant as a treatment option, patient readiness for such an option, possible alternative treatment options and challenges faced by patients post-transplant.

Statement of the Problem and Specific Objectives to Be Achieved

Orthotopic liver transplantation (OLT) is the treatment of choice for end stage liver disease of various causes with one-year survival rates in adult transplant recipients of about 85% and nine-year survival rates of 55% in most of the 200 international centers (Rothenhauser, Ehrentraut, Kapfhammer, Lang, Zachoval, Bilzer, Shelling & Gerbes, 2002; Russell, Feurer, Wisawatapnimit, Salomon, Pinson, 2008). According to the United Network for Organ Sharing (UNOS), as of April 8, 2016, there are over 121,137 people on the transplant waiting list in the United States and 24,382 transplants were performed in 2014 (www.unos.org, 2016). The imbalance between the number of potential transplant recipients and available donors results in long wait times and 10% to 20% of all liver transplant candidates die before an organ is available (Dobbles, Vanhaecke, Dupont, Nevens, Verleden, Pirenne, & De Geest, 2009). In the United States, all patients who are candidates for liver transplant undergo a psychosocial evaluation before they are cleared for transplant listing. The psychosocial evaluation is used to predict a patient's ability to have a successful transplant process and to recommend interventions that may help foster patient success based on this evaluation. Psychosocial evaluations are used to assess numerous factors that can affect successful transplant process including: substance use history, housing stability, legal history/issues, family dynamics, support system, education, work history, future oriented goals, financial stability (including health insurance), transportation plan, psychiatric concerns (including psychopathology), cognitive function (including ability to understand and follow medical directions), brief mental status exam, developmental history, relational issues, motivation

issues, understanding of illness, and past medical compliance and management (Freeman III, Davis, Libb, & Craven, 1992; Olbrisch, Benedict, Ashe & Levenson, 2002; Fisher, 2006; Reed, Baz, McGinn & Schofield, 2001). When listed on an active liver transplant waiting list, a patient is deemed to be an adequate candidate from a psychosocial perspective.

Research has shown that assessment for these factors is critical in predicting outcomes of graft survival of the new organ (Freeman III et al., 1992). For example, patients with unmanaged depression before transplant tend to have poor medical adherence post-transplant and a higher occurrence of organ failure (Olbrisch et al., 2002). Even with pre-transplant evaluations conducted by experienced social workers, some patients unexpectedly struggle emotionally and psychologically after a transplant, thus effecting the survival of their graft (Rodin & Abbey, 1992). Soos (1992) documents multiple risks for depression and anxiety post-transplant including body image changes, coping with threat of organ rejection, meeting medical management expectations and intrapsychic integration of the new organ.

Research suggests that a significant number of transplant recipients do not experience, or do not sustain improved psychological and social functioning or an improved quality of life. After a transplant, recipients often experience both physical and emotional transitions and, therefore, concerns must be considered regarding a recipient's psychological well-being (Rainer, Thompson & Lambros, 2010). Instead of improved mood and quality of life, some recipients suffer from depression, anxiety or other psychosocial stress after transplantation (Goetzmann, Ruegg, Stamm, Ambuhl, Boehler,

Halter, Muellhaupt, Noll, Schanz, Wagner-Huber, Spindler, Buddenburg & Klaghofer, 2008). Goetzmann et al. (2008) studied 131 transplant recipients (heart, lung, liver, kidney and bone marrow) for 24 months after transplant and found that 40.5% of recipients had poor psychosocial outcomes after transplant. Lough, Lindsey, Shinn & Scotts (1985) found that more than 25% of heart transplant recipients reported a lower quality of life and found life less rewarding following heart transplant. Changes in body image such as weight gain and surgical scarring are also risks for despair, anxiety and depression post-transplant (Rainer et al., 2010). Drug side-effects, organ rejection episodes, infection and hospitalizations post-transplant have proven to be stressful and accompanied by dysphoria and depression (Freeman III et al.,1992).

Social workers in the field of transplant are adequate at assessing a candidate for transplant according to several general categories: Available support persons, transportation plan to medical appointments, substance use history, psychiatric history, cognitive skills/impairment, coping skills, finances, education and work history, future oriented goals, and past medical compliance (Olbrisch et al, 2002). However, even when a patient appears to have a concerned, reliable support person (as assessed in the pre-transplant evaluation), there are instances when a patient becomes reluctant to rely on their support person and their medical team for help post-transplant.

Despite best efforts of social workers who assess patients for psychosocial risk post-transplant, certain patients struggle after surgery in ways that were not predicted. Perhaps what is occurring post-transplant is not only psychiatric symptoms or non-adherence. Instead, as detailed in the previous section, a patient may be having an

unconscious reaction based on early attachment patterns. A post-transplant patient has just undergone a life-saving, but also life threatening surgery that requires a host of medical management strategies including certain complex medication regimens, physical restrictions and office visits. Should these not be followed, the death of the organ (also known as organ rejection) may result. It is possible that the anxiety and stress of the responsibility of caring for a new organ feels daunting and patients often have a heightened sense of mortality. With this serving as a threat to their relationship to their primary support person and others, patients with less secure attachment styles may engage in non-adherence behavior as an unconscious attempt to attach to the other (although it is viewed by the outsider as counterproductive).

Very little has been published that considers psychodynamic theory and transplantation. Attachment theory and transplant, specifically, is not represented in the literature. The literature review will further discuss the existing literature and highlight a need for more. Attachment theory and health research was reviewed in place of the non-existent literature on transplant and attachment. The main objective of this study was to determine if adult attachment styles have an impact on liver transplant success.

A deeper examination of an adult's attachment style (including ability to depend on and receive care from support persons and medical providers) may improve the social worker's overall understanding of a patient and the patient's ability to cope post-transplant surgery. Such an understanding can lead to improved interventions and policies that can better assist patients achieve better outcomes post-transplant.

Hypothesis and Research Questions

Although this is a quantitative pilot study, the projected sample size of 20 is limited and warranted exploration of research questions rather than a hypothesis. The following two research questions were considered:

Research Question 1: Is there a relationship between attachment scale scores and liver transplant outcomes?

Research Question 2: Is there a relationship between the Standard Integrated Psychosocial Assessment for Transplant (SIPAT) score and attachment scale scores?

Theoretical and Operational Definitions of Major Concepts

1. *Attachment* was defined as the quality of an individual's relationship to another (or others) and the individual's ability to feel safe and secure in a relationship with another or others (Holmes, 1993).
2. *Attachment Behavior* was defined as "any form of behavior that results in a person attaining or maintaining proximity to some other clearly identified individual who is conceived as better able to cope with the world. It is most obvious whenever the person is frightened, fatigued, or sick, and is assuaged by comforting and caregiving" (Bowlby, 1988, p. 26-27).
3. *Attachment Style* was defined as "the chronic pattern of relational expectations, emotions, and behaviors that results from internalization of a particular history of attachment experiences" (Shaver & Mikulincer, 2007, p. 447).

4. *Insecure Anxious Attachment* – "Individuals with insecure anxious attachment style expect that close others will not be readily available; as a result they respond to threat by using hyperactivating strategies, including persisting in signaling their emotional distress to their partners and in trying to maintain proximity to partners, and excessively seeking reassurance and support from their partners" (Pietromonaco et al., 2015, p. 288).
5. *Insecure Avoidant Attachment* – "Individuals with an insecure avoidant attachment style typically expect that their attachment figures will be unavailable and unresponsive to their needs. As a result, avoidantly attached individuals often respond to threat by suppressing or minimizing their distress and not turning to close others for support" (Pietromonaco et al., 2015, p. 288).
6. *Secure Attachment* – "Individuals with secure attachment style expect that their attachment figures will be available and responsive, and they are comfortable turning to their attachment figures when they are in need of support or reassurance" (Pietromonaco et al., 2015, p. 288).
7. *Compliance or Adherence* was defined by Rainer and Thompson (2010) as "the extent to which a person's behavior coincides with medical or therapeutic advice" (p. 407).
8. *Adherence to Medical Prescriptions* – "implies not only the correct intake of medicines but also the consistency in attending outpatient appointments, taking prescribed blood tests, and promptly reporting all potential medical complications

to health care providers" (Burra, Germani, Gnoato, Lazzaro, Russo , Cillo & Senzolo, 2011, p. 770).

9. *Medication Adherence or Compliance* was defined as the extent to which patients take medications as prescribed by their health care providers (Osterberg & Blaschke, 2005).
10. *Noncompliance or Nonadherence* was defined as: poor attendance to clinics or laboratory appointments, delay in the notification of problems, poor adherence to diet and/or consistent weight gain, and poor adherence to their drug schedule including minor deviations" (Rodriguez, Diaz, Colon, & Santiago, 1991, p. 1807).
11. *Health Related Quality of Life* was defined as "the value assigned to duration of life as modified by impairments, functional states, perceptions, and social opportunities influenced by disease, injury, treatment, or policy (King & Hinds, 2003, p. 7).
12. *Caregiver or Primary Support Person* was defined as "the individual who is responsible for caring for another person that suffers from mental health problems, has physical disabilities or had poor health because of his/her age or illness" (Duci & Tahsini, 2012, p. 162). Responsibilities include: arranging things for a patient with chronic illness, managing medications/having discussions with doctors and nurses on behalf of the patient, assisting patient with daily necessities, ensuring patient attends appointments and caring for the household

including chores, meals and/or bills for someone who cannot so do him/herself (Duci & Tahsini, 2012).

13. *Medical Record Review (MRR)* "refers to any study that uses prerecorded, patient-focused data as the primary source of information to answer a research question" (Worster & Haines, 2004, p. 187).
14. *Graft failure/Rejection* was defined as "failure of a transplanted organ that occurs when antigens on the surface of the grafted organ are recognized as foreign and non-self" (Cupples & Ohler, 2003, p. 271).

Statement of Assumptions

1. Attachment style has an impact on ability to have a successful liver transplant.
2. Although psychosocial evaluations are considered thorough, they do not accurately predict transplant success in all cases, therefore, it is assumed that evaluations may be missing a component that may be better assessed.
3. If a relationship between attachment and transplant recovery exists, this study can be a springboard for follow-up studies that can incorporate interventions to better prepare and work with such patients to better avoid psychosocial post-transplant obstacles.

Epistemological Foundation of the Project

This study used a quantitative methods design. A postpositivist paradigm was used to guide the study. "Postpositivism represents the thinking after positivism,

challenging the traditional notion of the absolute truth and recognizing that we cannot be positive about our claims of knowledge when studying the behavior and actions of humans" (Creswell, 2014, p 7). Research of such a paradigm starts with a test of a theory which may lead to refinement or dismissal of original claims. Data or evidence is gathered with use of instruments (Creswell, 2014). "Research seeks to develop relevant, true statements, ones that can serve to explain the situation of concern or that describe the casual relationships of interest . . . Researchers advance the relationship among variables and post this in terms of questions or hypothesis." (Creswell, 2014, p 8). Such research stresses standards of validity and reliability to best ensure objectivity and eliminate bias (Creswell, 2014).

Foregrounding

Introduction.

Since July 2009, I have held the position of Liver Transplant Social Worker at an urban hospital and liver transplant center in a major urban city in Pennsylvania. As an active member of the transplant committee who determines who may be listed for liver transplant, I am entrusted with the important task of conducting comprehensive psychosocial evaluations that will clear patients for listing or determine if they are not eligible as a result of psychosocial contraindications for liver transplant. During my tenure at this position I have noticed that some patients have struggled post-transplant in ways that were surprising and unexpected based on their psychosocial evaluation. I have

seen certain patients struggle to rely on their identified support persons and/or rely on, reach out to and trust the transplant team.

In 2013-2014, 10% of patients transplanted at our center struggled with medical adherence and ability to receive help from support or medical team for a period of six months or more. Recovery from liver transplant can have many complications, sometimes resulting in a prolonged hospital stay. Most transplanted patients are able to endure unpleasant recovery, often with the support of their transplant team and primary support person. In contrast, there were two specific instances during the period of 2013-2014 (5% of the transplanted patients) where patients had prolonged hospital stays post-transplant of over six months during which they refused to follow recommendations of the medical providers/transplant team (such as eating meals/necessary nutrition, participating in physical therapy and complying with medication). These patients often refused interventions recommended by medical team. Even with the support and urging of the primary support person, the patient struggled to thrive. Post-transplant, both patients had symptoms that would meet the DSM-IV criteria for depression, although they had no significant history of depression or mental illness prior to transplant. Both patients seemed detached from communication with other humans, even the person with whom they were closest. These are more severe occurrences, however, even when recovery is not prolonged, there are times when patients miss important clinic visits or fail to receive assistance with proper medical management. Because of the patient's resistance to receiving help, it can even be difficult to fully assess for depression/anxiety. Patient verbal communication during these instances tends to be minimal, making it even

harder to understand a patient's individual struggle. Research has documented the occurrence of increased depression and anxiety post-surgery. However, research has not fully explored the significance of adult attachment styles and how this may impact the occurrence of depression, anxiety, adherence and ability to receive help from those with whom a secure attachment is expected or assumed.

As the social worker on this a multidisciplinary transplant team, I designed this study out of my interest in learning more about the struggles that patients experience post-transplant. I believe insecure attachment could be the source of psychiatric symptoms and non-adherence post-transplant. It was hoped that a study of transplant outcomes and attachment could provide me with better insight and knowledge that can assist me in better supporting both transplant patients and the multidisciplinary team who serves these patients.

Explanation of the multidisciplinary transplant team and Transplant Evaluation Process.

The following description of the transplant team's involvement with the patient has been included to demonstrate that transplant patients have a consistent transplant team with whom they have multiple points of contact pre and post-transplant. It is important that patients are able to trust and rely on this team as well as their identified primary support person. As the transplant social worker, I work directly with the patient to help ensure best care. I also work closely with this multidisciplinary team and provide them with guidance and consultation regarding best practices to work with a range of

patients with a variety of differing backgrounds and complex psychosocial histories. The transplant committee at the transplant center where I hold my position is comprised of a multidisciplinary team (see table 1).

Table 1

Transplant Interdisciplinary Team Members

Three transplant surgeons
Four hepatologists/gastroenterologists (with specialty in liver transplant)
Various surgical and medical residents and fellows
Three transplant coordinators (each is a registered nurse and a Certified Clinical Transplant Nurse)
One Licensed Clinical Social Worker (who is a Certified Clinical Transplant Social Worker)
One pharmacist
One nurse practitioner in the department of hepatology/gastroenterology
One registered nurse in the department of hepatology/gastroenterology
One nurse practitioner in the outpatient surgery department
One transplant department administrator (who is a registered nurse)
One liver transplant financial coordinator
Various medical assistants and ancillary staff

The transplant committee meets weekly. Potential transplant candidates are presented by the physicians (either hepatologist/gastroenterologist or surgeon). Prior to this presentation, the patient has been followed in some manner by the presenting

physician and will continue to be followed by that physician regardless of staff decision to move (or not move) forward with transplant evaluation.

If a patient seems like a reasonable medical candidate for liver transplant, a patient begins a formal transplant evaluation. The patient must be evaluated by certain specialists (i.e.: cardiology and pulmonology) and have certain labs drawn. Depending on evaluation by specialists and lab outcomes, certain medical procedures or additional tests may be necessary prior to listing (i.e.: cardiology may recommend a need for a cardiac catheterization). During this pre-listing/transplant evaluation phase, all these medical appointments are managed by a transplant coordinator. Each patient is assigned to a transplant coordinator and this coordinator serves as the primary point person for the patient. Throughout the evaluation process, the transplant coordinator is in constant contact with the patient addressing medical questions and concerns and ensuring that patient is following through with evaluation appointments. The transplant coordinator is monitoring test results and informing the physicians of outcomes and progress of patient. During this phase, the patient continues to meet with their surgeon or hepatologist/gastroenterologist as needed (this can range from multiple visits/month to twice/year depending on patient's current medical situation).

During the evaluation phase, each patient and their primary support person(s) participates in a psychosocial evaluation for transplant conducted by the liver transplant social worker. Psychosocial factors such as substance use, psychiatric symptoms, adult attachment, legal history, work history, financial situation/financial plan for transplant, insurance coverage, transportation, strength and commitment of support person,

adherence to medication and medical directions, living situation and family history are considered. Certain absolute psychosocial contraindications (no social support, current substance abuse or untreated psychiatric condition such as schizophrenia, bipolar disorder, anxiety or major depression) may rule-outa patient as a viable transplant candidate. However, the social worker then provides recommendations to improve candidacy. Along with treating physician, the social worker assists and monitors the patient's progress with these psychosocial recommendations. If a patient complies (i.e., participates in substance abuse treatment or mental health care) the patient will be re-evaluated by the social worker and may become an adequate transplant candidate.

A transplant coordinator and transplant social worker remain available to patients throughout the transplant process, including evaluation, listing, while the patient is on the waiting list and post-transplant surgery. The same hepatologist/gastroenterologist is assigned to each patient throughout the process as well.

Due to the serious and multiple medical problems associated with end stage liver disease, patients on the waiting list are often hospitalized on multiple occasions prior to transplant. Such patients are seen in the hospital by their hepatologist/gastroenterologist and the transplant surgeons and are discussed at weekly transplant committee meetings. As needed, a transplant coordinator, a transplant social worker or other members of the transplant team are available to meet with the patient and family. This is also true post-transplant.

Post-transplant, a transplant coordinator and social worker are involved in each patient's discharge planning. After discharge, a patient is required to attend clinic visits

with a surgeon twice weekly for the first six to eight weeks. Depending on each patient's recovery, the visits are tapered down, but the patient is followed by the surgeon and transplant team very closely for the initial six-months after surgery. A transplant coordinator facilitates these visits and meets with the patient in addition to the surgeon. This transplant coordinator reviews their medication management and plan for home care. As needed, the social worker is involved to assist patients who may be struggling with adherence, social support, depression (or other psychiatric symptoms), transportation issues, insurance coverage/financial issues and any other psychosocial issues that may arise. Usually, once a patient is beyond six months post-transplant, primary medical care and management is transferred back to the referring physician.

Chapter II

Literature Review

Key Words

Transplant, transplantation, abdominal organ transplant, solid organ transplant, liver, renal, kidney, heart, lung, pancreas, end stage renal disease, heart failure, end stage liver disease, lung failure, kidney transplant, liver transplant, lung transplant, heart transplant, pancreas transplant, fantasies, attachment, attachment theory, object relations, psychodynamic, psychodynamic theory, outcomes, behavior, immunosuppressant medications, medications, medicine, adherence, nonadherence, compliance, noncompliance, complications, drug holidays, side-effects, surgery, chronic illness, illness, health, medical, nursing, support, family support, social support, family, family relationships, couples, network, social work, social work(er), transplant social work(er), evaluation, transplant evaluation, assessment, transplant assessment, psychosocial, biopsychosocial, contraindications, absolute contraindications, relative contraindications, psychotherapy, psychiatry, psychiatric morbidity, psychology, psychological, psychological implications, consultation, quality of life, mental health, meta-analysis, health care, anxiety, depression, posttraumatic stress disorder, risk factor

Search Engines

Academic Search Premier, Article First, EBSCO Magazines and Journals, Education Resource Information Center (ERIC), ERIC EBSCO, ERIC OCLC, Google, Google Scholar, Health Source, MEDLINE, Medscape, PsycINFO and PsycARTICLES.

Literature Review Inclusion/Exclusion Criteria

This study focused on liver transplant recipients who received organs from deceased donors whom they have never met (rather than living donation from family members, friends or acquaintances). The transplant center where the study is being conducted does not perform living liver donation surgery. Furthermore, a level of attachment is assumed when receiving a living donation from someone known to the recipient. Therefore, research with a main focus on living donation was excluded. Searches mostly focused on the experience of solid organ recipients (kidney, liver, pancreas, heart and lung) and mostly excluded articles where the main focus was on other types of transplants (e.g., bone marrow, face, eyes, etc).

Introduction

The following review of the literature surveys best practices for psychosocial assessment of potential organ transplant candidates as well as psychosocial obstacles

faced by patients post-transplant (also referred to as recipients). The literature review will survey research regarding the etiology of such obstacles, methods to predict a patient's likelihood for transplant success and possible interventions to assist with a successful transplant process. The established importance of social support for transplant success will be reviewed. The literature will explore existing psychodynamic research related to transplant as well as the lack of literature specific to attachment theory and transplant. An overview of attachment theory literature will be addressed to first defend attachment theory as a useful psychodynamic theory driving this research and second, to provide a better understanding of the possible relevance of considering attachment theory in relation to transplantation.

Development of the Psychosocial Evaluation for Transplant

Orthotopic liver transplantation is the treatment of choice for end stage liver disease of various causes with one-year survival rates in adult transplant recipients of about 85% and nine-year survival rates of 55% in most of the 200 international centers (Rothenhauser et al., 2002; Russell, et al., 2008). The first successful organ transplant in the United States occurred on December 23, 1954 at Bringham Hospital when a kidney was transplanted from one identical twin brother to another. By 1983, the Food and Drug Administration (FDA) had approved Cyclosporine, an anti-rejection medication and results indicated that two thirds of all heart transplant patients had a survival rate of five

or more years. With current medications, organ transplants can now last decades (www.donatelife.net, 2012). According to the United Network for Organ Sharing (UNOS), as of April 8, 2016 there are over 121,137 people on the transplant waiting list in the United States and 24,382 transplants were performed in 2014 (www.unos.org, 2016).

The imbalance between the number of potential transplant recipients and available donors results in long wait times and 10% to 20% of all liver transplant candidates die before an organ is available (Dobbles, et al., 2009). Because of the limited supply of available organs, every patient who is a candidate for solid organ transplant participates in a psychosocial evaluation in addition to medical evaluation for transplant. "The aim of this assessment is a better understanding of the patient" (Grover & Sarkar, 2012, p. 389). Just as the medical evaluation predicts a patient's potential to survive and thrive physically/medically after transplant surgery, a psychosocial evaluation is used to identify potential psychosocial barriers to transplant, best predict a patient's ability to thrive psychosocially after transplant and to determine what psychosocial interventions need to be employed to aid in successful transplantation (Bunzel & Laeferach-Hoffmann, 2000; Copeland, Emery, Levinson, Icenagle, Carrier, Ott, Copeland, McAleer-Rheman, & Nicholson, 1987; Fisher, 2006; Freeman III et al., 1992; Grover & Sarkar, 2012; Heinrich & Marcangelo, 2009; Levensen & Olbrisch, 1993; Morana, 2009; Olbrisch et al., 2002; Shapiro, Williams, Foray, Gelman, Wukich, Sciacca, 1995). Identifying and

reducing psychosocial risk factors in the pre-transplant phase is important in the overall long-term success of transplant (Morana, 2009). "As transplant surgery has dramatically advanced, the success of orthotopic liver transplantation is no longer judged solely by its effects on morbidity and mortality but by its influence on the transplant recipient's psychosocial well-being" (Rothenhauser, et al., 2002, p. 286). Psychosocial evaluations are not conducted to simply rule a candidate suitable or not-suitable for transplant; they help the medical team decipher if a transplant will improve or impede quality of life and a patient's psychological well-being (Rothenhauser, et al., 2002).

In a study by Frierson and Lippman (1987), 13 out of 70 heart transplant candidates were declined transplant for psychosocial factors including concerns with regard to a patient's ability to wait for a donor, psychological incorporation of the new organ, compliance with the medical regimen and certain diagnoses from the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association. "Many psychiatric disorders may lead to the need for liver transplant, and if kept unchecked can adversely affect outcomes" (Grover & Sarkar, 2012, p. 382). Grover and Sarkar (2012) identify the following as the most commonly encountered psychological problems pre-liver transplant: alcohol use disorders, opioid use disorders, anxiety disorders and depressive disorders. If a patient is transplanted without having these disorders treated and stabilized, transplant outcomes are usually poor.

Research has indicated that brief instruments such as the Psychosocial Assessment of Candidates for Transplant (PACT) and the Transplant Evaluation Rating Scale (TERS) are valid and reliable in their ability to assess the appropriateness of a transplant candidate (Foster, McLellan, Rybicki, Dabney, Visnocky & Bowell, 2009; Freeman III et al., 1992; Grover & Sarker, 2012; Jowsey, Taylor, Schneekloth & Clark, 2001; Olbrisch et al., 2002; Twillman, Manetto, Wellisch & Wolcott, 1993). In 2012, The Society for Transplant Social Workers endorsed the use of the Stanford Integrated Psychosocial Assessment for Transplant (SIPAT) after findings supported excellent inter-rater reliability and a robust association between SIPAT scores and post-transplant psychosocial problems (Maldonado et al., 2012; (www.transplantsocialworker.org, 2012).

Other research supports evidence that a more intensive, psychodynamically oriented approach is worthwhile for predicting transplant success, although the research is very limited in this area (Olbrisch et al., 2002). No studies could be found using a psychodynamically oriented approach in liver or other solid organ transplant. Hoffman, Szkrumelak and Sullivan (1999) used what they labeled a psychodynamically-oriented approach when evaluating bone marrow transplant candidates. Psychiatric assessments were conducted over two to three psychodynamically-oriented interviews. They assessed for individual psychological maturity (what they labeled the “I” Parameter) by assessing the quality of relationships through an object relations lens; thus considering the

individual's sense of uniqueness, separateness, individuality perceived by the self, and ability to relate to others as separate from the self (Hoffman et al., 1999). "By examining present relationships with important persons in the context of significant past relationships, it is possible to infer certain characteristics of that person in both the external and intrapsychic worlds" (Hoffman et al., 1999, p. 16). The "I" parameter was also assessed by considering defense mechanisms as categorized by Sigmund Freud, Anna Freud, Otto F. Kernberg and Melanie Klein (Hoffman et al., 1999). The "T" parameter (attitude towards transplant) assessed the individual's ability to formulate psychologically sound construct of the bone marrow transplant. "The capacity to imagine him/herself undergoing the procedure, as well as the readiness to discuss its potential complications and consequences, including the positive and negative aspects, all reveal the extent to which a person can acknowledge the transplant as a unique event" (Hoffman et al., 1999, p. 18). Results indicated that both the "I" and "T" parameters were strong predictors of success and adherence post bone marrow transplant.

