Prevention of Medical Non-Adherence in University of Kentucky Cardiothoracic Transplant Patients

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The document mentioned above has been reviewed and accepted by the student’s advisor, on behalf of the advisory committee, and by the Associate Dean for MSN and DNP Studies, on behalf of the program; we verify that this is the final, approved version of the student’s Practice Inquiry Project including all changes required by the advisory committee. The undersigned agree to abide by the statements above.

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Prevention of Medical Non-Adherence in University of Kentucky Cardiothoracic Transplant Patients

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Summer 2016

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Introduction/DNP Final Project Overview

The population of focus is the University of Kentucky heart and lung transplant patients. Patients eligible for heart transplants are typically in end-stage heart failure caused by viral infections, damage to heart valves or muscle, coronary heart disease or hereditary conditions. Lung transplant patients also have end-stage disease (ESLD) caused by conditions such as idiopathic pulmonary fibrosis, chronic obstructive pulmonary disease, cystic fibrosis, alpha-1 antitrypsin deficiency, or pulmonary hypertension. Research over the years supports the need for continuous psychiatric monitoring for these patients with end-stage diseases due to the higher incidence of anxiety and depression within this population. According to Campbell and Etringer (1999), a review of the literature suggests depression is a cause and a consequence of non-adherence in transplant patients. Non-adherence with medical treatment is the third leading cause of rejection of organs after simple allograft rejection and systemic infection (Campbell & Etringer, 1999, p. 59S).

Transplant Background

The United Network for Organ Sharing (UNOS) is a non-profit, scientific and educational organization that administers the only Organ Procurement and Transplantation Network (OPTN) in the United States. UNOS (2015) is involved in many aspects of the organ transplant and donation process including the following:

- Managing the national transplant waiting list, matching donors to recipients 24 hours a day, 365 days a year;
- Maintaining the database that contains all organ transplant data for every transplant event that occurs in the U.S.;
• Bringing together members to develop policies that make the best use of the limited supply of organs and give all patients a fair chance at receiving the organ they need, regardless of age, sex, ethnicity, religion, lifestyle or financial/social status;
• Monitoring every organ match to ensure organ allocation policies are followed;
• Providing assistance to patients, family members and friends;
• Educating transplant professionals about their important role in the donation and transplant processes;
• And educating the public about the importance of organ donation.

The following are examples of criteria set by UNOS for transplant candidates: age, ability of the patient to recover, ABO type, height and weight, life support status, listing status and time on the waiting list. Each organ type has individual criteria. For example, with heart transplantation, candidate recipients are given one of four status levels (1A – the highest level, 1B, 2, and 7). A matching candidate of Status 1A within the donor region, of matching ABO type, and within 500 miles will be given the highest priority, with multiple matches being ranked by time on the waiting list. Each of those criteria will be progressively relaxed until a match is found.

The OPTN Ethics Committee recognizes the difficulty applying broad measures of adherence to accepting transplant candidates since empirical measures are limited, and medical professionals often approach these issues subjectively. In social and medical venues, debate continues to focus on alcoholism, drug abuse, smoking, eating disorders and other behaviors as diseases or character flaws. Such behaviors are associated with disease processes in many adults. The Ethics Committee has historically supported the conclusion that past behavior that results in organ failure should not be considered a sole basis for excluding transplant candidates. However, transplantation should be considered very cautiously for individuals who have
demonstrated serious, consistent, and documented non-adherence in current or previous treatment.

**Adherence Background**

Adherence and compliance are synonyms defined as the extent to which patients follow the instructions they are given for prescribed treatments (Haynes, McDonald, Garg, & Montague, 2002, p. 1). The terms are used interchangeably; however, the term adherence is intended to be non-judgmental, a statement of fact rather than to blame of the patient, prescriber or treatment (Haynes et al., 2002, p. 1). Causes of non-adherence include the following: problems with the regimen such as adverse effects of medications, poor instructions, poor provider-patient relationships, patients’ disagreement with the need for treatment and inability to pay for treatment.

In 2010, the costs of health care in the U.S. exceeded $2.7 trillion and accounted for 17.9% of the gross domestic product (Iuga & McGuire, 2014, p. 35). According to Iuga & McGuire (2014), the U.S. health care system wastes 20% to 30% of dollars spent. Between $100 and $300 billion of avoidable health care cost have been attributed to non-adherence in the U.S. annually, representing 3% to 10% of total U.S. health care cost (Iuga & McGuire, 2014, p. 37).

Many reasons exist for non-adherence to medical regimens, including problems with the regimen (such as adverse effects); poor instructions; poor provider-patient relationship; patients’ disagreement with the need for treatment or inability to pay for it (Haynes et al., 2002, p. 2). The most common regimens assessed for adherence include the following: medications, screening, exercise, health behavior, appointment and diet (DiMatteo, 2004). Health behaviors, appointment-keeping, and diet yield lower adherence averages; each is significantly lower than
its comparison with other regimens (DiMatteo, 2004, p. 204). Methods of measuring adherence include the following: pill count, physical test, medical record/chart, self-report, collateral report and electronic monitoring (DiMatteo, 2004). The quantitative review by DiMatteo (2004) determined self-reporting, collateral reporting, and medical records yield lower average adherence scores compared to pill counting, physical tests, and electronic monitoring.

The National Center for Health and Statistics (2012) reports the U.S. spent $259 billion on prescription drugs. According to Iuga & McGuire (2014), medication non-adherence is widespread and varied by disease, patient characteristics, and insurance coverage, with non-adherence rates ranging from 25% to 50%. Patient non-adherence to prescribed medications is associated with poor therapeutic outcomes, the progression of the disease, and an estimated burden of billions per year in avoidable direct health care costs (Iuga & McGuire, 2014, p. 35).

Missed appointments are associated with an increased risk of hospitalization and mortality (Nwabuo, Dy, Weeks, & Young, 2014, p. 1). According to a quantitative review by Dr. DiMatteo (2004), appointment non-adherence is approximately 34.1%. Past research indicates patients who miss appointments tend to be younger and of lower socioeconomic status (Lacy, Paulman, Reuter, & Lovejoy, 2004, p. 541). According to Lacy et al., (2004), these patients typically have a history of failed appointments, government-provided health benefits, and psychosocial problems. Lacy et al., (2004) also determined longer waiting times have been shown to be related to lower satisfaction, which, leads to less reliable appointment keeping.

