

Employment after Liver Transplantation

by

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DEDICATION

I wish to thank my husband, my two kids and my parents for their support in the completion of my doctoral dissertation. Without their love and support I would not have been able to complete my studies. They gave me the encouragement to pursue my dreams.

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Abstract

Employment after Liver Transplantation: A National Study

by

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Purpose

To describe those who were employed within 24 months after receiving an orthotopic liver transplant compared with those who were not employed during the period 2002-2008 and to examine the factors associated with those who were employed after receiving an orthotopic liver transplant.

Background & Significance

Liver transplantation has become the treatment of choice for many patients with end-stage liver disease. The goal of transplantation is to maximize both the length and the quality of life, while minimizing the effects of disease and costs of care. Short-term post-transplant survival is exceptionally high, averaging just under 90% in United States centers. Physicians and policy makers are increasingly interested in the impact of major health interventions on employment and quality of life. Liver transplantation has clearly improved survival in patients with significant liver disease. However, the total societal costs of liver transplantation are high. Enabling patients to reenter society as active and productive members is a key goal of liver transplantation. Today, orthotopic liver transplantation is limited by the scarcity of donor organs. In light of this organ shortage, the transplant community is increasingly called upon to justify its practices and to show the impact of transplantation beyond survival.

Methods

This study utilized the secondary analysis of the United Network for Organ Sharing (UNOS) data set to examine the employment status of liver post-transplant patients. The current analysis uses data collected since the adoption of the acuity-based MELD scoring system on February 27, 2002. Multivariate analysis was used to identify independent variables associated with post transplantation employment.

Results

There were 23,144 liver transplant recipients in the U.S. between February 27, 2002 and December 2008 who met the inclusion criteria for this study. This study analyzed employment status of post-transplant patients within a 60 day window of the following target times: 6 months, 12 months, and 24 months. About one quarter of the liver transplant recipients (N= 5,656; 24.4%) were employed within 24 months post-transplant. The rest of the patients had not returned to employment during the same period. The demographic variables that were independently associated with post-transplantation employment included the following: age 18-40 years (OR = 1.00); male (OR = 1.00); college degree + (OR = 1.75); white (OR = 1.00); and working pretransplant (OR = 3.8). Patient with alcoholic liver diseases had significantly worse employment outcomes than patients with other etiologies of liver disease (OR = 1.00). Patients that were employed had significantly better functional status than those who were not employed (OR=1.00). The study found that patients with a pretransplant history of diabetes were 0.84 times and those with a prior history of angina were 0.63 times as likely to be employed as those without these histories.

Discussion

This is the first known study to examine employment status of liver transplant patients in the United States at the national level using UNOS data. It is important in an era of evidence-based medicine to ensure that healthcare interventions such as liver transplantation produce improved health outcomes. New policy strategies are needed to improve the high unemployment rate among liver transplant recipients.

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Chapter 1: Introduction to the Problem and Study Purpose

Introduction

Patients' employment outcomes after solid-organ transplantation have been an area of concern to transplant professionals as well as the general public. The economic burden of transplantation has created concern in governmental agencies regarding the funding of this procedure, as demonstrated by Oregon's withdrawal of Medicaid funding for solid-organ transplantation in 1987 (Evans, 1990). In addition, in our society, securing gainful employment is associated with normal socialization, achievement of personal goals, financial independence and self-esteem. (Paris, Woodbury, Thompson, et al., 1992, 1993)

Yet, there have been disappointing findings regarding patients' employment (ranging from 26% to 60%) after liver transplantation (Cowling, Jennings, Goldstein, Sanchez, Chinnakotla, Klintmalm, et al. 2004a; Hunt, Tart, Dowdy, Bue, Williams, & Clavien, 1996; Newton, 1999; Rongey, Bambha, Vanness, Pederesen, Malinchoc, Therneau, et al. 2005; Saab, Wiese, Ibrahim, Peralta, Durazo, Yersiz, et al., 2007; Sahota, Zaghla, Adkins, Ramji, Lewis, Moser, et al., 2006). Several factors may be associated with unemployment after liver transplant surgery. From 60 to 70 percent of patients who have received a liver transplant and do well medically do not become employed following the procedure (Belle et al., 1997; Bravata et al., 2001). Further research has shown that unemployment post-transplantation is associated with poor health, disability status, early retirement, and fear of losing disability or Medicaid benefits (Hunt et al. 1996; Rongey et al. 2005).

With the high expense of liver transplantation, issues such as long-term functional recovery and employment outcomes have become an important means of evaluating the cost-utility and cost-effectiveness of this therapy. The ability to return to work following liver transplantation is an important health goal for recipients to achieve and is an indicator of overall transplant success. The majority of liver transplant operations have been performed on working age adults, but recent data from United Network for Organ Sharing (UNOS) (2008) showed that only 22% of adult liver transplant recipients return to work after transplantation. Over the years, research in the area of employment after liver transplantation has focused on quality of life, societal reintegration, and working competence. Employment status of adults after liver transplantation was reviewed for this paper as it relates to the theoretical framework developed by Michael Grossman (1972). The theoretical underpinnings of this framework are discussed in great detail in Chapter 2.

History of Liver Transplantation

The first experimental attempts at liver transplantation, in dogs, were initiated more than 50 years ago, in 1955, by first name Welch of Albany, New York. Welch described the insertion of an auxiliary liver engrafted heterotopically in either the pelvis or right paravertebral gutter (Keeffe, 2000). The portal vein was anastomosed to the inferior vena cava and the hepatic artery to the aorta or iliac artery. No immunosuppression was used. The first experimental liver replacement, that is, orthotopic liver transplantation, was reported by Cannon at the University of California, Los Angeles in 1956, but none of those dogs survived (Keeffe, 2000).

The first attempted human liver transplantation was reported by Starzl in 1963 (Keeffe, 2000). The recipient was a 3-year-old boy with biliary atresia who had had multiple previous operations. He died of blood loss during surgery because of uncontrollable coagulopathy. Two other liver transplantations were carried out in the same year, but the recipients died after 22 and 7 days, respectively. In the next year, isolated attempts at human liver transplantation were unsuccessful in Boston and in Paris. These first seven human liver transplant operations achieved patient survivals ranging from zero to 23 days (Keeffe, 2000).

The first truly successful human liver transplantation was performed in 1967 by Starzl at the University of Colorado. The recipient was an 18-month-old child with hepatocellular carcinoma who survived more than 1 year before succumbing to recurrent tumor (Keeffe, 2000). Six other patients underwent liver transplantation in 1967 and 1968, with a maximum survival of 30 months. During the next 12 years, approximately one liver transplantation per month was performed at the University of Colorado. The 1-year mortality rate was greater than 50%. The long-term survival rate of liver transplant recipients remained at 30% (Starzl, Iwatsuki, & Van Thiel, 1982).

Overall, liver transplantation during the 1960s was marked by a record number of consecutive failures with patients dying from infection, hemorrhage, and other problems (U.S. Department of Health and Human Services [HHS], 1990). By the late 1970s, there was definite improvement in recipient survival, but mortality rates remained high, approximately 70% after one year (HHS, 1990). It was not until the immunosuppressive agent cyclosporine was introduced in 1979 that survival rates surpassed mortality rates in adult liver transplant recipients (HHS, 1990). With improved liver transplant recipient

survival rates and other positive patient outcomes, a new era of liver transplantation was heralded in the United States. By 1980, liver transplantation had become a common treatment for adults with end-stage liver disease. However, it has only been since 1990, when Medicare extended entitlement benefits to adult patients with end stage liver disease (ESLD) for liver transplantation, that liver transplantation was no longer considered experimental for adult recipients (HHS, 1990). Liver transplantation for adult recipients is now considered safe and effective when performed in government approved liver transplant centers. Liver transplantation is now performed at over one hundred centers in the United States as well as numerous centers in Europe and elsewhere.

Liver transplantation is now the treatment of choice for ESLD, for many malignancies of the liver and biliary tract, for acute liver failure, and for many inherited metabolic derangements. The scope of treatment for ESLD has expanded to provide a durable and good quality of life outcome for many adult and pediatric patients. Advances in surgical technique, immunosuppression, supportive and anesthetic care, and a more refined application of organ allocation based on outcomes analysis underlie the growth in this exciting and dynamic field.

Significance of the Phenomenon

Liver transplantation is defined as the replacement of a diseased liver with a healthy liver allograft. The most commonly used technique is orthotopic transplantation, in which the native liver is removed and the donor organ is placed in the same anatomic location as the original liver. Orthotopic liver transplantation (OLT) has become an accepted treatment for end-stage liver disease of various etiologies. Recent data from the United Network for Organ Sharing (UNOS) showed that more than 86,000 liver

transplantations have been performed in the United States (UNOS, 2007). As a result of improved surgical techniques and immunosuppressive regimens, one, three, and five year survival rates after OLT are 87.7%, 79.9%, and 74.3% respectively (UNOS, 2004). In light of the increasing survival rates after liver transplantation, the current focus of liver transplantation has expanded to include not only patient survival, but monetary costs and social impact as well.

Given that the average age for adult liver transplant recipients is 45 years, a time in life when many expect to spend a significant portion of the day engaged in work-related activities, employment concerns influence the quality of life for patients with end-stage liver disease and liver transplant recipients. Recent data from UNOS (2008) revealed that only 22% of adult liver transplant recipients return to work after transplantation. Employment results from 2004 to 2006 compared employment patterns of transplant recipients of different age groups and are shown in Figure 1. Post-transplantation, the percentage of adult recipients aged 35 to 49 years (30%) who were employed was less than the percentage for recipients aged 50 to 64 years (55%). This statistic is strikingly low when one considers that many liver transplant recipients are receiving transplantation during their most productive years.

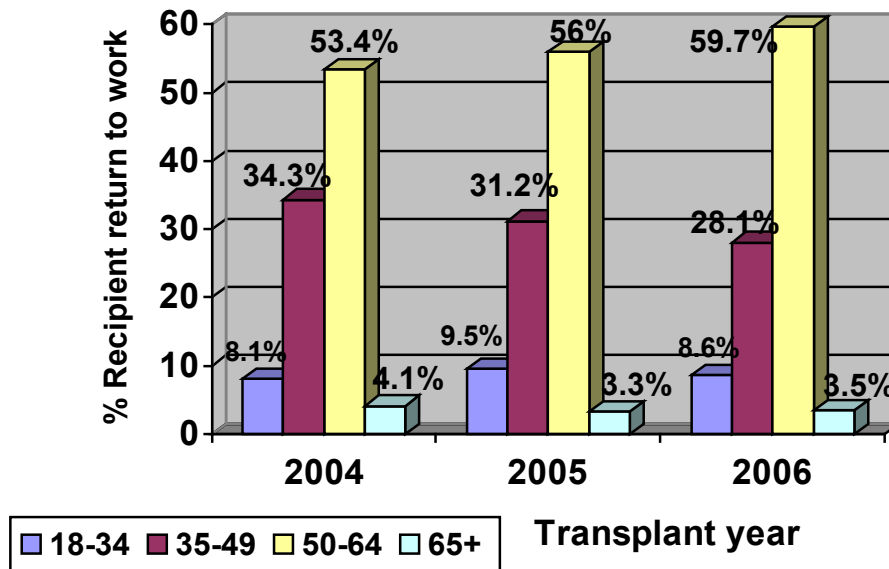


Figure 1. UNOS Data of Adult Patients Employment Following Liver Transplantation from 2004-2006 by Age Group

Although liver transplantation has been a success story of modern medicine, it is also a particularly resource-intensive medical procedure (Evans, Manninen & Dong, 1993). In the current era of cost containment and seeking “value for money,” all medical procedures are increasingly subject to economic scrutiny. This is particularly true for solid-organ transplantation, which is often reimbursed as a negotiated global fee covering all aspects of the procedure (Best, Veenstra & Geppert, 2001). There is increasing emphasis on continuous quality improvement processes and outcomes analysis in health care delivery. Due to the high cost and intense resource utilization associated with liver transplantation as a procedure, there is a particular need for documenting the outcomes of these efforts. This includes not only the usual medical outcomes but also quality of life and financial measures.