Unlike the more standardized, brief assessment instruments previously described above (that require specific questions and guide the person conducting the psychosocial interview), the study by Hoffman et al. (1999) did not offer more guidance on how to provide a psychodynamically oriented evaluation for transplant. The shorter interviews do ask patients questions about readiness and understanding of transplant, but do not as fully consider psychodynamic theory. Many mental health practitioners who are

conducting the psychosocial interviews in the United States, whether they be social workers, psychologists or psychiatrists, have varying levels of professional knowledge of object relations and psychodynamic theory, making it more difficult to replicate the interviews conducted by Hoffman et al. (1999) if the clinician does not have a strong psychodynamic understanding of the human mind and behavior.

Whatever method used, a patient cannot be listed for transplant in the United States without psychosocial clearance by a social worker, psychologist, psychiatrist or other mental health practitioner. No matter which tool or tools are used, many psychosocial factors are considered and assessed before a person is placed on a waiting list for an organ transplant. Research has shown that assessment for these factors is critical in predicting outcomes of graft survival of the new organ (Bunzel & Laeferach-Hoffmann, 2000; Copeland et al., 1987; Fisher, 2006; Freeman III et al., 1992; Grover & Sarkar, 2012; Levenson & Olbrisch, 1993; Shapiro et al., 1995).

Psychosocial evaluations are used to assess numerous factors that can affect successful transplant process including: substance use history, housing stability, legal history/issues, family dynamics, family support, other support systems, relational issues, education, work history, future oriented goals, socioeconomic support/financial stability (including health insurance), socioeconomic status, transportation plan, psychiatric concerns (including psychopathology and psychiatric history), defense mechanisms employed, coping skills, motivation for surgery, motivation history, cognitive function (including ability to understand and follow medical directions, give informed consent,

and understand and consider risks of transplant), mental status exam, developmental history, past medical treatment adherence/management, and awareness of information regarding the actual surgical event and future treatments (Bunzel & Laeferach-Hoffmann, 2000; Fisher, 2006; Freeman III et al., 1992; Grover & Sarkar, 2012; Levenson & Olbrisch, 1993; Morana, 2009; Olbrisch et al., 2002; Yoo & Thuluvath, 2004). Another goal of the psychosocial evaluation "is to determine how much the candidate knows or is aware of his/her medical status, or better yet, whether he/she has accepted his/her medical condition" (Morana, 2009, p. 694). Morona (2009) lists the following as absolute psychosocial contraindications for liver transplant: irreversible cognitive-neurological deficits, active psychosis and active addiction to drugs and/or alcohol. Grover and Sarkar (2012) recommend all of the following be part of the psychosocial evaluation of psychological attributes of the patient: coping styles, grief, hopelessness, adaptation to illness, illness behavior, commonly applied defense mechanisms, motivation for surgery, personality, past treatment compliance and quality of life. Morona (2009) lists the following as relative psychosocial contraindications that may be addressed through appropriate intervention: personality disorder, history of psychiatric disorders, history of alcohol and/or drug addiction, depression, neurosis, history of use of psychotropic/neuroleptics, limited family and social support, limited ability to adhere to therapies, and inadequate motivation.

A recent study by Amoyal, Fernandez, Ng and Fehon (2016) suggests that measuring ability to cope through use of the Brief COPE scale can be predictive of transplant outcomes and it is useful to add to the psychosocial evaluation of liver

transplant. In a sample of 120 liver transplant candidates, those who reported active coping, humor and religious coping had coping strategies that were significantly related to higher levels of resilience. "Religious coping was significantly related to lower levels of depression whereas maladaptive coping was significantly related to higher levels of anxiety and depression and lower levels of resilience" (Amoyal et al., 2016, p. 281).

This study looked at the use of an adult attachment scale as a way to better incorporate psychodynamic understanding when evaluating liver transplant patients. As will be further discussed in this literature review, attachment theory developed out of object relations and has its root in psychodynamic theory. The implementation of an attachment scale as part of the psychosocial assessment may prove useful in having a more psychodyamically oriented understanding of a patient through use of a reliable, valid scale that can be administered by mental health clinicians, independent of their level of understanding of or familiarity with psychodynamic theory.

Adherence/Compliance

Medical adherence is critical for both short and long term outcomes in liver transplantation (Burra et al., 2011). "Survival outcomes after liver transplantation in adult patients have gradually improved with a five-year survival of about 70% and a ten-year survival of about 60%" (Drent, De Geest, Dobbles, Kleibeuker, & Haagsma, 2009, p. 161). With regards to organ transplantation, adherence to life-long immunosuppressant medication and other prescription medications is paramount for graft survival as well as survival overall. Non-adherence post-transplant impacts patient

mortality, life-span, quality of life, and potential for graft failure and leads to a high incidence of post-transplant complications (Bunzel & Laeferach-Hoffmann, 2000; Burra et al, 2011). "The effectiveness of any treatment does not only depend on the right choice of therapy, but largely also on the active cooperation of the patient in the therapeutic regimen" (Bunzel & Laeferach-Hoffmann, 2000, p. 711). This is typically referred to as compliance/noncompliance or adherence/nonadherence. "Adherence to a medical regimen has been defined as the extent to which a patient's behavior coincides with clinical prescriptions" (Burra et al., 2011, p. 760). "Adherence" has become the more accepted term as "compliance" has been perceived to imply ranking or hierarchy. The word "compliance" has been thought to infer a relationship that involves a superior physician and a subordinate patient. The word "adherence" is believed to increase patient autonomy, reduce practitioner paternalism and foster a more cooperative patient/health care professional relationship (Bunzel & Laeferach-Hoffmann, 2000; Burra et al., 2011). However, in the literature, as well as in this study, the terms are used interchangeably.

Most transplant programs consider a patient's risk for nonadherence as part of the patient selection/evaluation process (Rodrigue, Nelson, Hanto, Reed & Curry, 2013). Heinrich and Marcangelo (2009) suggested that an assessment of past medical records in combination with monitoring a patient's behavior pre-transplant can provide important data with regards to expected post-transplant adherence. "Clinical assessments of non-adherence risk are based largely on factors associated with medication nonadherence in the nontransplant literature, including mood disturbances, passive coping strategies, substance abuse, prior medication nonadherence, and limited social support" (Rodrigue et

al, 2013, p. 320). Patients with a history of medical non-adherence are typically labeled 'high-risk patients' due to such a history (Bunzel & Laeferach-Hoffmann, 2000). "It must be mentioned that patients with preoperative risk factors for postoperative noncompliance are not usually excluded a priori from transplantation. If possible, transplant surgery is postponed, the underlying problems are addressed and the patient is given the opportunity to show compliant behavior in the meantime" (Bunzel Laeferach-Hoffmann, 2000, p. 715). These high-risk patients require more attention, care and guidance as interventions prior to listing usually need to be employed (Bunzle & Laeferach-Hoffmann, 2000).

Pre-transplant medical adherence has been (as is still) considered a measure that can predict post-transplant adherence outcomes. "However, whether the presence of these pre-transplant factors increases the risk of immunosuppression nonadherence after transplant is not currently known" (Rodrigue et al, 2013, p. 320). Many studies support the occurrence of non-adherence post-transplant, but few compare pre-transplant adherence rates with post-transplant adherence. So, while there is general agreement that nonadherence occurs post-transplant and that pre-transplant adherence should be considered during assessment for transplant, it is unclear if pre-transplant adherence is a significant predictor for post-transplant adherence.

In the world of transplant, one of three situations can occur with transplant adherence outcomes. (1) The first is what one may predict: poor medical outcomes occur for patients with pre-transplant adherence problems (including death before opportunity for transplant, graft rejection, graft loss or death post-transplant) and good outcomes for

those with a history of good adherence pre-transplant. (2) Secondly, there are instances where patients with a history of medical adherence problems do well post-transplant. (3) Lastly, instances exist where patients were adherent pre-transplant, but struggled with adherence post-transplant. (Dew, Dunbar-Jacob, Switzer, Dimartini, Stilley, & Kormos, 2001).

In their literature overview, Bunzel and Laeferach-Hofmann (2000, p 711) concluded, "Unfortunately, there has not been a systematic and comprehensive review of the literature on predictors of noncompliance in organ transplantation so far." Although much research has been done on the topic of adherence and transplant, results vary. Reasons for the variance in literature stem from the lack of a standardized definition of the term non-adherence, the use of different methods to measure adherence and small sample sizes (Bunzel & Laeferach-Hofmann, 2000). This makes the findings difficult to interpret. Evaluated areas of nonadherence have been measured in several different ways including:

(1) Clinical appointment attendance,

(2) immunosuppressant medication adherence,

(3) other medication adherence,

(4) alcohol/drug relapse,

(5) significant psychiatric symptoms,

(6) unstable psychosocial support,

(7) graft function/rejection or,

(8) some combination of the first seven.

The methods for data collection have also varied and include: review of patients medical record, patient questionnaire, self-report, patient interviews, and monitoring of blood-levels for medications (Berlakovich, Langer, Freundorfer, Windhager, Rockenschaub, Sporn, Soliman, Pokorny, Steininger, & Mühlbacher, 2000; Berlakovich, Steininger, Herbst, Barlan, Mittlbock, & Mühlbacher, 1994; Burra et al, 2011; Dew, Roth, Thompson, Kormos, &Griffith, 1996; Drent, Haagsma, De Geest, Van Den Berg, Ten Vergert, Van Den Bosch, Slooff & Kleibeuker, 2005; Drent et al., 2009; Maldonado et al., 2012; Mor, Gonwa, Husberg, Goldstein, & Klintmalm, 1992; Osorio, Ascher, Avery, Bachetti, Roberts & Lake, 1994; O'Carroll, McGregor, Swanson, Masterton, & Hayes, 2006; Rovelli, Palmeri, Vossler, Bartus, Hull, & Schweizer, 1989; Schweizer, Rovelli, Palmeri, Vossler, Hull & Bartus, 1990; Stilley, DiMartini, De Vera, Flynn, King, Sereika, Tartar, Dew, & Rathnamala, 2010).

Unfortunately, most studies simply measure post-transplant adherence/nonadherence. Some offer explanations that theorize what psychosocial factors may predict poor adherence post-transplant. Yet, very few studies compare pre-transplant with post-transplant adherence.

Significance of Non-Adherence in Solid Organ Transplant

Because transplant patients are well-informed by their medical team, It is often assumed that they are all highly motivated and will be adherent post-transplant, but this assumption is incorrect (Bunzel & Laeferach-Hoffmann, 2000). "Overall, non-compliance rates range between 20 and 50%" (Bunzel & Laeferach-Hoffmann, p. 712).

De Geest, Borgermans, Gemoets, Abraham, Vlaminck, Evers and Vanrenterghem (1995) concluded that 22.3% of 150 adult kidney transplant patients were non-compliant with immunosuppressant medications. Dew et al. (1996) found a 20% non-compliance rate (n=101) with medications and a 9% non-compliance rate with clinic attendance. De Geest, Dobbles, Martin, Williams and Vanhaecke (2000) studied 101 heart transplant recipients and results showed an appointment non-compliance rate of 7%. Rejection rates of non-compliant patients in this study was 57%, in significant contrast to a 2% rejection rate of compliant patients. In a meta-analysis of 147 transplant adherence studies, Dew, DiMartini, De Vito Dabbs, Myaskovsky, Steel, Unruh, Switzer, Zomak, Kormos, and Greenhouse (2007) reported that 19 to 25% of patients were non-compliant with immunosuppressants, diet, exercise, and other healthcare expectations.

Mor et al. (1992) conducted a retrospective review of 375 consecutive orthotopic liver transplants to determine incidence and outcome of late rejection episodes. A total of 31 episodes (in 26 patients) were identified. Seven (22.6%) were related to non-compliance with immunosuppressant medication.

Schweizer et al. (1990) measured non-compliance in kidney and liver transplant recipients by evaluating adherence to clinical appointments and medications. Out of 260 kidney transplant recipients, the non-compliance rate was 18% and with liver (N = 13), the rate was 23%. A higher rate of non-compliance existed with Black and Hispanic groups, but this may have been explained by a higher rate of low socioeconomic status in these groups. They concluded that non-compliant behavior was usually not predictable and was often without identifiable reason (Schweizer et al., 1990).

O'Carroll et al. (2006) measured adherence of liver transplant patients (N = 435) by assessing follow-up clinic appointments, blood immunosuppressant levels, and episodes of cellular rejections. The study concluded that "poor adherence to medication may have contributed to the death of 10.2% of patients" (p. 1865). One in five living patients either missed or cancelled more than 25% of clinic appointments compared to one in three patients who had since died. The percentage of immunosuppressant levels found to be below the minimum level was calculated for 302 living patients and 51 patients who had died; no significant difference was found. However, 15% of all patients had low levels on more than 25% of occasions with poor adherence to immunosuppressant medication being a "likely explanation" (p. 1865).

Drent et al. (2005) assessed patient adherence with one post-transplant medication (N = 108), prednisolone, using electric event monitoring (EEM). "The EEM is a pill bottle fitted with a cap containing a microelectronic circuit that registers date and time of bottle openings and closings" (p. 960). Using EEM, they found an overall high level of adherence for prednisolone: median taking compliance was 100%, median dosing compliance was 99% and median timing compliance as 94%. A drug holiday (a period greater than or equal to 48 hours during which medication is not taken) was found in 39% of the patients. Timing compliance was lower and tendency for a drug holiday was more prevalent for patients below 40 years of age. Psychosocial reasons or theories for drug holidays and timing compliance were not offered by the researchers.

Psychosocial Predictors of Post-Transplant Non-Adherence

Schweizer et al. (1990) concluded that non-compliant behavior was usually not predictable and was often without identifiable reason. However several studies have attempted to find correlations between poor adherence and psychosocial factors so that psychosocial assessments could better predict risk for poor adherence post-transplant.

In detailed psychological assessments of 33 liver transplant recipients, "the results indicated that low self-reported patient adherence was related to greater concerns regarding potential adverse effects of medication, and a stronger belief that medicines in general are harmful. In addition, the greater negative effect the transplantation had on patients' lives and the more it affected them emotionally, the less adherent the patients were likely to be" (O'Carroll et al., 2006, p. 1862).

Denhaerynck, Steiger, Bock, Schafer-Keller, Kofer, Thannberger and De Geest (2007) studied 249 adult kidney transplant recipients and measured adherence in terms of adherence to immunosuppressant medication. Data supported a low-occurrence of non-adherence to medication regimen; mean taking adherence was 98%, the mean dosing adherence was 96% and the mean timing adherence was 92%. Patient non-adherence was associated with low self-efficacy, higher self-reported nonadherence, no pillbox usage, and male gender.

Stilley et al. (2010) used an interview process with 152 patients. Patients were questioned about their medication (and psychosocial measures such as alcohol use). Medication was monitored through use of electronic caps, and medication diaries were kept by the patient to explain instances of non-adherence. Level of emotional distress

was measured with the Hamilton Anxiety and Depression semi-structured interviews. Nonadherence occurred at a rate of 47% with appointments and 73% with medication. “Patterns of coping, decision making, attitude, and social support were correlated with adherence, clinical markers and psychological functioning. Avoidant coping, affective dysregulation, and caregiver support emerged as robust predictors of negative clinical and mental health outcomes” (p. 58).

Rodrigue et al. (2013) studied adherence rates in 236 liver transplant recipients through structured telephone interviews and medical record reviews. Results show that 35% were missed-dose non-adherent, 14% were altered dose non-adherent and 30% reported one or more 24-hour immunosuppressant holidays in the past six months. The study also examined adherence and six hypothesized psychosocial risk factors: (1) mood/anxiety disorder, (2) poor primary style, (3) history of poor medication adherence pre-transplant, (4) substance abuse/dependence, (5) support system availability and (6) support system stability. “Male sex and longer time since transplant were significant predictors of immunosuppression missed-dose non-adherence” (p. 325). Mood disorder history and social support instability were also significant predictive factors for poor adherence. Also, having more than one of the six psychosocial risk factors increased likelihood for non-adherence. “Recipients who had 4 or more psychosocial risk factors at the time of initial evaluation were significantly more likely to show signs of immunosuppression non-adherence than did those with one or fewer risk factors” (p. 326).

Dew et al. (2007) conducted a meta-analysis of 147 solid organ transplant studies between 1981 and 2005. Results found that non-white race, inadequate social support, and poorer perceived health were the only significant psychosocial variables associated with immunosuppression non-adherence. Non-adherence in liver transplant appears to be related to patients' personalities, their understanding of their disease, the complexity of their medical prescriptions, their family support, and their relationships with their medical providers (Burra et al., 2011; Drent et al., 2005).

When considering psychological variables, Bunzel and Laeferach-Hoffmann (2000) found that anxiety, anger/hostility and denial are the ones that are most often linked to non-compliance in heart transplant recipients. Dew et al. (1996) reported that anxiety was the most important predictor in their research with heart transplant recipients. The authors found a 20% non-compliance rate with medications and a 9% non-compliance rate with clinic attendance.

Dew et al. (2001) suggest that poor-adherence post-transplant may be due to the fact that humans change over time. A patient may be in either a better or worse emotional state post-transplant than they were at the time of psychosocial evaluation. This change in emotional state may be the result of a variety of factors related to or unrelated to transplant. Therefore, psychosocial evaluation (including evaluation of adherence) occurs at one moment in time and it can never predict post-transplant behavior with 100% accuracy.

Low socioeconomic status had been considered a risk factor for non-adherence (Bunzel & Laederach-Hofmann, 2000; Rovelli et al, 1989; Yoo & Thuluvath, 2004). Yoo

and Thuluvath (2004) studied the impact of neighborhood income, education and insurance on liver transplant recipients. Results showed that neighborhood income had no effect on graft or patient survival rates. Education had a marginal impact as survival rates were lower in patients with a high school education verses those with graduate education. Medicare and Medicaid patients had lower survival rates than patients with private insurers. African American and Asian American patients had poorer outcomes than white Americans and Hispanic Americans, after adjusting for socioeconomic status and other confounding variables (Yoo & Thuluvath, 2004).

Drent et al, (2009) considered the patient experience of symptoms related to side effects of immunosuppressant medication as they studied liver post-transplant adherence and quality of life. In their review of the literature, the authors conclude that it has not been studied extensively enough. They summarized that there are differences in reported symptoms that cause distress between men and women; for example, women were more likely to report distress secondary to cosmetic side-effects. "Important risk factors were found to be the costs of drugs, age < 40 years old, psychiatric disorders, side effects of drugs, beliefs that drugs were harmful and large influence of the liver transplant on the patient's life" (Drent et al., p. 161). Health related quality of life was found to be satisfactory overall, but still below the level of the general population.

Pre-Transplant Adherence as a Predictor of Post-Transplant Adherence

Dobbles et al. (2009) conducted a study of 141 heart, liver and lung recipients. The study is rare in that it studied pre-transplant non-adherence as a predicator of post-

transplant nonadherence. Patient self-report was used to measure immunosuppressant adherence. Results showed that 13.6% reported adherence problems with taking the medications and 36% reported adherence problems with regards to timing of the medication doses. Pre-transplant non-adherence, a higher education, less received specific social support with medication taking and lower scores on the personality trait 'conscientiousness' were all independent predictors of medication nonadherence at one year post-transplant (Dobbles et al.). Conscientiousness was defined as "degree of organization, persistence, and motivation in goal-directed behavior" (Dobbles et al, p. 1498). Pre-transplant medication non-adherence was the only predictor of late acute organ rejection. (Dobbles et al.)

Douglas, Blixen and Bartucci (1996) studied 126 kidney transplant recipients and found that approximately five to 18% were non-compliant with medical treatment. More importantly, 61% of the patients that were non-compliant pre-transplant experienced graft loss or early death post-transplant. Dew and Kormas (1999) explain that graft rejection from poor medication adherence is responsible for up to 25% of deaths in heart transplant patients after the initial recovery period from transplant surgery.

Interventions for Post-Liver Transplant Adherence Enhancement

"Few studies have concentrated on the problem of enhancing adherence in the liver transplant population" (Burra et al., 2011, p. 767). In cases where it is clinically appropriate, simplifying the doses of immunosuppressive medication to a once a day dose has proven effective in improved medication adherence (Burra et al., 2011). Shemesh,

Annunziato, Shneider, Dugan, Warshaw, Kerkar, and Emre (2008) found that increasing the frequency of clinic visits had a positive impact on adherence in the pediatric population. Patient education with regards to immunosuppressive medication has shown to have a significant positive impact on patient adherence post-transplant in both adult and pediatric patients (Annunziato, Emre, Shneider, Dugan, Aytaman, McKay, & Shemesh, 2007; Burra et al., 2011; Klein, Otto & Kramer, 2009).

At the center where this study was conducted, immunosuppressant education (by both a registered nurse transplant coordinator and a transplant pharmacist) is part of the discharge plan of all patients. Such education is also reviewed as needed during the weekly post-transplant clinic visits after discharge.

Other Psychosocial Factors Post-Transplant

The variation in the literature supports the idea that many factors impact a transplant patient's ability to thrive and adhere to medical management post-transplant. Research has found that, overall, quality of life and psychosocial well-being usually improve after an organ transplant (Freeman III et al., 1992; Goetzmann et al., 2008; Goetzmann, 2010; Rainer, et al., 2010). However, even with pre-transplant evaluations conducted by experienced social workers and mental health practitioners, some patients unexpectedly struggle emotionally and psychologically after a transplant, thus affecting their perceived quality of life and the survival of their graft (Rodin & Abbey, 1992).

The hope of liver transplantation is that it will improve a patient's quality of life and overall physical and mental health. The prevalence of anxiety and depressive

disorders in the general population is estimated to between 5.1% and 6%. In contrast, the prevalence of anxiety and depression in the liver pre-transplant population is estimated to be between 25 and 30% (Russell et al., 2008). This increased prevalence in affective symptoms may be in response to their poor overall medical condition or related to the distress of awaiting a liver transplant (Russell et al., 2008). Heinrich and Marcangelo, (2009, p. 399) state:

> Liver transplants are distributed by how ill the patient is rather than by the amount of time they have waited. This approach leads some patients with liver disease to spend years on the list waiting to get sicker, all the while feeling they are unable to lead a normal life. Although many patients adapt to the limitations that their illnesses create, the sick role remains a major challenge and source of stress for the majority of transplant patients. In addition to facing declining health, patients also must face the possibility that they will not pass the transplant evaluation. This uncertainty can cause tremendous anxiety for patients and their families.

In a study of 107 patients, Russell et al. (2008) found that improvement in symptoms of anxiety and depression was greatest in those patients with the most severe physical symptoms and complications pre-transplant. This study supports the concept that depression and anxiety symptoms secondary to poor liver function can improve with liver transplant and that liver transplant can have both physical and mental health benefits. This is the intended outcome with any patient who is transplanted. Although a number of psychosocial difficulties are reported with transplantation, most patients find the transplant experience to be a positive one (Heinrich & Marcangelo, 2009).

However, research indicates that a significant number of transplant recipients do not experience, or do not sustain improved psychological and social functioning or an improved quality of life. Psychiatric symptoms sometimes remain for a significant period post-transplant and impact a patient's ability to successfully recover from transplant. After a transplant, recipients often experience both physical and emotional transitions and, therefore, concerns must be considered regarding a recipient's psychological well-being post-transplant (Rainer et al., 2010). Transplant recipients with a history of psychiatric disorders and poor social support are at increased risk for significant psychiatric symptoms or psychiatric disorders post-transplant (Heinrich & Marcangelo, 2009). Patients with unmanaged depression before transplant have poor medical adherence post-transplant and have a higher occurrence of organ failure (Olbrisch et al, 2002). "The prevalence of mental disorders among post-liver-transplant patients has ranged from 30% to 70% depending on the study sites, the time of investigation after transplantation, and the diagnostic criteria used" (Chiu, Chen & Cheng, 2009, p. 471). Transplantation itself may create significant psychological stress both before and after transplant (Chiu et al, 2009 ; Morana, 2009). "Orthotopic liver transplantation (OLT) is a major surgical procedure that can precipitate distress, anxiety and depression" (Morana, p. 694). Some of the psychological problems post-transplant are believed to be related directly to transplant (Chiu et al, 2009). "Delirium is the most frequently observed short-term psychiatric compilation in patients undergoing liver transplantation, followed by adjustment disorders and affective disorders" (Chiu et al, 2009, p. 475).

Chiu et al. (2009) evaluated 30 consecutive inpatients post-transplant surgery; 70% received a psychiatric diagnosis of either delirium (n = 8), depressive disorder (n = 5) and anxiety/dyssomnia disorder (n = 8). Patient symptoms that warranted psychiatric evaluation include irritable mood, delirium, mutism, destructive behavior, confusion, acute psychosis, poor memory, insomnia, depressed mood, past depression history, multiple somatic discomforts, depression secondary to worse liver function, and long hospital stay resulting in anxiety and depression. Psychotropic medication proved beneficial in the short-term outcomes of the patients in this study (Chiu et al, 2009).

Yet, many studies have shown that psychological symptoms and distress remain post-transplant for a significant period of time. Instead of improved mood and quality of life, some recipients suffer from prolonged depression, anxiety or other psychosocial stress after transplantation (Goetzmann et al., 2008). Rothenhauser et al. (2002) studied 75 liver transplant patients who had a median of being post-transplant for a period of 3.8 years (range = 5-129 months). Results showed that 22.7% met criteria for a DSM-III-R diagnosis of Posttraumatic Stress Disorder (PTSD), Major Depressive Disorder (MDD) or comorbid PTSD and MDD.

Freeman, Watts and Karp (1984) studied eight cardiac patients and results showed high incidents of depression, anxiety and organic mental disorders. Goetzmann et al. (2008) studied 131 transplant recipients (heart, lung, liver, kidney and bone marrow) for 24 months after transplant and found that 40.5% of recipients had poor psychosocial outcomes after transplant. Lough, Lindsey. Shinn and Scotts (1985) found that more than 25% of heart transplant recipients reported a lower quality of life and found life less

rewarding following heart transplant. Soos (1992) documents multiple risks for depression and anxiety post-transplant including body image changes, coping with threat of organ rejection, meeting medical management expectations and intrapsychic integration of the new organ. Changes in body image such as weight gain and surgical scarring are also risks for despair, anxiety and depression post-transplant (Rainer et al., 2010). Drug side-effects, organ rejection episodes, infection and hospitalizations post-transplant have proven to be stressful and accompanied by dysphoria and depression (Freeman III et al., 1992).