The final DNP project is a compilation of my work over the last five years. I have selected these articles because they represent my abilities to understand and apply the DNP Essentials. All of the papers within the final DNP project address different aspects of the transplant population.
Manuscript 1:

Patient Flow within the University of Kentucky Transplant Clinic

Lisa Yearsley, Harold Dennis, Dawn Jones, Madeleine Lansberry, and Kimberly Rolley

University of Kentucky
Abstract

Patient wait times inversely correlate with patient satisfaction. The University of Kentucky Transplant Clinic conducted a patient satisfaction survey, which indicated that inefficient clinic processes are prolonging patient wait times. Transplant Clinic patients experience several processes before rooming, which significantly contributes to their total wait time. The Transplant Clinic established a goal of having at least 50% of patients roomed within 30 minutes of their scheduled appointment time. Transplant Clinic audits revealed that the largest number of patients not reaching this goal were liver transplant patients. The audit also indicated that the period that contributed greatest to the delay in rooming was the wait time encountered after phlebotomy. Patients were asked to arrive 60 minutes before their appointment time as part of a new scheduling protocol. Results indicated that 75% of appointments that utilized this protocol met the goal of being roomed within 30 minutes of appointment time. By decreasing wait time and improving clinic flow, it is predicted that patient satisfaction will improve.
Introduction

Patient flow logistics are an important component of a clinic’s process. For effective scheduling, outpatient ambulatory clinic systems need to match demand with capacity, so that resources are better utilized and patient waiting times reduced (Dhar, Michel, & Kanna, 2011; Edward et al., 2008; Racine & Davidson, 2002). Patient waiting time and waiting room congestion are quality indicators that are related to the efficiency of ambulatory care systems and patient satisfaction (Camacho, Anderson, Safrit, Jones, & Hoffmann, 2006). Medical institutions are increasingly sensitive to the impact of patient satisfaction in a competitive medical marketplace. Patient satisfaction depends not only on the surgical outcome, but also on the entire process from initial scheduling of the appointment to the time before the date of operation, to the postoperative visit (Gibler, Nyswonger, Engel, Grannan, & Welling, 2011).

Background

Previous studies have identified an indirect relationship between the length of time that a patient waits in an office and that patient’s level of satisfaction with their medical provider (Dhar et al., 2011; Camacho et al., 2006; Gibler et al., 2011; Bleustein et al., 2014; Guglielmo, Plesnick, Greenspan, & Sharif, 2013; Harnett, Correll, Hurwitz, Bader, & Hepner, 2010; Huang, 2013). Because satisfaction scores are reflections of the quality of care patients feel they have received, many facilities have studied how to improve clinic flow to decrease patient wait times and improve patient satisfaction (Dhar et al., 2011; Edward et al., 2008; Racine & Davidson, 2002; Huang, 2013). The University of Kentucky (UK) Transplant Clinic performed a patient satisfaction survey, which identified patient waiting times as having the poorest satisfaction score. Based on the findings of previous studies, this long wait time experienced by patients may
not only decrease the overall efficiency of clinic processes but can potentially negatively influence the patient experience (Dhar et al., 2011; Harnett et al., 2010). Also, research indicates that extended waiting times also affect the patients’ perceived quality of care (Dhar et al., 2011; Bleustein et al., 2014). Therefore, the goal of this project was to utilize the 8-step process to improve patient flow through the clinic, the overall quality of care and patient satisfaction.

Over a 30-day period, from May 30, 2014, through June 30, 2014, the UK Transplant Clinic performed an audit on patient flow from check-in to checkout for all patients seen in the clinic. During this audit, 906 patients were tracked through patient check-in, registration, labs, vital signs, and rooming. The focus of this audit was to identify the delays that contributed to patient rooming times greater than 30 minutes from the scheduled appointment times.

The UK Transplant Clinic is divided into the following organ groups: heart and lung, kidney and pancreas, and liver. Of the transplant clinics, the liver clinic was found to have the greatest number of patients roomed in greater than 30 minutes from appointment time. For all organ groups, the longest waiting period occurred between the labs station and the vital signs station. Another trend noted was the liver clinic patients were not directed to arrive early for their scheduled appointments.

Methods

The initial patient population consisted of patients who received pre-transplant or post-transplant care at the University of Kentucky Transplant Clinic from June 1, 2014, to June 30th, 2014. The Transplant Quality Assurance and Performance Improvement (QAPI) manager, Jennifer Watkins, RN, CCTC, de-identified the data, removing protected health information before releasing the data to our team of researchers. Therefore, per Institutional Review Board protocols, patient consent was not required for this study.
All UK Transplant Clinic appointments were audited daily as part of the clinic performance improvement initiatives. Data for the month of June, collected in the APM and Lobby registration systems, was utilized for this project. For each of these appointments, the following descriptive data were collected: appointment date, organ transplant team, the reason for appointment, and patient-provider. Additionally, numerical data was comprised of the recorded times for the following patient checkpoints: appointment time, check-in, beginning and completion times of registration, phlebotomy, vital signs collection, time of patient placement in the exam room, and patient discharge time. From the 904 original appointments, all appointments that were missing one or more descriptive or numerical data points were excluded, leaving 465 patient encounters to be analyzed.

Using Microsoft Excel for data analysis, each appointment was evaluated as to whether it met the clinic’s goal of patient placement in the exam room within 30 minutes of the appointment time. Overall, 214 patients met this standard, leaving a gap of 251 patients who failed to be roomed within 30 minutes. The organ transplant team further sorted these 251 appointments by organ group to identify which group had the greatest volume of patients not meeting the 30-minute standard. This organ-based division revealed that ten heart patients, 45 kidney patients, 91 lung patients, and 105 liver patients did not meet the standard, identifying the liver transplant group as the group with the greatest number of patients not meeting the standard (See Table 1).

For the 105 appointments in the data set, the time elapsed between each checkpoint was calculated to identify the specific point in the patient flow which contributed the greatest amount to the overall wait time and then averaged to determine the overall delay for each point-of-
occurrence. The greatest waiting time was found to be the period between the phlebotomy and vital sign collection; on average this time was 44.4 minutes.

In early December 2014, our team met with the Transplant Clinic QAPI Manager and the Transplant Clinic staff to identify possible countermeasures that would reduce the phlebotomy to vital signs waiting time, thereby facilitating the rooming of patients within the 30-minute standard. Creating a new protocol for scheduling appointments to allow time for the phlebotomy process would be the most practical and efficient solution. Data analysis demonstrated the kidney transplant team has a greater number of appointments and the largest number of patients who meet the 30-minute standard. The new scheduling protocol for the liver team modeled the kidney team’s schedule which requires patients to arrive at the clinic an hour before their scheduled appointment time. Per the new protocol, as liver team patients scheduled new appointments, they would be asked to arrive 60 minutes earlier than their appointment time. This small cycle of change would allow time for the phlebotomy process and have patients to roomed within 30-minutes of their scheduled appointment time.

In December 2014, a trial of this protocol was conducted. The QAPI Manager identified four liver transplant patients who had multiple appointments scheduled within a 30-day trial period. Front desk clerks were directed to give verbal instructions to these trial patients to arrive 60 minutes before their scheduled appointment time to allow for completion of labs. As with the initial audit, time point data was collected via APM and Lobby registration systems. For each encounter in which the patient did arrive at least one hour early, data was further analyzed manually. Appointment time to rooming time was calculated and compared to the 30-minute standard to assess the effectiveness of the countermeasure.
Results

Of the four Transplant Clinic patients who were asked to arrive 60 minutes before their originally scheduled appointment time, two patients refused to comply with new scheduling protocol. The two patients that participated in the new scheduling protocol arrived 60 minutes before their scheduled appointment time on two separate occasions for a total of four appointments (Table 1). Three out of 4 appointment times met the standard of being roomed within 30 minutes of their scheduled appointment times (Figure 1). As a comparison, before implementation of the new scheduling protocol, 56 of 161 liver patients (35%) met the standard of being roomed within 30 minutes of their appointment time.