Liver transplantation has become the treatment of choice for many patients with end-stage liver disease. The goal of transplantation is to maximize both the length and the quality of life, while minimizing the effects of disease and costs of care. Short-term post-transplant survival is exceptionally high at just under 90%. Transplantation professionals are shifting their focus to achieve long-term survival, free of morbid and mortal complications, in association with an acceptable quality of life (Karam, Castaing, Danet, Delvart, & Gasquet et al., 2003). Traditionally, the success of liver transplantation has been measured by one, three, and five year survival rates. Over the past 35 years, advances in medical and surgical therapies have dramatically improved these survival rates. Specifically, the introduction of the calcineurin inhibitors (CNI), cyclosporine and tacrolimus, revolutionized solid organ transplantation by decreasing acute allograft rejection and early graft loss, and increasing patient and graft survival. Due to these advances, the population of long-term survivors with a liver transplant is now tenfold greater than the number of transplantations done each year. Ultimately, outcomes of liver transplantation will need to be judged not only by survival, but also by the number of quality life years restored, a measure which incorporates both survival rate and the quality of the time survived. In addition to prolonging survival, a substantial number of studies have found that orthotopic liver transplantation improves recipient quality of life (Belle, Porayko, Hoofnagle, Lake & Zetterman, 1997; Bravata, Olkinn, Barnato, Keefe & Owens, 1999; Caccamo, Azara & Dogila, 2001; Gross et al., 1999; Levy et al., 1995; Tarter, Switala, Arria, Plail & Van Thiel, 1991).

Despite these achievements in overall patient outcomes, liver transplantation has been criticized for its expense (Evans et al., 1993). The national expenditure for liver

transplantation was estimated to have reached \$1.4 billion in mid-1990 (Evans, 1995). In an era of budgetary constraints in health care, consideration of cost-effectiveness of medical interventions has become critically important. There has been increasing emphasis on improving the economic efficiency with which liver transplants are performed (Evans, 1995; Showstack, Katz & Lake, 1999).

Physicians and policy makers are increasingly interested in the impact of major health interventions on employment and quality of life. Liver transplantation has clearly improved survival in patients with significant liver disease. However, the total societal costs of liver transplantation are high. These costs would be diminished, in part, by return to employment among healthy patients after liver transplantation (Hunt et al., 1996). Enabling patients to reenter society as active and productive members is a key goal of liver transplantation. Today, liver transplantation sustains favorable rates of patient survival. Nevertheless, its use remains limited by the scarcity of donor organs. In light of this organ shortage, the transplant community is increasingly called upon to justify its practices and show the impact of transplantation beyond survival.

Chapter 2: Literature Review and Theoretical Framework

Review of the Literature

The purpose of this paper is to provide a thorough literature review of those variables that contribute to employment after liver transplantation. It is the aim of this author to give the reader insight into some of the more important issues that affect the transplant recipient's employment status. This paper is organized into two sections. The first is a literature review of those demographics, health related and external variables relevant to employment post transplantation. The second section describes the theoretical framework developed by Michael Grossman.

Grossman's health capital model (1972) is used to assess how liver transplantation affects optimal health stock and labor force participation after transplantation. This literature review is organized in relation to the demographic, health-related and external variables described by the Grossman model used to assess the effect of liver transplantation on employment outcomes. This model is presented as a guide for understanding the relationships between the variables discussed and the outcome measure employment after liver transplantation as they relate to recipient's overall functional status and quality of life.

A literature search plan was developed and systematically applied. The data search was carried out with PubMed (1983-2007), CINAHL (1982-2007), MEDLINE (1980-2007), and PsycINFO (1980-2007). The lengthy search period was chosen because of changes over the years in the field of liver transplantation and the potential consequences in the daily lives of patients. The search was restricted to articles published in the English language.

Key search terms entered were: liver transplantation, transplantation, and health related outcomes after transplantation. Because of the lack of a clear definition of the outcome variable, quality of life and employment, it was considered important to perform a sensitive and broad search. Therefore, keywords related to a variety of aspects of quality of life and employments were included. For MEDLINE, the keywords were: employment, vocational rehabilitation, social adaptation, social adjustment, work capacity, and return to work after transplantation.

The keywords and initial searches of the online databases produced 40 potentially useful references. Subsequently, the abstracts and titles of these references were screened. Only literature which met the following three criteria was considered appropriate for critique and review. (1) The study population was exclusively concerned with adult patients (18 years and older) with a functioning graft after liver transplantation or was concerned with adult patients after successful liver transplantation. (2) The study population had a mean follow-up of at least one year after liver transplantation. (3) The study presented sufficient information based on patient self-reported data about variables considered to be indicators of quality of life and employment, such as social participation, schooling, household activities, return to work, and social relations. The following criteria were used for exclusion: (1) the study population consisted solely of patients with combined liver–kidney transplantation or included solely patients after retransplantation.

There are no formal guidelines established to study employment in the transplant population. To study employment outcomes post-transplantation, this paper used the

operational definition of the variable “employment” to mean employed following liver transplantation.

Factors Associated with Employment after Liver Transplantation

Demographic Characteristics

Individual demographic characteristics are important to consider when examining employment outcomes. According to the Health Capital Model, the depreciation rate increases with age which causes health to deteriorate (Grossman, 1972). As less health capital leads to less chance of being employed after transplantation, age would be positive. In addition, the Health Capital Model predicts that more highly educated individuals will demand a larger optimal health stock (Grossman, 1972). Highly educated liver transplant recipients would then have a larger stock and consequently have a higher chance of being employed after transplantation. This analysis addressed the demographic variables of age, education, race, gender and pre transplant employment.

Age. Seven studies were found evaluating employment after liver transplantation in regard to age. Researchers have found that age proved to be a significant factor affecting post-transplantation employment status. A study by Loinaz et al. (1999) provides a detailed evaluation of employment patterns of 137 patients before and after transplantation at a center in Madrid, Spain. Fifty-six patients (41%) returned to work an average of 2.6 months after transplantation. Patients younger than 50 years old and those who had worked within 12 months pre-transplantation were significantly ($p = .004$) more likely to return to work than patients older than 50 years who had been unemployed for the year before transplantation. In another single center study, researchers from a Canadian medical center, Adams, Ghent, Grant and Wall (1995), concluded that the age

of the recipient was related to the likelihood of returning to work. The mean age of employed patients was significantly younger than that of unemployed patients (41.7 ± 1.2 years versus 49.6 ± 1.3 years, $p < .0001$).

This was not a surprising finding because older patients are more likely to seek early retirement and the ability to find new gainful employment decreases with age. Older patients tend to have (a) longer pre-transplantation disability and are more likely to be on a disability pension at the time of transplantation. It is common for patients to take an early retirement after a major health problem. These patients are not considered to be unemployed in the sense that they are not actively seeking employment (Blanch et al., 2004; Moyzes, Walter, Rose, Newhaus & Klapp, 2001).

In a stronger single center study from the Mayo Clinic, Rongey et al. (2005) conducted a study of 186 adult liver transplant recipients who survived for at least one year post-transplant. The study showed that age was a predictive variable for employment and suggested that individuals transplanted at an older age were less likely to be employed. The study demonstrated that the employment rate was higher in liver transplant recipients who were less than 65 years of age (61%), whereas only 26% of those 65 years or older were employed. In logistic regression analysis, the study showed that age 56 years or younger was a significant (OR: 5.1; CI 1.8-14.3) variable associated with post-transplant employment. Other studies concluded that age was not a predictor of return to work after transplant (Hunt et al., 1996; Nicholas, Oleske, Robinson, Switala & Tarter, 1994).

In summary, it can be very difficult to interpret the results of studies presenting employment data for liver transplant recipients in regard to age. This is primarily because

the reviewed literature discussed the fact that the age of the recipients proved to be related to the likelihood of returning to work because older patients were more likely to seek early retirement. However, the published studies failed to explain the reasons for not returning to work for younger, healthy transplant recipients. The reviewed literature found that younger transplant recipients are more likely to work after transplant than older recipients. However, the frequency with which patients go back to work post-transplant is perhaps disappointingly low. Given that the average age of adult liver transplant recipients is 45 years, a time in life when many expect to spend a significant portion of the day engaged in work-related activities, issues of returning to work after transplant for younger patients will only become more pronounced because of the intense resource utilization that transplantation demands. It will be important to research employment outcomes in the transplant population, particularly among younger transplant recipients.

Gender. Liver transplantation has been investigated extensively, but little is known about its relationship to gender, and the effects of gender on many transplant issues such as employment. One study (Cowling et al., 2004b); specifically conducted to address some of the issues of gender and transplantation studied 88 male and 61 female liver transplant recipients. The recipients completed the questionnaire at their pre-transplant evaluation and again at their one and two year follow-up visits at Baylor University Medical Center, Dallas, Texas. The study found that a significantly greater percentage of men compared with women reported current employment at the initial or pre-transplant evaluation ($p = .001$) and again at one year post OLT ($p = .019$). By the second year, employment rates between the sexes were similar.

A five-year longitudinal study by Moyzes and colleagues (2001) of 91 transplant patients found that the effect of gender was an unexpected finding. They reported that after transplant surgery significantly more men than women returned to work. In contrast, Hunt et al. (1996) studied 52 patients who subsequently underwent liver transplantation and survived for at least six months. The specific objective of this study was to identify potential social and economic factors that might prevent return to work for healthy patients after liver transplant. The authors compared those patients who were employed post-transplantation with those who were not. They found that there was no difference in gender between employed and unemployed post-transplant patients.

These studies have mixed findings because much of the work-related literature, specifically that pertaining to transplantation, describes work as synonymous with employment. Only a few articles have discussed the contributions of household workers (Berlakovich et al., 1994; Matas et al., 1996; Newton, 1999). A well designed, retrospective, cross-sectional post-transplant return to work survey by Newton (1999) indicated that, after transplant, 63% of recipients were working. One reason for the significant increase in return to work rates was the inclusion of household workers in the operational definition of work. Using the classic definition of work for this study would have resulted in a return to work rate of 36%. Similarly, another study by Newton (2001), using an operational definition of work which included both employment and household work, found that 59% of the sample's female alcoholic liver transplant recipients were working post-transplant. Of this group, 17% reported that they were household workers.

The reviewed literature had inconsistent findings regarding return to work by gender. A possible explanation for this discrepancy is that the studies did not have a

precise definition of employment. In some studies, those who did household work were considered employed, but in others they were considered unemployed. For example, Hunt et al., (1996) designated “employed” to refer to those who had returned to work after transplant. Adams et al., (1995) and Newton (1999) used a broader focus, categorizing homemakers and students as “employed” if they had returned to their same pre-transplant roles. The difficulty in synthesizing and generalizing the results of these studies derives from the lack of a uniform definition of employment. A standard approach in defining the term “employed” would permit more accurate comparisons. Further research needs to be undertaken using an operational definition of work, which includes both employment and household work.