In a study of 161 post-transplant liver patients, Sebaaly, Fleming, Pilch, Meadows, Finn, Chavin, Baliga, Bratton, McGillicuddy, Nadig and Taber (2016) found that patients with inadequately treated depression had higher rates of graft loss and significantly more encounters with health care providers. They concluded that "inadequately treated depression led to increased health-care resource utilization. Patients with adequately treated depression had similar outcomes as those with no depression. Use of sleep aids early post-liver transplant may be a surrogate indicator of inadequately treated depression" (Sebaaly, et al., 2016, p 270). They believe their study supports the notion that early identification and proper treatment of depression with anti-depressant medication may improve post-transplant outcomes in liver transplant recipients (Sebaaly, et al., 2016).

Blanch, Sureda, Flavia, Marcos, de Pablo, De Lazzari, Rimola, Vargas, Navarro, Margarit and Visa (2004) studied the psychosocial adjustment to liver transplant in 266 recipients who were at least one year post-transplant. Findings showed that attitudes

toward health were poorer in women, in patients who were employed at the time of transplant and patients in lower socioeconomic class. Sexual functioning was worse in female and older patients. Psychological distress was higher in women and lower in currently employed patients. Overall, women showed a poorer psychosocial adjustment to liver transplant (Blanch et al, 2004). Although this study did not conclude reasons for these outcomes based on its data, Blanch et al. (2004) suggested that women tend to report higher psychiatric morbidity, a higher percentage of medical problems and that a lower percentage of women were active as found in a study of bone marrow transplant recipients by Preito, Saez, Carreras, Atala, Sierra, Rovira, Batlle, Blanch, Escobar, Vieta, Gomez, Rozman and Cirera (1996). Furthermore, poor organ integration, (ability to perceive a transplanted organ as part of the self), or emotional distance from the donated organ, is often accompanied by low medical adherence and high feelings of guilt (Goetzmann, Moser, Vetsch, Klaghofer. Naef, Russi, Buddeberg & Boehler, 2007; Goetzmann, Irani, Moser, Schwegler, Stamm, Spindler, Budderberg, Schmid, Boehler & Klaghofer, 2009). A close donor relationship (fantasies that the recipient has adopted traits of the deceased donor), has shown links to chronic stress and psychological distress (Goetzmann et al, 2007; Goetzmann et al, 2009).

Basch (1973) documented a male recipient's concern that, because his kidney donor was female, his male functioning might be reduced. Male recipients of female organs have worried that the female organ caused impotence, while female recipients of male organs have worried that the transplanted organ negatively impacts their ability to bear children and reproduce (Basch, 1973).

A study of heart transplant recipients was conducted by Bunzel, Schmidl-Mohl, Grundbock and Wollenek (1992) and findings indicated that 79% of recipients reported no change in personality after transplant, however patients showed high defense and denial reactions. Fifteen percent attributed change in personality to surviving a life threatening event. Six percent did report experiencing a change in feelings and reactions related to taking on perceived or fantasized donor qualities. In another study with heart transplant recipients it was discovered that "despite sophisticated knowledge of anatomy and physiology, almost half the heart recipients had an overt or covert notion of potentially acquiring some of the donor's personality characteristics along with the heart" (Inspector, Kutz & David, 2004; p. 161).

Psychodynamic Theory and Organ Transplantation

There is little research with regards to psychodynamic theory and organ transplantation. Goetzmann (2010, p. 360) states: “sometimes, in spite of medical success, patients turn away from the treatment and give up the self-care that is essential for survival (e.g., by not taking their medication regularly or not taking it at all).” Goetzmann (2010) explores this phenomenon through the lens of Freud’s pleasure principle and life and death drives; a patient’s life experience and history of destructive tendencies (death drive) can significantly impact a patient’s behavior and health care management after transplant.

Castelnuovo-Tedesco (1978) offers an alternate explanation; he explains that most surgeries remove something “bad” or potentially deadly from the body. For example, a

nephrectomy removes a diseased kidney and cancer surgery removes deadly cancerous tissue. A transplant may remove an organ but a major difference between general surgery and transplant surgery is the addition of a new object. Castelnuovo-Tedesco (1973, p. 381) states that "the frequency of postoperative psychosis or major emotional disturbance is considerably greater after organ transplantation than after general surgery." He proposes that it is the adjustment to a new body part that may cause a disturbance in the individual. Basch (1973) conducted a study with kidney transplant recipients from deceased donors and he found that the recipients "seemed affected by their fantasies about the cadaver . . . and conflict over guilt and indebtedness was also present" (p. 383). Basch (1973) found there is a relationship in some recipients between a negative fantasy about the organ donor and the recipient's rejection of the transplanted kidney.

Goetzmann (2004) emphasizes how a transplant recipient may perceive the transplanted lung and the donor as a transitional object (based on the writings of Donald Winnicott) by considering insight into child development. Transplant recipients "do the same hard work done by a small child who is emancipating himself from his parent's body and is about to acquire his own body" (Decker, 2014, p. 21). Goetzmann focuses on how this imagined embodiment of the donor may initially serve as a positive assimilation strategy for coping with a new transplant, but may progress into an obstacle for reintegration into a social or professional life if the recipient remains preoccupied with the transitional object (organ donor) for too long. Goetzmann further expresses concern that if the recipient were to endow his donor (and organ) with negative qualities and the transitional object became negative, the recipient may struggle with assimilation

post-transplant (including a negative impact on health-care adherence and survival of transplant).

Goetzmann (2006) found a significant number of lung transplant patients have heightened anxiety caused by fear that the new lung will not work. "Although triggered by the lung transplant, this insecurity can be aggravated by previous traumatic psychological experiences that result in unsafe internal object relations" (p. 165).

Psychosocial Interventions in Transplantation

As documented earlier, multiple psychological and psychosocial obstacles occur during the transplant process. In a study of 323 liver patients, it was reported that a substantial increase in utilization of social work interventions occurred post-transplant that correlate with increased patient report of psychological concerns (Zilberfein, Hutson, Snyder, & Epstein, 2002). The authors emphasize that social work intervention is paramount to a recipient's survival both pre and post-transplant. Although Zilberfein et al. (2002) suggest the importance of counseling and social work interventions, they do not further specify what interventions, psychological theories, psychosocial interventions or psychotherapy practices could be beneficial.

Rainer et al. (2010) suggest the importance of interventions and activities that focus on assisting the transplant recipient and support system to try to maintain status quo as much as possible as they cope with the transplant. They further suggest that support groups provide a good source of information, commiseration, education, socialization, advocacy and support; these groups have proven to increase quality of social functioning,

foster a return to work, increased compliance with medical regimens, and lower post-transplant anxiety and depression rates (Rainer et al., 2010).

Other literature reports that a variety of therapeutic interventions can have a positive impact on patients including progressive muscle relaxation, systematic desensitization, self-hypnosis, visual imagery, assertiveness training, anger management, problem solving, psychoeducation, dreamwork, cognitive behavioral therapy, psychotropic medications and electroconvulsive therapy (Goetzmann, 2006; Olbrisch et al., 2002). Goetzmann (2010) suggests the importance of a psychotherapy strategy that focuses on Freud's pleasure principle and death/life instincts. Goetzmann (2006) discusses the importance of psychotherapy that focuses on object relations to assist lung transplant recipients with post-surgery anxiety. Castelnuovo-Tedesco (1978) and Basch (1973) emphasize the use of an object relations based psychotherapy to foster a relationship with the new organ that can be better understood, positive and life-sustaining.

Support

Many studies have shown that social support is beneficial when a patient is recovering from surgery (Schwarzer and Knoll, 2010). In a study of men who underwent coronary artery bypass graft surgery, Kulik and Mahler (1989) found that those with spouses who visited them often in the hospital experienced a faster recovery resulting in earlier hospital discharge dates. King, Reis, Poeter and Norsen (1993) found that

perceived availability of support was associated with emotional and functional outcomes up to one year post coronary artery surgery.

Appropriate social support is an important component of organ transplant outcomes and is an area of interest during the psychosocial evaluation. Perceived social support has been shown to result in fewer mental health symptoms and a better quality of life (Duci & Tahsini, 2012). Social support had been described in several ways in the research literature: “the presence of social ties, the perception that support is available from others, the functions performed for an individual by others and the adequacy of the support provided” (Littlefield, 1992, p. 51).

“The presence of an enduring social network is required to assist a patient who is otherwise compromised in achieving satisfactory survival and quality of life during the transplant process” (Krahn & DiMartini, 2005, p. 1158). Grover and Sarkar (2012) recommend the following components when evaluating the support of a liver transplant candidate: availability of an identified caregiver, and the availability of alternative person(s) in case primary caregiver is not available on a particular day. An adequate support person is usually required to provide several important functions, including a combination of basic cares, transportation, medication verification and emotional support during flare-ups or difficult period of illness/recovery (Krahn & DiMartini, 2005).

Higher levels of family and social dysfunction have been found to be more prevalent in patients who did not survive post-transplant (Trzepacz & DiMartini, 1992). Strong social support has been considered a predictive factor for low risk of non-adherence; limited or no social support has been considered to be predictive of high-risk

(Krahn & DiMartini, 2005). Heinrich and Marcangelo (2009) suggest that social support can be evaluated through data regarding living situation, close relationships, financial standings and access to health insurance.

"The absence of a support person is a relative contraindication to acceptance in heart transplant in 67 percent of US and 43 percent of non-US centers and is an absolute contraindication in nine percent and three percent respectively. Yet the validity of this criterion with respect to patient outcome (either medically or psychologically) has not been established" (Littlefield, 1992, p. 50). Littlefield believed that research examining social support with regards to transplantation was still in its infancy when the article was published in 1992. Cohen and Wills (1985) discuss that there are two conceptual models that explain how social support may impact a person. The main effect model predicts that a person with adequate social support will be healthier and happier than those without social support, independent of other life circumstances. In this model, it is believed that social support can protect a person from ill health.

The second model, the buffering model, predicts that the protective effect of social support is apparent specifically in the face of adversity. In this model, social support is not expected to influence the well-being of a person who is not experiencing stress. Yet, if a person is experiencing high stress and has good support, the outcome is expected to be better than a person with inadequate support (Cohen and Wills, 1985).

Broadhead, Kaplan, James, Wagner, Schoenbach, and Grimson (1983) had a different concept as they proposed the person-environment fit model. Well-being relies

on the goodness-of-fit between the environmental demands and the social resources of the individual.

In liver transplant recipients, “the lack of a robust social network may tax a patient’s limited intrapersonal resources or coping abilities and increase stress that compromises more favorable adherence behaviors” (Rodrigue et al., 2013, p. 326). Studies have shown that patients who were non-compliant post-transplant had higher rates of having an unstable relationship with their partner (De Geest et al., 1995; De Geest et al., 2000). In a study of 141 heart, liver and lung transplant patients, Dobbles et al., (2009) found that a lack of partnership (unmarried or not living together in a stable relationship) was a significant predictor of graft loss. “Caregiver strain and burden, too, may reduce the quality and effectiveness of the support provided and, indirectly, may increase rates of medication non-adherence” (Rodrigue et al., 2013, p. 326).

Campbell (2003) identified that families have a powerful impact on health factors and the absence of family or social support is a major medical risk factor. Martial relationships have the strongest impact on health, affecting both mortality and morbidity rates (Campbell, 2003). Family factors that impact medical outcomes include family closeness, mutuality, connectedness, caregiver coping skills, supportive family relationships, clear family organization, and direct communication about the illness and its management. Family factors that are linked to poorer outcomes in the management of chronic illnesses include intrafamilial conflict, criticism, blame, perfectionism, rigidity, delayed family developmental tasks, lack of extra-familial support system, and

psychological trauma related to diagnosis and treatment (Weihs, Fisher, & Baird, 2002). In a meta-analysis of 122 studies from 1948 to 2001, DiMatteo (2004) concluded that "practical support bears the highest correlation with adherence. Adherence is 1.74 times higher in patients from cohesive families and 1.53 times lower in patients from families in conflict. Marital status and living with another person increase adherence modestly" (p. 207).

Attachment Theory

Introduction.

At the beginning of their chapter written about social support and the psychology of health, Schwarzer and Knoll (2010) include the following quote about John Bowlby's attachment theory: "emotional attachment in early life promotes a sense of security and self-esteem that ultimately provides the basis on which individuals develop lasting, secure and loving relationships in adult life" (p. 284). In writing their chapter, these authors understand that adult attachment style influences a person's ability to cope with complicated health and medical conditions. For a better understanding of how attachment theory is relevant when discussing social support, medical adherence and recovery from liver transplant surgery, a brief history of attachment theory is useful.

Attachment theory is known to have its roots in psychodynamic foundations. Mikulincer and Shaver (2007, p. 44-45) offer this explanation of core components of all psychodynamic theory:

> Contemporary psychodynamic theorists agree on five core postulates: First, a large portion of mental life is unconscious. Second, cognitive and affective processes operate in parallel, so that people can have conflicting motives, thoughts, and feelings toward the same situation or person and psychological defenses are often used to deal with these conflicts. Third, childhood experiences play a crucial role in the formation of adult personality. Forth, mental representations of self and others are major components of personality they often explain a person's behavior in interpersonal and social settings, and account for or contribute to psychological disorders. Fifth, healthy personality development is a journey from social dependence to mature autonomy.

Attachment theory is consistent with the five postulates described above (Mikulincer & Shaver, 2007). "Attachment theory is perhaps best seen as a variant of Object Relations Theory, using updated terminology and informed by Neo-Darwinism." (Holmes, 1993, p 132).

John Bowlby.

John Bowlby is credited as the first to develop a theory of attachment and is known as the father of attachment theory (Mooney, 2010). Bowlby believed that "first relationships in infancy set the tone for all later love relationships. He believed that disruption of these first relationships or poor quality in these relationships accounted for trauma and troubling behaviors in adolescence and adult life" (Mooney, 2010, p. 18). Bowlby moves away from classic drive theory as he develops his theory of attachment. However, Bowlby was certainly not the first and was not alone in his dissatisfaction with classic Freudian-based psychoanalytic thought. Object relations theorists (as in the writings of Melanie Klein, Donald Winnicott and William Ronald Dodds Fairbairn) were all influenced by the emphasis on the early infant-mother relationship. A distance or even abandonment from drive theory emerges in their theories and relationships become a primary focus (Mooney 2010).

Bowlby first completed medical school and training as a psychiatrist. He then became a candidate in the British Psychoanalytic Society. He was analyzed by Joan Riviera, a close friend and colleague of Melanie Klein. He was supervised by Melanie Klein during his training and graduated in 1938 (Palombo, Bendicsen & Kosh, 2010; Holmes, 1993; Mikulincer & Shaver, 2007). "From these mentors, Bowlby learned a great deal about the importance of early relationships with caregivers; the tendency of troubled children to deal with painful experiences, especially separation and losses, by defensively excluding them from conscious memory; and the emotions of anxiety, anger

and sadness" (Mikulincer & Shaver, 2007, p. 6). Initially, under the influence of object relations theory, Bowlby rejects Freudian drive theory (Holmes, 2007). Bowlby was not convinced with the prevailing psychoanalytic belief that an emotional bond to a primary caregiver was a secondary drive based on desire to gratify oral needs or drives. He was interested in examples from animal research where species could become attached to adults who did not feed them (Fonagy, 2001).

In contrast to orthodox Freudians, Bowlby theorized that security, not drive, is the primary focus. He saw attachment as primary, not a derivative of orality. In Bowlby's concept of attachment, people are not drive-driven beings in search of an object on whom to discharge accumulated tension. Instead humans seek to relate to another person (or persons). Relation to the world is more than unconscious fantasies, but rooted in internal working models which include affective, cognitive and behavioral elements. In his theory of attachment, Bowlby viewed aggression as a response to frustration and loss, not an intrinsic property of an individual dominated by the death instinct (Holmes, 1993).

Even though object relations served as a foundation for Bowlby's early clinical understanding, he struggled to accept the heavy importance of fantasy (Mikulincer & Shaver, 2007). While learning from Klein, "their fundamental disagreement came to a head, at least for Bowlby, when Klein forbade him to speak with or focus attention on a child client's schizophrenic mother, because Klein thought child psychoanalysis should deal with the child's conflicts and fantasies, not with the actual experiences Bowlby thought had probably caused and certainly contributed to them" (Mikulincer & Shaver, 2007, p. 6). Bowlby emphasized a focus on each child's actual experience, with specific

focus on what he termed ‘mental deprivation’ (the separation from or loss of one’s mother in early life) and the child’s tie to his mother (Mikulincer & Shaver, 2007). “For Bowlby, both Freud and Klein failed to take the all-important step of seeing attachment between infant and mother as a psychological bond in its own right, not as an instinct derived from feeding or infant sexuality” (Holmes, 1993, p 63). Bowlby believed that a child’s hunger for his mother’s love and presence was of equal importance and separate from his hunger for food or other basic needs (Holmes, 1993).

Although rooted in object relations, Fonagy (2001) explains the difference between object relations and Bowlby’s attachment theory:

> There is a subtle but important difference between Bowlby’s formulations and those of object relations theorists at the molecular behavioral level. The goal of the child is not the object, for example, the mother. The goal that regulates the system is initially a physical state, the maintenance of a desired degree of proximity to her. This physical goal is later supplanted by the more psychological goal of a feeling of closeness to the caregiver. Because the goal is not an object but a state of being or feeling, the context in which the child lives, that is, the response of the caregiver, will strongly influence the attachment system because if the child perceives the attachment goal to have been attained this will affect the system of behaviors (p. 8-9).

When commenting on object relations, Bowlby (1988) stated, “In its best-known version, the one advocated by Melanie Klein, mother’s breast is postulated as the first object, the greatest emphasis is placed on food and orality and on the infantile nature of

'dependency'. None of those features matched my experience of children" (p 24-25). Bowlby challenged the popular belief that food is a primary drive and the personal relationship secondary. He based this on witnessing that the infant does not simply accept food in the same way from anyone providing nourishment (Bowlby, 1988). Bowlby (1988) explains:

> Having discarded the secondary-drive, dependency theory of the child's tie to his mother, and also the Kleinian alternative, a first task was to formulate a replacement. This led to the concept of attachment behaviour with its own dynamics distinct from the behaviour and dynamics of either feeding or sex, the two sources of human motivation for long widely regarded as the most fundamental. Strong support for this step soon came from Harlow's finding that, in another primate species – rhesus macaques – infants show a marked preference for a soft dummy 'mother', despite its providing no food, to a hard one that does provide it (p. 26).

Holmes (1993) explains how this concept remains significant in relationships beyond infancy, including adult relationships:

> Like Fairbairn, but unlike Freud for whom affection was 'aim inhibited sexuality', Bowlby saw bodily pleasure not as an aim in itself, but as a 'signpost to the object' and so tends to rather downplay the role of sexuality in marriage. Just as the mother-infant relationship cannot in Bowlby's eyes, be understood as primarily based on feeding, so adult pair-bonding cannot be adequately explained by sexuality. Sex without attachment and sexless marriages are both all too

> common, and suggest that the attachment system and sexual behaviour are separate psychological entities, however much society might wish that this were not so. 'In sickness and in health' is a reminder that the psychological purpose of marriage is to provide a secure base and an attachment system which can be awakened in time of need (p. 82).

Bowlby's most significant contribution was his focus on the infant's need for an unbroken (secure) early attachment to the mother (Fonagy, 2001). "He thought that the child who does not have such provision was likely to show signs of *partial deprivation* – an excessive need for love or for revenge, gross guilt, and depression – or *complete* deprivation – listlessness, quiet unresponsiveness, and retardation of development, and later signs of superficiality, want of real feeling, lack of concentration, deceit, and compulsive thieving" (Fonagy, 2001, p. 7). Bowlby theorized that people are born with an innate psychobiological system of attachment that motivates them to seek proximity to attachment figures in times of need (Shaver & Mikulincer, 2007). "Attachment behaviour is any form of behaviour that results in a person attaining or maintaining proximity to some other clearly identified individual who is conceived as better able to cope with the world. It is most obvious whenever the person is frightened, fatigued, or sick, and is assuaged by comforting and caregiving" (Bowlby, 1988, p. 26-27). Proximity seeking is the natural and primary strategy of the attachment behavioral system when a person needs protection or support (Mikulincer & Shaver, 2007). This strategy consists of signals meant to indicate to a relational partner that one is interested in maintaining proximity. Such signals include "overt displays of negative emotion (e.g.,

anger, anxiety, sadness) that call upon a partner to provide support and comfort; active approach behaviors that result in greater physical and psychological contact; and explicit requests for emotional and instrumental support" (Mikulincer & Shaver, 2007, p. 13). This system of attachment through proximity accomplishes basic regulatory functions (protection from threats and alleviation from distress) in humans of all ages, but it is most directly observable during infancy and early childhood. Availability, responsiveness and supportiveness of attachment figures impact the function of this attachment system (Shaver & Mikulincer, 2007).

In Bowlby's theory of attachment, "Interactions with attachment figures who are available and responsive in times of need facilitate the optimal functioning of the attachment system and promote a sense of attachment security" (Shaver & Mikulincer, 2007, p. 447). This pervasive sense of security is based on implicit beliefs that the attachment figures are helpful and reliable when needed, that it is possible to explore the environment curiously, that the world is generally a safe place, and that it is possible to engage effectively and enjoyably with other people (Shaver & Mikulincer, 2007). This sense of security is rooted in positive mental representations of self and others, which Bowlby called internal working models (Shaver & Mikulincer, 2007). Such circumstances support secure attachment. However, if attachment figures are not reliable and supportive, do not successfully provide relief from distress, or cause a child to feel overly dependent (and unsafe to explore the environment and begin to develop autonomy), negative working models of the self are developed, resulting insecure attachment and secondary attachment strategies: either protest (or hyperactivation) or

compulsive self-reliance (deactivation) (Shaver & Mikulincer, 2007). The table below, based on Shaver and Mikulincer's explanation, outlines the two different secondary attachment strategies, their defense strategies and their typical outcomes.

Table 2

Secondary Attachment, Defense Strategies and Outcomes

Secondary Attachment Forms	**Defense Strategies**	**Outcomes**
Protest (Hyperactivation) is characterized by intense efforts to attain proximity to attachment figures and insistent attempts to induce a relationship partner, viewed as insufficiently available or responsive, to provide more satisfying and reassuring care and support	-clinging, controlling, and coercive behaviors -cognitive and behavioral efforts to establish physical contact and sense of merger or oneness -overdependence on relationship partners for protections	-Compulsively seek proximity and protection -chronically hypersensitive to signs of possible rejection or abandonment
Compulsive Self-Reliance (deactivation) – is characterized by inhibition of proximity seeking inclinations and actions	-suppression or discounting of threats that might activate the attachment system -determination to handle stress alone	-Maximize autonomy and distance from relationship partners -experience discomfort with closeness and intimacy -strive for personal strength and control of relationship partners

Holmes (1993, p. 141-142) explains Bowlby's thoughts about insecure attachment (in absence of a secure base):

> The anxiously attached child is caught up in a vicious circle in which he lacks a secure base; feels angry and wants to attack the attachment figure for premature separation; doesn't dare to do so in fear of retaliation or pushing attachment figure even further away; and so suppresses his feelings of anxiety and rage thereby increasing the sense of insecurity; leading ultimately to an expectation of lack of care, and danger in emotional expression with potentially disastrous implications for self-esteem and intimate relationships.

Bowlby and Winnicott.

Although Donald Winnicott is generally associated with object relations theory and Bowlby with attachment theory, Winnicott and Bowlby shared many similarities in their lives and in their theories. Both were influenced by Melanie Klein and her theory of object relations. They were both analyzed by Joan Riviere. Both were of English decent, thus having a different perspective or outlook than the European/Jewish/Celtic atmosphere of the Psycho-Analytical Society at the time. Both were primarily concerned with the welfare of children (Holmes, 1993). There are many similarities between their theoretical viewpoints, despite the different language and points of view of each theorist (Holmes, 1993). Holmes (1993) explains:

> Bowlby and Winnicott's overall view of the infant-mother relationship, and what may go wrong with it, is very similar. Winnicott postulates a 'holding

> environment' provided by the mother, in which, on the basis of her 'primary maternal preoccupation', she can empathize with the needs and desires of the growing child. The main job of the holding environment is, like attachment, protection, although, in contrast to Bowlby, Winnicott describes this in existential rather than ethological terms: 'The holding environment . . . has as its main function the reduction to a minimum the impingement to which the infant must react with resultant annihilation of personal being' (Winnicott, 1965). Winnicott sees 'handling' and general management' equivalent to the Bowlbian concept of the maternal responsiveness, as the framework within which need can be met. The mother's actual physical holding and handling are primary (p. 138).

Both Bowlby and Winnicott theorize that pathology is rooted in failures of the holding environment (or maternal responsiveness) and that separation from the mother may lead to delinquency. Although this core belief is consistent, a subtle difference exists in their verbiage and theories (Holmes, 1993). Holmes (1993) explains:

> For Bowlby theft is a sociological phenomenon, which can be well accounted for by the disrupted lives and maternal separations of the thieves' early childhood. Winnicott is reaching towards an understanding of the symbolism of the act of theft itself. He is suggesting that the stolen object stands in for the missing mother which the youth is using to bridge the emotional gap left by her absence. Bowlby is reaching for explanation, Winnicott is reaching for meaning (p. 139)

Both also consider two mothers. Winnicott first describes the environmental mother (who protects the child from impingement and serves as an ego until the child develops an autonomous ego). Affection and sensuous coexistence are provided by the environmental mother. With the atmosphere and safety provided by the environmental mother, the child can then relate to the object mother, who can be sucked and bitten, loved and hated (Holmes, 1993). The mother's response can have significant consequences: "overintrusiveness can in a seductive way be as traumatic as neglect, and both can lead to defensive moves such as self-holding, disintegration and the development of a false self" (Holmes, 1993, p .140).

For Bowlby, the first mother is the provider of the secure base and equal to Winnicott's environmental mother. Holmes (1993) explains how Winnicott and Bowlby's second mother differ in theory:

> The second mother is the companion with whom the child, once a secure base has been established, engages in exploratory play. This . . . is different from Winnicott's second object mother with whom the child engages in orgiastic play. Bowlby seems less interested in orgasmic activities, although the sexual foreplay of trusting adults can be seen as a form of mutual exploration (analogous to the sensuous intimacy of mother and child), which enables a greater build-up of the intense pleasure than orgasm not preceded by exploration (p. 140).