Discussion

Summary of main findings

The purpose of this project was to identify and implement a change that would improve patient flow through the transplant clinic, reduce patient waiting room time and congestion, and improve overall patient satisfaction. Patient waiting time and waiting room congestion are quality indicators related to the efficiency and patient satisfaction of ambulatory care systems (Camacho et al., 2006; Bleustein et al., 2014; Harnett et al., 2010; Huang, 2013). A comprehensive audit in June 2014 of the patient flow through the UK Transplant Clinic identified the liver team as the group with the largest number of patients with a waiting time longer than 30 minutes, and the period between labs and vital signs as the time with the greatest average waiting time. By implementing a scheduling protocol change in December 2014, which allotted time for lab collection and processing, participating patients were able to get their blood drawn, and results returned from the lab to the clinic before the time that they were scheduled to meet with their clinical provider. When they arrived 60 minutes before appointment time, our
sample population met the standard of being roomed within 30 minutes of their scheduled appointment time with a 75% success rate, an improvement over the 35% success rate before the change. By decreasing wait time and waiting room congestion, it is expected that patient satisfaction will improve.

Comparison with existing literature

The initial Transplant Clinic audit successfully identified specific points of delay that could be addressed in quality improvement measures to improve patient satisfaction. The process and findings of this audit were congruent with several recent studies on patient flow (Dhar et al., 2011; Harnett et al., 2010; Racine & Davidson, 2002). This project identified patient wait times as a measure of patient satisfaction and perceived quality of care, as similar studies have demonstrated this to be effective means for improvement (Camacho et al., 2006; Bleustein et al., 2014; Harnett et al., 2010). More specifically, the intervention of having patients arrive early for pre-appointment testing was found to reduce waiting time and improve overall patient satisfaction by 7-9% in one surgical clinic (Huang, 2013). The results are supported by previous research that demonstrates an inverse correlation between patient wait time and satisfaction (Camacho et al., 2006; Gibler et al., 2011; Bleustein et al., 2014; Guglielmo et al., 2013; Harnett et al., 2010; Huang, 2013).

Limitations

The sample population was very small in comparison to the number of patients the Liver team sees on a daily basis. Several factors limited the sample population: transplant clinic patients are chronically ill, they have frequent appointments, and many patients travel several hours to receive care at the UK transplant clinic. These patients are familiar with the previous
clinic flow, and it is imperative to give them as much notice as possible when making changes to reduce the amount of stress they incur. The nature of the project failed to afford the time to phase in changes at a rate comfortable for patients; during this trial, two of the four patients asked to arrive early refused. Although the sample was small, and adherence was inconsistent, the positive results complement the current success the kidney team has with their early arrival protocol, suggesting that phasing in this change for the liver patients will be successful in meeting the goal of reducing wait time and improving patient satisfaction.

**Future recommendations**

It is recommended that the liver team study this small cycle of change on a larger trial population--without causing stress to current patients--by phasing in protocol changes as new patients get referred to the clinic. Rather than phrasing the instructions as a request to arrive early, the scheduler should inform the patient that the appointment for labs is at “X” time and the appointment with the clinician is at “Y” time, scheduling these two events as separate entities and prohibiting refusal by the patient. Performing patient satisfaction surveys and comparing results among patients scheduled arrive early for their appointment and patients who do not arrive early will provide additional data supporting these changes as a means to achieve greater patient satisfaction. Future quality improvement projects should consider additional ways to improve patient satisfaction, which could include streamlining lab processes to reduce time spent in the clinic and improving consistency between scheduling protocols of the different organ teams within the transplant clinic.
References


Figure 1. Pie chart representing the percentage of patients roomed and not roomed within the standard 30 minutes of appointment time after the protocol change.
Table 1. Breakdown of patients who met and did not meet the standard 30 minute room time before and after implementation of new schedule protocol

<table>
<thead>
<tr>
<th></th>
<th>Standard Met</th>
<th>Standard Not Met (Gap)</th>
<th>Number Of Patients</th>
<th>Percentage Meeting Standard</th>
</tr>
</thead>
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<tr>
<td>Before new Scheduling Protocol</td>
<td>56</td>
<td>105</td>
<td>161</td>
<td>35%</td>
</tr>
<tr>
<td>After new Scheduling Protocol</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>75%</td>
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</table>
Manuscript 2:
The Importance of Psychosocial Evaluation for Heart and Lung Transplant Patients: Evidence Review Paper

Lisa Yearsley
University of Kentucky
Abstract

Background: The purpose of this literature review is to identify scientific evidence supporting the need for continuous psychosocial evaluation beginning in the pre-transplant stage and continuing through the post-transplant stage for the duration of the patient’s life.

Methods: A comprehensive search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), COCHRANE Library, Medical Literature Analysis and Retrieval System Online (MEDLINE), PUBMED and Center for Medicare and Medicaid approved transplant program databases was conducted using the following combinations of keywords and terms: Adult Heart Transplant, Adult Lung Transplant, end-stage heart disease, end-stage lung disease, anxiety, stress, depression, psychosocial and psychological needs. Studies were selected if they assessed the psychological and the psychosocial needs of adult heart or lung transplant patients.

Results: Ten journal articles met the inclusion criteria. The primary level of evidence was systematic reviews of cross-sectional and correlational studies with non-independent reference standards which is Level IV. Two of the studies were systematic reviews of cross-sectional studies and one expert opinion study.

Conclusion: All studies were in agreement that end-stage lung disease, end-stage heart disease, and heart and lung transplant patients are susceptible to anxiety, depression, and non-adherence. The studies also recommended a multidisciplinary team approach with ongoing psychosocial health assessments to improve the quality of life for this population. Finally, these studies recommended a combination of medication and psychoeducational interventions to further improve their quality of life for end-stage disease and transplant patients.
Introduction

The purpose of this literature review is to determine if ongoing psychosocial assessments improve patient outcomes and quality of life in heart and lung transplant patients. Patients with end-stage heart and lung disease are chronically ill and frequently suffer from psychosocial problems. Patients eligible for heart transplants are typically in end-stage heart failure caused by viral infections, damage to heart valves and muscle, coronary heart disease or hereditary conditions (National Institutes of Health National Heart Lung and Blood Institute Explore Heart Transplant website, 2012). Lung transplant patients also have end-stage lung disease (ESLD) caused by conditions such as idiopathic pulmonary fibrosis, COPD, cystic fibrosis, alpha-1 antitrypsin deficiency, or pulmonary hypertension (National Institutes of Health National Heart Lung and Blood Institute Explore Lung website, 2011). Research over the years supports the need for continuous psychiatric monitoring for these patients with end-stage diseases due to the higher incidence of anxiety and depression within this population. Recommended options for treating anxiety and depression include but not limited to the following: counseling, pharmacological therapy, and support groups.