Marital Status. Employment by marital status has shown inconsistent results. There was a dispute in the literature regarding the influence of an individual’s marital status on post-transplant employment status. A study conducted by Nicholas et al. (1994) examined the quality of life after liver transplantation in 166 patients. The study found that post-transplant employment was related to marital status. Recipients who were married were 3.18 times more likely to be employed post-transplant than unmarried recipients. In contrast, the studies by Hunt et al. (1996) (n = 52), Sahota et al. (2006) (n = 126), and Saab et al. (2007) (n = 308) did not confirm the Nicholas et al. (1994) study findings. Unfortunately, these authors did not suggest any reasons why this should be so.

Race. Racial disparities in post-transplant care and outcomes are not well studied. Liver transplantation has been investigated extensively but little is known about its relationship with race and ethnicity, and the effects of race and /or ethnicity on many transplant issues. Although liver transplantation has been established as a durable therapy

for all forms of ESLD, several studies have identified racial barriers to liver transplantation (Reid, Resnick & MChang, 2004). African American (AA) patients appear to be underrepresented among liver transplant recipients. In 2005, only 6.8% of all patients on the liver transplant (LT) waiting list and 9.4% of LT recipients were African American. Compared with the U.S. population, AAs represent 12.9% of the total population. In contrast, the fraction of Hispanic patients on the waiting list (16%) has nearly tripled in the last decade. Hispanics comprise 13% of LT recipients and 12.5% of the U.S. population (Pomfret, Fryer & Sima, 2007). Success rates for transplantation also are related to post-transplant employment outcomes. Studies have found racial barriers to liver transplantation. However, none of the reviewed studies (Hunt et al., 1996; Saab et al., 2007) identified ethnicity as predictive of employment. A study by Hunt and colleagues (1996) (n = 52) found no significance difference in race between employed and unemployed post-transplant patients. Further studies need to focus on the impact of race and ethnicity on post-transplant employment outcomes.

Education. Employment following liver transplantation has been studied in regard to the impact educational level plays on employment status. Results in the literature appear mixed. More recent studies are more likely to report that years of education have a statistically significant effect on employment after liver transplantation (Cowling et al., 2004a; Moyzes et al., 2001; Sahota et al., 2006) than earlier reports (Hunt et al., 1996; Newton, 1999). In a cross-sectional study of adult liver transplant recipients conducted to identify predictors for employment after liver transplantation, Sahota et al. (2006) found that the level of education attained prior to OLT was predictive of employment status. Patients with a post-graduate education were more likely to be working before and after

OLT compared with patients who had not completed a high school education ($p = 0.0005$). In this study, approximately 49% of post-transplant patients returned to work: non-high school (4 patients), high school (12 patients), undergraduate (7 patients), and post-graduate (15 patients). This finding that employed patients were better educated is supported by Moyzes et al. (2001).

Another well designed, prospective study by Cowling et al. (2004b) studied 88 male and 61 female OLT recipients to compare levels of health-related quality of life between males and females, both before and after liver transplantation. The study found that among men, the more educated (> 12 years) reported higher employment rates than the lesser educated (< 12 years) at one year after transplant and again at two years post-transplant (45% versus 19%; $p = .04$). Among women, the findings revealed no significant influence of education on employment rates at one or two years post-transplant.

The findings of Sahota et al. (2006), Moyzes et al. (2001), and Cowling et al. (2004b) contradict the findings of earlier reports. Hunt et al. (1996) studied 52 patients who had undergone orthotopic liver transplantation at Duke University from 1984 to 1993 and survived greater than six months. Sixty percent (31/52) of patients were employed after transplantation. Employed and unemployed post-transplant patients exhibited no significant difference in education. The authors argue that the reason for this is that their sample was small. A study by Newton (1999) of 230 patients from a large, mid-western liver transplant program found that 63% of the sample was working after transplant. The study found that the recipients' educational background did not have a significant effect on return to work.

The issue of heterogeneity regarding characteristics of the study population in the reviewed studies makes it difficult to draw firm conclusions about the effect educational background has on post-transplant employment status. For example, Cowling et al. (2004b) designated levels of education to refer to those patients with >12 years or <12 years of education. Sahota et al. (2006) used a broader focus, categorizing levels of education as non-high school, high school, undergraduate, or post graduate. A standard approach for defining the term level of education would permit fitting criteria.

Employment Status Prior to Transplantation. With regard to pretransplant employment status, the reviewed studies have found that employment status prior to transplantation was highly predictive of whether patients returned to work or not. A study by Rongey et al. (2005) examined factors affecting health insurance and employment status in 186 long term liver transplant recipients. Of the 186, 98 patients were employed post-transplant, including 62 working full-time and 19 working part-time. Of those with paid employment, managerial or professional employment was the most common job category. In the logistic regression analysis, Rongey et al. (2005) found that employment prior to transplantation was significantly associated with employment post-transplant (odds ratio: 5.1; CI: 1.8- 14.0). This data was supported by Sahota et al. (2006). Individuals who worked during the previous five years before transplantation were more likely to return to work ($p < 0.0001$), particularly patients who had held a job for longer than six months prior to transplantation ($p < 0.0001$). Patients such as farm hands or unskilled laborers who held “low skill” jobs were much less likely to return to work than executives, administrators, managers, or technicians ($p < 0.0001$). This finding was also reported by Adams et al. (1995), who found that liver transplant recipients working

previously in non office jobs were significantly less likely to return to work after transplantation than patients who held office jobs ($p = .009$). Hunt et al. (1996) found that pre-transplant employment correlated strongly with post-transplantation employment ($p < .0005$).

Unfortunately, these studies do not demonstrate causality between pre-transplant and post-transplant employment. One might surmise that transplanting patients before they become ill enough to become disabled and lose employment could potentially increase the probability of post-transplant employment. However, the recent change in organ allocation using the Model for End Stage Liver Disease (MELD) scale favors patients with advanced liver disease and may have an adverse effect on the proportion of patients still employed by the time of transplantation.

Health-Related Characteristics

The second component of the model includes the health-related variables. Health is an important human capital and vital to the explanation of labor force participation. The endogeneity of health status is the central contribution of the Grossman model. In this approach, poor health is likely to have an adverse effect on work performance and leads to lower productivity. As a result, people with poor health have a lower probability of being employed under prevailing wages. On the other hand, low productivity associated with poor health decreases individuals' earning potential, and therefore their willingness to participate in the labor force. Thus, according to human capital theory, health and labor force participation are positively correlated. That is, better health is likely to lead to a higher probability of being employed. This analysis addressed the

effect of health-related variables (etiology of liver disease, MELD score, health status and history of comorbidities) on the employment status of liver transplant patients.

Health Status/ Functional Status. Health status has been widely used as a measure of need when examining factors that influence return to work phenomena. The individual's health status following liver transplantation can have an effect on their likelihood of successful employment. Adams et al. (1995) used the Sickness Impact Profile (SIP) to study 217 patients who had undergone liver transplantation and survived for at least 9 months. The SIP is a multidimensional instrument that quantifies health status with respect to physical, cognitive, and behavioral function as subjectively experienced by the patient. The specific objective of this study was to identify the factors affecting employment after liver transplantation. The authors compared those patients who were employed post-transplantation with those who were not. They found the individuals in the employed group to be younger, to have had shorter pre-transplant disability, and to have had significantly lower SIP scores in ambulation, home management, physical function, and pain than those individuals who remained unemployed. Unfortunately, the authors did not provide the actual scores from these profiles, which would have allowed direct comparison with other studies. Hunt et al., (1996) reported similar findings. When patients were queried about the most important factor preventing their return to work, 80% of respondents cited “problems with their health.”

A Danish study conducted by Aadahl, Hansen, Kierkegaard and Groenvold (2002) assessed fatigue and physical function after orthotopic liver transplantation. The aim of the study was to assess the health related quality of life (HRQL) of Danish liver

transplant recipients. The researchers investigated the nature of the patients' fatigue in detail, compared their HRQL against that of the Danish general population, and identified predictors of physical function and physical fatigue. The study used the 36-Item Short Form Health Survey (SF-36), the Multidimensional Fatigue Inventory (MFI-20), and the Hospital Anxiety and Depression Scale (HAD), as well as a number of questions about work, marital status and education.

The SF-36 was used to measure physical, social and mental functioning and well-being. The SF-36 was scored according to standard procedure on a range from 0 to 100. A score of 100 is defined as the best possible health in each health dimension. The MFI-20 was used to measure different types of fatigue. The MFI-20 consists of 20 items scored as five different fatigue scales: general fatigue, physical fatigue, reduced activity, reduced motivation, and mental fatigue. Each scale was transformed into a score from 0 to 100, in which 0 indicates absence of fatigue.

The study sample consisted of 126 liver transplant recipients. It found that Danish liver transplant recipients did not differ from the general population on mental health, but differed on all physical and social health dimensions. On the two SF-36 component summaries, a significant difference was found on the physical component summary (PCS) (liver transplant PCS = 44.8, general population PCS = 49.9, $p < .01$), whereas no difference was found on the mental component summary (MCS) (liver transplant MCS = 53.3, general population MCS = 53.8, $p = \text{NS}$). The authors found that patients who were not working had poorer physical function ($n = 70$, SF-36 score = 64 ± 25) and more physical fatigue ($n = 70$, MFI-20 score = 57 ± 34) than patients who were either working or studying ($n = 60$, SF-36 = 90 ± 14 , MFI-20 = 31 ± 26). Multiple

regression analysis indicated that the liver transplant recipients with alcoholic or cryptogenic cirrhosis experienced significantly poorer physical function (SF-36 = -12.2 ± 4.5 , $p = .007$) and significantly more fatigue (MFI-20 = 17.3 ± 6.7 , $p = .01$) than patients with other diagnoses (hepatitis, primary biliary cirrhosis, primary sclerosing cholangitis: SF-36 = 1.7 ± 4.4 , $p = \text{NS}$; MFI-20 = 2.6 ± 6.6 , $p = \text{NS}$).

Although this study showed significant differences between employed and unemployed patients post-transplantation, it did not reveal the impact of liver transplantation on each patient's individual status because the authors did not include any pre-transplantation values as controls. This makes interpretation of the results difficult. It is possible that the patients with lower functioning and more physical fatigue before transplantation could be those with lower functioning after transplantation, with little overall improvement in each individual patient.

In a study population of 186 liver transplant recipients, Rongey et al. (2005) reported similar findings that poor health was the most common reason for unemployment. Overall, there were 42 respondents who were unemployed. One-half of the unemployed stated that they wished to return to work, whereas one-third of the unemployed were actually looking for work. Of the 21 who wished to return to work, 8 expressed interest in a work rehabilitation program. The majority (76%, $n = 32$) of those unemployed cited disability (poor health) as the reason for unemployment.