Klein's depressive position in Winnicott's terms is known as the stage of concern (Holmes, 1993). In this stage, the environmental and object mother come together. The mother, of course, is not able to be perfectly responsive and gaps occur in the continuity

of care and responsiveness. The child responds to the object mother with rage and aggression. However, the mother survives the attacks, continues to show love to the child and balance is restored. The child is able to understand that the mother who lets him down is the same mother he loves. (Holmes, 1993). "Clouds of guilt and anxiety appear on this horizon, but also the seeds of gratitude and reparation" (Holmes, p. 141). Bowlby also believes that if the mother can withstand the child's aggression, and these early experiences lead to a mental frame later in life (based on internal working models) that feelings can be expressed and processed and that conflicts can be successfully resolved. However, if the mother does not respond in this manner insecure attachment forms (Holmes, 1993).

Mary Ainsworth.

Mary Ainsworth was a research assistant for John Bowlby who made her own mark on attachment theory, most notably through her Strange Situation study. "The Strange Situation is briefly described as a twenty-minute observation of infant play in an unfamiliar room while both familiar and unfamiliar adults enter and leave the room. Its purpose is to determine a child's attachment behaviors" (Mooney, 2010, p. 31). Results from the Strange Situation categorize infant behaviors into three forms of attachment behavior: (1) secure attachment, (2) anxious-ambivalent insecure attachment and (3) anxious-avoidant insecure attachment. The following table, based on the writing of Mooney (2010) and Wallin (2007), will further explain Ainsworth's categories and the impact on infancy, childhood and adulthood:

Table 3

Ainsworth's Strange Situation

	Securely Attached	**Anxious-Ambivalent Insecurely Attached**	**Anxious-Avoidant Insecurely Attached**
Infant Behavior in Strange Situation	Explores surroundings with enthusiasm, checking back with secure base (mother) periodically. Engages with strangers if mother is near. Cries when mother leaves the room, but is happy to reunite with mother.	Expresses distress when near strangers or in unfamiliar settings, independent of whether the caregiver is present or not. Child exhibits extreme anxiety and distress when parent departs and, yet, is often resistant to reuniting when the parent returns	Shows little interest in exploration or other adults in the room regardless of the presence or absence of mother. Tends to avoid parents or caregivers regardless of proximity to strangers.
Child/Infant Tendencies	Child tends to develop a sense of security that allows her to cope with problems and to adapt well to unfamiliar situations. This child is comfortable and confident.	Tend to be angry or passive. Angry: upon reunification oscillated between active overtures for connection to mother and rejection (ranging from leaning away from mother to tantrums). Passive: upon reunification, infants had only faint or implicit bids for solace. Reunions did not ameliorate the distress or with mother's whereabouts.	Show little emotional response and lack affect. Strangers are not treated much differently from parents or primary providers. Such children believe communication of their needs make no impact at all. Go limp when held, rather than cuddling or clinging.

	Securely Attached	**Anxious-Ambivalent Insecurely Attached**	**Anxious-Avoidant Insecurely Attached**
Parents	Parents tend to be responsive and sensitive to needs in an appropriate way. Encourages appropriate autonomy.	This parent responds to the child on his/her own schedule rather than based on the needs of the infant/child. Can be a result of inconsistent parenting styles. Parents are unpredictably and occasionally available. Parent (perhaps unconsciously), discourages autonomy	Parent tend to rebuff bids for connection and withdraw when their infant seemed to be sad. Inhibition of emotional expression, aversion to physical contact and brusqueness when it occurred were all signatures of mothering that seemed to produce avoidant infants.
Long-Term Effects	Show greater self-esteem, emotional health, ego, resilience, positive affect, initiative, social competence and concentration in play. In school, these children are treated warmly and age appropriately by teachers. Able to have satisfying adult relationships without traits of pathology.	Often seen as clingy or immature. In school, they tend to be indulged or infantilized. In adulthood, can develop hysteric or histrionic problems.	Often seen as sullen, arrogant and/or oppositional. In school, they tend to elicit angrily controlling responses. In adulthood, obsessional, narcissistic and schizoid problems may occur.

Attachment and Medical Research

De Geest et al. (2013) state "a number of studies have shown that patients with higher levels of trust in their health care provider are more likely to adhere to recommended health behaviors such as medication adherence" (p. 237). Although this does not specifically speak to attachment theory and transplant, it is an important concept because trust is typically a component of secure attachment whereas patients with insecure attachment may struggle with trust, including their relationships with medical providers.

There exists no documented research specific to transplant and attachment theory. Instead, this section will focus on the existing research of attachment and health. In their writing about attachment style and its impact on medical patients, Pietromonaco, DeVito, Ge, and Lembke (2015) consider three types of attachment styles: (a) insecure anxious, (b) insecure avoidant and (c) secure. Pietromonaco et al. (2015) define these styles as such:

> Individuals with insecure *anxious* attachment style expect that close others will not be readily available; as a result, they respond to threat by using hyperactivating strategies, including persisting in signaling their emotional distress to their partners and in trying to maintain proximity to their partners, and excessively seeking reassurance and support from partners. Individuals with insecure *avoidant* attachment style typically expect that their attachment figures will be unavailable and unresponsive to their needs. As a result avoidantly

> attached individuals often respond to threat by suppressing or minimizing their distress and by not turning to close others for support. In contrast, individuals with a secure attachment style expect that their attachment figures will be available and responsive, and they are comfortable tuning to their attachment figures when they are in need of support or reassurance (p. 288).

People with anxious and avoidant attachment styles are more likely to have symptoms significant for depression, which may have a negative impact on immune functioning and make them more prone to become patients with infectious disease and chronic illnesses (Pietromonaco et al, 2015). "Attachment-related expectations and beliefs constitute an important antecedent condition that is likely to predict the extent to which individuals reap the health benefits of receiving and giving social support" (Pietromonaco et al, 2015, p. 289).

Ravitz et al. (2010) document research findings that support the relevance of attachment theory and measurement tools when considering psychosomatic medicine, including: relationship with care providers in diabetic patients, pain, chronic diseases (including ulcerative colitis), alopecia, leg ulcers, breast cancer, somatization, hypochondriacal concerns and health care utilization.

Mikulincer and Florian (1998) conducted a study that measured the impact of attachment style and ability to cope with chronic lower back pain. Their study supports the theory that secure persons coped better and showed better mental health than insecure persons. "Secure persons appraised their back pain in less threatening terms, appraised themselves as being more able to deal with the pain, and relied on more problem focused

strategies and less emotion-focused strategies in coping with pain than both avoidant and anxious-ambivalent persons" (Mikulincer & Florian, 1998 p. 160).

Attachment style has also been shown to have an impact on individual self-regulation and ability to achieve health goals. Secure attachment has been associated with better self-control and more effective behavioral regulation (Pietromonaco et al., 2015). Findings suggest that patients with insecure attachment will have greater struggle with behaviors related to supporting better health, including taking preventative measures such as having regular physical exams and immunizations, healthy eating and avoidance of risky behaviors (Pietromonaco et al., 2015). Research done by Hill and Glick (2013) found that women who tend to have insecure attachment are less likely to receive cervical cancer screenings and perceive more barriers to screening. In a study of diabetic patients, those with avoidant attachments showed less adherence to their treatment plans, including diet, foot care, medication, exercise and smoking recommendations (Ciechanowski, Russo, Katon, Von Korff, Ludman, Lin, Simon & Bush, 2004).

Individuals with anxious attachment tend to report more physical and somatic symptoms than securely attached individuals (Pietromonaco et al, 2015). Multiple studies have shown that insecure attachment is correlated with a variety of physical symptoms that lead to poor health outcomes including poor sleep quality, higher tendency to contract a cold, cardiovascular disease, high blood pressure, and a lower threshold to tolerate pain and recovery (Pietromonaco et al, 2015). McWilliams and Bailey (2010) examined adult attachment and a range of health conditions with a sample of 5,692 people. Attachment avoidance was associated with a higher probability of

having a condition defined by pain (headaches, arthritis, back/neck pain or other chronic pain). Attachment anxiety was also linked to a higher prevalence of headaches and chronic pain, but additionally, a higher prevalence of ulcers, high blood pressure, heart attack and stroke (McWilliams & Bailey, 2010).

Conclusion

Despite the fact that that research has provided tools and structure for evaluating potential psychosocial function of organ transplant recipients post-transplant, research has documented that a significant number of patients experience psychological struggles that impede their ability to adhere to medical instructions and have successful transplant outcomes. Research has documented that poor-adherence and psychiatric symptoms post-transplant are significant problems; however, research has multiple theories on why these problems may occur. Research has supported the idea that insecure attachment can lead to poor adherence and negative physical and mental health outcomes, however, a study focusing specifically on transplant patients had yet to be done. Although psychosocial evaluations for transplant always assess for social support, a specific measure of a patient's attachment to that support has been difficult to assess. This research attempted to see if the use of an adult attachment measurement can further predict patients who may struggle post-transplant so that social workers can facilitate improved interventions including encouraging a patient to utilize psychotherapeutic services both pre and post-transplant.

Chapter III

Methodology

Introduction

The purpose of this retrospective, secondary data analysis pilot study was be to see if a relationship exists between adult attachment (as theorized by John Bowlby and Mary Ainsworth) and liver transplant outcomes for patients at a liver transplant center in a major urban city in Pennsylvania. A patient's ability to successfully recover from transplant surgery was generally defined as the patient's ability to comply with medical treatment (including post-surgery clinic visits, medication adherence and other medical recommendations), appropriately utilize support (including their primary support person and team of transplant professionals), avoid significant psychiatric symptoms, avoid substance use and avoid rejection of the transplanted liver (Maldonado et al., 2012). A secondary analysis was used to test the following research questions: (1) Is there a relationship between Attachment Scale Scores and liver transplant outcomes? (2) Is there a relationship between the Standard Integrated Psychosocial Assessment for Transplant (SIPAT) score and Attachment Scale scores?

As outlined by Bloomberg and Volpe (2014), this chapter describes the study's research methodology and includes discussion around the following areas: (a) rationale for research approach, (b) description of research sample, (c) overview of research design, (d) methods of data collection, (e) analysis and synthesis of data, (f) ethical

considerations, (g) issues of trustworthiness, and (h) limitations of the study. The chapter ends with a brief summary.

Rationale for Quantitative Research Design

A postpositivist paradigm was used to guide the study. Postpositivism "represents the thinking after positivism, challenging the traditional notion of the absolute truth and recognizing that we cannot be positive about our claims of knowledge when studying the behavior and actions of humans" (Creswell, 2014, p. 7). Such a paradigm starts with a test of a theory which may lead to refinement or dismissal of original claims. Evidence or data are gathered with the use of instruments (Creswell, 2014). "Research seeks to develop relevant, true statements, ones that can serve to explain the situation of concern or that describe the casual relationships of interest . . . Researchers advance the relationship among variables and pose this in terms of questions or hypothesis" (Creswell, 2014, p. 8). Quantitative research stresses standards of validity and reliability to best ensure objectivity and eliminate bias (Creswell, 2014). To better understand how an adult attachment scale can assist the transplant team and the patient, it is important to obtain data that will explain the relationship between attachment and transplant outcomes.

Fonagy (2001) stated, "Attachment theory is almost unique among psychoanalytic theories in bridging the gap between general psychology and clinical psychodynamic theory" (p. 5). Bowlby developed his attachment theories with a belief in science and the need for empirical evidence to support ideas (Holmes, 1993). Attachment, whether

secure or insecure, can be observed, rated, measured and correlated (Holmes, 1993). Because this research was being conducted in a medical setting and is hoped to be presented to medically-minded practitioners, a quantitative study that can provide empirical evidence based on measurable variables was desired. A mixed methods design may have been ideal, but it is near impossible to recruit post-transplant patients for such interviews because non-adherent patients would be unlikely to adhere to an interview schedule. It would also be unlikely that non-adherent or struggling patients would be open to dedicating more time to a discussion about their struggle with transplant, as these patients can already be difficult to reach and avoidant of help offered to them. Therefore, a quantitative secondary data analysis with use of a retrospective medical record review (MRR) was employed to obtain data for analysis.

A quantitative study examining attachment styles of liver transplant patients was a unique opportunity to research a psychodynamic understanding of human behavior as it pertains to liver transplant outcomes through use of a research method that is accepted by medical providers and institutions responsible for the creation and implementation of transplant policy.

Rationale for Secondary Data Analysis

A secondary data analysis was used to examine if a relationship exists between a transplant recipient's psychosocial evaluation scores, attachment scale score and post-transplant outcomes. Secondary data analysis originated in the 1960's when survey researchers realized that existing data could be of use for analysis, even if the data were

not collected for that specific reason (Rubin & Babbie, 2008). "Secondary analysis is a form of research in which the data collected and processed in one study are re-analyzed in a subsequent study. Often the subsequent study is conducted by a different researcher, and, often, for a different purpose" (Rubin & Babbie, p. 408). In the case of this study, the initial psychosocial evaluation and Attachment scale data were originally collected and used to evaluate patients as transplant candidates and guide best interventions to prepare a patient for transplant. The data that were analyzed to measure transplant outcomes for this study were also originally recorded in the medical record for medical documentation purposes and treatment purposes. This study used these same data to see if a relationship exists between adult attachment scale scores, psychosocial evaluation scores and post-transplant outcomes.

For the purposes of this study, a retrospective secondary data analysis of medical records was implemented. Specifically, a medical record review (MRR) was utilized. A Medical record review “refers to any study that uses prerecorded, patient-focused data as the primary source of information to answer a research question” (Worster & Haines, 2004, p. 187). The greatest advantage to this design is that the data were already collected and the patient is not exposed to any additional emotional risks such as having a patient sign up for additional questioning or testing. Utilization of this method allowed research to be conducted on transplant recipients without adding any additional undue psychological stress. Data from the chart (that was already gathered as part of the candidate’s evaluation for transplant and ongoing medical care) were collected and analyzed. Worster and Haines (2004) published a protocol for MRR based on emergency

medicine journals as such studies make up 25% of all scientific studies published in such journals. Their guidelines were considered and adapted to inform the data that were collected and analyzed for this study.

Research Sample

Worster and Haines (2004) address two important differences between MRRs and prospective studies:

1. Case selection – with MRR "the cases have already occurred and the information on them is mixed with that of all the non-eligible subjects . . . the study cases need to be sorted out after they have been mixed with all nonstudy cases" (Worster & Haines, 2004, p. 187).
2. Data quality – "the data of MRR were not originally recorded for research purposes, and therefore, may be lacking in quality and quantity" (Worster & Haines, 2004, p. 187).

Worster and Haines (2004) address the importance of how correct diagnosis should be used to ensure good data collection in emergency health care. They suggest that both the initial identifying patient complaint, as well as the discharge diagnosis, both be considered when selecting a patient record to be included in the research study. This current study on liver transplant outcomes was able to ensure consistent patient diagnosis because patients are not listed for liver transplant without a confirmed diagnosis that would indicate liver transplantation. All post-transplant patients also all carry the medical diagnosis of 'Liver Replaced by Transplant' post-transplant surgery.

"A common method of sampling is to select all of the consecutive cases within a given time frame" (Worster & Haines, 2004, p. 190). This is a type of purposive sampling that is acceptable in MRR research (Worster & Haines, 2004). The transplant center where the research was conducted typically completes about 20 liver transplants per calendar year. Therefore, for this pilot study, 20 patient medical records of patients who were at least six-months post-liver transplant were included for analysis. The study used consecutive, study-eligible patients who received a liver transplant at one hospital in the years 2015-2016 (beginning with January 1, 2015). Once IRB approval was obtained by both ICSW and Drexel University on 10/17/16, the investigator reviewed the medical records to see if at least 20 study eligible patients could be identified. As of October 13, 2016, 20 eligible patient charts were identified and all 20 were already six months post-transplant. Pediatric patients, non-English speaking patients, patients who have already received a transplant in the past, patients diagnosed with acute liver failure (also referred to as fulminant liver failure), patients whose medical record is labeled "restricted" and patients who were unable to complete the attachment scale due to altered mental status were excluded from this study's sample due to reasons explained below.

The transplant center where the study was conducted does not perform pediatric transplants and patients must be at least 18 years of age to receive a transplant at this program. There is technically no maximum age for liver transplant evaluation selection it is based more on the patient's overall health factors. Therefore, any adults transplanted during the study timeframe (age 18 and older) were included in the study (and no pediatric patients were included).

Because the adult attachment scale is only available in English, it is not administered pre-transplant to non-English speakers. Therefore, only transplant recipient data from patients who were fluent enough in English to complete an adult attachment scale could be used for this study.

This study only considered patients who are receiving a transplant for the first time and did not include any patient who underwent an additional transplantation for any reason. Patients who have gone through transplant before have an enhanced or altered understanding and perspective of the transplant process and, therefore, differ from first time transplant patients.

Patients who receive a liver transplant as a result of acute liver failure or fulminant hepatic failure were also not included in this study. Ostapowicz, Fontana, Schiødt, Larson, Davern, Han, McCashland, Shakil, Hay, Hynan, Crippin, Blei, Samuel, Reisch, and Lee (2002, p. 947) explain:

> Acute liver failure is characterized by severe and sudden liver cell dysfunction leading to coagulopathy and hepatic encephalopathy in previously healthy persons with no known underlying liver disease. Sometimes termed fulminant hepatic failure, acute liver failure is thought to affect approximately 2000 persons per year in the United States. This catastrophic illness can rapidly progress to coma and death from cerebral edema and multiorgan dysfunction.

If transplanted, such patients are usually on a liver transplant waiting list for a brief period of time (sometimes only a few hours) as they will die without an emergency liver transplant. These patients are atypical transplant recipients and often undergo an

abbreviated psychosocial evaluation as the patient often has a limited ability to communicate due to their illness. Such patients often are not alert or have an altered mental status. A psychosocial evaluation may need to rely heavily on collateral information from the family. As a result, the adult attachment scale often cannot be administered in these instances. Due to the atypical nature of these liver transplants and the limited patient capacity to be active in a psychosocial evaluation, fulminant patients were excluded from this study.

Patients who suffer from liver failure often suffer from hepatic encephalopathy (HE), which causes them to have an altered mental status. "Hepatic encephalopathy (HE) is a syndrome of neuropsychiatric dysfunction caused by portosystemic venous shunting, with or without intrinsic liver disease. Patients with HE often present with the onset of mental status changes ranging from subtle psychologic abnormalities to profound coma" (Munoz, 2008, p795). The patient is usually unaware of the change in mental capacity. HE can range in severity (from mild to severe) and manifest in ways including impairment in memory and concentration, mental fogginess, mild to gross confusion, mild to grossly inappropriate behavior, slurred speech, marked personality changes and agitation (Munoz, 2008). HE can be successfully treated with medication until a liver transplant occurs. Liver transplant is the best long term treatment for HE (Munoz, 2008). Most patients HE can be managed well enough with medication to participate in psychosocial evaluation and complete the Attachment Scale. However, if a patient's HE interfered with the ability to complete the attachment scale, the medical record could not

be used in this study. If a patient had an altered mental status due to encephalopathy at the time of psychosocial evaluation, an attachment scale was not administered.

A patient's medical record can be listed as "restricted" due to sensitive health history or personal history documentation. To access a restricted medical record, an additional step of security and reason for chart access must be documented before the clinician can open and have access to the medical record. Because this is a retrospective study and not linked to current patient care, restricted charts were not accessed and, instead, excluded from this study.

Although the transplant center where this study will occur is located in a large metropolitan city, many of the patients transplanted at the center were from suburban and rural areas (as there are often no closer liver transplant centers located in these parts of the state). The affiliated gastroenterology/hepatology practices have multiple satellite locations to serve patients outside of the city limits. Because of this, the transplant center serves a diversity of races, socio-economic backgrounds and types of neighborhoods. All genders, races, and socio-economic backgrounds were included in this study.

Research Design

This study was a quantitative study that utilized a medical record review. All the data collected for this study were data that had already been obtained as part of the evaluation for liver transplant and as part of pre and post-transplant medical follow-up and care. Quantitative studies are common in medical research, however little research has been done with regards to psychodynamic theory and transplant patients. There

were no previous studies that address the impact of adult attachment on transplant patient medical adherence and post-transplant success. This study had the potential to look at medical transplant outcomes through a psychodynamic lens; it was hoped that results could be useful in improved understanding of patients as they go through the transplant experience. It was hoped that if a patient's attachment could be better understood and post-transplant outcomes based on attachment could be better predicted, possible interventions and recommendations for patient care could be instituted that may allow more successful outcomes for the patient post-transplant.

Because the patient had already received a the desired liver transplant, any issue regarding patient self-determination with regards to worry about continued post-transplant care was eliminated. Post-transplant, it is in the best interest of both the patient and the transplant program to have a positive medical outcome for transplant recipients. The transplant program's continued ability to operate depends on the success rate of transplanted patients. If a certain success rate is not met, the program will be in jeopardy of becoming non-operational. As such, the liver transplant social social worker, being part of the transplant team, is invested in successful outcomes for patients for both the good of the patients' quality of life and for continued operation of the department that provides employment for the transplant social worker.

All patients whose medical records were used in this study were already at least six-months post-liver transplant. Patients who are greater than six months post-liver transplant typically transition back to the care of their referring physician (usually a hepatologist or gastroenterologist). They no longer follow

regularly at the post-transplant clinic. Therefore, this study met the criteria for a retrospective medical record review. As such, a Waiver of the Consent Process and a Waiver of HIPAA Authorization was granted for this project by both the ICSW and Drexel University IRBs. The Office for Human Research Protections states in 45CFR 46.116(d):

> An IRB may approve a consent procedure which does not include, or which alters, some or all of the elements of informed consent set for thin this section, or waive the requirements to obtain informed consent provided the IRB finds documents that:
>
> 1. The research involved no more than minimal risk to the subjects;
> 2. The waiver or alteration will not adversely affect the rights and welfare of the subjects;
> 3. The research could not practically be carried out without the waiver of alteration; and
> 4. Whenever appropriate, the subjects will be provided with additional pertinent information after participation" (www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/#46.111).

This supports the notion of a waiver request as this study met the criteria cited above:

(1) The collection of data was able to be recorded in such a manner that

subjects were de-identified and could be linked to any private medical information. This research was not FDA regulated, and only involved minimal risk to the subjects.

(2) The waiver did not affect the rights and welfare of the subjects as all data were without identifiers. The use of the protected health information involved no more than minimal risk to the subjects, and the plan to protect the subjects' identifiers from improper use and disclosure was that the data were available to only persons involved in the study. The data were stored in a private computer that is secure, in a private office. The researcher recorded the data in such a manner that the identifiers were destroyed as soon as the data were collected. The protected health information will not be reused or disclosed to any other persons except to those who are involved in the study.

(3) The research could not practicably have been conducted without the waiver, because the research could not be conducted without the access to and use of the protected health information in order to help with the conclusion of the research Because the patients were no longer coming to the transplant clinic on a regular basis, traditional consent would had to have been mailed and returned to the investigator. If full consent was mailed to the patients, "the participation rate would undoubtedly be very low" for such a study. (Littenberg & MacLeaon, 2006, p. 210).

(4) Because no additional participation was required of the patients in this retrospective medical record review, this criterion did not apply.

When this proposal was originally drafted, it was not yet known if all patients would be six months post-liver transplant when the study began. It was not until the study received IRB approval from both IRB's that the medical records were reviewed for patient eligibility. Although 30 liver transplants occurred between January 1, 2015 and April, 13 2016, ten were not eligible (see table below).

Table 4

Study Non-Eligibility

Reason not study-eligible	Number of medical records not eligible for this reason
English is second language and Attachment Scale was not administered	3
Fulminant liver failure	2
Patient was previously transplanted	3
Patient was encephalopathic at time of psychosocial evaluation (due to liver disease); therefore patient did not have the orientation or mental capacity to complete the Attachment Scale	1
Chart was labeled "restricted."	1

Because eligibility of patient medical records was unknown at the time of the IRB proposal submissions, the IRB proposals stated that consent was to be obtained if patients were not yet six-months post-transplant at the time of both IRB approvals. Appendix A documents the consent form that was to be used if a patient was not yet six-months post-transplant. However, since a sample of 20 study eligible patients who were all at least six-months post-transplant prior to the dual IRB approval date (October 17, 2016),

consent was not required (since a waiver for consent and HIPAA has been obtained through both the ICSW and Drexel University IRB's).

Below is a step-by-step outline of the research process:

1. Once the research proposal was approved by the dissertation committee, data collection commenced. Beginning with records of patients transplanted in January 2015, the investigator logged and coded each of the 20 patient medical records who met the study eligible criteria to create a master list of records to be used in the study.
2. Data from the patient's medical record were extracted and recorded onto the Medical Record Review Data Collection Tool (see Appendix B).
3. The investigator first completed the 'Negative or Positive Outcomes Post-Transplant Measure', (See Appendix C) based on the information documented in the patient's medical record for a period of six months from the patient's transplant date. This is a five question tool; a positive answer to one or more of the questions results in a negative liver transplant surgery outcome (Maldonado et al, 2012). The data from this tool were recorded onto the Medical Record Review Data Collection Tool.
4. Next, the investigator accessed the patient's medical record and extracted data from the patient's psychosocial evaluation, including the Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) score and SIPAT category from the psychosocial evaluation that had already been completed as part of each

patient's evaluation for liver transplant (See Appendixes D and E). The data were entered onto the Medical Record Review Data Collection Tool.

5. The investigator then accessed the medical record and extracted the scores from the Adult Attachment Scale that had been administered as part of the pre-transplant psychosocial evaluation (See Appendixes F and G). The data were entered onto the Medical Record Review Data Collection Tool.
6. The researcher then extracted all the demographic and other data from the patient record with use of the Medical Record Review Data Collection Tool.
7. Once all the data were extracted, data analysis was conducted.
8. All pre and post-transplant data, as well as additional relevant data were entered into SPSS for further analysis.

The psychosocial evaluation (SIPAT) and Adult Attachment scale documents are kept in the patient's medical chart as they are documents completed as part of the evaluation for transplant evaluation. The psychosocial evaluation and Adult Attachment Scales are re-administered periodically as part re-evaluation for liver transplant. The most recent psychosocial evaluation data and Adult Attachment scale results will be utilized for the study.

Data Collection

Four separate measurement instruments were used as a source of data. The first, The Medical Record Review Data Collection Tool (see Appendix B) was developed to record data extracted from the medical record, including data from the other three

measurement instruments. The other three instruments were developed through previous research and not created by this study: The Negative or Positive Outcomes Post-Transplant Measure (Maldonado et al., 2012), The Stanford Integrated Psychosocial Assessment Tool (SIPAT) (Maldonado et al., 2012), and The Revised Adult Attachment Scale – Close Relationships Version (Collins & Read, 1990; Collins, 1996) are further explained below.