According to Campbell and Etringer (1999), a review of the literature suggests depression is a cause and a consequence of non-adherence in transplant patients. Non-adherence with medical treatment is the third leading cause of rejection of organs after simple allograft rejection and systemic infection (Campbell & Etringer, 1999, p. 59S). A comprehensive literature review by Fusar-Poli et al. (2007) identifies the following as having a central role in causing depressive states in lung transplant recipients: personality disorders, coping strategies, stressful life events, physical complications, corticosteroid medications, age, gender, and psychosocial support. Fusar-Poli et al. (2007) concluded depression in lung transplant recipients
is a risk factor for future non-adherence, poor quality of life, increased the risk of physical complications and likely increased morbidity and mortality.

**Methods**

**Data Sources**

A comprehensive search of the Cumulative Index to Nursing and Allied Health Literature (CINAHL), COCHRANE Library, Medical Literature Analysis and Retrieval System Online (MEDLINE), PUBMED and Center for Medicare and Medicaid approved transplant program databases was conducted using the following combinations of keywords and terms: Adult Heart Transplant, Adult Lung Transplant, anxiety, stress, depression, psychosocial and psychological needs. Studies were selected if they assessed the psychological and psychosocial needs of adult heart or lung transplant patients.

**Data Extraction**

The search was limited to articles in the English language, published after January 1999, which reported on assessments of and interventions for psychological needs of adult heart and lung transplant patients. References in the extracted articles were examined for potentially relevant articles. Studies were selected if they assessed the psychological needs of adult heart and lung transplant patients pre-operatively and post-transplantation, and end-stage heart and lung disease patients. Exclusion criteria included articles that focused on pediatric transplant recipients and other transplanted organs. A total of sixteen publications were obtained from the search of databases. After assessing titles and abstracts of the retrieved articles, ten publications met the inclusion/exclusion criteria.
Results

From the ten journal articles that met the inclusion/exclusion criteria, 2 are well-designed systematic reviews, 7 are descriptive studies, and 1 is expert opinion. The Center for Evidence-Based Medicine (CEBM) grades evidence on a scale in which Level I is the strongest evidence decreasing to Level V, the weakest evidence (See Table 1). The CEBM classifies the systematic review as Level I evidence (See Table 1). The seven descriptive studies ranked as Level IV (See Table 1). The Level V evidence is one expert opinion (See Table 1). The CEBM further evaluates the levels on a scale and assigns a grade of recommendation (See Table 2). The grade of recommendations for the articles included the following: grade A (n=2); grade C (n=7); and grade D (n=1).

The systematic review of depression following transplantation or the efficacy and safety of therapeutic interventions in lung transplant patients thoroughly identifies causes and treatments in this population. This study identifies serotonin reuptake inhibitors and new generation antidepressants as the best therapeutic choices for this group (Fusar-Poli et al., 2007, p. 55). It also makes a point to stress the need for careful monitoring by experts due to the risk of drug-drug interactions (Fusar-Poli et al., 2007). Complementary therapies and psycho-educational intervention also help recipients to strengthen their coping strategies, offering further advantages after transplantation (Fusar-Poli et al., 2007, p. 55).

The Level IV evidence was primarily descriptive cross-sectional studies. These articles further supported the same conclusions found in the systematic review. Singer et al. (2001) wanted to identify personality styles and psychopathology in patients presenting with end-stage lung disease (ESLD) (Singer, Ruchinskas, Riley, Broshek, & Barth, 2001, p. 1246). This study determined separate and distinct personality styles that could affect the quality of life, the need
for adjunct treatments, and medical adherence in individuals with ESLD (Singer et al., 2001). According to Limbos et al., even though lung transplant recipients have better general, physical, and psychological health than their pre-transplant counterparts, both pre- and post-transplant patients experience impairment in several psychological functioning.

Level V evidence included expert opinions. For example, the American Heart Association, the Heart Rhythm Society and American Association of Critical Care Nurses endorse the need for patients with implantable cardioverter defibrillators (ICDs) to receive education and psychiatric care to cope with the anxiety, stress and post-traumatic stress disorders (PTSD) (Dunbar et al., 2012). ICDs are frequent in end-stage heart disease patients; therefore assessment for anxiety, depression, and PTSD is imperative in this population. Development or modification of coping skills in both the patient and those close to the patient would work the best to counter depression-driven etiology of non-adherence (Campbell and Etringer, 1999). Non-adherence in the transplant population leads to decreased quality of health and a decreased quality of life.

**Conclusion**

The levels of evidence were primarily Levels IV and V and a recommendation grade of C and D. All studies were in agreement that end-stage lung and heart disease patients and heart and lung transplant patients are susceptible to anxiety, depression, and non-adherence. Evidence-based practice recommends a multidisciplinary team approach with continuous psychosocial evaluation of transplant patients. To further improve quality of life, these studies recommended a combination of medication and psychoeducational interventions would be beneficial. This literature review demonstrates the importance of ongoing mental health assessments to improve the quality of life for end-stage heart and lung disease patients and transplanted patients.
References


Level of Evidence Grading Table Adapted from the Center for Evidence-Based Medicine (CEBM) Levels of Evidence website. (n.d.). http://rheum.ca/images/documents/2012CFG_AppendixB.pdf


## Table 1. Level of evidence grading table

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
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<th>Level 4</th>
<th>Level 5</th>
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<td><strong>Treatments</strong></td>
<td><strong>Outcome</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Systematic review of cross-sectional studies</td>
<td>Systematic review of cross-sectional studies with consistently applied reference standard and blinding</td>
<td>Systematic review of nonconsecutive studies, or studies without consistently applied reference standards</td>
<td>Systematic review of case-control study, or cross-sectional study with non-independent reference standard</td>
<td>Opinion</td>
</tr>
<tr>
<td></td>
<td>Randomized trial or (exceptionally) observational studies with dramatic effect</td>
<td>Non-randomized controlled cohort/follow-up study</td>
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<tr>
<td>Systematic review of inception cohort studies</td>
<td>Inception cohort studies</td>
<td>Cohort or control arm of randomized trial</td>
<td>Systematic review of case series</td>
<td>Opinion</td>
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</table>

*Adapted from the Centre for Evidence-Based Medicine (CEBM) Level of Evidence March 2009*

## Table 2. Grades of recommendation

<table>
<thead>
<tr>
<th>A</th>
<th>Consistent level 1 studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>Consistent level 2 or 3 studies or extrapolations from level 1 studies</td>
</tr>
<tr>
<td>C</td>
<td>Level 4 studies or extrapolations from level 2 or 3 studies</td>
</tr>
<tr>
<td>D</td>
<td>Level 5 evidence or troublingly inconsistent or inconclusive studies of any level</td>
</tr>
<tr>
<td>Consensus</td>
<td>Opinion supported by entire Canadian Fibromyalgia Guidelines Committee</td>
</tr>
</tbody>
</table>

The level may be graded down on the basis of study quality, imprecision, indirectness, because of inconsistency between studies, or because the absolute effect size is very small; Level may be graded up if there is a large or very large effect size.