A large cohort study ($n = 316$) was conducted by Saab et al. (2007) at the University of California, Los Angeles (UCLA) transplant center focusing on employment and quality of life of post-liver transplant patients. All SF-36 domains collected post-transplantation were significantly lower in the cohort compared with the general

population ($p < .001$). Two domains were significantly associated with post-transplantation employment: physical functioning (OR: 1.17; 95% CI, 1.10-1.26; $p < 0.01$), which assesses limitations in physical activities because of health problems, and role physical (OR = 1.1; 95% CI, 1.02-1.16; $p < 0.01$), which assesses limitations in usual role activities because of physical health problems. Mental health had no association with employment (OR = 0.98; 95% CI, 0.95- 1.00; $p = 0.09$). The study results showed that poor physical health is a factor in unemployment post-transplantation. Physical functioning, but not mental health, was significantly associated with employment post-transplantation in the study. This finding was not surprising, as patients are extensively screened by psychiatrists prior to transplantation but undergo no formal physical therapy evaluation after transplantation.

In summary, the reviewed studies found that poor physical health and disability affect post-transplant employment status. However, none of the studies categorized the reasons for poor health. The prevalence and severity of specific symptoms and problems after liver transplantation have not been sufficiently addressed by the generic questionnaires used in the reviewed studies. In addition, information about whether quality of life was improved by liver transplantation is limited. It also is rather confusing given the question of the direction of causality. Are patients unemployed because they have more functional problems, or do they have more functional problems because they are unemployed? The reviewed studies are very heterogeneous, with some being short term and others long term (>5 years) post-transplant. Because the factors affecting a patient's ability to work may be different at different times after surgery, it is difficult to interpret the findings of these studies.

MELD (Model for End-Stage Liver Disease) Score. Liver transplantation has been investigated extensively but little is known about its correlation with pre-transplantation liver disease severity and the effects of the pre-transplant liver disease severity score (MELD score) on transplant issues such as employment. Although the MELD score was originally proposed as a model to predict short-term mortality in patients with end-stage liver disease, in clinical practice it is often used as an overall indicator of the patient's functional health status. Two research studies were found that evaluated employment after liver transplantation in regard to the MELD score. Sahota et al. (2006), in a cross sectional study of liver transplant recipients, investigated the correlation between post-transplant employment and clinical variables before and after transplantation. Sahota and colleagues (2006) found no association between the severity of clinical status before and after transplantation and employment. Saab et al. (2007) supported the findings of Sahota et al. (2006) that MELD scores were not predictive of post-transplant employment. Future studies need to focus on the impact of pre-transplant clinical measures of disease severity on post-transplant employment status.

Alcoholic Liver Diseases vs. Non Alcoholic Liver Diseases. Five studies compared the employment patterns of transplant recipients with alcoholic liver diseases (ALD) with those without ALD. A University of Michigan study by Newton (2001) (n = 122) studied the differences between the participants who returned to work and those who did not. The study sample was comprised of 47 women with ALD, 60 women without ALD, 48 men with ALD and 20 men without ALD. The study showed that work outcomes for female transplant recipients with ALD (n = 24) were similar to those of females without ALD. However, female transplant recipients with ALD returned to work at rates higher than

male transplant recipients either with ALD (52%) or without ALD (56%). This high return to work rate in transplant recipients with ALD could be due to the inclusion of household workers in the definition of work. Ten of the recipients with ALD (10%) who returned to work post-transplant were household workers, all of whom were female. On the other hand, a French study (Pageaux et al., 1999) showed that 30% of alcoholics and 60% of non-alcoholics regained employment post-transplant. The significant difference between alcoholics and non-alcoholics seems to be related to the level of occupation before transplantation. Employment rates were lower in alcoholics than in non-alcoholics. The poorer medical condition of alcoholics (81% Child-Pugh's score C) than non-alcoholics (63% Child-Pugh's score C) before transplantation also contributed to the discrepancy.

Nicholas et al. (1994) found that history of alcohol use does not influence the transplant recipient's employment after transplantation. These findings were supported by the investigation by Cowling et al. (2000) which found no difference in employment rates between non-ALD and ALD liver transplant recipients. Cowling et al. (2004a) studied 84 alcoholic liver disease and 68 non-alcoholic liver disease orthotopic liver transplantation recipients who underwent liver transplantation at a single center urban teaching hospital in Dallas, Texas. The specific objective of this study was to describe and quantify liver transplant recipients' societal reintegration post liver transplant. The study also compared the degree of societal reintegration of individuals transplanted for alcohol related and non-alcohol related liver disease. No significant difference between the groups was noted in the proportion of subjects employed. Nearly 70% of employed individuals in both groups reported working at least 40 hours per week.

The analysis of these studies suggests that slightly more patients with ALD than non-ALD worked at one year post-transplant, but that long term employment was substantially greater in patients with non-ALD. Because these studies were not designed specifically to compare the rates of employment, this evidence is suggestive but not definitive. In addition, these studies were statistically heterogeneous. Finally, in the reviewed studies, the mean age of transplant recipients with non-ALD was significantly younger than that of transplant recipients with ALD, a potentially confounding factor because younger patients are more likely to return to work. Because none of the studies described the nature of employment (beyond whether it was full time or part-time), it could not be determined whether patients returned to the same or equivalent jobs.

External Characteristics

Medical Insurance. Health insurance is closely tied to employment in the United States, as most private insurance is obtained through the workplace. Fear of insurance loss may act as an incentive for employment in an era of rising medical costs, especially for those with private insurance (HMO/PPO). On the other hand, those with government medical insurance such as Medicaid may lose their medical insurance coverage if they seek gainful employment and their incomes rise above the Medicaid income qualification thresholds. While recipients with Medicaid and HMO/PPO insurance strive for the same goal of maintaining insurance coverage, the HMO/PPO group has a financial incentive to work, while the Medicaid group may have an incentive to remain unemployed. Indeed, in a study by Hunt et al. (1996), being on Medicaid pre-OLT was found to be a significant negative factor for post-transplant employment. Patients insured by Medicaid before transplantation were 1.7-fold more likely to remain unemployed after transplantation than

those with other forms of insurance. For those patients returning to work after transplantation, 19 of 31 (61%) returned to the same job. These patients received health insurance from their employer. In contrast, the largest group of unemployed patients (41%) received health insurance from Medicaid (Hunt et al., 1996).

A study by Rongey et al. (2005) examined factors affecting health insurance and employment status in 186 long term liver transplant recipients. Out of 186, 98 patients were employed post-transplant, including 62 paid full-time and 19 paid part-time. A large majority (98%, n = 183) of respondents had some type of health insurance coverage, including 18% who received their insurance through their spouse. Seventy one (38%) reported having more than one source of health insurance coverage. The majority (55%, n = 102) of the respondents carried private insurance, while 56 (36%) had public insurance, including Medicare, Medicaid, Veteran's Administration or Native American programs. In the regression model, Rongey et al. (2005) found no evidence that health insurance coverage significantly impacted employment status.

In summary, in light of the magnitude of the expenses associated with the transplantation procedure and post-transplant care, it is impossible for someone to undergo liver transplant without health insurance coverage. Therefore, liver transplant patients have health insurance coverage, some from more than one insurer.

Disability Benefits. Many of the studies cited have indicated that a significant number of recipients failed to return to work post-transplant for fear of losing their disability benefits. Thomas (1996) and Saab et al. (2007) indicated that the idea of losing health insurance and disability benefits was associated with post-transplantation unemployment. In a study of employment and health insurance in long term liver

transplant recipients, Rongey et al. (2005) found that 24% of the recipients studied were unemployed and, of these, one-third considered themselves unable to work because of poor health. Another 12% of that sample indicated they were able to work or desired to work, but were afraid to do so for fear of losing their disability benefits. The authors identified potential loss of benefits as one reason for unemployment. However, they did not find any association between Medicaid and unemployment.

Sahota et al. (2006), in a cross-sectional study of liver transplant recipients, investigated the association between patients' socioeconomic and quality of life parameters and employment status after transplant. Sahota and colleagues (2006) noted that patients who received Social Security Insurance for more than six months were less likely to return to work after transplantation. Among patients who were not working after liver transplantation, 65% cited poor health and 20% cited loss of their health insurance coverage if they returned to work as the reason for not working.

The duration of disability before transplantation also influences post-transplant employment. An early study of employment after liver transplantation from the University Hospital of Ontario, Canada found that 40 % of liver transplant recipients were employed full-time after liver transplantation (Adams et al., 1995). Seventeen percent of patients were employed part-time and 43% of patients were unemployed. The authors found that the duration of disability before transplantation had a significant effect on post transplantation employment status. Only 33.6% of patients who had not worked in the five years before receiving their transplant returned to work, whereas there was a 75% employment rate in patients who had worked during this period ($p < .0001$). Similarly, the mean period of pretransplant disability was significantly less in the

employed patients compared with the unemployed patients ($p < .01$) (Adams et al., 1995). It appeared that the longer the disability period pretransplant, the more difficult it became for recipients to return to work post-transplant.

In summary, the issue of disability benefits and their effects on employment is a controversial subject. Patients who have developed a disability prior to transplantation may continue to suffer from ailments that further limit their employability after surgery. However, a secondary goal may also exist. Although the reviewed studies discussed those receiving disability incomes, a distinction should be made between being disabled and receiving disability income since these terms are not necessarily synonymous. Patients in the studies may have received disability income, but may not necessarily have been disabled. This area still needs consensus on what constitutes patient disability.

It is possible that poor employment rates after transplant are not related as much to physical disabilities or symptomatology, but instead relate more to the financial burdens that develop with the loss of disability insurance. However, legislation has changed over the years to help patients overcome financial burdens. For example, a program entitled "Ticket to Work," is a Medicare funded program designed to assist transplant patients to secure employment after surgery. In addition, there is a new Medicaid Buy-In program that encourages disabled people to go back to work and allows them to retain their health care coverage through Medicaid. This program allows working people with disabilities to earn income without the risk of losing vital health care coverage. However, the published studies failed to explain why some patients with disability benefits provided by the new legislation do not work after transplant. That

makes it difficult to draw firm conclusions about the relationship between disability benefits and post-transplant employment rates.

Geography. Another variable that influences an individual's return to work following liver transplantation is geography or where the recipient lives. Table 1, presents data from some of the most representative studies performed across different regions of the United States (Cowling et al., 2004a; Hunt et al., 1996; Newton, 1999; Nicholas et al., 1994; Rongey et al., 2005; Saab et al., 2007; Sahota et al., 2006).

Table 1

Employment Rates After Liver Transplant Across Different U.S. States

| Author/Year | States | Sample | Employment % |
|--------------------|----------------|---------------|---------------------|
| Cowling/2004a | Texas | 152 | 36% |
| Hunt/1996 | North Carolina | 52 | 60% |
| Newton/ 1999 | Michigan | 122 | 55% |
| Rongey/2005 | Minnesota | 217 | 55% |
| Saab/ 2007 | California | 308 | 26% |
| Sahota/2006 | California | 105 | 49% |

These studies showed considerable variation in the employment rate after liver transplantation. A 60% employment rate was found in North Carolina in a study conducted to identify social and economic factors that might influence return to work after liver transplantation (Hunt et al., 1996). Saab et al. (2007) found a 26% employment rate during a period of poor economic conditions and a high rate of unemployment in the United States. A possible explanation for the low employment rate (36%) reported in a Texas study (Cowling et al., 2004a) is the high unemployment rate in the South. Further

attention to employment outcomes in transplant populations, particularly the effects of geographic region, will be important to research.