1. Medical Record Review Data Collection Tool.

The Medical Record Review Data Collection Tool (see Appendix B) was created and used to extract all data from the pre and post-transplant tools (further described below) as well as additional demographic and other information from the patient's chart.

2. Negative or positive outcomes post-transplant measure.

The investigator tracked liver transplant recipients' ability to cope and succeed post-transplant (this will be referred to as positive or negative outcomes) using criteria determined by Maldonado et al. (2012) when the SIPAT was developed and tested:

> Transplant coordinators and social workers were asked to rate in each case, whether the transplant had been successful (i.e., positive or negative outcomes) based on specific post-transplant psychosocial criteria including issues with adherence, stability of the psycho-social support system, recidivism of substances of abuse, or the development/relapse of psychiatric problems. A negative outcome

> was defined as meeting one or more of the following conditions: difficulty with treatment adherence, unstable psycho-social support system, substance abuse recidivism, the development of (or relapse) psychiatric problems, or graft failure. A positive outcome was defined by the absence of these complications (p.127).

As this tool was implemented in the creation of the SIPAT, its reliability is also supported under the explanation of the reliability of the SIPAT tool.

The investigator reviewed the medical chart and considered records for a six-month period post-transplant date. Each patient's post-transplant outcome was documented as 'positive' or 'negative' based on the criteria of 'Negative or Positive Outcomes Post-Transplant Tool' (see Appendix C). The rating was based on information recorded in patient medical records (i.e.: number of missed clinic appointments, lab results, social work notes, physician notes, nursing notes, phone calls, etc.). The data were entered onto the Medical Record Review Data Collection Tool.

3. The Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT).

Prior to actual transplant, during the evaluation phase, all patients participate in a psychosocial assessment conducted by a transplant social worker. The Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT) is a reliable psychosocial assessment tool that endorsed for use by the Society of Transplant Social Workers (Maldonado et al., 2012, www.transplantsocialworker.org, 2012). "The SIPAT instrument has excellent inter-rater reliability (Pearson's correlation coefficient 0.853)

even among novice raters" (Maldonado et al, 2012, p 128). To view this tool, see Appendices D and E.

At the transplant center where patients' charts were reviewed for this study, the SIPAT is administered during the psychosocial evaluation before each patient is placed on the liver transplant waiting list. All psychosocial evaluations are completed by the one liver transplant social worker in the transplant department. Access to data collected during evaluation by one social worker decreased the occurrence of skipped questions, misunderstood questions or answers such as "I don't know" (Rubin and Babbie, 2011).

The SIPAT places transplant patients into the following transplant candidate categories based on their scores: excellent, good, minimally acceptable, high risk, and poor. The researcher extracted the SIPAT scores and candidate categories from the transplanted patients' medical records.

Candidates with a SIPAT score in the poor category are typically not able to be listed for liver transplant. Patients in the high risk category may be listed with expectations that would, hopefully, continue to address their high risk status (i.e.: continue to abstain from alcohol, or be actively involved in mental health treatment) and assist in ability to cope with transplant. It is possible that a patient is able to improve a SIPAT score over time through making some positive life changes (i.e.: developing a longer period of abstinence from a substance through participation in a treatment program). In such an instance, a second additional psychosocial evaluation and attachment scale may be completed as part of the patient's re-evaluation. Even if a patient is listed for transplant, all patients are re-evaluated periodically as they await

transplant. For purposes of this study, the most recent SIPAT (as the most recent scores are the ones being considered by the transplant team to determine candidacy) scores and concurrent category will be extracted for analysis and recorded on the Medical Record Review Data Collection Tool.

4. Revised Adult Attachment Scale – Close relationships.

The Revised Adult Attachment Scale – Close Relationships Version (Collins & Read, 1990; Collins, 1996) is administered as part of the psychosocial evaluation for liver transplant patients (see Appendixes F and G.) along with the SIPAT. This scale, along with the SIPAT is placed in the patients' medical record after it is administered. The 18 question Adult Attachment Scale provides scores for the following adult attachment subscale measures: close, dependent, anxious, and avoidant. This scale originally contained three subscales, each composed of six items. The three subscales are "close", "depend", and "anxiety". The "close" scale measures the extent to which a person is comfortable with closeness and intimacy. The "depend" scale measures the extent to which a person feels able to depend on others to be available when needed. The "anxiety" subscale measures the extent to which a person is worried about being rejected or unloved (Collins, 1996). A fourth subscale, "avoid", composed of 12 items, was added when the scale was revised and it measures a person's tendency to reject or avoid assistance or support (Collins, 1996).

The scale was originally implemented with 406 subjects. To ensure reliability, a subset (N=101) of the original sample completed the scale a second time two months

later (test-retest reliability). "Overall, scores were fairly stable over a 2-month period." (Collins & Read, 1990, p 647). Collins (1996) revised the scale to improve reliability. The correlation between the revised scale and the original version was r = .98 (with a sample of N = 295).

Because learning about a patient's attachment may help the social worker and the transplant team better understand, intervene and care for a patient, the Revised Adult Attachment Scale – Close Relationships was added to psychosocial assessment protocol prior to this study. After the SIPAT psychosocial evaluation interview, the Adult Attachment Scale is given to the patient. The social worker explains to the patient that the attachment scale will be used to help the social worker and transplant team better understand his/her attachment style and areas where they may or may not feel as comfortable receiving help and relying on medical providers or personal support person(s). The social worker explains to the patient that this information may provide further insight that the social worker and transplant staff may use to provide support or interventions that can be more individualized to his/her needs.

After the social worker's explanation with regards to the use and purpose of the attachment scale, the social worker reads the instructions of the attachment scale aloud to the patient (the patient is able to read along as the instructions are on the copy of this scale given to the patient to complete). The patient then completes the 18 question scale. The social worker remains present to addresses any questions or clarity needed by the patient completing the scale. Because the attachment scale is completed after the SIPAT, the social worker is usually aware if the patient is unable to read the attachment scale

(due to literacy, visual impairment, etc.). In such cases, the social worker reads the questions aloud to the patient.

Plan for Data Analysis

The scores and data collected from the four instruments described above (Medical Record Review Data Collection Tool, The Negative or Positive Post Transplant Outcomes Scale, the SIPAT, and the Revised Adult Attachment Scale) were entered into an SPSS database for statistical analysis. Descriptive statistics such as mean, median, mode and standard deviation were calculated and analyzed for each attachment category as well as other data collected with the Medical Record Review Data Collection Tool. Frequencies of categorical data (such as SIPAT categories and demographic information collected in the Medical Record Review Data Collection Tool) were gathered for descriptive purposes. A measure of association was conducted to see of a relationship existed between the independent variable (attachment style scores) and the dependent variable (transplant outcomes measure).

Issues of Trustworthiness

Reliability of data abstraction from medical records can often be difficult to determine. (Worster & Haines, 2004). "However, researchers can measure and report the degree to which the results obtained from data abstraction by one observation were reproduced in subsequent observations of the same record" (Worster & Haines, 2004, p. 190-191). However, in this study, such measures were not necessary as the data

abstracted from the records utilized psychosocial assessment based on tools that were already deemed reliable through past research (Negative or Positive Outcomes Post-Transplant Measure, SIPAT, Adult Attachment Scale). In other words, although a medical record review (MRR) model was used, the data to be collected were already organized in the records using assessment tools that have a measurable score and an established reliability based on past research of the assessment tool.

"In prospective studies the variables are defined a priori and collected in an organized manner with quality assurance measure in place to ensure that the data are complete and accurate. This is generally not true of medical records. In fact, each individual medical record is composed of different interpretations of different scenarios, often by different observers" (Worster & Haines, 2004, p. 188). Worster and Haines state this not to discredit MRR, but to explain the importance of considering this as an obstacle. "The use of explicit criteria for abstracting variables results in higher inter and intraobserver reliability because it reduces subjectivity in interpretation" (Worster & Haines, p. 189). However, in this study, the pre-transplant documentation in the medical record was completed by one clinician (the liver transplant social worker) using standardized tools (SIPAT and Adult Attachment Scale). The use of one social worker in combination with standardized tools increased consistent quality of data that were extracted from the medical record. The post-transplant outcomes data were also determined by data extracted by specific criteria (as outlined in the "Data Collection Methods and Instruments" section above) by one researcher, the investigator. Again, the

use of only one researcher and a specific data collection criterion ensured quality of data extraction.

Ethical Considerations

Because an MRR is being utilized, patients were not subject to any questions or research methods that were not part of the evaluation process or pre/post-transplant care at the transplant center. Therefore, the study did not pose any additional psychological risks. To reduce risk in relation to patient privacy and confidentiality, the following steps were implemented. When data collection was complete, identifiable information such as personal names were removed from the SIPAT, Adult Attachment Scale, Negative or Positive Outcomes Post-Transplant Measurement Tool and the Medical Record Review Data Collection Tool. Instead, an identification number was assigned to each patient and a master list of patients' names and identification numbers was placed and stored in a locked desk drawer in a locked office. The identification number was not a birth date, social security number, or any other number that may identify a patient. Instead, a number such as 01, 02, 03, etc. was assigned. After data entry was completed, the master list was shredded. All electronic forms of data such as an electronic database were kept in a password protected file on a password protected computer.

Limitations

Because this pilot study only included patients at one transplant center, location is the major delimitation of this study and generalizability may be limited. It will also

measure all study-eligible transplants conducted at this once center for a certain period, making time a limitation of this study. The pilot study used a sample of 20 patients, so volume is the final limitation of this study.

The Role and Background of the Researcher

I am a novice, unpublished researcher. While earning an undergraduate degree in psychology, I earned 10 credits as a research assistant in the university's psychoacoustics lab. I also earned 10 credits as a teacher's assistant in research methods and psychological statistics.

I completed quantitative and qualitative research methods courses while earning my Master of Social Work degree in 2005. For my Master's level research project, I looked at the medication adherence rates for HIV positive youth who resided in a transitional living home. Since graduating with my master's degree in 2005, I have not been involved in any further research until I began this doctoral program at ICSW. At ICSW, I have completed the following research related coursework: Research Process, Research Design, Qualitative Methods, Quantitative Methods, Dissertation Seminar I, Dissertation Seminar II and Independent Studies I, II III and IV.

I currently am employed as the liver transplant social worker at the hospital where the study is being conducted. As, such, I have a professional investment in the outcomes of each transplant. For a transplant center to continue to function as a business, a certain number of transplants must be conducted with a certain measure of success of survival of the organ (one year post-transplant surgery). I wanted to conduct this study to better

understand if patients' attachment can contribute to post-transplant success both as a way to support a possible need for improved interventions for patients based on their attachment scores (thus leading to improved post-transplant outcomes) and as a way to help ensure successful outcomes for the success of our transplant program.

Another role of the transplant social worker (as well as all transplant professionals) is to be a good steward of organs. My hope was that the results of this study can help me as well as my interdisciplinary transplant team, make the best decisions regarding organ allocation.

Summary

A quantitative retrospective pilot study looking at adult attachment and post-transplant surgery outcomes was conducted using a secondary data analysis method grounded in a postpositivist paradigm. The study was conducted at one transplant center. A secondary analysis was conducted through a retrospective medical record review using a convenience sample of 20 that included all study-eligible patients who received liver transplants between January 1, 2015 and April 16, 2016. A measure of association was conducted to see of a relationship exists between the independent variable (attachment style) and the dependent variable (transplant outcomes).

Chapter IV

Results

Introduction

The data were analyzed to address the proposed research questions:

Research Question 1: Is there a relationship between Attachment Scale scores and liver transplant outcomes?

Research Question 2: Is there a relationship between the Standard Integrated Psychosocial Assessment for Transplant (SIPAT) score and Attachment Scale scores?

T-tests, Pearson's r correlation and descriptive data results were analyzed. As an exploratory study with a small sample size of 20, it is unsurprising that the analysis did not reveal any statistical significance, but the results suggest some possible trends in relationships that would be interesting to explore further in the future with a larger sample size.

Attachment Scale Descriptive Statistics

The Revised Adult Attachment Scale (Collins, 1990; Collins 1996) is an 18 question scale that provides scores for the following adult attachment subscales: close, dependent, anxious, and avoidant. The "close" subscale measures the extent to which a person is comfortable with closeness and intimacy. The "depend" subscale measures the

extent to which a person feels able to depend on others to be available when needed. The "anxious" subscale measures the extent to which a person is worried about being rejected or unloved (Collins, 1996). The fourth subscale, "avoid" was added when the scale was revised by Collins in 1996. The "avoid" subscale measures a person's tendency to avoid or reject assistance or support (Collins, 1996).

The first three subscales (Close, Depend and Anxious) were developed when the scale was initially created and tested by Collins (1990). Each of these original subscales have six questions with a range of 1-5 (1=not characteristic of me, 5=very characteristic of me) that are scored for each category. For these categories, the maximum score is 30 and the minimum is six.

The "Avoidant" subscale was added when Collins (1996) revised the scale in 1996. This subscale is based on 12 questions (with the same 1-5 range); therefore, for this category, the maximum score is 60 and the minimum score is 12.

To assist with ease of interpretation and analysis, the average (or mean) score for each subscale was computed and analyzed rather than using the sum of the score. For example, rather than reporting a "Close" subscale score of "24," the average score (24 divided by 6=4) was used. This way, it can be more easily compared to the question range of 1-5. For example, an average of four on the subscale would indicate that this category is "more characteristic" of the patient with that average score. Also, because the "avoid" subscale is based on 12 rather than six questions, the average makes the various subset scores more easily comparable. Table 5 shows the descriptive statistics for the attachment subscales.

The higher the attachment scale subscale score, the higher the tendency for that subscale trait. As such, a higher score in the “close” and “depend” subscales are secure attachment indicators, as they suggest that the patient is better able to be close with others or feel comfortable depending on others. A lower score on the “close” or “depend” would indicate more of an insecure attachment. Conversely, higher scores on the “Anxious” or “Avoid” subscales are more descriptive of insecure attachment as they suggest a higher level of anxious or avoidant attachment. Thus, a lower score on these subscales would indicate more secure attachment.

Table 5

Attachment Scales Descriptive Statistics

		Close - Attachment Scale Score	Depend - Attachment Scale Score	Anxious - Attachment Scale Score	Avoid - Attachment Scale Score
N	Valid	20	20	20	20
	Missing	0	0	0	0
Mean		4.13298	3.59148	1.55832	2.12083
Std. Error of Mean		.113961	.129351	.127548	.106010
Median		4.08333	3.58330	1.41665	2.12500
Range		1.840	2.500	1.667	1.833

On average, the mean scores fell in ranges of secure attachment. The “close” mean (4.13) indicates that it is characteristic of the patients to feel comfortable being close with others and feeling securely attached. The “depend” mean (3.59) indicates that it is characteristic of the patients to feel comfortable depending on those close to them when needed and feel more securely attached. It is of interest to note that the range of 2.5 in the “depend” subscale shows much more dispersion than that of the other subscales;

with a larger sample this would warrant further exploration to see if this trend continued and to further explore why this might occur. The "anxious" mean (1.56) indicates that patients do not seem to have an anxious attachment or worries about feeling rejected or unloved. The "avoid" mean score (2.12) indicates that patients may not have a tendency to have an avoidant insecure attachment or a tendency to avoid or reject assistance or support. So, the mean scores were all in the desired direction when considering secure attachment as positive attribute for transplant selection.

Overall, it appears that patients who were selected for transplant and transplanted in the time range of this study tended to have a secure attachment. This means that the patients approved for transplant tended to score in a secure attachment range based on the Adult Attachment Scale scores.

Although not covered by the scope of this study, it would be interesting to see if a relationship occurs between patients who were declined for psychosocial contraindications and the attachment score. Perhaps a cohort of patients who did not meet psychosocial criteria for liver transplant had attachment scale scores more indicative of insecure attachment. This would make for a useful follow-up study.

Attachment Scales and Positive/Negative Outcomes

Based on the original study done to validate the SIPAT, one or more occurrences of a negative outcome category post-transplant indicate a negative transplant outcome (because these categories have been shown to be risk factors for graft failure, death and

poor quality of life post-transplant (Maldonado et al., 2012). The negative outcome categories are:

1. Difficulty with treatment adherence,
2. unstable psychosocial support,
3. substance abuse recidivism,
4. development or relapse of psychiatric problems, and
5. graft failure.

Nine of the 20 patients sampled had a "poor outcome," putting them at higher risk for graft failure, death or poor quality of life. Four of the nine had difficulty with treatment adherence post-transplant, four patients had unstable psychosocial support post-transplant, one patient had substance abuse recidivism post-transplant and six patients had a development or relapse of psychiatric problems post-transplant. None experienced graft failure.

Table 6

Frequency of Positive or Negative Outcomes

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Negative Outcome	9	45.0	45.0	45.0
	Positive Outcome	11	55.0	55.0	100.0
	Total	20	100.0	100.0	

Table 7

Frequency of Negative Outcomes By Category

Negative Outcome Category	Frequency
Difficulty With Treatment Adherence	4 patients
Unstable Psychosocial Support	4 patients
Substance Abuse Recidivism	1 patient
Development or Relapse of Psychiatric Problems	6 patients
Graft Failure	0 patients

Relationships between Attachment Subscale Scores and Positive/Negative Outcomes

Using SPSS, an independent samples t-test was done for each of the four Attachment Scales subscales (close, depend, anxious and avoid) in relation to negative or positive post-transplant outcome.

Table 8

Relationship Between Attachment Subscale Scores and Outcomes

	t	Sig.
Close - Attachment Scale Score	-.458	n.s.
Depend - Attachment Scale Score	-.245	n.s.
Anxious - Attachment Scale Score	.895	n.s.
Avoid - Attachment Scale Score	.539	n.s.

According to the t-test, no significant statistical difference is supported. To further contemplate what the results may indicate, a look at the actual means is of interest.

Table 9

Means of Attachment Subscale Scores and Outcomes

	Positive or Negative Outcomes	N	Mean	Std. Deviation	Std. Error Mean
Close - Attachment Scale Score	Negative Outcome	9	4.07407	.595777	.198592
	Positive Outcome	11	4.18118	.451521	.136139
Depend - Attachment Scale Score	Negative Outcome	9	3.55553	.807927	.269309
	Positive Outcome	11	3.62089	.333905	.100676
Anxious - Attachment Scale Score	Negative Outcome	9	1.68518	.668976	.222992
	Positive Outcome	11	1.45454	.483573	.145803
Avoid - Attachment Scale Score	Negative Outcome	9	2.18518	.651889	.217296
	Positive Outcome	11	2.06818	.283380	.085442

Although, according to the t-test, no significant statistical difference is supported, it is of interest to note that in all four attachment subscales (close, depend, anxious and avoid), the positive outcomes group each had a mean score that was slightly more secure than the negative outcomes group.

Attachment Subscale Scores and Negative Outcomes Categories

Next, using SPSS, an Independent Samples t-test was done for each of the four Attachment Scales subscales (close, depend, anxious and avoid) in relation to each negative post-transplant outcome category.

Attachment Subscale Scores and Adherence

A t-test was conducted to look at the significance when comparing the means.

Table 10
Attachment Subscale Scores and Adherence

	t	Sig.
Close - Attachment Scale Score	-.144	n.s.
Depend - Attachment Scale Score	-.126	n.s.
Anxious - Attachment Scale Score	-.911	n.s.
Avoid - Attachment Scale Score	.077	n.s.

The t-test results do not support a statistical significance, so a closer look was taken at the means of the outcomes.

Table 11

Attachment Subscale Score Means and Adherence Outcomes

	Difficulty With Treatment Adherence	N	Mean	Std. Deviation	Std. Error Mean
Close - Attachment Scale Score	No	16	4.12456	.493396	.123349
	Yes	4	4.16666	.652643	.326322
Depend - Attachment Scale Score	No	16	3.58310	.554347	.138587
	Yes	4	3.62498	.762216	.381108
Anxious - Attachment Scale Score	No	16	1.49999	.547726	.136931
	Yes	4	1.79166	.685495	.342747
Avoid - Attachment Scale Score	No	16	2.12500	.435678	.108919
	Yes	4	2.10417	.688444	.344222

Although not statistically significant, it is interesting to note that the four patients who had a negative outcome in the adherence category had a mean subscale scores that was slightly more secure in close, depend, and avoid subscales and slightly more insecure in the anxious subscale.

Attachment Subscale Scores and Support

A t-test was conducted to look at the significance when comparing the means.

Table 12

Attachment Subscale Scores and Support

	t	Sig.
Close - Attachment Scale Score	1.141	n.s.
Depend - Attachment Scale Score	1.170	n.s.
Anxious - Attachment Scale Score	-1.083	n.s.
Avoid - Attachment Scale Score	-1.434	n.s.

Again, t-test results do not support a statistical significance, so a closer look was taken at the means of the outcomes.

Table 13

Attachment Subscale Score Means and Support Outcomes

	Unstable Psycho-Social Support System	N	Mean	Std. Deviation	Std. Error Mean
Close - Attachment Scale Score	No	16	4.19747	.510867	.127717
	Yes	4	3.87499	.478726	.239363
Depend - Attachment Scale Score	No	16	3.66644	.557706	.139427
	Yes	4	3.29163	.643677	.321839
Anxious - Attachment Scale Score	No	16	1.48957	.539098	.134775
	Yes	4	1.83333	.693887	.346943
Avoid - Attachment Scale Score	No	16	2.04687	.474311	.118578
	Yes	4	2.41667	.390865	.195433

Although not statistically significant, it is of interest to note that the four patients who had a negative outcome in the support category had a mean subscale scores that were more insecure for all four attachment subscales.

Attachment Subscale Scores and Substance Abuse

A t-test was conducted to look at the significance when comparing the means.

Table 14

Attachment Subscale Scores and Substance Abuse

	t	Sig.
Close - Attachment Scale Score	.593	n.s.
Depend - Attachment Scale Score	-.130	n.s.
Anxious - Attachment Scale Score	-.786	n.s.
Avoid - Attachment Scale Score	-.273	n.s.

Again, the t-test results do not support a statistical significance, so a closer look was taken at the means of the outcomes.

Table 15

Attachment Subscale Score Means and Substance Abuse Outcomes

	Substance Abuse Recidivism	N	Mean	Std. Deviation	Std. Error Mean
Close - Attachment Scale Score	No	19	4.14875	.518576	.118970
	Yes	1	3.83333	.	.
Depend - Attachment Scale Score	No	19	3.58752	.594049	.136284
	Yes	1	3.66660	.	.
Anxious - Attachment Scale Score	No	19	1.53508	.576225	.132195
	Yes	1	2.00000	.	.
Avoid - Attachment Scale Score	No	19	2.11403	.486079	.111514
	Yes	1	2.25000	.	.

The one patient who had a negative outcome in the substance abuse category had a mean subscale score that was more secure on the dependent subscale and less secure on the close, anxious and avoidant subscale. Because this is only one patient, this does not have any meaning in this context.

Attachment and Development or Return of Psychiatric Problems

A t-test was conducted to look at the significance when comparing the means.

Table 16

Attachment Subscale Scores and Psychiatric Problems

	t	Sig.
Close - Attachment Scale Score	-1.161	n.s.
Depend - Attachment Scale Score	-.372	n.s.
Anxious - Attachment Scale Score	1.166	n.s.
Avoid - Attachment Scale Score	.737	n.s.

Again, the t-test results do not support a statistical significance, so a closer look was taken at the means of the outcomes.

Table 17

Attachment Subscale Score Means and Psychiatric Problems Outcomes

	Development or Relapse of Psychiatric Problems	N	Mean	Std. Deviation	Std. Error Mean
Close - Attachment Scale Score	No	14	4.04711	.500591	.133789
	Yes	6	4.33333	.516398	.210819
Depend - Attachment Scale Score	No	14	3.55926	.361483	.096610
	Yes	6	3.66664	.960303	.392042
Anxious - Attachment Scale Score	No	14	1.65475	.611378	.163398
	Yes	6	1.33333	.421636	.172132
Avoid - Attachment Scale Score	No	14	2.17262	.349702	.093462
	Yes	6	2.00000	.714919	.291864

The six patients who had a negative outcome in the “development or relapse of psychiatric problems” category had a mean subscale score that was slightly more secure in all four attachment categories.

Relationship Between SIPAT and Attachment Subscales

Consistent with other results, a t-test did not show a significance of a relationship between SIPAT categories and Attachment Subscales. However, comparison of the means did show that that candidates whose SIPAT scores fell in the "excellent" and "good" candidate categories had a mean score on the "close" and "depend" subscales that were slightly above the mean of the "minimally acceptable" candidates. Additionally, comparison of the means also showed that that candidates whose SIPAT scores fell in the "excellent" and "good" candidate categories had a mean score on the "anxious" and "avoid" subscale that were slightly below the mean for the "minimally acceptable" candidates. Therefore, the "good" and "excellent" mean scores were slightly more consistent with secure attachment than the "minimally acceptable" category on all four attachment subscales. The one patient who fell into the "high risk" category scored as more secure than all other SIPAT categories in all four subscales. Because that sample size is one, this is most likely an outlier.

Table 18

Relationship Between SIPAT Categories and Attachment Subscales

SIPAT Category		Close - Attachment Scale Score	Depend - Attachment Scale Score	Anxious - Attachment Scale Score	Avoid - Attachment Scale Score
Excellent Candidate (0-6)	Mean	4.16500	3.66581	1.66667	2.00000
	N	4	4	4	4
	Std. Deviation	.723168	.332809	.707108	.360044
Good Candidate (7-20)	Mean	4.14285	3.64285	1.38093	2.10714
	N	7	7	7	7
	Std. Deviation	.279355	.310759	.356348	.253287
Minimally Acceptable Candidate (21-39)	Mean	4.02078	3.37497	1.72916	2.30208
	N	8	8	8	8
	Std. Deviation	.573457	.744011	.666295	.587462
High Risk Candidate (40-68)	Mean	4.83333	4.66660	1.00000	1.25000
	N	1	1	1	1
	Std. Deviation	.	.	.	.
Total	Mean	4.13298	3.59148	1.55832	2.12083
	N	20	20	20	20
	Std. Deviation	.509649	.578475	.570410	.474091

Outcomes and SIPAT

Results confirmed the validity of the SIPAT as a good predictor of transplant success and a useful screening device. In terms of SIPAT scores, the lowest score is more optimal; the lower the SIPAT score, the more likely a patient is predicted to have a positive transplant outcome. Overall, the mean SIPAT score for the patients who fell into

the “positive outcomes group” was lower than the mean scores of the “negative outcome” group. The mean for the “positive outcomes” group was 12.09, which fell in the SIPAT category range of “good candidate” (score of 7-20). The mean of the “negative outcomes” group was 25.56; a mean score that feel into the range of “minimally acceptable” category (score of 21-39). Results from this tool appear to confirm that our transplant center is doing a good job in collecting data from psychosocial evaluations that are consistent with what the SIPAT predicts.