<table>
<thead>
<tr>
<th>Author/Year/Journal/Title/Reference Information</th>
<th>Type of Literature/Design</th>
<th>Sample Size</th>
<th>Purpose of Article/Findings/Implications</th>
<th>CEBM Evidence Level</th>
<th>CEBM Evidence Grade</th>
</tr>
</thead>
<tbody>
<tr>
<td>Singer, H. K., Ruchinskas, R. A., Riley, K. C., Broshek, D. K., &amp; Barth, J. T. (2001). The psychological impact of end-stage lung disease. <em>CHEST, 120</em>(4), 1246-1252. Retrieved from <a href="http://uky.worldcat.org.ezproxy.uky.edu/oclc/4590203890">http://uky.worldcat.org.ezproxy.uky.edu/oclc/4590203890</a></td>
<td>Cross-sectional survey</td>
<td>243</td>
<td>The purpose of this article is to elucidate personality styles and the presence of psychopathology of in a clinical sample of patients with ESLD presenting for a possible lung transplant. The majority of patients evidenced mild somatic and depressive symptoms. Approximately one fourth of the sample exhibited marked anxiety and mood disturbances. A small cluster also evidenced features consistent with an antisocial personality disorder. Separate and distinct personality styles that could affect the quality of life, the need for adjunct treatments and medical adherence emerged from this sample of individuals with ESLD.</td>
<td>IV</td>
<td>C</td>
</tr>
<tr>
<td>Dunbar, S. B., Dougherty, C. M., Sears, S. F., Carroll, D. L., Goldstein, N. E., Mark, D. B., ... Zeigler, V. L. (2012). Educational and psychological interventions to improve outcomes for recipients of implantable cardioverter defibrillators and their families. <em>Circulation, 126</em>, 2146-2172. <a href="http://dx.doi.org/10.1161/CIR.0b013e31825d59fd">http://dx.doi.org/10.1161/CIR.0b013e31825d59fd</a></td>
<td>Systematic Review &gt;5000</td>
<td>The purpose of the review is to describe the psychological and quality-of-life outcomes after receipt of an ICD and describe related factors, such as patient characteristics; (2) describe the concerns and educational/informational needs of ICD patients and their family members; (3) outline the evidence that supports interventions for improving educational and psychological outcomes for ICD patients; (4) provide recommendations for clinical approaches for improving patient outcomes; and (5) identify priorities for future research in this area. The ultimate goal of this statement is to improve the precision of identification and care of psychosocial distress in ICD patients to maximize the derived benefit of the ICD.</td>
<td>I</td>
<td>A</td>
<td></td>
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<tr>
<td>Study Details</td>
<td>Study Design</td>
<td>Study Outcome</td>
<td>Study Outcome Description</td>
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<tr>
<td>Campbell, B., &amp; Etringer, G. (1999). Post-transplant quality of life issues: depression-related noncompliance in cardiac transplant patients [Supplemental material 4A]. Transplantation Proceedings, 31, 59S-60S. <a href="http://dx.doi.org/10.1016/S0041-1345(99)00130-X">http://dx.doi.org/10.1016/S0041-1345(99)00130-X</a></td>
<td>Descriptive, Retrospective</td>
<td>185</td>
<td>The purpose is to determine to what degree unrecognized or untreated depression causes noncompliant behavior and subsequent allograft rejection in cardiac transplant recipients. Our survey established that the depression-driven etiology of non-adherence would best be countered by development or modification of coping skills in both the patient and those close to the patient. More detailed studies of depression and non-adherence including intervention strategies are needed to improve understanding and the impact these strategies could have on post-transplant outcomes.</td>
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<tr>
<td>Miller, M.D., M. (2002). Depression after cardiac transplant treated with interpersonal psychotherapy and paroxetine. Depression after cardiac transplant treated with interpersonal psychotherapy and paroxetine, 56(4), 555-61.</td>
<td>Descriptive case study</td>
<td>1</td>
<td>Discuss the treatment of a 67-year old man with no prior history of psychiatry illness diagnosed with major depression following heart transplantation. Psychotherapy and paroxetine were successful in treating depression in this heart transplant patient. These efforts may apply to other heart transplant patients.</td>
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<tr>
<td>Stavem, K., Bjortuft, O., Lund, M. B., Kongshaug, K., Geiran, O., &amp; Boe, J. (2000). Health-related quality of life in lung transplant candidates and recipients. Respiration, 67(2), 159-165.</td>
<td>The study is a cross-sectional postal survey</td>
<td>46</td>
<td>The objective is to compare the health-related quality of life of lung transplant recipients with lung transplant candidates, using lung-specific and general instruments, and to assess the reliability and validity of these questionnaires. Patients surviving lung transplantations can expect a considerable improvement in most dimensions of health-related quality of life. Lung transplant patients can expect to have improvements in health-related quality of life.</td>
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<tr>
<td>Bright, M. J., Craven, J. L., &amp; Kelly, P. J. (1990). Assessment and management of psychosocial stress in lung transplant candidates. Health &amp; Social</td>
<td>Descriptive, Prospective</td>
<td>40</td>
<td>Describe the psychosocial aspects of lung transplant and the role of the social worker been described as it applies in this clinical context. This assessment alerts staff to the individual strengths and vulnerabilities of the candidates, facilitates the team in working with individual coping styles, allows</td>
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<td>Work, 15(2), 125-32. <a href="http://dx.doi.org/10.1093/hsw/15.2.125">http://dx.doi.org/10.1093/hsw/15.2.125</a></td>
<td>implementation of prophylactic interventions, and ensures that program resources adequately meet the demands of patients who are accepted to the waiting list. These efforts have proven to be effective and well received with a minimum of complications.</td>
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<td>Fusar-Poli, P., Lazzaretti, M., Ceruti, M., Hobson, R., Petrouska, K., Cortesi, M,...Politi, P. (2007). Depression after lung transplantation: causes and treatment. Lung, 185(2), 55-65. <a href="http://dx.doi.org/10.1007/s00408-006-0093-1">http://dx.doi.org/10.1007/s00408-006-0093-1</a></td>
<td>The purpose is to explore the causes of depression following transplantation or the efficacy and safety of therapeutic interventions in this patient group. Personality disorders, coping strategies, stressful life events, physical complications, corticosteroid medications, age, gender, and psychosocial support all play a central role in causing depressive states in lung transplant recipients. Serotonin reuptake inhibitors (SSRIs) and new-generation antidepressants (mirtazapine) represent the best therapeutic choices for this group of patients. Complementary therapies and psychoeducational intervention also help recipients to strengthen their coping strategies, offering further advantages after transplantation. This review aimed to promote a debate between clinicians and non-psychiatric health care workers to organize efficient health services able to screen patients for depressive symptoms and to refer them for appropriate treatment.</td>
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<tr>
<td>Grandi, S., Fabbir, S., Tossani, E., Mangelli, L., Branzi, A., &amp; Mangelli, C. (2001).</td>
<td>The aim of this study was to compare these new criteria (Diagnostic Criteria for Psychosomatic Research, DCPR) with DSM-IV in a population where a high prevalence of</td>
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<tr>
<td>Study</td>
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<td>Summary</td>
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<tr>
<td>Psychological evaluation after cardiac transplantation: the integration of different criteria. <em>Psychotherapy and Psychosomatics</em>, 70(), 176-183. <a href="http://dx.doi.org/10.1159/000056250">http://dx.doi.org/10.1159/000056250</a></td>
<td>Descriptive correlational study</td>
<td>2000</td>
<td>Psychological problems are expected (heart-transplanted patients). At least one DCPR diagnosis was found in 85 (66%) patients, whereas at least one DSM diagnosis was present in 23 (18%) patients. The joint use of DSM and DCPR criteria was found to improve the identification of psychological factors which could result in a worsening of quality of life in heart-transplanted patients.</td>
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<tr>
<td>Limbos, M. M., Joyce, D. P., Chan, C. K., &amp; Kesten, S. (2000). Psychological functioning and quality of life in lung transplant candidates and recipients*. <em>CHEST</em>, 118(2), 408.</td>
<td>Descriptive correlational study</td>
<td>2000</td>
<td>The purpose of the study is to examine the psychological functioning and quality of life (QOL) of lung transplant candidates and recipients. Although lung transplant recipients have better general, physical and psychological health than their pre-transplant counterparts, the present research suggests that both groups experience impairment in several areas of psychological functioning. Additional research should be aimed at recognizing, intervening, and improving patients’ psychological and emotional well-being.</td>
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Manuscript 3:

Comparison of the Stanford Integrated Psychosocial Assessment for Transplant and UK Transplant Center Social Work and Family Risk Assessment Tools in the UK Cardiothoracic Transplant Population

Lisa Yearsley

University of Kentucky
Introduction

Background and Significance

Transplant psychosocial listing criteria are not well standardized in the tools and techniques utilized by medical providers (Maldonado et al., 2012). The United Network for Organ Sharing (UNOS) has established minimal medical listing criteria for each organ system (Maldonado et al., 2012). The Organ Procurement Transplant Network (OPTN) bylaws (2015) state “all transplant programs shall identify appropriately trained individuals who are designated members of the transplant team and have primary responsibility for coordinating the psychosocial needs of transplant candidates, recipients, living donors and families.” The use of assessment tools, such as the Stanford Integrated Psychosocial Assessment for Transplant (SIPAT), not only assists clinicians in eliminating the emotional factor from the decision-making process but also in presenting the facts during the selection process (Maldonado et al., 2012, p. 129). The function of psychosocial consultants should not be to make a determination regarding the patient’s worthiness as a candidate, but to assist the transplant selection committee in making the best clinical decision based on currently available data (Maldonado, 2009).

Review of Literature and Conceptual Perspective

A qualitative analysis literature review, from 1970 thru 1990 by Dew et al. (2000), concluded the following regarding psychosocial assessments: 1.) They differ in content and application to candidate selection; 2.) Psychosocial status pre-transplant does not consistently affect medical outcomes post-transplant; 3.) Patients’ psychosocial status typically improves with transplant, although difficulties are prevalent in psychological adjustment and adherence to medical regimens; 4.) Psychiatric history can predict psychological outcomes after transplant but does not consistently predict adherence; 5.) Social supports and coping strategies strengthen
psychosocial outcomes; and 6.) Post-transplant psychosocial outcomes may predict physical morbidity and mortality. Studies have demonstrated an association with the transplant psychiatrist’s global rating of risk for post-transplant psychosocial problems that affect management and post-transplant non-adherence and the number of rejection episodes (Shapiro, Williams, Gelman, Foray, & Wukich, 1997). According to Campbell and Etringer (1999), a review of the literature suggests depression is a cause and a consequence of non-adherence with anti-rejection medications in transplant patients. Non-adherence with medical treatment is the third leading cause of rejection of organs after simple allograft rejection and systemic infection (Campbell & Etringer, 1999, p. 59S). Depression in transplant recipients is a risk factor for future non-adherence, poor quality of life, physical complications, morbidity, and mortality (Fusar-Poli et al., 2007).

There are three other standardized tools available for psychosocial assessment for transplant patients. The PACT uses a 5-point scale for ten items and the rater’s overall impression (Olbrisch, Levenson, & Hamer, 1989). Allowing for rater’s overall impression defeats the attempt at objectivity (Presberg, Levenson, Olbrisch, & Best, 1995). The Psychosocial Levels System (PLS) assesses patients on three gradations of intensity: Level 1 (mild/minimal); Level 2 (moderate); and Level 3 (severe), taking into account past psychiatric history, quality of family and social support, prior coping history, coping with disease and treatment, quality of affect, proneness to anticipatory problems, and mental status (Futterman, Wellisch, Bond, & Carr, 1991, p. 177). Beyond the original paper nothing else was published about the PLS most likely because The Transplant Evaluation Rating Scale (TERS) is a revision of the PLS and it seems to have replaced it (Maldonado et al., 2012). TERS classifies patients’
level of adjustment in 10 aspects of psychosocial functioning that are thought to be important in adjusting to transplantation (Twillman, Manetto, Wellisch, & Wolcott, 1993, p. 144).

The SIPAT tool (See Appendix A) was presented to the UK transplant physicians in January 2013 by Dr. Maldonado from Stanford University. The SIPAT tool standardizes the psychosocial assessment evaluation process so all transplant candidates undergo the same rigorous psychosocial scrutiny helping identify areas of strength that can be built upon, and areas of weakness needing assistance or further consultation and treatment (Maldonado et al., 2012, p. 129). The SIPAT tool uses 18 identified risk factors divided into four domains. Based on the assessment of these factors, the SIPAT provides an overall risk severity score for psychosocial variables significant in predicting post-transplant behavior, psychosocial support viability and effectiveness, treatment adherence, substance abuse, recidivism and mental health (Maldonado et al., 2012, p. 126). Currently, the University of Kentucky (UK) Cardiothoracic Transplant Clinic uses the UK Transplant Center Social Work and Family Risk Assessment Tool (See Appendix B) developed by the social workers in the transplant clinic to assess the patient’s psychosocial needs and identify areas which may lead to poor outcomes if the patient is transplanted. This tool uses a qualitative design to the identified risk factors.

Objectives

The aim is to determine if the SIPAT tool produces highly predictive transplant psychosocial outcomes compared to the current tool, the UK Transplant Center Social Work and Family Risk Assessment tool, in the University of Kentucky (UK) cardiothoracic post-transplant patient population.
Methods and Procedures

Study Population

The UK Cardiothoracic Transplant Clinic post-transplant population is comprised of chronically ill male and female patients with either end-stage heart or lung disease who have received a heart or lung transplant. To retrospectively apply the SIPAT tool at the period of transplant selection, a convenience sample of 100 electronic medical records (EMR) of transplanted cardiothoracic patients during January 1, 2012, through September 15, 2015, was selected. After the SIPAT tool had been applied to 100 EMRs, the chart was reviewed for the following negative outcomes: lack of adherence, lack of stability of psychosocial support system, recidivism of substances of abuse, the development/relapse of psychiatric problems or graft failure. Positive outcomes are defined as the absence of these complications.