Attitudes of Potential Employers. The literature consistently shows that potential employers' attitudes towards transplant recipients are a barrier to return to work (Commander, Neuberger & Dean, 1992; Heyink, Tymstra, Sloof & Klompmaker, 1990). Heyink et al. (1990) interviewed 29 patients who had undergone orthotopic liver transplantation in Groningen, Netherlands. This qualitative study was designed to investigate the psychosocial problems of OLT patients. The interviews were recorded on tape and the discussions were led by a clinical psychologist. There were 22 women and 7 men in the group of respondents, with an average age of 42 years and 36 years respectively (range 17-58 years). Only two respondents had a paid job at the time of the interview. At least four others had tried in vain to find suitable employment. The authors found an unsupportive attitude from potential employers, with transplant recipients being rejected by medical examining bodies, employment agencies, and employers. Unfortunately, the authors failed to describe the demographics of the study population.

Employment is a common vehicle for obtaining health insurance coverage. A transplant recipient may be deemed too 'high risk' for employment-based health insurance and be excluded from job opportunities. The latter is especially true with small businesses that lack a large pool of employees to disperse the burden of high costs associated with organ transplantation without increasing overall health insurance costs. In a Mayo Clinic study on health insurance and post-transplant employment, Rongey and colleagues (2005) reported that out of 179 respondents, a small percentage reported they were denied (6%, n=10) or were terminated (3%, n= 6) from employment because of

their transplant. Of 42 respondents who were unemployed, five (12%) reported having been denied employment and two (5%) were terminated for having a transplant. In a more recent post-transplant employment and quality of life study, Saab et al. (2007) supported the findings of earlier reports. Out of 308 adult liver transplant recipients, 13 patients reported having been denied employment due to their transplant (Saab et al., 2007). Future studies need to focus on work-related discrimination.

Other Factors. Another factor associated with post-transplant employment identified in other studies is depression. In a sample of adult liver transplant recipients (n=122) from one large Midwestern transplant program, 23% were assessed as having moderate-to-severe depression (Newton, 2003). Depression was found to be a major predictor of post-transplant employment. A majority (60%) of depressed recipients tended not to work post-transplant. However, it is not known whether depression post-transplant makes it less likely for liver transplant recipients to return to work, or whether not working predisposes an adult liver transplant recipient to depression. The study did not provide an answer to this question. Adult liver transplant recipients who have jobs to return to may be spared some of the detrimental effects depression may cause post transplant. On the other hand, adult liver transplant recipients who do not have a job to which they can return post-transplant may be particularly susceptible to the effects of depression.

Another interesting factor related to employment after transplantation is that the probability of returning to work appears to diminish over time. A study by Saab et al. (2007) found that of recipients who did return to work, 42% returned to work within 6 months of transplantation. Within 2 years, 22% of recipients were able to return to work.

It is not clear in the study findings if the decreasing probability of employment over time is a reflection of waning patient motivation and/or the accumulation of chronic diseases/illnesses. One possible explanation could be that many patients find it difficult to enter the workforce not only after major surgery, but also as an aging individual. With recuperation time comes advancing age, which is critical given that most transplant recipients are in their 50s at the time of transplantation. Thus, most patients have a critical window for reentering the workforce, leading to the decreased probability of employment over time.

Summary of Findings

The intent of this paper was to provide a thorough review of the literature in regard to those variables that Grossman describes as demographics, health-related and external variables that contribute to employment after liver transplantation. The question of a transplant recipient's likelihood of returning to work is not new, but the ability to achieve the ideal of full post-transplant employment for those physically able is yet to be realized. In this systematic review, an extensive search strategy was performed to identify studies of employment after liver transplantation. In this era of increasing emphasis on the cost-effectiveness of care and interventions that not only prolong life, but also improve quality of life, evaluation of functional status outcomes after such a highly resource-intensive procedure as liver transplantation is critical. Increasingly, rigorous evaluations of employment before and after liver transplantation are providing a more comprehensive description of the impact of this technology on patients' lives.

The implications from the empirical literature regarding post-transplant employment suggest that social rehabilitation is not synonymous with the medical results

of transplantation. Although most transplant recipients were assessed by their health care providers as being physically able to return to work, the rates at which they did so were low. The combined factors of age, increased length of pre-transplant disability, pretransplant dependence on government financial assistance, self report of not being able to work, and less than six months post-transplant appeared to be barriers that prohibited many of the recipients who were not medically disabled from returning to work.

The majority of post-transplant employment studies were descriptive and atheoretical. Few authors used a conceptual framework to guide their investigations. Another flaw noted in the employment literature has to do with study methodologies. There were inconsistencies regarding post-transplant timeframes when the data were collected (ranging from less than one month to greater than two years). Many of the studies had inclusion or exclusion criteria that practically guaranteed positive outcomes. For example, some studies did not include alcoholic recipients (Tarter et al., 1991), or those recipients considered “unemployed” by the investigators (Hunt et al., 1996). In addition, they did not report the proportions of transplant recipients who returned to the jobs they held before transplantation or took jobs with equivalent wages and benefits. They did not report the extent to which insurance factors may have motivated some transplant recipients to return to work and others to remain unemployed or underemployed.

The primary difficulty in synthesizing and generalizing the results of these studies derives from the lack of a uniform definition of employment to evaluate these outcomes. With regard to the domain of work and employment, this researcher found that the

definition of employment (e.g., full-time, part-time) and the criteria applied to classify patients as employed (e.g., full-time student, housewife, etc.) are often not stated. Within the literature, the term “employed” has taken on various meanings. For example, Hunt et al. (1996) designated “employed” to refer to those who had returned to work after transplant. Adams et al. (1995) used a broader focus, categorizing homemakers and students as “employed” if they had returned to their same pretransplant roles. Levy et al. (1995) defined employment rate by including not only those currently working for pay but also those who were unemployed at the time of follow-up if they had been working for pay at some point within the year prior to follow-up. The results of this review show the necessity of a clear definition of employment status and its distinguishing categories. A standard approach in defining the term “employed” would permit fitting comparisons.

Given that the average age of adult liver transplant recipients is 45 years, employment outcomes in transplant populations, particularly in younger transplant recipients will be important to research. Research regarding racial disparities should be undertaken to evaluate long-term employment outcomes for liver transplantation in African American recipients compared with those of other races and to determine the factors responsible for any observed differences.

Specific focus on the enabling variable of attitudes of employers found the need for future studies on work-related discrimination. Employers may be resistant to hiring transplant recipients because of concerns about physical functioning, infection risks, need for ongoing office visits and higher insurance costs. Geographical disparities should be further studied, since the existing studies are small local studies and geographical region could be a factor in low employment rates after transplant surgery.

Another important problem is the lack of a universal definition of disability. Within the literature, the distinction between being disabled and receiving disability income is often not made. Because these terms are not necessarily synonymous, transplant recipients in the studies may have received disability income, but may not necessarily have been disabled. This area still needs consensus on what constitutes patient disability. Further research needs to be done on post-transplant employment and disability benefits and on the Medicaid and Medicare funded programs that assist patients to return to work without the risk of losing vital health care coverage.

Based on the information available from these studies, we conclude that pretransplant employment is greater in transplant recipients with non-ALD. The proportion of patients who use alcohol is similar in short-term follow-up, but those transplant recipients with ALD who drink may consume more alcohol than transplant recipients with non-ALD. Additional studies that directly compare clinical outcomes, employment, and alcohol use among different transplant populations would improve our understanding of long-term outcomes after liver transplantation.

With fewer economic resources available and the majority of adult liver transplant recipients failing to work post-transplant, it is not surprising that both the public and private sectors have raised the question of whether the benefits of liver transplantation have warranted its expenditures. Some factors contributing to non-return to work post liver transplant were described and summarized. Factors related to transplant recipient employment have been poorly understood. In addition, the existing literature on employment after liver transplantation is based on single center experiences. Missing from the literature is an analysis of the impact of gender, age, education, pre-transplant

disability and alcoholic liver disease on employment after liver transplantation using the UNOS database. Much research could be conducted to inform the field. Much needs to be accomplished. Given the extensive data set maintained through UNOS, each of these issues can and should be addressed.

Theoretical Framework

This chapter contains discussions of Grossman's Health Capital Model in an effort to better understand the post-transplant employment phenomena from a theoretical perspective. Although this model has never been used to explain post transplant labor force status, the model is useful for elucidating potential factors contributing to post-transplant employment. This chapter is divided into three sections. First, the health capital model will be reviewed to provide the foundation upon which the demand for time spent on labor force participation after liver transplantation will be based. This will be followed by the expanded version of the model and its implication for its use in future research related to liver transplantation and employment outcomes post transplant.

Health Capital Model

The theoretical discussion of this paper aims to explain the labor market characteristics of individuals after liver transplantation. Grossman's Health Capital Model (1972) is used to assess how liver transplantation affects optimal health stock and labor force participation after transplantation. Health is an important human capital and vital to the explanation of employment status following liver transplantation. The health capital model (HCM) is built on the human capital model of Gary Becker (1964), according to which individuals invest in themselves through education, training, and health to increase their earnings.

The health capital model developed by Michael Grossman is an economics-based theoretical work focusing on health and health investment. The main innovation in his work is that health is considered to be an endogenous variable that people can improve through investment in health, even though they are facing depreciation of health at the same time. With this theoretical framework, it is important to note that health is conceptualized as “stock,” which accumulates over time. Besides production of health, the model emphasizes the consumption aspect of health. People desire health because they can directly enjoy being healthy. In addition, people can increase the amount of health time (or decrease the amount of sick time) that may be utilized to increase income, providing more resources to invest in health or to consume more non-health goods. Moreover, to improve or maintain health status, individuals need to invest in their health, which requires both time and material resources. The availability of resources may depend on the individual’s labor force status (past and current).

Grossman shows that the demand for health differs in several aspects from the demand for other commodities (Folland & Goodman, 2004). First, it is not medical care per se that individuals demand but rather good health. Second, individuals do not purchase health from the market but are instead producing it themselves by making health improvement efforts. Furthermore, health is regarded both as a consumption commodity and as an investment commodity. As a consumption commodity, health is demanded because it makes you feel better. As an investment commodity health yields monetary, not utility gains, and is demanded as it increases the number of healthy days available to work and earn income. Finally, health is viewed as durable capital stock, yielding healthy time, and thus lasting for more than one period.

In the health capital model, individuals derive satisfaction from health and from the consumption of other commodities. Furthermore, individuals inherit an initial stock of health that depreciates over time. The stock of health today depends on previous health investments and the rate of depreciation, such that

$$H_{i+1} = H_i (1 - \delta_i) + I_i$$

Where H_i is health in period i , I_i is gross investment and δ_i is the rate of depreciation. The rate of depreciation is assumed to be exogenous and to increase with the age of the individual. Individuals invest in health capital by devoting time and medical care to the production of health. Individuals are therefore able to “choose” their health status as well as their length of life. An important feature of the model is that health is endogenous and depends on the resources allocated to its production in addition to the initial inherited stock of health. The uses of healthy time consist of work time, time spent producing health and time spent producing other commodities. These activities are mutually exclusive and add up to total time. Time spent being sick is subtracted from total time and is assumed to be lost time. Leisure consists of time spent producing health and time spent producing other commodities.

A marginal efficiency of capital curve (MEC) is displayed in Figure 2 (Grossman, 1972). The MEC curve shows the relationship between the stock of health and the marginal efficiency of health capital, γ_i . The supply curve is assumed to be constant, and equal to the market rate of interest, r , the marginal cost of gross investment in health $\pi_i - 1$, and the rate of depreciation, δ_i . The optimal health stock in period i is H^* .