Table 19

Means of SIPAT Scores by Positive or Negative Outcome

	Positive or Negative Outcomes	N	Mean	Std. Deviation	Std. Error Mean
SIPAT Score	Negative Outcome	9	25.56	9.580	3.193
	Positive Outcome	11	12.09	7.765	2.341

To analyze relationship between SIPAT categories and outcomes, categories were combined from five to two categories. Since no transplanted patients fell into the “poor candidate” category, that category was eliminated from the analysis. The four remaining categories were condensed into two categories: (1) *Excellent/Good Candidate* and (2) *Minimally Acceptable/High Risk Candidate*. Of the 11 patients in the *Excellent/Good Candidate* category, only one had a poor outcome. Of the nine patients in the *Minimally Acceptable/High Risk* category, eight had poor outcomes.

Table 20

SIPAT Category and Positive or Negative Outcomes

		Negative Outcome	Positive Outcome	
SIPAT Category	Minimally Acceptable/High Risk	8	1	9
	Excellent/Good	1	10	11
Total		9	11	20

Relationship Between Alcoholic Hepatitis and Attachment Subscale Scores

Although results are not statistically significant with use of a t-test, patients with a significant alcohol history that impacted liver function (N=12) had a more insecure subscale mean in all four attachment subscale categories. There were no such patterns with the other diagnoses that led to the patient's listing for liver transplant (Hepatitis C, NASH, liver cancer, primary biliary cirrhosis or polycystic liver disease).

Table 21
Relationship Between Alcoholic Hepatitis and Attachment Subscale Scores

	t	Sig.
Close - Attachment Scale Score	1.840	n.s.
Depend - Attachment Scale Score	.332	n.s.
Anxious - Attachment Scale Score	-1.043	n.s.
Avoid - Attachment Scale Score	-1.361	n.s.

Table 22
Alcoholic Hepatitis and Means of Attachment Subscale Scores

	Alcohol Diagnosis	N	Mean	Std. Deviation	Std. Error Mean
Close - Attachment Scale Score	No	8	4.37499	.305375	.107966
	Yes	12	3.97163	.564186	.162866
Depend - Attachment Scale Score	No	8	3.64540	.273369	.096651
	Yes	12	3.55552	.725894	.209548
Anxious - Attachment Scale Score	No	8	1.39582	.387683	.137067
	Yes	12	1.66666	.659047	.190250
Avoid - Attachment Scale Score	No	8	1.94791	.208633	.073763
	Yes	12	2.23611	.569459	.164389

Correlations Between SIPAT Scores and Attachment Subscale Scores

No pattern of correlation is present between the SIPAT score and any of the attachment subscales. The lack of correlation indicates that there are no significant relationships between the scores

Table 23

Correlations Between SIPAT Scores and Attachment Subscale Scores

		SIPAT Score
Close - Attachment Scale Score	Pearson Correlation	.010
	Sig. (2-tailed)	.968
	N	20

		SIPAT Score
Depend - Attachment Scale Score	Pearson Correlation	-.070
	Sig. (2-tailed)	.768
	N	20

		SIPAT Score
Anxious - Attachment Scale Score	Pearson Correlation	-.149
	Sig. (2-tailed)	.531
	N	20

		SIPAT Score
Avoid - Attachment Scale Score	Pearson Correlation	.090
	Sig. (2-tailed)	.706
	N	20

Longevity of Negative Post-Transplant Outcomes

When looking at the length of time that the nine patients struggled with post-transplant categories, longevity ranged from a three week period to a 12 week period (about three months). Three patients struggled for duration of nine to 12 weeks. Two patients struggled for duration of five to eight weeks. Four patients struggled for duration of three to four weeks post-transplant. After a 12 week post-transplant period,

all nine patients no longer experienced ongoing struggle in the negative outcome categories.

Length of Stay in Hospital Post-Liver Transplant

The average post liver transplant hospital stay is 10-12 days (http://www.hopkinsmedicine.org/transplant/programs/liver, 2017). The average length of stay for patients in this current study was 19.55 days, with a median of 13.50 and a range of 52.

Table 24

Length of Hospital Stay Post-Transplant (Days)

N	Valid	20
	Missing	0
Mean		19.55
Median		13.50
Mode		9
Std. Deviation		15.810
Range		52

When looking at the length of stay for the nine patients in this study with a negative outcome, the mean was 28.11, the median was 24 and the range was seven to 58 days (for a range of 51). Three patients (33%) had a stay of 12 days or less (at or below the average length of stay reported by John Hopkins Medical Center (http://www.hopkinsmedicine.org/transplant/programs/liver, 2017). Three patients (33%)

had a length of stay between 13-30 days. Three patients (33%) had a prolonged length of stay of 30 days or more.

When looking at the length of stay of stay for the 11 patients with positive outcomes, the mean was 12.54, the median was nine and the range was from six to 28 days (for a range of 22). Seven patients (64%) had a length of stay of 12 days or less (at or below the average length of stay reported by John Hopkins Medical Center (http://www.hopkinsmedicine.org/transplant/programs/liver, 2017). Four patients (36%) had a length of stay of 13-30 days and no patients had a prolonged length of stay (over 31 days).

Conclusion

Overall, patients included in this study had Attachment Scale scores that were consistent with secure attachment. This suggests that the transplant center is selecting patients for transplantation listing that tended to report a more secure attachment. Therefore, it is possible that there is a relationship between Attachment Scale and SIPAT scores. It is also possible that the attachment scores measure psychosocial factors that are not completely measured by the SIPAT scores.

Although not created for this purpose, it seems the SIPAT scores may be predictive of a secure attachment. Although not covered by the scope of this study, it would be interesting to see if a relationship occurs between patients who were declined for psychosocial contraindications and the attachment score to see if patients declined due to psychosocial contraindications differ in attachment scores from listed patients.

Based on the limited sample size and data available for analysis, there is no definitive relationship between transplant outcomes and attachment scale scores. Although the study did not yield statistically significant results, certain trends were seen and would merit further attention in future research:

1. Patients in the positive outcome group had mean subscale scores that were slightly more secure than those of the negative outcome groups.
2. Patients who had a negative outcome in the "adherence" category had mean subscale scores that were slightly more secure in close, depend, and avoid subscales and slightly more insecure in the anxious subscale.
3. Patients who had a negative outcome in the "support" category had mean subscale scores that were slightly more insecure for all four attachment subscales.
4. Patients who had a negative outcome in the "development or relapse of psychiatric problems" category had mean subscale scores that were slightly more secure in all four attachment subscales.
5. Patients with the "good" and "excellent" SIPAT scores had attachment scores consistent with more secure attachment than the "minimally acceptable" category on the four attachment subscales.
6. The mean SIPAT scores for the patients who fell into the "positive outcomes group" was lower (indicating better candidacy) than the mean scores of the "negative outcome" group.

7. Patients with a significant alcohol history that impacted liver function had a more insecure subscale mean in all four Attachment subscale categories as compared to other diagnoses.
8. Length of stay was shorter, and occurrences of prolonged length of stay (PLOS) were less for patients without negative outcomes post-transplant.

Chapter V

Discussion

Introduction

One of the primary goals of this study was to see if there was any relationship between liver patients' attachment style and their recovery post-transplant. The results suggested that patients who met criteria for a *negative outcome* post liver transplant did not have attachment scale scores that differed significantly from patients who met criteria for a *positive outcome* post liver transplant. More specifically, according to the results of the attachment scale/subscales, patients all seemed to report secure attachment overall.

The results support three findings:

1. All patients included in the study had secure attachment based on their scores.
2. Based on the brevity of post-transplant negative outcomes (including length of stay, adherence, and psychiatric symptoms), patients transplanted in 2015-2016 (who qualified for this study), fared better overall after transplant than the patients transplanted in 2013-2014.
3. Negative outcome markers experienced post-transplant by the patients in this study were relatively short-lived and manageable and did not have a long-term negative impact on the patient's health and recovery.

Discussion will focus on how attachment theory is relevant to the explanation of these findings.

Another goal of this study was to examine the SIPAT and attachment scale measures for any relationships. These tools measure different dimensions. All of the mean attachment scale scores of the sample show the desired direction, which is a positive indication that attachment scores may well be a useful indicator. In other words, there were no patients selected for transplant listing that had an overall insecure attachment based on the attachment scale. This suggests that, although SIPAT was not designed to measure adult attachment, the data variables collected by the SIPAT can possibly be predictive of a level of secure adult attachment scores. With a larger sample size, it is possible that more variance in attachment scores and SIPAT results may exist and this would be worthwhile for further study. It would also be useful to see if there occurs a difference in attachment scores between patients who were listed for transplant and patients who were declined for psychosocial reasons. It is possible that patients who were declined had attachment scores that were insecure in contrast to the patients who "passed" psychosocial evaluation. However, this was beyond the scope of this study.

Longevity of Post-Transplant Outcomes and Attachment

Given the results, it makes sense to look more closely at the *negative/positive outcomes* post-transplant. Recall that interest in this study was sparked by unexpected negative post-transplant occurrences in 2013-2014 where 10% of patients transplanted at our center struggled with medical adherence and the ability to receive help from support

persons or the medical team for a duration of six months or more. In addition, 5% of this cohort had more severe challenges, as these transplant recipients greatly struggled to follow recommendations of the medical providers/transplant team (such as eating meals/necessary nutrition, participating in physical therapy and complying with medication). This resulted in atypical, prolonged post-transplant hospitalizations that lasted more than six months as well as significant psychiatric symptoms that lasted more than six months (without a prior significant history of psychiatric symptoms). Patients in this cohort in 2013-2014 experienced a poor quality of life during these prolonged hospital stays. Unfortunately, these patients participated in psychosocial evaluations prior to the time when the Attachment Scale was incorporated to compliment the use of the SIPAT. This pilot study was designed, in part, to look at the attachment scores of struggling post-transplant patients when such unexpected outcomes occurred.

Results from this study showed that nine of the 20 patients (45%) included in this study (transplanted between January 2015 and May 2016) fell into the negative outcomes category post-transplant. However, it is important to recall that to qualify for the negative outcomes category, patients needed to have a period where they struggled in at least one of the five categories:

(1) difficulty with treatment adherence,

(2) unstable psychosocial support,

(3) substance abuse recidivism,

(4) development or relapse of psychiatric problems, or

(5) graft failure.

It is pertinent to highlight that, when struggles did occur post-transplant with patients included in this study, they did not last the duration of six months (or longer) as was seen in 2013-2014. Instead, the range of the duration of the problem lasted from three weeks to 12 weeks (3 months).

Smith, Shiffman, Behnke, Stravitz, Luketic, Sanyal, Heuman, Fisher, Cotterall, Maluf, Posner and Sterling (2009) label a hospitalization of more than 30 days post liver transplant as a prolonged length of stay (PLOS). In their study of 521 transplant recipients, 13% had a PLOS with a median duration of 50 days verses 10 days for patients discharged within 30 days. In the current study, three of the 20 patients included in this study had a PLOS (these three patients all happen to fall into the negative outcomes category post-transplant) and no patients had a hospital stay of longer than 58 days (< 2 months).

Based on the brevity of post-transplant negative outcomes (including length of stay, adherence, and psychiatric symptoms), the major finding of this study is that patients transplanted in 2015-2016 (who qualified for this study), overall, fared better after transplant than the patients transplanted in 2013-2014. This may be coincidence, as the sample size in the current study and in 2013-2014 were both small (N=20). The absence of attachment scales for most patients transplanted in 2013-2014 makes a comparison of the two cohorts impossible in terms of the factor of attachment scale scores. However, it is still worthwhile to consider attachment as a possible factor for this discrepancy.

This study found that the psychiatric symptoms experienced and the non-adherence that occurred post-transplant were relatively short-lived and manageable; although not ideal, the psychiatric symptoms and non-adherence did not have a long-term negative impact on the patient's health and recovery.

In addition to concerns of graft loss, medical non-adherent patients are often labeled high-risk and they require more attention, care and guidance (Bunzle & Laeferach-Hoffman, 2000). Although some non-adherence was noted with patients in this study, the range (as reported above) was brief (a maximum of 12 weeks). Time spent on outpatient visits and the number of outpatient interactions by the physicians, nurses or social worker was not significantly higher. This is atypical because patient struggle usually results in more time spent on patient interventions. In this study, while non-adherence did occur, interventions were successful (i.e., there were no graft failures) and the non-adherence occurred at a shorter duration.

In contrast to post-discharge outpatient visits, there was a notable difference in length of hospital stay post-transplant between patients who had a negative outcome and patients who did not. In other words, patients with negative outcomes did require more resources during longer hospital stays post-transplant, which required more ongoing services during their length of stay. However, the, the longest length of stay for patients in this study was 58 days as compared to 2013-2014 cohort, who had patients with hospitalizations of greater than six months. Therefore, overall, fewer resources were drained in the current study as compared to 2013-2014.

This raises the question as to why patients in the time period of the study may have fared better post-transplant than the patients in 2013-2014. What is known is that all the patients involved in this study reported secure attachment overall during pre-transplant evaluation. The trend that we may be seeing is that, perhaps, because the patients had secure attachments overall, it is possible that they were able to recover or recuperate from any negative outcome in a shorter period of time. Also of note, none of the patients lost their graft, which further illustrates this concept.

Attachment Theory and Outcomes

Transplant surgery recovery is a major life disruption, even though it eventually can lead to improved health, improved quality of life and improved mood. Recovery often involves feelings of vulnerability, being faced with mortality, a reliance on loved ones, a reliance on transplant medical providers, coping with the unknown, not to mention physical pain and discomfort. It is in these times that attachment may feel less secure for a time. However, the fact that patients were able to respond to interventions and persist past the negative outcome indicators after a relatively brief period may speak to the patients' overall secure attachment.

Secure attachment lends to a sense of security that allows people to cope with problems and adapt to unfamiliar situations. Secure attachment leads to greater self-esteem, emotional health, ego resilience, positive affect, initiative and social competence (Mooney, 2010; Wallin 2007). These factors may have influenced the patients' ability to cope and be successful post-transplant. A post-transplant patient must have the ability to

adapt to unfamiliar situations. Perhaps some of the short-term depression, non-adherence, or substance relapse was part of the adaptation or adjustment to the new, post-transplant circumstance. The fact that all instances were short-term is more indicative of secure attachment, for struggle is a normal human condition, but to overcome and adapt to the struggle often requires a secure attachment and a strong sense of self.

One's attachment style is not necessarily a constant but exists on a continuum. People can have different kinds of attachments to different people at different times and a primary attachment style with elements of others. Disruptions of feelings of safety and stability can impact a human's attachment to another in a given period of time. "As Bowlby mentions, experiences of attachment and/or its disruption are prone to evoke the most intense of feelings. Thus, our representations of ourselves, of others, and of relationships do not merely have a powerful emotional component; they are in most cases *dominated*, outside awareness, by emotions that underpin them" (Wallin, 2007, p65-66). If transplant surgery is understood as a disruption that impacts secure feelings of safety and stability, we can better understand that difficulties faced by patients post-transplant may manifest in one of the negative outcome categories. Consider the following statement:

> It is largely the unconscious emotional dimension of our inner representations that renders them resistant to revision. If, for example, we learned through our formative interactions that being close to others was risky, then defenses will have been instituted to keep us unaware of our need for closeness; we simply won't be motivated to make the bids for closeness that, if successful, might update our old

> (avoidant) model of attachment to a more secure one. Likewise, because emotions have bodily signals to others as well as to our selves, the expectation that our overtures will be rejected may well result in feelings of fear or anger, the unconscious bodily expression of which provokes the very rejection our working model has led us to expect. As both Bowlby and Main emphasize, working models—especially insecure ones—tend to have a self-perpetuating quality. (Wallin, p 66).

It is possible that vulnerability of health and psyche post-transplant impacted the outcomes in an unconscious manner, resulting in a temporary period of avoidant and/or anxious attachment that manifested through one (or more) of the five negative outcome categories. It is also possible that patients were able to recuperate because of overall secure attachment. This may, at least in part, account for the greater length of hospital stay post-transplant for patients who experienced negative outcomes and the event that even these patients experienced a departure in the negative post-transplant measures by a maximum of 12 weeks.

Alternatively, this quote may instead support the notion that some patients who reported secure attachment pre-transplant struggled post-transplant when defenses were triggered. It may be that improvement in *negative outcome* categories was more a result of the typical recovery from transplant accompanied by reduced vulnerability rather than constant secure attachment. In other words, as the pain subsided, and transplant recovery felt less overwhelming, a patient might have returned to a more secure state of attachment. John Hopkins Medical Center's website states, "The average post liver

transplant hospital stay is 10-12 days, with two of those days spent in the intensive care unit. It may be up to three months before patients feel normal" (www.hopkinsmedicine.org/transplant/programs/liver/#surgery, 2017). Patients in this study all had negative outcome struggles subside within a three month period, right around the longer duration of time where John Hopkins Medical Center expect a patient to feel "normal." Perhaps once a patient is in the typical timeframe where "feeling normal" occurs, a patient may be more able to return to feeling more securely attached.

Earned-Security versus Continuous Security

The concept of earned-security versus continuous-security must also be considered here. Based in the Adult Attachment Interview scoring system created by Main and Goldwyn, a differentiation between earned and continuous-security was established (Pearson, Cohn, Cowan & Cowan, 1994). Earned-security is a term used to depict adults who describe difficult early relationships with parents, but have developed secure working models in their adult life despite childhood experiences that may lend to less secure attachment. Continuous security is a secure attachment that has its roots in the preverbal child/caregiver relationships (Pearson et al., 1994). In the study by Pearson et al. (1994), results showed that adults with earned-secure attachment had comparable depressive symptomology to adults with insecure attachment when confronted with a life disruption. This suggests that with earned-secure attachment, reconstructions of past-difficulties may remain emotional liabilities despite a secure working model. While earned verses continuous security in an attachment theory concept that was beyond the

scope of this study, it is useful to consider that this may have impacted patient outcomes. It may be conjectured that patients who reported secure attachment, but still struggled post-transplant, may have a history more consistent with earned-security.

Alcoholic Hepatitis and Attachment

Liver transplant recipients are known to involve a population of people with history of alcohol and substance abuse disorders. Patients with substance abuse disorders are known to have less secure adult attachment styles that non-substance users (Descutner & Thelen, 1991). Perhaps the transplant recipients with substance use histories may fall more into the earned-security category and this may impact them more significantly and lend to more struggle post-transplant then there continuously secure counterparts. This may also be connected to the findings as to why the patients in this study who had alcohol histories that resulted in need for transplant tended to have scores in all four subscales that were less secure than other causes of liver failure (fatty liver, hepatitis C, liver cancer, primary biliary cirrhosis, or polycystic liver disease).

Attachment to the Transplanted Liver

Castelnuovo-Tedesco (1978) explains that most surgeries remove something "bad" or potentially deadly from the body (i.e., cancerous cells, or removal of an injured or diseased body part). A transplant may remove an organ but a major difference between general surgery and transplant surgery is the addition of a new object. Castelnuovo-Tedesco (1973) states that "the frequency of postoperative psychosis or

major emotional disturbance is considerably greater after organ transplantation than after general surgery" (p. 381). He proposes that it is the adjustment to a new body part that may cause a disturbance in the individual. But what if the concept of "adjustment" is expanded to the notion of attachment?

It is of interest to consider post-liver transplant not simply as a period where a person must adapt to coping with surgery, – i.e., intense pain, the new burden of a medical care regimen, the possible overwhelming feeling that they owe healthy success to the deceased donor/family, and conflict over guilt and indebtedness that is often present (Basch, 1973) – but also as a period where a patient must develop a secure attachment with the transplanted liver. "Despite forces promoting stability, change in working models does occur, particularly when significant events in the social environment disconfirm expectations . . . a secure person who is involved in a particularly negative relationship may become insecure as a result of that experience" (Feeney, 2008, p 465). Once a transplant occurs, it is important to consider the relationship with the new organ and how one may feel a secure or insecure attachment to a new organ. Like a trustworthy romantic partner, a liver transplant is coveted and longed-for. However, transplant patients may often not fathom ahead of time that the coveted organ will result in such intense initial pain, worry and a fatigued body that is fighting to heal, recover and to accept a new organ. This intense, difficult part of the post-transplant experience is challenging to describe to a patient and to mentally prepare a patient for pre-transplant. Liver transplant is a gift from a deceased donor and bears a level of responsibility and commitment. Accepting such a gift is both a blessing and a

burden, depending on how it is processed. The coveted liver transplant arrives with luggage: pain, physical rehab, an incision, a scar, discomfort, immunosuppressant medications with a strict regimen and a reminder that post-transplant recovery is hard, physical and emotional work. A patient's *negative outcome,* as measured by this study, may be indicative of an unexpected significant negative relationship (with the transplanted liver rather than a person) that impacts secure attachment.

Back in 1973, Basch conducted a study with kidney transplant recipients from deceased donors and he found that the recipients "seemed affected by their fantasies about the cadaver . . . and conflict over guilt and indebtedness was also present (p. 383)." Basch (1973) found there is a relationship in some recipients between a negative fantasy about the organ donor and the recipient's rejection of the transplanted kidney. Goetzmann (2004) emphasizes how a transplant recipient may perceive a transplanted lung and the donor as a transitional object (based on the writings of Donald Winnicott). Goetzmann (2004) further expresses concern that if the recipient were to endow his donor (and organ) with negative qualities and the transitional object became negative, the recipient may struggle with assimilation post-transplant (including a negative impact on health-care adherence and survival of transplant).

The fantasy described by Basch (1973) seems to be a conscious worry about taking on negative personality traits of the deceased donor, whereas Goetzmann (2004) seems to be discussing the unconscious or implicit effect of a transitional object. If this concept is considered in attachment theory terms, the post-transplant patient may experience a disruption of security that is not necessarily attributed to or explained by the

fantasy of inheriting the traits of the deceased donor. Instead, perhaps faced with recovery and doubt, fears and insecurities are triggered and a patient may unconsciously feel less securely attached. In terms of Ainsworth's strange situation, if anxious-ambivalent attachment exists, the patient may be overly clingy or immature, they may behave in a way that will elicit others to indulge or infantilize them, and they may exhibit hysteric or histrionic traits. If anxious-avoidant attachment exists, the patient may present as sullen, arrogant and/or oppositional. Such patients would tend to elicit angrily controlling responses. They may exhibit obsessional, narcissistic and schizoid traits (Mooney, 2010; Wallin, 2007).

Our first attachment is to our caregiver. In some ways a new liver is a caregiver of sorts, but one that comes with many complications or strings attached. It is feasible that as patients begin to heal they can trust and develop a more secure attachment with the transplanted organ. Secure attachment is usually established through a connection to caregiver that begins in the preverbal state, or it can be a result of a corrective experience with another human, such as a romantic partner, other family member, friend etc. What may exist with the negative outcome lasting for a relatively brief period is a disruption, followed by a return to secure attachment once a trusting relationship is developed between patient and organ.

Limitations

The study had some significant limitations. The first is the use of a small sample size. This limited statistical exploration of associations between SIPAT

scores/categories, attachment subscale scores and post-transplant outcomes and the findings are not generalizable. The second was time, as this study looked at a patients transplanted only between January 2015 and May 2016. It also looked at outcomes in a period of only six months post-transplant. While this is the most crucial period of time for transplant patients, results may differ with an extended period of study. The third major limitation is the use of retrospective review of medical records. Although the psychosocial information was collected in real time, patients were aware that they were participating in an evaluation for liver transplant listing. This may limit openness, honesty and accuracy of information reported during the psychosocial evaluation, including the Adult Attachment Scale administered as part of that evaluation. This study looked at liver transplant in terms of attachment theory only. There are many other theoretical lenses through which this topic could and should be explored (e.g., object relations, self psychology, trauma, grief/loss, etc.) Lastly, like most transplant studies, the results are affected by the selection process as a result of the candidate selection criteria required by both the United Network for Organ Sharing and the Centers for Medicaid and Medicare services (Zimbrean & Emre, 2015).

Implications for Social Work Practice

In its purest form, transplant evaluation is meant to lead to a patient's improved physical and mental health rather than eliminate patients from transplant as a life-saving treatment. If further study of the concept of transplant and attachment continues to suggest possible connections, this could better help social workers understand some of

the obstacles a patient may face post-transplant. Interventions that could help promote a more secure attachment could be better identified and implemented in the pre-transplant phase of treatment so that a patient may be better prepared for post-transplant challenges. This may lead to a decrease in negative outcomes post-transplant in terms of frequency and longevity of occurrence. Psychoeducation about a patient's attachment may be useful so that the patient is better aware of her/his attachment and the defenses and tendencies that may be triggered. Possibly, with this knowledge pre-transplant, a patient may better understand the triggering of defenses that may occur post-transplant and, therefore, be better able to respond to a social worker's clinical intervention with regards to attachment and negative post-transplant outcomes. The social worker would also be able to provide the physician, nurses and other members of the transplant team with education and guidance with regards to attachment so that they can tailor interventions that may have an increased probability of positive influence on the patient.

If attachment based interventions both pre and post-transplant prove useful, they may have a positive impact on transplant in terms of reduced graft loss, reduced length of hospital stay, reduced drain of resources, reduced occurrences of need for re-transplant, improved medical adherence, improved patient psychological health, and reduced substance use recidivism

Suggestions for Future Research

It would be worthwhile to see if patients who have prolonged negative outcomes (including graft failure) in the future have less secure attachment. This study looked at

post-transplant outcomes for a six-month period, as this is the most critical period for transplant outcomes and the period where graft-failure is most common. However, it would be worthwhile to look at longer time periods with a larger sample size and analyze negative outcome and/or graft failure rates to see if there is a relationship with attachment scores.

It would be interesting to research the SIPAT and attachment scale scores of the patients who were denied liver transplant listing due to psychosocial contraindications. It is possible that a relationship occurs where these patients may have attachment scores that are more consistent with insecure attachment styles.