Adherence was assessed by patient’s ability to keep scheduled appointments, refill anti-rejection medication on time and take only medications approved by the transplant team. The stable support system was identified by the presence of a support person post-transplant and the support person being actively involved in patient care by ensuring the patient had appropriate access to medical care at all times. Appropriate living space and the environment was assessed by appropriately connected utilities. Recidivism of substances of abuse was determined by the review of the chart for relapse of tobacco or illicit drugs. Development or relapse of psychiatric problems was assessed by the addition of psychiatric medication prescribed to the patient post-transplant that wasn’t previously prescribed. Graft rejection was determined by biopsy per the transplant protocol. One point was assigned to each outcome if the patient had a complication or was non-adherent; therefore a patient could be 0 with no negative outcomes or 5 with a negative outcome in each category.
Data Analysis

Subgroup analysis of all results was conducted to determine if there was significant variability in the results by demographic factors (e.g. gender, ethnicity, organ implanted, age at the time of transplant, and distance from patient’s home to the transplant clinic). Simple linear regression was conducted to compare the SIPAT score with the number of complications encountered by each patient. All statistical analysis was carried out using Microsoft Excel (Microsoft Office Home and Student 2010, Version 14.0.7166.5000).

Results

A total of 105 charts were reviewed, with five charts removed because the patients did not follow up postoperatively at the UK Cardiothoracic Transplant Clinic and outcomes were unable to be assessed (See Table 1). The group was comprised of (n=52) heart transplant patients, (n=2) heart and lung transplant patients and (n=46) lung transplant patients. The self-identified ethnicity of the group consisted of the following: 90% Caucasian; 7% African-American/Black; 1% Hispanic; 1% Asian; and 1% Biracial. In eighty percent of the charts reviewed the patient was living, and 20% were deceased. The mean age at the time of transplant was 49.4 (SD=15.7) years. The distance the patient lived from the UK Transplant Clinic was a mean of 108.65 (SD=146.1) miles.

The mean SIPAT score was 15.9 (SD=13.3) with an average number 1.97 (SD=1.37) negative outcomes. The regression analysis for this study indicates a significant moderate positive correlation (r = 0.52) between the SIPAT scores and the number of negative outcomes patients will experience post-transplant (See Figure 1.) In the simple linear regression analysis, SIPAT score was a significant predictor of the number of negative outcomes (b=.054; p< .0001). The SIPAT score explained 27% of the variability in the number of negative outcomes in post-
transplant patients. Furthermore, based on the listing criteria set forth by the SIPAT tool, 37% of the patients had absolute contraindications to listing the patients for a transplant. Based on their psychosocial assessments these patients would not have been transplanted until the contraindications had been addressed adequately.

**Discussion**

The SIPAT had only been studied in Stanford’s transplant population. This study validates the tool within the UK Cardiothoracic Transplant population because it shows a correlation between the number of post-transplant negative outcomes and the SIPAT score. The SIPAT tool is quantitative, and this provides the committee with a visual of predicted post-transplant negative outcomes. Both tools provide an opportunity to develop interventions to prevent negative outcomes.

Current recommendations set forth by UNOS and OPTN include comprehensive medical evaluation and a psychosocial assessment (Maldonado et al., 2012). The data collected by the UK Transplant Center Social Work and Family Risk Assessment Tool is the same data gathered in the SIPAT tool. However, the UK Transplant Center Social Work and Family Risk Assessment Tool do not assign a numerical value to the data, and it does not have clear guidelines for listing criteria. The data in this study confirms the SIPAT scores were highly predictive of the transplant patients’ psychosocial outcomes. These findings are consistent with the original study performed by Stanford (Maldonado et al., 2012).

**Limitations of the Project**

The SIPAT tool is designed for prospective assessment of patients; however, the time constraints of the project prevented this type of study. Retrospectively using the tool allowed assessment of its usefulness in this population without having to wait extended periods of time.
while patients on the waiting list are transplanted and eventual outcomes presented. The original study had four reviewers, and they were able to evaluate inter-rater reliability compared to this study with one reviewer of the charts. The Stanford study included heart, lung and liver transplant patients. The instrument was limited to historical data contained within the patient’s chart rather than having the opportunity to perform the exam on a live patient. Stanford was already utilizing a quantitative tool, so there was a comparison of scores between the tools. UK’s tool is qualitative, and a direct comparison cannot be made with the SIPAT tool. Finally, it cannot be determined if patient outcomes would be affected by the application of strengths or interventions for weaknesses.

**Conclusion**

The application of a standardized psychosocial assessment tool that utilizes a weighted value to each identified risk factors for transplant outcomes demonstrated its strength to identify patients who are at risk for negative outcomes after the transplant. The SIPAT scores were found to be highly predictive of the psychosocial outcomes in the UK cardiothoracic transplant population. Utilization of a standardized tool will allow for the development of interventions directed at improving the patient’s candidacy (Maldonado et al., 2012, p. 130). Further study is recommended utilizing additional people to review charts to determine inter-rater reliability along with applying the tool in a prospective method to determine if patient outcomes improve with interventions.
References


http://dx.doi.org/http://dx.doi.org/10.1016/S0033-3182(91)72089-6


http://dx.doi.org/10.1016/S0033-3182(95)71626-7

http://dx.doi.org/10.1176/ajp.154.11.1627


Table 1. Demographic characteristics of study participants

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<th>Organs</th>
<th>n=100(%)</th>
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<tr>
<td>Heart</td>
<td>52 (52%)</td>
</tr>
<tr>
<td>Heart and Lung</td>
<td>2 (2%)</td>
</tr>
<tr>
<td>Lung</td>
<td>46 (46%)</td>
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<table>
<thead>
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<tbody>
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<td>Male</td>
<td>67 (67%)</td>
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<tr>
<td>Female</td>
<td>43 (43%)</td>
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<table>
<thead>
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<tbody>
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<td>African-American/Black</td>
<td>7 (7%)</td>
</tr>
<tr>
<td>Asian</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Biracial</td>
<td>1 (1%)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>90 (90%)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (1%)</td>
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<table>
<thead>
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<tr>
<td>Living</td>
<td>80 (80%)</td>
</tr>
<tr>
<td>Deceased</td>
<td>20 (20%)</td>
</tr>
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</table>

| Average age of patient       | 49.4 years |

| Average distance from the UK Transplant Clinic | 108.65 miles |
Figure 1. Regression analysis of SIPAT scores vs. # of negative outcomes
DNP Final Project Report Conclusions

According to UNOS (2015), approximately 120,152 people need a lifesaving organ transplant. An active transplant candidate is eligible to be considered for organ offers at any given point in time. Of the approximate 120,000 people, 77,353 people are active waiting list candidates. From January through June 2016, 16,445 organ transplants have been performed with 7,764 total donors (United Network for Organ Sharing, 2015). As medical advances continue, people will continue living longer with comorbidities and the transplant candidate waiting list will continue to grow. Therefore, it is obvious the availability of organs is low, and the demand is high.

Research has demonstrated the importance of continued assessment of psychosocial needs to minimize non-adherence in chronically ill patients. Standardizing psychosocial assessment tool criteria will help to quickly identify areas for potentially negative outcomes in end-stage organ disease patients and transplant patients. Qualitative tools collect verbal data which is analyzed and has rater bias; however, a quantitative tool will minimize bias by presenting the data objectively.