In the health capital model, health is also analyzed from a life cycle perspective by examining the effect of the depreciation rate on the demand for and investment in

health (Grossman, 1972). The depreciation rate is assumed to grow continuously with age after some point in the life cycle and the health stock will thus decline over time.

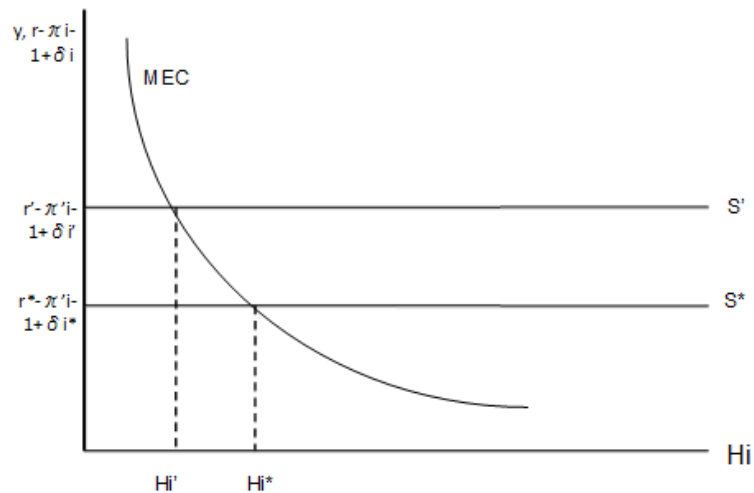


Figure 2. The Demand Curve for Health (Grossman, 1972)

The effect of declining health on the demand for health producing time is unclear. However, Grossman concludes that if the elasticity of the MEC curve were less than one, gross investment and the depreciation rate would be positively correlated while gross investment and health stock would be negatively correlated over the life cycle. This means that individuals would desire to offset part of the reduction in the health stock, caused by the increased depreciation rate, by increasing gross investment and hence the demand for health producing time.

To elaborate, the HCM posits a utility function that includes health as a “valued fundamental object of choice” among many fundamental objects of choice (Grossman, 1972). A person’s “health,” as with any fundamental object, is valued because it yields an increase in the sense of personal satisfaction, or well-being. Better health is assumed to

be desirable, but every incremental improvement in a person's health yields a smaller increase in the experienced satisfaction of this valued object of choice.

Health Capital Model and Liver Transplantation

In the health capital framework, a health shock, such as liver transplant surgery, potentially has several effects. The first effect is an increase in the rate of depreciation due to the fact that liver transplantation increases mortality. The higher depreciation rate increases the cost of holding capital which results in less health capital being held. In Figure 2, this implies a shift in the supply curve from S^* to S' resulting in a fall in the optimal health stock. The health stock and the number of healthy days are positively correlated (Grossman, 1972). Therefore, as the stock of health increases the number of health days also increases, although at a diminishing rate. Conversely, a decline in the optimal health stock will increase sick days. Hence, liver transplantation will result in a lower health stock that would contribute to labor participation decisions. As sick time is regarded as lost time, time being sick will result in less time available for work.

The health capital model also predicts the increased depreciation rate to increase demand for gross investment in health, given elasticity of less than one in the MEC curve (Grossman, 1972). Hence, the demand for health producing time would increase. The effect of an increased demand on health producing time is a decline in time available for other uses. That is, working time and time spent producing other commodities as these activities are assumed to be mutually exclusive. Thus, in the health capital model, it is not possible to maintain health while working. As a result, the marginal utility of leisure will increase relative to the marginal utility of work.

Moreover, liver transplantation causes a fall in the health stock. The health stock could initially fall below the new optimal health stock, leading to even more days lost to illness. For a liver transplant recipient, the health shock should not disable the recipient, but this could be the time needed for medical treatment and time needed for changing and adapting to a lifestyle in accordance with the transplantation. In addition, it could also take time to recover after the surgery that may last 6 months or longer. The theory suggests that the liver transplant recipient is likely to reduce labor supply in response to a health shock, at least for 6 months or possibly more depending upon the recipient's medical condition and health status after transplant.

Not only can current and future health declines affect the current labor supply, health history (e.g., history of comorbidities) also matters. This is because both contemporary and past health conditions determine the future health condition. An individual who has been in poor health (e.g., history of diabetes in addition to liver disease) for a long time before transplantation may value time out of the labor market more since time needed to care for one's health increases with ill health. In this case, the person who has been in poor health for a longer time will have diminished expectations about the future compared to a person who has recently experienced a negative health stock. Thus, according to health capital theory, health and labor force participation are positively correlated. That is, better health is likely to lead to a higher probability of labor force participation.

A central assumption in the health capital model is that health is not a determinant of the wage rate (Grossman, 1972). Instead, health impacts income primarily through the number of sick days. However, as already noted, health is valued for more than its

satisfaction value according to the HCM. As human capital, health has the capacity to influence a person's productivity in the market, as reflected in the ability to obtain a job and in earned wages if employed as well as in the production of other valued objects. In addition, a person's health will influence the quality of time available for all activities, as well as the most basic valued object, life itself. A negative health stock might lower productivity and hence wages (Curie & Madrian, 1999). However, it would be reasonable to assume that liver transplantation should not affect productivity, at least as long as the liver transplant recipient does not have any complications. On the other hand, an employer, with knowledge about the health stock could, due to prejudices, perceive the liver transplant patient as less productive. Hence, the wage could decrease, regardless of whether the liver transplant patient is less productive or not. If the wage rate were to decrease, this would result in the MEC curve, in Figure 2, shifting inwards in the health capital model. This would decrease optimal health stock even more. Consequently, over the life cycle, a lower wage would also contribute to less likelihood of work after transplantation.

Moreover, the health capital model predicts that more highly educated individuals will demand a larger optimal health stock (Grossman, 1972). Educated individuals are assumed to be more efficient producers of health capital. A higher education would then shift the MEC curve in Figure 2 to the right, given a constant wage rate and marginal product of health. As the cost of capital is independent of education there would be no shift in the supply curve. Hence, the more educated would demand a larger optimal health stock. The more highly educated liver transplant recipients would then have a larger

health stock and consequently a higher probability of returning to work following transplantation.

Liver transplantation is assumed to affect the set of physical abilities that individuals employ both within the labor market and in home production. These abilities include strength, endurance, emotional fitness and the ability to perform tasks at work and within the household. Liver transplantation can affect a subset of the total ability set and, depending on factors such as education and occupation, the surgery and recovery will have differential effects upon employment probability.

Liver transplantation affects labor supply through at least three different pathways. First, liver transplant surgery can induce a change in abilities and can, depending on how abilities affect the marginal utilities of consumption and leisure, affect work decisions. If liver transplantation lowers the marginal utility of leisure sufficiently, the individual may actually work more. But the stronger the effect of abilities on the marginal utility of consumption, the greater is the probability of working. The second pathway is a simple income effect induced by out-of-pocket medical expenses. Simply put, individuals are induced to keep their jobs in order to pay medical costs. This is particularly true in the United States, where health insurance is often tied to employment. These costs may be incurred whether or not the liver transplantation results in any disability. The fourth pathway is a reduction in the total time available to the agent because of increased time in health maintenance. A reduction in time will induce a reallocation of labor and leisure that depends on the preferences and resources of the agent.

In sum, liver transplantation can affect employment decisions in a variety of ways. The empirical implication of the discussion above is that no summary variable can capture the multiple ways in which liver transplantation affects labor supply. Sometimes liver transplantation affects labor supply through disability, sometimes through medical costs, and sometimes through changing the amount and value of time, including changes in life expectancy. Summarizing health with a single variable such as health capital stock is very useful in some contexts, but a clear understanding of labor market behavior depends critically on expanding the conceptualization of health beyond single-measure methods.

Conclusion

Many crucial policy issues of the twenty-first century spring from the relationship between the health and labor supply of liver transplant recipients. Although this relationship has received considerable attention over recent decades, one is still able to say relatively little about how current trends in health will affect the labor supply in the coming decades.

There is little literature related to the theoretical foundation for employment post-transplant. A multitude of factors place post transplant patients at risk for a nonproductive life after transplantation. The factors that place them at risk must be systematically studied and documented. The majority of the studies related to employment post transplant were not based on a theoretical framework. The health capital model developed by Grossman (1972) is used to examine the relationship between liver transplantation and post-transplant employment. This paper examines the relationship between health status and labor force participation of working age men and women after

transplantation. The intent of this analysis to examine the factors that contribute to employment outcomes post transplant within Grossman's Health Capital Model. If poor health reduces labor force productivity and leads to reduced labor force participation, health problems impose a cost on the economy in terms of production loss.

Chapter 3: Methods

Liver transplantation is a successful treatment modality for individuals with ESLD. There have been more than 86,000 liver transplants performed in the United States since 1988 (United Network of Organ Sharing [UNOS], 2007), about 90% of which have come from cadaveric donors. As of November 2007, greater than 16,000 candidates await liver transplant. Almost 15 percent or 2400 of these candidates will become too ill to receive a transplant or will die waiting for an organ. Approximately 38 percent or 6500 candidates will actually undergo transplantation, after waiting from one to five years for the procedure. Annually, about 10,000 additional patients will be added to the waiting list and close to 60 percent of those in medical need will go without a liver transplant. In light of this organ shortage, the transplant community is increasingly called upon to justify its practices and show the impact of transplantation beyond survival. One aspect of the impact on survival is employment. This is the focus of this study.

Employment post-transplant is poorly understood phenomenon. When the goal of liver transplantation is conceptualized as more than recipient survival and includes social and behavioral outcomes as well, then it becomes clear that more information and a better understanding of the outcomes of liver transplantation are warranted. Even with the majority of liver transplants performed on working age adults, the literature indicates that only approximately half of the recipients return to work after surgery (Adams, Ghent, Grant & Wall, 1995; Hunt et al., 1996; Rongey et al., 2005; Sahota et al., 2006). This statistic is strikingly low when one considers that many liver transplant recipients receive transplantation during their most productive years.

A number of early studies have demonstrated improvement in the quality of life after liver transplantation and have examined the factors that predict whether or not patients return to work after liver transplantation (Adams, Ghent, Grant & Wall, 1995; Cowling et al., 2004; Hunt et al., 1996; Loinaz et al., 1999; Moyzes, Walter, Rose, Newhaus, & Klapp, 2001; Newton, 1999, 2001; Rongey et al., 2005; Saab et al., 2007; Sahota et al., 2006). These studies, although informative, have often analyzed and compared data from different allocation periods and different points of time.

Contributing to the limitations of prior studies is the absence of a consistently used and precise definition of employment. For example, in some studies, those who did household work were considered employed, but in others they were considered unemployed. In addition, the published studies of the employment status of transplant candidates and recipients used self-developed questions about employment or questions from quality of life scales. Another difficulty in synthesizing and generalizing the results of these studies is derived from the heterogeneity of measurement instruments used to evaluate outcomes other than employment. Further, most of the existing literature on return to work after liver transplantation has been conducted in single centers with small patient cohorts. This has limited regional generalizability and may involve selection differences in how the samples were drawn or in who responded to the follow-up tracking. Advances in the field of transplantation may have rendered older studies from different stages of allocation and from different points in time somewhat obsolete. The most of the early studies were conducted in the 1980s and 1990s, before the adoption of acuity-based MELD scoring, a liver disease severity of illness rating system.