The notion of earned-security verses continuous security and how this impacts post-transplant outcomes/recovery is an important concept that could be better understood through research. Because past research has indicated that patients with alcoholism tend to have less secure attachments, more research with patients with alcohol as the cause of liver transplant may be useful. It may be found that these patients may tend to have earned-security and may be at more risk post-transplant, even though secure attachment was reported with the Adult Attachment Scale used in this study.

In this study, a relationship did exist between SIPAT and attachment scale scores; all the patients had scores that indicated secure attachment and all the patients had SIPAT scores that supported transplantation. This suggests that, although not designed specifically for this purpose, the SIPAT may be a useful predictor of adult attachment. However, a larger sample size and further analysis would be needed.

Additionally, future research could concentrate on specific interventions that can be implemented by the transplant social worker and transplant team to help promote a more secure attachment, hopefully resulting in better outcomes for patients.

Finally, future research should utilize a more significant sample size to further investigate the trends seen in the results, including the following questions:

1. Would the positive outcome group continue to have mean subscale scores that were more secure than those of the negative outcome groups?
2. Would patients who had a negative outcome in the “adherence” category continue to have mean subscale scores that was slightly more secure in Close, Depend, and Avoid subscales and slightly more insecure in the Anxious subscale?
3. Would patients who had a negative outcome in the “support” category continue to have mean subscale scores that were more insecure for all four attachment subscales?
4. Would patients who had a negative outcome in the “development or relapse of psychiatric problems” category have mean subscale scores that are more secure in all four attachment subscales?
5. Would patients with the “good” and “excellent” SIPAT scores have attachment scores consistent with more secure attachment than the “minimally acceptable” category on the four attachment subscales?
6. Would the mean SIPAT scores for the patients who fell into the “positive outcomes group” continue to be lower (indicating better candidacy) than the mean scores of the “negative outcome” group?

7. Would patients with a significant alcohol history that impacted liver function have a more insecure subscale mean in all four Attachment subscale categories as compared to other diagnoses?
8. Would length of stay be shorter, and occurrences of PLOS be less for patients without negative outcomes post-transplant?

Conclusion

The purpose of this retrospective, secondary data analysis pilot study was to see if a relationship exists between adult attachment (as theorized by John Bowlby and Mary Ainsworth) and liver transplant outcomes for patients at a liver transplant center in a major urban city in Pennsylvania. More specifically, this study was developed to see if a relationship existed between attachment scale scores and negative/positive outcome categories and if a relationship existed between attachment and SIPAT scores. While the sample was too small to yield any statistically significant data, all subjects were found to have overall scores consistent with secure attachment. Although nine of 20 patients struggled post-transplant (as indicated by one or more of the five negative outcome indicators), the struggle was relatively brief and did not negatively affect their transplant survival. This suggests that secure attachment may have had a role in the overall positive outcomes of the transplanted patients. What may exist with the negative outcome lasting for a relatively brief period is a disruption, followed by a return to secure attachment once a trusting relationship is developed between patient and organ

Although not intended to measure attachment security, the outcomes suggest that the SIPAT may also prove to be a predictor of attachment as all the patients in this study were chosen for transplant, in part, based on the SIPAT scores and all the patients had overall attachment scores that indicated secure attachment.

There exists myriad ways to further research this topic including more research on the contrast of attachment scores between patient chosen for listing and patients denied listing; research of attachment and outcomes over a longer period of time post-transplant; how earned-security verses continuous security may affect transplant success; SIPAT as an attachment predictor; and specific interventions based on attachment research that could better prepare patient for post-transplant triggers and defenses.

Appendix A

Consent to Take Part in a Human Research Study

Consent to Take Part In a Research Study

1*. *Title of research study: An Examination of Adult Attachment and Liver Transplant Success

2. Researcher: James Rao, LCSW

3. Why you are being invited to take part in a research study

You are invited to take part in a research study because you have received a liver transplant at Hahnemann University Hospital in 2015 or 2016.

4. What you should know about a research study

Someone will explain this research study to you.
Whether or not you take part is up to you.
You can choose not to take part.
You can agree to take part now and change your mind later.
If you decide to not be a part of this research no one will hold it against you.
Feel free to ask all the questions you want before you decide.

5. Who can you talk to about this research study?

If you have questions, concerns, or complaints, or think the research has hurt you, you may talk to this investigator, James Rao, at: ***215-762-8118.*** The investigator is a student at The Institute for Clinical Social Work (ICSW). The research will be used as part of his learning and dissertation for his doctorate degree in clinical social work. As such, Mr. Rao and the research will be supervised by his dissertation chair at ICSW: Denise Duval Tsioles, PhD.

This research is being done at Hahnemann University Hospital/Drexel University College of Medicine in conjunction with:

The Institute for Clinical Social Work (ICSW)
At Robert Morris Center
401 South State St
Chicago, IL 60605
312-935-4232

Therefore, you may also speak with the chair of this research at ICSW:

Denise Duval Tsioles, PhD: phone: 773-880-1485 or email dduval@icsw.edu

This research has been reviewed and approved by an Institutional Review Board (IRB) both at Drexel University and at ICSW. An IRB reviews research projects so that steps are taken to protect the rights and welfare of human subjects taking part in research. You may talk to the Drexel IRB at (215) 762-3944 or email HRPP@drexel.edu or the ICSW IRB at (312) 935-4232 or email irbchair@icsw.edu for any of the following:

Your questions, concerns, or complaints are not being answered by the research team.
You cannot reach the investigator.
You want to talk to someone besides the investigator.
You have questions about your rights as a research subject.
You want to get information or provide input about this research.

If either of the IRB's are contacted, the researcher will alert the other IRB of the concern so that both IRB's may work together, along with the investigator, to address the concern.

6. Why is this research being done?

In the United States, a psychosocial evaluation is a standard part of the evaluation that each patient must complete as part of evaluation for liver transplant listing. Part of the evaluation serves to determine if the patient has necessary social support and coping skills to recover successfully from liver transplant surgery and do well post-transplant. Despite thorough psychosocial evaluation completed prior to transplant, research has shown that there are times that patients struggle after surgery in ways that were not predicted by the psychosocial evaluation. The purpose of this study is to see if a relationship exists between adult attachment styles and post-transplant outcomes. The main objective of this study is to determine if adult attachment style has an impact on liver transplant success. The following questions will be considered: Does secure or insecure attachment impact the ability to receive help and support from the patient's support network as well as the transplant medical team? Does attachment impact a patient's ability to adhere to a medical regimen post-transplant? Does attachment affect motivation and psychiatric stability post-transplant? Answers to these questions could help improve the transplant experience for future transplant candidates and recipients.

7. How long will the research last?

It is expected that you will be involved this research study for a period of 6 months after your liver transplant surgery. The research will include patients transplanted in 2015 and 2016. If you did/do not receive a transplant during this time, you most likely will not be included in this research.

8. How many people will be studied?

It is expected that about 20 people who received liver transplants at Hahnemann University Hospital in 2015 and 2016 will be included in this research study.

9. What happens if I say yes, I want to be in this research?

The following information from your medical record will be reviewed and used for data: your psychosocial evaluation and the Adult Attachment Scale. Both of these were completed during your evaluation for transplant. No further active participation is necessary to participate in this study. Six months after your transplant, your post-transplant medical records will be reviewed, including medical adherence that is documented in your chart. Again, no additional active participation is required of you beyond the post-transplant care you will already be receiving and participating in.

10. What are my responsibilities if I take part in this research?

You will have no additional responsibilities to participate in this research. If you agree to participate in this research, you are agreeing to having your medical record accessed for research purposes. There are no additional active participation responsibilities.

11. What happens if I do not want to be in this research?

You may decide not to take part in the research and it will not be held against you. You will continue to receive medical and post-transplant care, regardless of your decision to participate or not participate in this study.

12. What happens if I say yes, but I change my mind later?

If you agree to take part in the research now and change your mind at any time it will not be held against you. If you choose to be withdrawn from the study, you will continue to receive post-transplant treatment regardless of your choice to withdraw. There are no adverse consequences to withdrawing from the research. If data had been collected for use in the study, it will be removed. However once the study is complete, data cannot be eliminated from the study.

13. Is there any way being in this study could be bad for me?

You will not be asked to participate in any way that is not already part of your pre or post-transplant evaluation or medical care. Privacy is the only risk of being part of the study, but strong precautions will be used to secure your privacy.

14. Do I have to pay for anything while I am on this study?

There is no cost to you for participating in this study. This study will only involve reviewing your medical records. No additional procedures or medicine will be given to you.

15. Will being in this study help me anyway?

No benefits can be promised to you or others from your taking part in this research. However, possible future benefits include improved knowledge by transplant social workers and transplant professions that may lead to better interventions to assist patients in both preparation for transplant as well as coping with post-transplant stress.

16. What happens to the information we collect?

Efforts will be made to limit your personal information, including research study data and medical records, to people who have a need to review this information. However, complete confidentiality cannot be promised. Organizations that may inspect and copy your information include the IRB and other representatives of this organization.

It is likely that the results of this study will be published. However, we will keep your name and other identifying information confidential.

17. Can I be removed from the research without my OK?

The person in charge of the research study (Mr. James Rao) can remove you from the research study without your approval. Possible reasons for removal include incomplete data in your medical record.

18. What else do I need to know?

This research is being done at Hahnemann University Hospital/Drexel University College of Medicine in conjunction with

The Institute for Clinical Social Work (ICSW)

At Robert Morris Center
401 South State St
Chicago, IL 60605
312-935-4232

The investigator is a student at ICSW and the research will be used as part of his learning and dissertation for his doctorate degree in clinical social work.

Authorization to Use and Disclose Protected Health Information

A. Individually Identifiable Health Information That Will Be Collected

The following personal health information about you will be collected and used during the research study and may be given out to others:

- Your name, geographic location and, date of birth;
- Personal and family medical history;
- Information from laboratory tests, blood and urine tests, x-rays, physical exams and other tests or procedures documented in your medical record as part of post-transplant medical care.
- Information learned during telephone calls, and office visits related to your health care that have been documented in your medical record
- Information in medical records located at Hahnemann University Hospital/Drexel University College of Medicine
- Information gathered during your psychosocial evaluation including an adult attachment scale, social history, financial circumstances, work history, education history, legal history, family composition, substance use history, mental health history, social support(s), race, religion, and marital status.

B. Who Will See and Use Your Health Information within Drexel University

The researcher and other authorized individuals involved in the research study at Drexel University will see your health information during and may give out your health information during the research study. These include the researcher, the institutional review board and their staff, legal counsel, research office and compliance staff, officers of the organization and other people who need to see the information in order to conduct the research study or make sure it is being done properly. Your health information may be disclosed or transmitted electronically.

C. Who Else May See and Use your Health Information

Other persons and organizations outside of Drexel University may see and use your health information during this research study. These include:

- Doctors and staff at the hospital where this research study will take place.
- The research committee and institutional review board at The Institute For Clinical Social Work (where the research will be submitted for the researcher’s academic dissertation).
- A data safety monitoring board.

If your health information is given to someone not required by law to keep it confidential, then that information may no longer be protected, and may be used or given out without your permission.

D. Why your health information will be used and given out

Your health information will be used and given out to carry out the research study and to evaluate the results of the study. If you do not want to give authorization to use your health information

You do not have to give your authorization to use or give out your health information. However, if you do not give authorization, you cannot participate in this research study.

E. How to cancel your authorization

At any time you may cancel your authorization to allow your health information to be used or given out by sending a written notice to Human Research Protection at 1505 Race Street, 7th floor, Bellet Building, Mail Stop 444, Philadelphia, Pennsylvania, 19102. If you leave this research study, no new health information about you will be gathered after you leave. However, information gathered before that date may be used or given out if it is needed for the research study or any follow-up.

F. When your authorization ends

Your authorization to use and give out health information will continue until you withdraw or cancel your authorization or when the research study is finished.

G. Your right to inspect your medical and research records

You have the right to look at your medical records at any time during this research study. However, the researcher does not have to release research information to you if it is not part of your medical record

Signature Block for Capable Adult

Your signature documents your permission to take part in this research.

DO NOT SIGN THIS FORM AFTER THIS →

Signature of subject	Date
Printed name of subject	
Signature of person obtaining consent	Date
Printed name of person obtaining consent	Form Date

[Add the following block if a witness will observe the consent process. E.g., short form of consent documentation or illiterate subjects.]

My signature below documents that the information in the consent document and any other written information was accurately explained to, and apparently understood by, the subject, and that consent was freely given by the subject.

Signature of witness to consent process	Date
Printed name of person witnessing consent process	

H. Individually Identifiable Health Information That Will Be Collected

The following personal health information about you will be collected and used during the research study and may be given out to others:

- Your name, geographic location and, date of birth;
- Personal and family medical history;
- Information from laboratory tests, blood and urine tests, x-rays, physical exams and other tests or procedures documented in your medical record as part of post-transplant medical care.
- Information learned during telephone calls, and office visits related to your health care that have been documented in your medical record
- Information in medical records located at Hahnemann University Hospital/Drexel University College of Medicine
- Information gathered during your psychosocial evaluation including an adult attachment scale, social history, financial circumstances, work history, education history, legal history, family composition, substance use history, mental health history, social support(s), race, religion, and marital status.

I. Who Will See and Use Your Health Information within Drexel University

The researcher (Mr. James Rao) and other authorized individuals involved in the research study at Drexel University will see your health information during and may give out your health information during the research study. These include the researcher, the institutional review board and their staff, legal counsel, research office and compliance staff, officers of the organization and other people who need to see the information in order to conduct the research study or make sure it is being done properly. Your health information may be disclosed or transmitted electronically.

J. Who Else May See and Use your Health Information

Other persons and organizations outside of Drexel University may see and use your health information during this research study. These include:

- Doctors and staff at the hospital where this research study will take place.
- The research committee and institutional review board at The Institute For Clinical Social Work (where the research will be submitted for the researcher's academic dissertation).
- A data safety monitoring board.

If your health information is given to someone not required by law to keep it confidential, then that information may no longer be protected, and may be used or given out without your permission.

K. Why your health information will be used and given out

Your health information will be used and given out to carry out the research study and to evaluate the results of the study. If you do not want to give authorization to use your health information

You do not have to give your authorization to use or give out your health information. However, if you do not give authorization, you cannot participate in this research study.

L. How to cancel your authorization

At any time you may cancel your authorization to allow your health information to be used or given out by sending a written notice to Human Research Protection at 1505 Race Street, 7th floor, Bellet Building, Mail Stop 444, Philadelphia, Pennsylvania, 19102. If you leave this research study, no new health information about you will be gathered after you leave. However, information gathered before that date may be used or given out if it is needed for the research study or any follow-up.

M. When your authorization ends

Your authorization to use and give out health information will continue until you withdraw or cancel your authorization or when the research study is finished.

N. Your right to inspect your medical and research records

You have the right to look at your medical records at any time during this research study. However, the researcher does not have to release research information to you if it is not part of your medical record.

Signature Block for Capable Adult

Your signature documents your permission to take part in this research.

DO NOT SIGN THIS FORM AFTER THIS →

Signature of subject	Date
Printed name of subject	
Signature of person obtaining consent	Date
Printed name of person obtaining consent	Form Date

[Add the following block if a witness will observe the consent process. E.g., short form of consent documentation or illiterate subjects.]

My signature below documents that the information in the consent document and any other written information was accurately explained to, and apparently understood by, the subject, and that consent was freely given by the subject.

Signature of witness to consent process	Date

Appendix B

Medical Record Data Collection Tool

1. Patient ID : _____
2. Gender:
    (1) Male
    (2) Female
    (3) Transgender
3. Marital Status:
    (1) Single/Never Married
    (2) Married
    (3) Common law marriage
    (4) Separated
    (5) Divorced
    (6) Widow/Widower
    (7) other _____
4. If married, number of years married:
5. If Married, length of marriage (in years)
6. Number of times married (including current marriage, if married):
7. Primary Support Person:
    (1) Spouse
    (2) Parent
    (3) Adult Child
    (4) Sibling
    (5) Aunt/Uncle

(6) Friend

(7) Other _____

8. Number of Children/Ages:

_____

_____

_____

9. Number of Siblings: _____

10. Birth Order:

(1) Oldest

(2) Youngest

(3) Upper Middle

(4) Lower Middle

(5) Only Child

(6)

11. With whom does patient reside (circle all that apply)?

(1) Resides alone

(2) With spouse

(3) With an adult child(ren) (18 and older)

(4) With a young child(ren) (17 and younger)

(5) With parent(s)

(6) With sibling(s)

(7) With other family members (cousins, aunt/uncle, grandparents, etc)

_____

(8) With friend(s)

(9) With roommate(s)

(10) Other _____

12. Does patient live with primary support person? Y N

13. Patient Identified Race/Ethnicity:

(1) African American

(2) Caucasian

(3) Asian

(4) Latino/Latina

(5) Native American

(6) Other _____

14. Location of home:

(1) City

(2) Suburban

(3) Rural

(4) Other _____

15. Distance from transplant center (miles): _____

16. Employment Status (at time of psychosocial evaluation)

(1) Currently employed

(2) Disabled/plan to return to work

(3) Disabled/no plans to return to work

(4) Unemployed

(5) Other _____

17. Employment Status (6 months post-transplant)

(1) Currently employed

(2) Disabled/plan to return to work

(3) Disabled/no plans to return to work

(4) Unemployed

(5) Other _____

18. Primary Insurance

(1) Private Insurance

(2) Medicare

(3) Medicaid

19. Secondary Insurance

(1) Private Insurance

(2) Medicare

(3) Medicaid

(4) N/A

20. Highest level of education

(1) Graduate school or higher

(2) Bachelor's degree

(3) Associate's degree

(4) Some college

(5) HS graduate

(6) GED

(7) 11th grade

(8) 10th grade

(9) 9th grade

(10) 8th grade

(11) 7th grade

(12) 6th grade

(13) 5th grade

(14) 4th grade

(15) 3rd grade

(16) 2nd grade

(17) 1st grade

(18) Below 1st grade

21. Employed at date of transplant?

(1) Yes

(2) No

22. How long out of work prior to transplant?

(1) _____

(2) Never employed

23. Date of Transplant:

24. Age at date of transplant (in years):

25. Number of days in hospital post-transplant surgery to discharge _____

26. Number of days in hospital pre-transplant surgery _____

27. Discharged to:

(1) Home

(2) Relative, friend or other's home _____

(3) Physical Rehab facility

(4) Skilled nursing facility

(5) Other _____

28. Length of time on the liver transplant waiting list (in days): _____

29. Organ(s): (1) Liver Only

(2) Liver/Kidney

30. Primary Diagnosis related to liver disease:

(1) Alcohol use/abuse/dependence

(2) Hepatic C

(3) Hepatitis B

(4) Autoimmune Hepatitis

(5) cryptogenic cirrhosis/Nonalcoholic fatty liver disease (NAFLD)/ Nonalcoholic steatohepatitis (NASH)

(6) Liver Cancer/HCC

(7) Primary Biliary Cirrhosis

(8) Polycystic Liver Disease

(9) Other _____

31. Secondary Diagnosis related to liver disease:

(1) Alcohol use/abuse/dependence

(2) Hepatitis C

(3) Hepatitis B

(4) Autoimmune Hepatitis

(5) cryptogenic cirrhosis/Nonalcoholic fatty liver disease (NAFLD)/ Nonalcoholic steatohepatitis (NASH)

(6) Liver Cancer/HCC

(7) Primary Biliary Cirrhosis

(8) Polycystic Liver Disease

(9) Other _____

(10) N/A

32. Tertiary Diagnosis related to liver disease:

(1) Alcohol use/abuse/dependence

(2) Hepatitis C

(3) Hepatitis B

(4) Autoimmune Hepatitis

(5) cryptogenic cirrhosis/Nonalcoholic fatty liver disease (NAFLD)/ Nonalcoholic steatohepatitis (NASH)

(6) Liver Cancer/HCC

(7) Primary Biliary Cirrhosis

(8) Polycystic Liver Disease

(9) Other _____

(10) N/A

33. If patient has a history of alcohol abuse/dependence, how long has patient been abstinent from alcohol? _____

34. If patient has a history of hepatitis C, what risk factors contribute to possible cause of virus (circle all that apply)?

(1) IV drug use

(2) Intranasal drug use

(3) Blood transfusion

(4) Tattoo(s)

(5) Sexual contact

(6) Cause is unknown

(7) Other _____

35. Attachment Scale Score (close):

36. Attachment Scale Score (Depend):

37. Attachment Scale Score (Anxious):

38. Attachment Scale Score(Avoid):

39. SIPAT Score:

40. SIPAT Category:

    (1) Excellent Candidate (0-6)

    (2) Good Candidate (7-20)

    (3) Minimally Acceptable Candidate (21-39)

    (4) High Risk Candidate (40-68)

    (5) Poor Candidate (> 69)

41. Negative or Positive Outcomes Post-Transplant Measure (If one or more of 1, 2, 3, 4, and/or 5 is circled, a negative outcome is indicated).

    (0) No noted problems (Positive Outcome)

    (1) Difficulty with treatment adherence

    (2) Unstable psycho-social support system

    (3) Substance abuse recidivism

    (4) Development or relapse of psychiatric problems

    (5) Graft failure

Appendix C

Negative or Positive Outcomes Post-Transplant Measure

Note: Data from this document were collected and recorded on the ***Medical Record Review Data Collection Tool*** *(see Appendix A). This document is included in the appendix for review and reference purposes only.*

A negative liver transplant surgery outcome was defined as meeting one or more of the following conditions (Maldonado et al, 2012):

1	Difficulty with treatment adherence
2	Unstable psychosocial support system
3	Substance use recidivism
4	The development of (or return of) psychiatric problems
5	Graft failure

Appendix D

Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT)

*Note: Data from this document were collected and recorded on the **Medical Record Review Data Collection Tool** (see Appendix A). This document is included in the appendix for review and reference purposes only.*

Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT)

Assessment Long Form

Maldonado et al, 2008; Maldonado et al, Psychosomatics 2012

Psychosocial Transplant Medicine Program

Stanford School of Medicine & Stanford Hospital and Clinics

DEMOGRAPHIC INFORMATION

Type of transplant proposed: [ ] BMT [ ] Heart [ ] Heart/Lung [ ] Intestinal [ ] Kidney [ ] Liver [ ] Lung [ ] LVAD [ ] "Fulminant"

Name of Interviewer:

Date of evaluation: _____ Site of evaluation: _____ Present:

_____

*[ ] Examiner's **role/function explained** [ ] **Limits of confidentiality reviewed** [ ] **Informed consent obtained***

_____

Patient: _____ MRN: _____

DOB: _____ Age: _____ Gender: [ ] Male [ ] Female

Address: _____ Phone: _____

_____ _____

Relationship status: [ ] Single [ ] Married [ ] Separated [ ] Common-law

[ ] Divorced [ ] Widowed [ ] Gay [ ] Lesbian

Ethnicity: [ ] Caucasian [ ] African American [ ] American Indian [ ] Hispanic/Latino [ ] Asian Pacific Islander

[ ] South Asian [ ] Other: _____

Languages spoken: _____ Faith system: _____

Referring physician: _____ Primary care Physician: _____

HISTORY OF PRESENTING ILLNESS

(Brief chronological medical Hx pertinent to transplant, previous surgeries, hospitalizations, first experience with medications, "transplant")

SOCIAL HISTORY

Developmental History:

Born: The _____ of _____children.

Raised by:

Parental relationships during Childhood

Mother:

Father:

[ ] The patient reports good parental relationships during his/her early childhood.

Educational History:

Highest level of education obtained?

Primary language: _____

Can patient read, write, and understand English? [ ] Yes [ ] No If No, why? _____

[ ] Patient is literate [ ] Patient does not know how to read [ ] Patient has limited literacy

[ ] English is not patient's primary language [ ] Hx of special education or developmental delay

Employment History: *[ ] Employed [ ] Disabled [ ] Unemployed [ ] Retired [ ] Homemaker [ ] Self-employed*

Current occupation:

Spouse/partner employed? [ ] Yes [ ] No If Yes, where? _____

Financial & Insurance History:

Financial source(s):

Insurance source(s):

[ ] No financial concerns [ ] Financial concerns [ ] Insurance concerns [ ] Resource education provided [ ] Referred to transplant financial coordinator

Relationship History & Current Supportive Relationships (Duration/brief description/why ended/children):

1.

2.

3.

4.

SUPPORT SYSTEM

Living Space and Current Living Situation [SIPAT#8]:

Who lives in your household **[SIPAT#6]**?

Who will be involved as patient's caregiver support team? Primary: _____.

Secondary: _____.

RELATIONSHIP STABILITY [SIPAT#7]:

[ ] Strong/stable relationship [ ] Domestic violence [ ] Major sources of relationship disagreement

[ ] Evidence of current relationship discord [ ] Sexual issues reported [ ] Hx of relationship conflict/stress

Do caregiver(s) have a realistic understanding of caregiver role and responsibilities? [ ] Yes [ ] No

[ ] SH&C Caregiver Agreement reviewed and signed. [ ] Further caregiving counseling, education & teaching warranted.

RELOCATION **[SIPAT#8]**

Will the patient have to relocate post-transplant? [ ] Yes [ ] No

Has the patient been explained the post-transplant relocation requirements? [ ] Yes [ ] No

Has the patient been explained housing options? [ ] Yes [ ] No

Has the patient identified an acceptable relocation plan? [ ] Yes [ ] No

Are there any barriers that prevent patient from being able to relocate? [ ] Yes [ ] No

If yes, please explain:

SELF-MANAGEMENT WITH MEDICAL TREATMENT **[SIPAT#3,4,5,7,13]** *[ ] Unable to assess due to:* _____

Medical Treatment:

Has patient had difficulty following doctor's recommendations or restrictions?

[ ] Yes [ ] No If Yes, explain: _____.

Has patient had difficulty attending medical appointments or completing tests?

[ ] Yes [ ] No If Yes, explain: _____.

Has patient experienced difficulties taking their medications?

[ ] Yes [ ] No If Yes, explain: _____.

Has patient experienced side effects from their medications?

[ ] Yes [ ] No If Yes, explain how you have managed them: _____.

Medications:

How does patient manage his/her medications? ***[ ] Pt has a list of al his medications. [ ] Has basic understanding of what are they for.***

[ ] use pillbox [ ] does not use pillbox [ ] count them out daily [ ] use alternative system to organize

[ ] set alarm/watch [ ] patient brought list of rx [ ] patient did not bring list of rx

[ ] patient well aware of rx, dose and reason for use [ ] patient unaware of rx, dose and reason for use

Who manages the patient's medications?