The transplant committee is tasked with the goal to identify the most medically and psychosocially suitable candidates due to the lack of availability of organs. Providing the committee with a psychosocial assessment tool which was developed on evidence-based practices will ensure the best candidates are selected.
Appendix A

Stanford Integrated Psychosocial Assessment for Transplant (SIPAT)

Stanford University Medical Center

© Maldonado et al, 2008; updated 10/3/12; Maldonado et al, Psychosomatics 2012

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.
   1) Good: Patient may be challenging, but fully compliant.
   2) Moderate: Only partial compliance, requires multiple efforts and persuasion from the Transplant team and/or family.
   3) Limited: Only compliant after the development of complications.
   4) 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).

Score P1: ______
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 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 Mild Organic Psychopathology.
3) History of Moderate 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) Moderate: 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.

Score P3: ________
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. Patient required treatment/intervention in order to achieve sobriety. Moderate 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 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 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).
   5) Still currently smoking (per admission, accessory source report, or "+" test). Score P8:______
Stanford Integrated Psychosocial Assessment for Transplant (SIPAT)
Stanford University Medical Center
© Maldonado et al, 2008; updated 1/03'12; Maldonado et al, Psychosomatics 2012

**SIPAT TOTAL Score** (add scores for pp 1 - 4): ______

**SIPAT Score Interpretation**

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.*
Stanford's Minimal Psychosocial Listing Criteria - Risk Factors for Poor Outcome

➤ Absolute Contraindications:
A. Inadequate social support system
B. Active illicit substance use
C. Active alcohol dependence
D. Active nicotine abuse
E. Active psychotic sx’s that may impair adherence with Tx
F. Dementia
G. A history of multiple suicidal attempts
H. Non-adherence with treatment
I. History of recidivism of substance abuse after previous organ transplantation

➤ Relative Contraindications

A. High Risk:
• Active alcohol abuse
• Active abuse of prescribed substances
• Non-adherence with treatment
• Deceptive behavior
• Current suicidal ideation (in a patient with no prior Hx of multiple suicidal attempts)
• High degree of denial or ambivalence regarding transplantation
• Personality disorders
  – Cluster A (i.e., Paranoid, Schizotypal)
  – Cluster B (i.e., Antisocial, Borderline, Narcissistic)

B. Moderate Risk:
• Alcohol use (not directly causative of medical problem)
• Prescribed (“medical”) marijuana use
• Inability to understand relevant information and poor receptiveness to education
• Reluctance to relocate
• Absence of adequate living environment
• Limited or restricted access to resources
• Controlled major psychiatric disorder
  – History of suicidal attempts
  – Mood disorders
  – Psychotic disorders
  – Severe anxiety disorders
  – Mental retardation

C. Lower Risk:
• Obesity: BMI > 30 – 40kg/m²
• Limited literacy
• Cognitive disorders

➢ Stanford Guidelines for Deferment from Transplant List  <Link to PDF here>

A. Patients who meet **ONE SEVERE risk factor**
   - OR -

B. A **SIPAT score ≥ 40 – 69**, plus any of the following:
   o Questionable psychiatric history - until clarified; or a well-documented history of currently unstable psychiatric symptoms in need of active treatment
   o Patient having ≥2 high risk factors
   o Patient having ≥3 moderate / low risk factors
   o Failure to meet substance use and/or behavioral contract
Stanford Guidelines for Recommending Declining Listing/Removal from Transplant List

A. Patients who meet **ONE ABSOLUTE risk factor**

OR

B. A **SIPAT score ≥69**, plus any of the following:

- Patient meeting multiple risk factors (≥2 High Risk; ≥3 Moderate & Low Risk).
- Failure to meet abstinence contract terms within the prescribed deferment period.
- Listed patient with a positive toxicology screening test for any substance of abuse, alcohol, or nicotine.
- Listed patient who is not fully adherent with:
  - Clinic visit
  - 12-step program or Chemical Dependency Treatment Program
  - Psychiatric care
  - Development of adequate support team

C. Remediation:

- Patient will receive an intervention, and be given 2 months to modify his/her behavior or correct deficiencies.
- Above step may be repeated once, but on second reassessment (3rd talk) if behavior is still problematic or conditions are still suboptimal a recommendation may be made for the patient to be removed from the transplant list.
- A patient who has been previously declined or removed from the list: After 1 year, during which time must have followed with previous recommendations or corrective measures, must undergo a comprehensive psychosocial evaluation prior to representation to selection committee.
Appendix B

University of Kentucky Transplant Center
Social Work and Family Risk Assessment

Patient Name:
Medical Record#:
Date:
Address:
County: Distance to UK:
Phone Number:
Date of Birth: Age:
Place of Birth:
Social Security #
Nurse Coordinator:

Household Members/Significant Others:

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<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
<th>Age</th>
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Evaluation of Support System:

Housing:

Transportation:

Financial Information:

Source(s) of income:
☐ Employment
☐ Social Security Disability
☐ Social Security Retirement
☐ Supplemental Security Income
☐ Food Stamps
☐ Other

Insurance Coverage:
☐ Medicare ☐ Part A ☐ Part B
☐ Medicaid ☐ Normal ☐ QMB ☐ Spenddown
☐ Private Insurance
☐ Other

Prescription Coverage:
☐ Yes – copay amounts:

Report Created: 12/20/2015
☐ No – How does patient pay for current Rx's?

**Employment:**
- Employment History:
- Level of Education:
- Military Service:
- Future Employment Plan/Voc. Rehab:

**Medical history/cause of heart or lung failure:**

**Functional Status:**

**Current Prescribed Meds:**
- Psychotropic meds?
- Pain meds?
- Does patient take meds regularly?

**Substance Use:**
- Tobacco Use:
  - Smoker ☐ Yes ☐ No
  - If yes, smoking cessation materials provided: ☐ Yes ☐ No
  - CarboxyHgb: Date Level

- Alcohol Use:
- Illegal Substance Use:
- Drug screen: Date Result

**History of Psych/Emotional Issues & Abuse/Neglect:**

**Current Emotional Status/Mood/Affect:**
- Denial
- Anger/Hostility
- Depression/Withdrawal
- Suicidal Thoughts/Ideations
- Passive Acceptance
- Proactive Acceptance

**Cognitive Ability:**
- Alert & oriented
- Participating in decision making
- Cognitively impaired
- Mentally ill

Report Created: 12/20/2015
Motivation for transplant/Understanding of risks and benefits:

Legal Issues:

Strengths/Coping Strategies:

Ability to comply with medical care:

Hobbies/Interests:

Church Involvement/Spirituality:

Advance Directives: ☐ Yes  ☐ No  Information provided:

Narrative Assessment:

Social Work Treatment Plan:

Social worker:

______________________________  __________________________
Social Worker Signature  Date
Bibliography


Level of Evidence Grading Table Adapted from the Center for Evidence-Based Medicine (CEBM) Levels of Evidence website. (n.d.). http://rheum.ca/images/documents/2012CFG_AppendixB.pdf


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