This study has elected to examine the employment post- transplant using data from the UNOS dataset. UNOS is a nationwide, transplant registry. The dataset provides a large multi-institutional population of adult liver transplant recipients. This registry features a uniform and more comprehensive assessment of employment outcomes in liver transplant recipients than has been previously possible from the single site studies. The study uses data collected since the adoption of the acuity-based MELD scoring system on February 27, 2002. The specific aims of the study are:

Research Aim #1

Describe those who were employed within 24 months after receiving a liver transplant during the period 2002-2008 compared with those who were not employed after receiving a liver transplant during the same period.

Research Aim #2

Examine the factors associated with those who were employed after receiving a liver transplant between 2002 and 2008, including individual demographic characteristics, health-related characteristics and external factors.

Study Research Design

UNOS is the contracted body under the Organ Procurement and Transplantation Network (OPTN) that has developed and maintains a system for data collection and storage of transplantation information (UNOS, 2003). Among the databases in UNOS is the Scientific Research Transplant Registry (SRTR), which receives transplant registry information from the Organ Procurement Transplant Network (OPTN) via an on-line database, called the Transplant Information Electronic Data Interchange (Tiedi).

Sources of Data & Sample: SRTR\UNOS Database

The SRTR is the primary source of information about transplant candidates and recipients for the study. The measures to be used in the study are drawn from Transplant Candidate Registration (TCR) forms, Transplant Recipient Registration (TRR) forms and Transplant Recipient Follow-up (TRF) forms (Appendix A) submitted by each transplant program. TCRs are generated when a patient is wait-listed for a liver transplant. TRRs are generated when a transplant has occurred. TRFs are generated at 6 months, 1 year and annually thereafter following transplantation, until graft failure, recipient death, or loss to follow-up is reported. Data from the OPTN is transferred to the SRTR on a monthly basis. This data is then linked by person to secondary data sources such as the Social Security Death Master File (SSDMF) and the National Death Index (NDI). Standard Analysis Files (SAS) are created and made available as public use files, which is the data source used by this study.

Study Sample

The primary unit of analysis for the current study was the individual liver transplant recipient. The sample frame for this study was adult liver transplant recipients who received a transplant sometime between February 2, 2002 and December 31, 2008. The analysis compared those that received cadaveric liver transplants and worked for income within 2 years of transplant with those that received cadaveric (also called 'deceased donor') liver transplants and did not work for income after transplant surgery. Children (age <18 years), patients with combined liver-kidney transplants and patients who received a previous liver transplant were excluded from the population. Additional exclusion groups were patients who had received a previous transplant (as they may be

reevaluated for a second transplant), those who were in school or undertaking full time study, and persons age 65 and older (as they may be retired).

Measures

Dependent Variable

The dependent variable was dichotomous, representing whether or not an individual was working. Employment was defined as the liver transplant recipient indicating that they were working full time or part-time. This variable was measured through SRTR (2008) data derived from questions on the Transplant Recipient Follow-up (TRF) form. On the TRF this variable is captured as “*working for income.*”

Independent Variables

This study is based on the labor health capital model. In this model, an individual’s participation in the labor force is determined by a series of demographic and health-related factors which influence his or her incentive or ability to work. The demographic variables within the model include: age, gender, ethnicity, education, pretransplant employment. These attributes condition the likelihood of work. Four health-related measures are available from UNOS: the MELD score at the time of transplant, etiology of liver disease, post-transplant functional status and a history of pretransplant comorbidities.

Description of Variables

Demographic Variables

Age. The studies reviewed for this paper found age to be a significant factor affecting post-transplant employment status. This result is consistent with Grossman’s (1972) suggestion that the depreciation rate increases with age. A higher depreciation rate

would be expected to yield lower optimal health and consequently lower the probability of returning to work following liver transplantation. Rongey et al. (2005) found that individuals transplanted at an older age were less likely to be employed post-transplant. The study demonstrated that the employment rate was higher in liver transplant recipients who were younger than 65 years of age. Age is a continuous variable derived from “*Date of Birth*” as recorded on the SRTR.

Gender. The reviewed literature reveals mixed findings on the relationship between gender and return to work. One explanation for this discrepancy is that some studies considered doing household work as being employed. Other studies considered such individuals as unemployed. Gender data was obtained from the SRTR Transplant Recipient Follow-up (TRF) form. Gender was coded 1 as female, 0 as male.

Race/ Ethnicity. Little is known about the effects of race and/or ethnicity on post-transplant issues such as return to work after transplantation. Studies have found racial barriers to liver transplantation. However, neither of the reviewed studies (Hunt et al., 1996; Saab et al, 2007) found that ethnicity was predictive of employment. Race was measured as a categorical variable: American White, Black or African American, or Hispanic/ Latino and others. American White was the reference category.

Education. Employment following liver transplantation has been studied in regard to the impact educational level plays on employment status. Results in the literature appear mixed. More recent studies report that years of education have a statistically significant effect on employment after liver transplantation (Cowling et al., 2004; Moyzes et al., 2001; Sahota et al., 2006). Earlier reports did not find an association (Hunt et al., 1996; Newton, 1999). Education was represented in the analysis as a categorical

variable: less than high school, less than college degree and college graduate degree and higher degree. < High school was the reference category.

Pretransplant Employment. With regard to pretransplant employment status, the reviewed studies have found that employment status prior to transplantation was highly predictive of whether patients returned to work or not. In the logistic regression analysis, Rongey et al. (2005) found that employment prior to transplantation (odds ratio: 5.1; CI: 1.8- 14.0) was significantly associated with employment post-transplant. This data was supported by Sahota et al. (2006). Individuals who worked during the previous five years before transplantation were more likely to return to work ($p < 0.0001$), particularly patients who had held a job for longer than six months prior to OLT ($p < 0.0001$). Hunt et al. (1996) found that pretransplant employment correlated strongly with post-transplant employment ($p < .0005$).

This research study evaluated the pretransplant employment status of transplant recipients from the implementation of MELD through 2008. Pretransplant employment status was identified through SRTR (2008) data derived from questions on the Transplant Candidate Registration (TCR) forms and Transplant Recipient Registration (TRR) forms.

Table 2

Definition of Independent Variables

| Variables | Definitions | Code/ Method of Collapse etc. |
|---|--|---|
| Demographic Variables | | |
| <i>Age</i> | Chronological age at time of follow up period | Continuous variable collapsed into 4 age categories 18-40 (ref), 41-55, 56-62, 63-65 |
| <i>Gender</i> | Male or female | Dichotomous variable coded 0 for male (ref) and 1 for female |
| <i>Race</i> | Background individual most identifies with | Categorical variable, 8 options collapsed into 4 categories: White (ref), Black, Hispanic, others |
| <i>Educational Level</i> | Highest level of education obtained | Categorical variable, 8 options collapsed into 3 categories: < high school (ref), < college degree and college degree + |
| <i>Pretransplant Employment</i> | Worked for income before transplant | Dichotomous variable coded 1 for yes worked and 0 for not worked. |
| Health-Related Variables | | |
| <i>MELD Score at the time of Transplant</i> | MELD quantifying acuity of illness in regard to liver disease | Analyzed as a categorical variable: MELD < 21 (ref), 22-30, 31+ |
| <i>Etiology of Liver Disease</i> | Diagnosis of liver disease | 69 options collapsed into 6 categories: hepatitis (ref), cirrhosis, alcohol, biliary, HCC, and others |
| <i>Functional status(FS)</i> | FS at the time of follow up period. FS 80%-100%: no limitation; FS 60% and 70%: mildly limited and FS 50% and less: moderately to severely limited | 10 options collapsed into three categories: no limitation (ref), mildly limited and moderately to severely limited |
| <i>Pre Transplant Comorbidities</i> | History of chronic illness | Diabetes, angina, hypertension, dialysis, peripheral vascular disease |

Note: Preliminary analysis included “Health Insurance” and “UNOS Geographical Regions as an attempt to adjust for two external factors available in UNOS thought to influence the likelihood of employment. The inclusion or omission of either or both measures did not affect the coefficients on the health status and primary predictor variables in the model. Further, it could not be determined whether insurance status was a cause or consequence of unemployment, and there were significant measurement limitations in the

regions. This measure was too aggregated to capture market area unemployment rates and the industrial base within the periods associated with the two year observation window for each transplant recipient. For both conceptual and modeling efficiency reasons, these external measures were not included in the final models.

Health-Related Variables

MELD Score. A MELD score is intended to prioritize the most acutely ill patients for transplants. This indicator is recognized as being an objective measure of need within the population of liver failure patients. It is possible that a higher MELD score prior to surgery will be associated with lower health or slower health recovery post surgery. The MELD score available for analysis was previously calculated within the OPTN database. The MELD score was represented in the analysis as a categorical variable. According to the MELD score, patients were stratified into < 21 (low risk), 22-30 (medium risk) or >31 (high risk) categories. A MELD score less than 21 was the reference category.

Etiology of liver disease. The etiology of chronic liver disease influences employment status after transplantation. Studies have compared the employment patterns of transplant recipients with alcoholic liver diseases (ALD) with those without ALD. Pageaux et al. (1999) showed that 30% of alcoholics and 60% of non-alcoholics regained employment post-transplant. However, Adams et al. (1995) found no significant differences in employment rates between patients with the four most common indications for liver transplantation (idiopathic chronic active hepatitis, primary biliary cirrhosis, sclerosing cholangitis, and alcohol-induced liver disease). This finding was supported by Hunt et al. (1996) looking at primary biliary cirrhosis, alcoholic cirrhosis, primary sclerosing cholangitis, autoimmune hepatitis, hepatocellular carcinoma (HCC), Budd-Chiari syndrome and viral hepatitis. A more recent study (Rongey et al, 2006) supports these findings among patients with HCC, alcoholic cirrhosis, or cholestatic liver disease.

In the current study etiology of liver disease was represented by six categories: (1) alcoholic liver disease (reference category), (2) hepatitis, (3) cirrhosis, (4) biliary diseases, (5) hepatocellular carcinoma and (5) other liver diseases.

Pretransplant comorbidities. The history of pretransplant chronic conditions can affect post transplant employment status. Chronic conditions are assumed to affect the set of physical abilities that individuals employ both within the labor market and in home production. This research study evaluated pretransplant comorbidities from the implementation of MELD through 2008. Pretransplant comorbidities were identified through SRTR (2008) data derived from questions on the Transplant Candidate Registration (TCR) forms.

Functional Status. An individual's functional/ health status following liver transplantation can have an effect on the likelihood of successful employment. Aside from the direct effect of health on the ability to work reported by Saab et al. (2007) and Rongey et al. (2005), the health capital model suggests that poor health may cause a fall in the health stock that requires committing time to change and adapt to a life-style in accordance with poor functional status. Or it may require time spent obtaining education and skills more consistent with the health status.

Post-transplant functional status as measured through the SRTR Transplant Recipient Follow-up (TRF) form was captured as: "Functional Status." The answer options were scored from 10% to 100%, with 10% representing moribund, 20% representing very sick, 30% -- severely disabled, 40% -- disabled, 50% -- requires considerable assistance, 60% --requires occasional assistance, 70%---cares for self, 80% - --normal activity, 90%---able to carry on normal activity and 100% -- normal, no

complaints. For the purposes of this study, these categories were further aggregated into three groups as shown in table 3.