Who is in charge of scheduling clinic appointments?

How involved is the patient in his/her own care?

UNDERSTANDING OF ILLNESS & TRANSPLANT PROCESS **[SIPAT#1, 2]**

[ ] Unable to assess due to: _____

When did patient first learn they might require a transplant?

What does patient think may have caused their organ failure?

Has the patient met anyone who has had an organ transplant?

[ ] Yes [ ] No If Yes, whom & when? _____.

Has patient been provided transplant education/teaching?

[ ] Yes [ ] No If Yes, from whom & when? _____.

What education/teaching materials has patient received?

[ ] Transplant Education Manual (SH&C) [ ] Partnering With Your Transplant Team (DHHS) [ ] Psycho-education

[ ] What Every Patient Needs to Know (UNOS) [ ] Other _____.

Has patient/caregiver read them?

[ ] Yes [ ] No If No, explain why? _____.

Knowledge about transplant process & procedure? *(indicate areas where patient is knowledgeable)*

[ ] selection process [ ] waitlist status [ ] unknown length of wait time

[ ] dry runs [ ] length/course of hospitalization [ ] rehab/recovery

[ ] benefits/risks of transplant [ ] immune-suppression therapy [ ] relocation

[ ] post-transplant follow-up [ ] personal monitoring & surveillance

WILLINGNESS/DESIRE FOR TRANSPLANTATION: [SIPAT#3]

- Who suggested the transplant?

- How did you react?

- How do you feel about it now?

- Why are you pursuing it?

- Who seems to be pushing for it more: you, your family, doctors?

Does patient have any concerns about the transplant surgery?

[ ] Yes [ ] No If Yes, explain: _____.

*Is patient aware of the Living Donor Program? ***(*KIDNEY, LIVER & BMT ONLY)***

[ ] Yes [ ] No If Yes, what is there understanding? _____.

[ ] Has not received sufficient information [ ] Has not read education materials [ ] Asked appropriate/meaningful questions [ ] Limited level

of understanding [ ] Reasonable level of understanding [ ] Good level of understanding [ ] Further counseling, education & teaching warranted

PSYCHOLOGICAL HEALTH *[ ] Unable to assess due to: _____ .*

Past Psychiatric History [SIPAT#9, 10, 11]

History of Abuse: *[ ] Verbal [ ] Physical [ ] Sexual [ ] Domestic Violence*

[ ] There is no Hx of verbal, physical, sexual or domestic violence.

[ ] History of ANTISOCIAL BEHAVIOR, EXPLAIN:

Hx of any significant past psychological symptom, diagnosis or treatment? OR any past psychiatric hospitalizations, prior mental health contact?

Hx of personality traits, self-destructive or aggressive behavior? **[SIPAT#11]**

History of psychotropic medication use (name of Rx, effect, date-length-reason for use, Rx'd by?, reason for d/c?):

Hx of adverse cognitive reactions to medical illness or its treatment? (e.g., confusion, delirium, dementia-like symptoms) **[SIPAT#10]**

Hx of adverse psychological reactions to medical illness or its treatment? (e.g., adjustment disorder, depression, mania)

[ ] The patient has never been seen, treated or diagnosed by a psychiatrist, psychologist or mental health professional. S/he has no prior

history of psychiatric hospitalizations, suicidal attempts or self-injurious behaviors.

SUBSTANCE USE HISTORY **[SIPAT#14, 12, 13, 17, 15]**

[ ] Unable to assess due to: _____

Onset of Use Date/Habitual Use Date/Problem Current Use (amount/frequency/problem?)

1. Alcohol:

[ ] CAGE Score: _____/ 4.

[ ] Administered AUDIT **AUDIT** score: _____/40 **AUDIT** interpretation:

_____.

Does patient currently consume alcohol? [ ] Yes [ ] No Amount of *"standard drinks"* per occasion?

_____.

Current alcohol consumption: [ ] "light" [ ] "moderate" [ ]" heavy"

DUI's? [ ] Yes [ ] No Drinking throughout the night? [ ] Yes [ ] No

Blackouts? [ ] Yes [ ] No Minor withdrawal symptoms? [ ] Yes [ ] No

Early AM drinking [ ] Yes [ ] No DT's? [ ] Yes [ ] No

ETOH-related arrests [ ] Yes [ ] No ETOH withdrawal seizures? [ ] Yes [ ] No

Has alcohol use ever affected your: work: [ ] Yes [ ] No family: [ ] Yes [ ] No relationships: [ ] Yes [ ] No

If Yes, explain:

_____.

Has your doctor ever requested you to stop drinking? [ ] Yes [ ] No If Yes, when: _____.

Evidence of alcohol abuse? [ ] Yes [ ] No Alcohol dependence? [ ] Yes [ ] No

Date of last use: _____.

Onset of Use Date/Habitual Use Date/Problem Current Use (amount/frequency/problem?) **Date of last use**

2. Tobacco:

3. Marijuana (PO, inhaled):

4. Cocaine (IN, IV):

5. Psychostimulants (PO, IV, IN):

6. Heroin (IN, IV):

7. Hallucinogens:

8. Prescription Medications:

9. Others:

[ ] Administered DAST **DAST** score: _____ **DAST** interpretation: _____ .

Previous alcohol or drug treatment? (include times and dates & why they terminated)

Any history of recidivism?

Has the patient use any substances after learning of their renal or other serious medical problems?

Average Length of Sobriety after Completion of Treatment?

Did the patient continue to use ANY substance of abuse (including ETOH & THC) after learning of their medical condition/organ

failure?

MENTAL STATUS **[SIPAT#9,10,11]** *[ ] Unable to assess due to:*_____ .

Description:

[ ] The patient was found sitting in the waiting room accompanied by _____ .

[ ] The patient was found resting comfortably in their hospital bed on _____ .

[ ] S/He was able to walk into the office exhibiting normal gait and strength.

Attitude toward Interviewer:

[ ] His/her attitude with interviewer was cooperative and appropriate. ***Or…***

Guarded Withdrawn Apathetic Indifferent Silly Overly-dramatic Irritable Hostile Defensive Demanding Sarcastic Aggressive

Eye Contact:

[ ] The patient maintained good eye contact through out the interview. ***Or…*** Glaring Avoided Fleeting Wary Patient kept eyes close

Appearance:

[ ] The patient was neatly groomed, appropriately dressed and adequately nourished. ***Or…*** Unkempt Undernourished Colorful Seductive

Psychomotor:

[ ] Psychomotor activity was normal. ***Or…*** Retarded Agitated Tics Tremors Myoclonus Dyskinesias Automatisms

Speech:

[ ] Speech rate, volume & articulation were normal. ***Or…*** Slow Stuttering Slurring Fast Pressured Stammering

Mood:

[ ] The patient reports his/her mood as: _____.

Depressed Gloomy Sad Tense Hopeless Resentful Fearful Empty OK Happy Ecstatic Elated Euphoric

Affect:

[ ] The patient exhibited a broad range of affect. There are no signs of anxiety or depression. ***Or…*** *The patient's affect was….*

Inappropriate Flat Blunted Unhappy Apathetic Anhedonic Dysphoric

Grandiose Tense Panicky Labile Anxious Excited Manic Hypomanic

Thought Content:

[ ] The thought content was appropriate to questions. The patient denies any suicidal ideation, homicidal ideation, or death wish. There are no signs of psychosis,

irrational fears, obsessions or phobias. ***Or…***

Suicidal Ideation Homicidal Ideation Paranoid Ideation Suspiciousness Phobias Obsessions _____

Delusions

Hypochondriasis Ideas of Reference Magical Thinking Grandiosity Hyper-religiosity **Thought:** insertion Withdrawal Broadcasting Blocking

Thought Process:

[ ] The thought process was goal directed and coherent. ***Or…***

Rambling Circumstantial Tangential Neologisms Flight of Ideas

Ambivalence Perseveration Clang Associations Clang Associations

Perceptions:

[ ] Perceptions were normal. The patient denied auditory, tactile or visual hallucinations. ***Or…***

Auditory Ill/Hall Visual Ill/Hall Tactile Ill/Hall Depersonalization Derealization

Neuro-Vegetative Functions:

Energy: *[ ] Energy level is good. The patient is able to perform most usual functions.*

[ ] Poor. Unable to carry out most of his/her usual functions.

[ ] Fatigued most of the time.

Sleep: *[ ] Sleep pattern was reported as intact and regular, with no initial, middle or late insomnia.* ***Or…***

[ ] Difficulties falling asleep *[ ]* Awakening too early in the morning *[ ]* Nightmares

[ ] Awakening many times during the night & difficulty falling back to sleep *[ ]* Difficulty falling asleep even with sleep medications

Appetite: *[ ] Appetite is reported to be intact, with no significant changes in weight.*

[ ] Decreased appetite with an associated weight loss of _____ lbs.

[ ] Increased appetite with an associated weight gain of _____ lbs.

Intelligence

[ ] Intelligence and general information appeared appropriate to the level of education. [ ] Impaired.

Cognition:

[ ] Cognition appears relatively intact. [ ] Impaired – formal psychiatric evaluation is recommended.

Abstraction

[ ] Abstraction was good; with similarities and proverbs interpreted correctly. [ ] Impaired.

Judgment

[ ] Judgment capacity appeared adequate, with appropriate response to a simple hypothetical situation. [ ] impaired.

Insight

[ ] Psychological insight into current circumstances was good. [ ] Impaired

IMPRESSION REGARDING PATIENT'S OPENNESS AND TRUTHFULNESS DURING EVALUATION **[SIPAT#12]**

(Especially in relation to available records, conversations with other members of the Transplant team or healthcare team and support):

PSYCHIATRIC DIAGNOSTIC IMPRESSION:

[ ] Psychiatric consult recommended – FOR PSYCHOLOGISTS AND SW's ONLY.

Appendix E

SIPAT Scoring Tool

Note: Data from this document were collected and recorded on the Medical Record Review Data Collection Tool (see Appendix A). This document is included in the appendix for review and reference purposes only.

Stanford Integrated Psychosocial Assessment for Transplant

(SIPAT) Stanford University Medical Center ***© Maldonado et al, 2008; updated 1'03'12 ; Maldonado et al, Psychosomatics 2012 Page 1 of 5***

Patient's Name: _____ Date: _____

Patient's MR#: _____ Total Score: _____

SIPAT Examiner: _____

A. PATIENT'S READINESS LEVEL

I. Knowledge & Understanding of Medical Illness Process (that caused specific organ failure)

0) Excellent Understanding: High degree of self-directed learning and excellent knowledge of treatment risks & benefits.
1) Good Understanding: Patient & support system are fully aware of the cause of illness & contribution to current health status.
2) Moderate Understanding: Patient has modest knowledge despite teaching/material provided.
3) Limited Understanding: Patient only has rudimentary knowledge despite of years of illness & extensive teaching by providers.
4) Poor Understanding: Extreme denial or indifference evident.

II. Knowledge & Understanding of the Process of Transplantation

0) Excellent Understanding: High degree of self-directed learning and excellent knowledge of treatment risks & benefits.
1) Good Understanding: Patient & support have studied & understood provided literature **– Or –**

A patient who just found out about his/her condition and no education has been provided.
2) Moderate Understanding: Patient has modest knowledge despite teaching/material provided.
3) Limited Understanding: Patient only has rudimentary knowledge despite of intensive teaching by providers.
4) Poor Understanding: Extreme denial or indifference evident.

III. Willingness/Desire for Treatment (Transplant)

0) Excellent: Patient highly motivated & directly involved in his/her medical care.
1) Good: Patient expresses interest but actions only acceptable at best.
2) Moderate: Patient appears ambivalent; only passively involved in process.
3) Limited: Family member or MD more interested in Transplant process than patient.
4) Poor: Family member or MD pushing patient to participate in the Transplantation evaluation process.

IV. Treatment Compliance/Adherence (Pertinent to medical issues)

0) Excellent: Full compliance & effective self-management.
2) Good: Patient may be challenging, but fully compliant.
4) **Moderate:** Only partial compliance, requires multiple efforts and persuasion from the Transplant team and/or family.
6) Limited: Only compliant after the development of complications.
8) Poor: Evidence of significant treatment non-adherence with negative impact in patient's health (i.e., Treatment non-adherence/compliance; continued substance use after learning of illness).

V. Lifestyle Factors **(Including diet, exercise, fluid restrictions; and habits according to organ)**

0) Able to modify & sustained needed changes- self initiated.
1) Patient is reluctant but compliant with recommended changes.
2) Patient complies with recommended changes only after much prompting and encouragement from support & Transplant team.
3) Patient complies with recommended changes only after the development of complications.
4) Unhealthy diet & sedentary lifestyle. Reluctant to change. (i.e., non-adherence with recommended restrictions; continued substance use after learning of illness).

B. SOCIAL SUPPORT SYSTEM

VI. Availability of Social Support System

0) Excellent: Several family, significant others &/OR friends have been identified and are actively engaged as part of the support system. Excellent back-up system in place.
2) Good: Only one support person has been identified & appears engaged. A back-up system has not been confirmed.
4) Moderate: The patient's identified support system appears unreliable or inconsistent. No reasonable backup system identified.
6) Limited: Patient identified support system, but support person appear conflicted, uncertain or uncommitted. No reasonable backup system identified.
8) Poor: Patient unable to identify reliable support system, or identified caregiver has failed to present to clinic.

VII. Functionality of Social Support System

0) Excellent: Support members have demonstrated initiative in learning & already committed to and engaged in patient's care. They are ready to help.
2) Good: A limited support system has already committed to and has had limited engagement in the patient's care. They may need some work before they are ready for transplantation.
4) Moderate: Patient's identified system seems to have medical or social problems themselves which may impair their ability to reliably assist the patient.
6) Limited: Identified support system has problems which may prevent them for being appropriate –**OR–** identified person(s) express doubts/hesitation/conflict.
8) Poor: Patient has suffered due to unreliable support system **–OR–** team has not been able to effectively work with support.

VIII. Appropriateness of physical living space & environment

0) Excellent: Patient has permanent and adequate housing.
1) Good: Patient has some stable arrangement albeit not optimal.
2) Moderate: Reported arrangement is only temporary & tenuous.
3) Limited: Unable to confirm reported arrangement or perceived to be inappropriate.

4) Poor: Non-existent; Patient has no stable living arrangements **–OR–** lives in environment that doesn't promote Transplant health.

C. *PSYCHOLOGICAL STABILITY & PSYCHOPATHOLOGY*

IX. Presence of Psychopathology **(other than personality disorders & organic psychopathology)**

0) None: No history of psychiatric problems

2) History of **Mild Psychopathology** (i.e. Adjustment disorder). Usually a self-limited problem without significant impact on functioning. No treatment needed. **No History of SI/SA.**

4) History of **Moderate Psychopathology.** Treatment has been effective, good compliance. No History of SI/SA at present; although **possible or + History SI/SA in past.**

6) History of **severe psychopathology.** Patient has needed **multiple psychiatric hospitalizations in the past or History of SI/SA.**

8) Extreme History of psychopathology present (i.e., History of multiple Psych Hosp; Treatment with ECT; History of multiple SI/SA). Patient is in need for acute psychiatric intervention before proceeding.

IXa. Assessment of Depression (Use clinical judgment; Patient Health Questionnaire [PHQ] or Beck Depression Inventory [BDI], if available)

0) No Clinical Depression; or PHQ < 5; or BDI= 0 – 13.
1) Mild Clinical Depression; or PHQ = 5 – 9; or BDI= 14 – 19.
2) Moderate Clinical Depression; or PHQ = 10 – 19; or BDI= 20 – 28.
3) Severe Clinical Depression; or PHQ ≥ 20; or BDI = 29 – 63.

IXb. Assessment of Anxiety (Use clinical judgment; Generalized Anxiety Disorder questionnaire [GAD-7] or Beck Anxiety Inventory [BAI], if available)

0) No Clinical Anxiety; or GAD-7 < 5; or BAI = 0 – 7.
1) Mild Clinical Anxiety; or GAD-7 = 5 – 9; or BAI = 8 – 15.
2) Moderate Clinical Anxiety; or GAD-7 = 10 – 14; or BAI = 16 – 25.
3) Severe Clinical Anxiety; or GAD-7 ≥ 15; or BAI = 26 – 63. **Score P2:_____**

X. History of Organic Psychopathology or Neurocognitive Impairment **(i.e., illness or medication induced psychopathology)**

0) None: No history of disease or treatment induced psychiatric problem.

1) History of M**ild Organic Psychopathology.**

3) History of M**oderate Organic Psychopathology.**

5) History of **Severe Organic Psychopathology.**

Xa. Assessment of Cognitive Functioning (Use clinical judgment or use MMSE, if available)

0) Cognitive Functioning Within Normal Limits; or MoCA / MMSE ≥ 26.
1) Borderline Level of Cognitive Functioning; or MoCA / MMSE = 22 – 25.
2) Impaired Cognitive Functioning; or MoCA / MMSE < 22.

XI. **Influence of Personality Traits vs. Disorder**

0) None; No history of significant personality disorder or psychopathology.

1) History of **mild** personality traits or psychopathology in response to illness, medical treatment or psychosocial stressors.

2) History of **moderate** personality traits or psychopathology in response to illness, medical treatment or psychosocial stressors. Treatment, if needed, has been effective. Patient with good compliance, no characterological interference with treatment. No history of SI/SA.

3) History of **severe** personality psychopathology or traits in response to illness, medical treatment or psychosocial stressors. Patient has needed multiple psychiatric hospitalizations in the past. History of SI/SA.
4) Extreme character pathology present in response to illness, medical treatment or psychosocial stressors. Patient is in need for acute psychiatric intervention before proceeding.

XII. **Effect of Truthfulness vs. Deceptive Behavior in Presentation**

0) No evidence of deceptive behavior by history or at present.
2) Patient has not volunteered some negative information, but truthfully answered direct questioning.
4) Patient has not been fully forthcoming with negative information, but provides it on confrontation.
6) Patient has not been fully forthcoming with negative information. Information obtained only from external sources.
8) There is clear evidence of deceptive behavior as evidence by records, collateral information or testing.

XIII. **Overall Risk for Psychopathology (including items IX – XII)**

0) None or minimal: No history of personal or familial psychiatric problems; no psychiatric complications to illness, medical treatment or psychosocial stressors**.**
1) Low: History of acceptable coping with previous medical challenges or psychosocial stressors.
2) Mild: History of poor coping with previous medical challenges or psychosocial stressors.
3) M**oderate:** Patient has experienced significant psychiatric complications to medical illness, interventions or treatment **–OR–** Presence of moderate psychopathology in family of origin.
4) Severe: History of significant psychopathology present in family of origin **–OR–** Patient has experienced severe psychiatric complications to medical.

D. LIFESTYLE & EFFECT OF SUBSTANCE USE

XIV. **Alcohol Use/Abuse/Dependence (Use clinical judgment or use AUDIT, if available)**

0) None: No history of alcohol use. No risk: Audit = 0.
2) ALCOHOL USE – NO ABUSE: History of minimal alcohol use which has caused no social or medical problems (i.e., no abuse). If requested by the team the patient promptly discontinued all alcohol use. Low Risk: Audit < 7.
4) MODERATE ALCOHOL ABUSE: History of moderate alcohol abuse evidenced by excessive drinking and possible deleterious bodily or social effects. Pt quit use as soon as patient learned of disease or when first told by MD. Patient may have required treatment/intervention in order to achieve sobriety. Mild Risk: Audit = 8 – 15.
6) DEPENDENCE OR SEVERE ABUSE: History of severe alcohol abuse or dependence. Patient required treatment/ intervention in order to achieve sobriety (or refused Treatment); or continued to use after disease progressed, developing medical complications. Moderate Risk: Audit = 16 – 19.
8) DEPENDENCE OR EXTREME ABUSE: History of extreme alcohol abuse & multiple relapses despite of warning and/or treatment. Patient continued to drink until just prior to presentation or only quit drinking when too sick to continue. High Risk: Audit > 20.

XV. **Alcohol Use/Abuse/Dependence - Risk for Recidivism**

0) None: No history of Alcohol use.
1) Low Risk.
2) Moderate Risk.
3) High Risk.
4) Extreme Risk: History of recidivism after prior treatment or after an extended period of sobriety.

XVI. **Substance Use/Abuse/Dependence – Including Prescribed & Illicit Substances**

(Use clinical judgment or use DAST, if available)

0) None: No history of illicit substance Use; or abuse of prescribed substances.
2) History of **minimal** substance abuse. Quit use as soon as patient learned of disease or when first told by MD. DAST= 1 – 2.
4) MODERATE SUBSTANCE ABUSE: History of moderate substance abuse, but quit use as soon as patient learned of disease or when first told by MD. Patient may have required treatment/intervention in order to achieve remission. DAST= 3 – 5.
6) DEPENDENCE OR SEVERE ABUSE: History of dependence or severe abuse. Patient required treatment/intervention in order to achieve sobriety (or refused treatment/intervention); or continued to use after disease progressed, developing medical complications. DAST= 6 – 8.
8) DEPENDENCE OR EXTREME ABUSE: History of dependence or extreme substance; History of multiple relapses despite of warning and/or treatment. Patient continued to use until just prior to presentation or only quit when too sick to continue. DAST = 9 – 10.

XVII. **Substance Use/Abuse/Dependence – Including Prescribed & Illicit Substances -**

Risk for Recidivism
0) None: No history of illicit substance Use; or abuse of prescribed substances.
1) Low Risk.
2) Moderate Risk.
3) High Risk.
4) Extreme Risk: History of recidivism after prior treatment or after an extended period of sobriety.

XVIII. **Nicotine Use/Abuse/Dependence**
0) None: No history of Nicotine Use/Abuse.
1) Quit >6 months (" – " test).
3) Quit <6 months (" – " test).

0 – 6 Excellent candidate
Recommend to list without reservations.

7 – 20 Good candidate
Recommend to list- although monitoring of identified risk factors may be required.

21 – 39 Minimally Acceptable Candidate
Recommend to list under certain conditions- identified risk factors must be satisfactorily addressed before representing for consideration.

40 – 68 High Risk candidate, significant risks identified
Recommend deferral while identified risks are satisfactorily addressed.

> 69 Poor Candidate
Surgery not recommended while identified risk factors continue to be present.

Considerations for Final Psychosocial Recommendations:

Overall numbers of Risk Factors (RF): Absolute_____ Severe_____ High_____ Moderate/Low_____

1. The patient has at least 1 absolute contraindication? Yes No

If the answer to the above question is yes please refer to guidelines and consider deferment/decline. If none present proceed to next question.

2. The patient has at least 2 high risk, relative contraindications? Yes No
3. The patient has at least 3 moderate/low, relative contraindications? Yes No
4. Patient failed to meet abstinence contract? Yes No
5. Listed patient who failed a toxicology screening test? Yes No N/A___
6. Listed patient who is not compliant? Yes No
7. The patient has active/unstable psychiatric symptoms in need of treatment or questionable psych history waiting clarification? Yes No

If the answer to any question #2-7 is yes, refer to guidelines for final recommendation. If none present proceed to SIPAT interpretation

Appendix F

Revised Adult Attachment Scale – Close Relationships Version

Note: Data from this document were collected and recorded on the Medical Record Review Data Collection Tool (see Appendix A). This document is included in the appendix for review and reference purposes only.

Revised Adult Attachment Scale (Collins, 1996)- Close Relationships Version

The following questions concern how you ***generally*** feel in ***important close relationships in your life***. Think about your past and present relationships with people who have been especially important to you, such as family members, romantic partners, and close friends. Respond to each statement in terms of how you ***generally*** feel in these relationships.

Please use the scale below by circling a number between 1 and 5 on the scale under each question.

1----------2----------3----------4----------5
Not at all characteristic of me — **Very characteristic of me**

1) I find it relatively easy to get close to people.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

2) I find it difficult to allow myself to depend on others.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

Please continue on the next page.

3) I often worry that other people don't really love me.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

4) I find that others are reluctant to get as close as I would like.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

5) I am comfortable depending on others.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

Please continue on the next page.

6) I don’t worry about people getting too close to me.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

7) I find that people are never there when you need them.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

8) I am somewhat uncomfortable being close to others.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

Please continue on the next page.

9) I often worry that other people won't want to stay with me.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

10) When I show my feelings for others, I'm afraid they will not feel the same about me.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

11) I often wonder whether other people really care about me.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

Please continue on the next page.

12) I am comfortable developing close relationships with others.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

13) I am uncomfortable when anyone gets too emotionally close to me.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

14) I know that people will be there when I need them.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

Please continue on the next page.

15) I want to get close to people, but I worry about being hurt.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

16) I find it difficult to trust others completely.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

17) People often want me to be emotionally closer than I feel comfortable being.

1----------2----------3----------4----------5

Not at all characteristic of me — Very characteristic of me

Please continue on the next page.

18) I am not sure that I can always depend on people to be there when I need them.

1----------2----------3----------4----------5

Not at all characteristic of me

Very characteristic of me

Appendix G

Scoring Instructions for the Revised Adult Attachment Scale – Close Relationships Version

Note: Data from this document were collected and recorded on the Medical Record Review Data Collection ***Tool*** *(see Appendix A). This document is included in the appendix for review and reference purposes only.*

Scoring Instructions for The Revised Adult Attachment Scale Close Relationships Version (Collins, 1996)

This scale contains three subscales, each composed of six items. The three subscales are CLOSE, DEPEND, and ANXIETY. The CLOSE scale measures the extent to which a person is comfortable with closeness and intimacy. The DEPEND scale measures the extent to which a person feels he/she can depend on others to be available when needed. The ANXIETY subscale measures the extent to which a person is worried about being rejected or unloved.

Original Scoring Instructions:
Average the ratings for the six items that compose each subscale as indicated below.

Scale	**Items**
CLOSE	1 6 8* 12 13* 17*
DEPEND	2* 5 7* 14 16* 18*
ANXIETY	3 4 9 10 11 15

* Items with an asterisk should be reverse scored before computing the subscale mean.

Alternative Scoring:

If you would like to compute only *two* attachment dimensions – attachment *anxiety* (model of self)
and attachment *avoidance* (model of other) – you can use the following scoring procedure:

Scale	**Items**
ANXIETY	3 4 9 10 11 15
AVOID	1* 2 5* 6* 7 8 12* 13 14* 16 17 18

* Items with an asterisk should be reverse scored before computing the subscale mean.

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