Table 3

Categories of Functional Status

| Functional Status | Categories |
|-------------------|--------------------------------|
| 10% to 50% | Moderately to severely limited |
| 60% and 70 % | Mildly limited |
| 80% to 100% | No limitation |

Data Analysis

To accomplish the aims of this study, data from the Organ Procurement Transplant Network (OPTN) was obtained via the Scientific Registry of Transplant Recipients (SRTR). A final working database was compiled in an SAS 9.0 data file in order to allow for the appropriate statistical measurement. Data was cleaned and codes were labeled as detailed in the SRTR code book provided by the OPTN except as previously described.

Research Aim #1:

Describe those who were employed within 24 months after receiving a liver transplant during the period from 2002 to 2008 compared with those who were not employed after receiving a liver transplant during the same period.

Research Aim # 2:

Examine the factors associated with those who were employed after receiving a liver transplant between 2002 and 2008, including individual demographic characteristics, health-related characteristics and external factors.

Descriptive Statistics

Descriptive statistics were utilized to describe the population of liver transplant recipients who received a liver transplant between the years 2002 and 2008 and who returned to work compared to those who did not return to work during this period. Frequency, percent, and measures of central tendency were employed to summarize the characteristics of the sample and evaluate the data.

A chi-square test was used to compare the proportion of the liver transplant patients who were employed after transplantation, because the chi-square test is the appropriate statistical test to use when comparing the difference in proportions between two groups (Munro, 2005). The objective of univariate analysis is to determine which of the independent variables correlate significantly with the dependent variable, which, in this study is working for income. Those variables are then placed into multivariate logistic regression models as explained below. The strength of the relationship between each independent variable and the dependent variable is expressed by the correlation coefficient that is produced by chi-square.

Regression Analyses

A simple logistic regression was run to identify the independent variables having a significant association with the dependent variable, which was employment status. The strength of the relationship between each independent variable and the dependent variable is expressed by the correlation coefficient, here converted into an odds ratio. A multiple linear regression was performed to ascertain whether liver transplant recipient demographic and health related characteristics had an effect on the recipient's

employment status after liver transplant. The multivariate logistic regression model has the general form:

$$y_i = \beta_0 + \beta_1x_1 + \beta_2x_2 + \beta_3x_3$$

Where,

y_i = employment status after liver transplant

x_1 = variables representing demographic characteristics

x_2 = variables representing health-related characteristics

x_3 = variables representing external factors

Protection of Human Subjects

There was no contact with subjects. In addition, this project involved secondary analysis of publically available data submitted to the UNOS and SRTR by individual transplant programs and organ procurement agencies. This data is managed by the SRTR through federal contract with HRSA. This data met the requirements for “exempt categories” of research. Category 4 exemption was sought from the Committee on Human Research (CHR) at the University of California, San Francisco.

Conclusion

Examination of the population of liver transplant recipients and the variables that contribute to employment status could provide valuable information regarding factors or barriers to return to work within the U.S. system. Data available from UNOS allowed for analysis of the demographic, the health-related and the external variables that play a role in employment status following liver transplantation. Statistical analyses included descriptive analysis, chi-square tests and multiple regressions. A detailed presentation of the findings from these analyses is presented in the next chapter.

CHAPTER 4: RESULTS

This study examined employment for income outcomes of liver transplant recipients within a 2 year follow up period after transplantation. Data from the UNOS was used as the basis for information on transplant recipients' employment status and various demographic, health status, and external factors thought to be associated with return to work. The population studied was that of eligible adults in the United States who received orthotopic liver transplantation between February 2002 and June 2008. Excluded were children (age <18 years), adults with combined liver-kidney transplants, adults who received a previous liver transplant and persons age 65 and older (who may be retired). Most of the existing literature on return to work after liver transplantation has been conducted in single centers with small patient cohorts. The current analysis uses data collected since the adoption of the acuity-based MELD scoring system on February 27, 2002. It is inclusive of all transplant centers in the United States. This chapter presents the findings from the investigation discussed in Chapter 3. Descriptive findings will be discussed first, followed by the analytical results.

Sample Descriptive Analysis

There were 23,144 liver transplant recipients between February 27, 2002 and December 2008 who met the inclusion criteria for this study. This study analyzed the employment status of post-transplant patients within a 60 day window of the following target times: 6 months, 12 months, and 24 months post-transplant. Because the post-transplant follow up dates do not aggregate precisely into intervals of 6, 12, and 24 months, the definitions of working at these times were changed to working at ANY time

before 6 months, working at any time before 12 months, and working at any time before 24 months.

The UNOS database does not provide time to return-to-work data. It only shows those who are working at the time of the follow-up measurement (e.g., 6 months, 12 months, or 24 months). The results presented allow for ever working within the 24-month observation window. Analyses were conducted with mortality cases both omitted and included. As the results are very similar, the findings shown are those with mortality cases included as some mortality recipients had returned to work and may have died for reasons not connect to the transplant or liver disease.

Baseline Characteristics of the Study Population

The baseline characteristics of the entire study population will be presented for individuals who were employed following liver transplantation between February 2002 and June 2008. These same characteristics will also be presented for those who did not work following transplantation during the same timeframe. Following presentations of both the descriptive statistics of these dependent variables as well as the independent variable, each factor's impact on post transplant employment will be discussed in regard to the findings from the multivariate logistic regression analyses.

The first aim of the study was to describe the study cohort of individuals who were employed following liver transplantation between February 2002 and June 2008. Table 4.1 presents the descriptive statistics of those liver transplant recipients who were employed at the 0-6, 0-12 and 0-24 month follow up periods. Examining employment status in the follow up period showed that only 6.5% of the patients had been employed at the 0-6 months post-transplant follow-up period. At 0-12 months, 17.1% had been

employed. The majority of the liver transplant recipients who returned to work (N = 24.4%) were employed by 24 months or earlier post-transplant.

Table 4

Number and percent of patients working for income at selected measurement intervals post-transplant

| Working | 0-6 months % (n) | 0-12 months % (n) | 0-24 months % (n) |
|---------|---------------------|----------------------|----------------------|
| Yes | 6.5% (1,510) | 17.1% (3,966) | 24.4% (5,656) |
| No | 93.5% (21,634) | 82.9% (19,178) | 75.6% (17,488) |
| Total | 100 % (23,144) | 100% (23,144) | 100% (23,144) |

There were 23,144 liver transplant recipients between February 27, 2002 and December 2008 who met the inclusion criteria for this study. Their characteristics are shown in the table 4.2. This table was organized according to the dimensions of the theoretical framework and presents the dependent and independent variables used in the analysis. Demographic data included age, gender, ethnicity, educational level and pre transplant employment. Pretransplant clinical measures included the etiology of liver disease, history of co-morbidities and the MELD score. According to the MELD score, patients were stratified into low risk (<21), medium risk (22-30) or high risk (31+) categories. Post transplant outcomes that have an effect on patient likelihood of successful employment include patient functional status. Table 4.2 shows high rates of missing values for the MELD score and functional status. A missing value is treated as a value in the multivariate analysis to test whether the missing values systematically bias the effect on employment status.

Table 5

Demographic and Health-Related Characteristics by Employment Status

| Variables | Working Post Transplant n = 5,656 (24.4%) |
|----------------------------------|--|
| Demographic Variables | |
| <i>Age (years)</i> | |
| Age 18-40 | 830 (32.3%) |
| Age 41-55 | 3322 (25.5%) |
| Age 56-62 | 1334 (21.1%) |
| Age 63-65 | 170 (13.8%) |
| <i>Gender</i> | |
| Male | 4300 (27.0%) |
| Female | 1356 (18.8%) |
| <i>Race/ Ethnicity</i> | |
| White | 4383 (25.8%) |
| Black | 499 (24.7%) |
| Hispanic | 470 (16.2%) |
| Others | 304 (25.1%) |
| <i>Educational Level</i> | |
| < high school | 1334 (18.3%) |
| < college | 3038 (24.7%) |
| college degree | 1284 (36.0%) |
| <i>Pretransplant Employment</i> | |
| No | 3442 (18.1%) |
| Yes | 2214 (54.0%) |
| Health-Related Variables | |
| <i>MELD Score at Transplant</i> | |
| missing | 296 (24.6%) |
| MELD ≤ 21 | 2030 (25.5%) |
| MELD 22-30 | 2648 (25.3%) |
| MELD 31+ | 682 (19.4%) |
| <i>Etiology of Liver Disease</i> | |
| Alcohol | 940 (20.6%) |
| Hepatitis | 393 (29.1%) |
| Cirrhosis | 2310 (22.7%) |
| Biliary | 677 (32.7%) |
| HCC | 817 (28.0%) |
| Others | 519 (25.5%) |

Table 5 (*continued*)

| | |
|---|--------------|
| <i>Functional Status Post Transplant</i> | |
| <i>missing</i> | 195 (3.6%) |
| No limitations | 5358 (37.4%) |
| Mildly limited | 85 (4.7%) |
| Moderately to severely limited | 18 (1.1%) |
| <i>Co morbidities</i> | |
| <i>Pre Transplant</i> | |
| Hypertension | |
| No | 5046 (24.8%) |
| Yes | 610 (21.5%) |
| Diabetes | |
| No | 4683 (26.0%) |
| Yes | 973 (19.0%) |
| Peripheral Vascular disease | |
| No | 5638 (24.5%) |
| Yes | 18 (13.6%) |
| Dialysis | |
| No | 5576 (24.5%) |
| Yes | 80 (21.4%) |

Table 5 shows the basic descriptive characteristics for liver transplant recipients who worked post-transplant within the 24 month follow-up period. In terms of the group demographics, males comprised 27 percent of the employed group which was predominantly white (25.8%), between the ages of 18-40 (32.3%), college degree educated (36.0%), and had worked before the transplant (54%). The group not actively engaged in employment was predominantly female (81.2%), between the ages of 63-65 (86.2%), Hispanic (83.8%), with less than a high school education (81.7%) and with no employment history before the transplant (81.9%).

As indicated in the following table, 25.5% of the employed transplant patients had MELD scores < 21 at the time of transplant and had no physical limitation post-transplant (37.4%). The most common diagnosis for transplant was biliary liver disease. Employed

transplant patients had histories of hypertension (21.5%), diabetes (19%), peripheral vascular disease (13.6%), and dialysis (21.4%) before the transplant. The unemployed patients had MELD scores of 31 and above, and had moderate to severe physical limitations. The most common liver disease diagnosis in the non-employed group was alcoholic liver disease.

Factors Associated with Post-Transplant Employment

The second aim of this research study was to examine the factors associated with employment following liver transplantation. Logistic regression was used for these comparisons. A chi-square test was used to examine the statistical significance of the association between working for income and demographic, health-related and external variables. The level of significance was set at $p < 0.05$. With the logistic regression analyses, first, univariate logistic regression was performed for patients who were employed after transplant compared to those who were not. Next, multivariate logistic regression analysis was performed to estimate the odds ratios (ORs) and the 95% confidence intervals (CIs) to examine the impact of demographic, health-related and external factors on the likelihood of working for income after transplantation. The results of the multivariate analysis can be seen in Table 6.

Table 6

Multivariate Logistic Regression Analysis of Employment Status Following
Liver Transplantation at any Time during the 24 Month Follow Up Period
(N = 23,144)

| Variables | Odds Ratio | CI = 95% | p-value |
|---------------------------------|------------|-------------|---------|
| Age | | | |
| 41-55 | 0.62 | 0.55-0.70 | <.0001 |
| 56-62 | 0.44 | 0.38-0.50 | <.0001 |
| 63-65 | 0.27 | 0.22-0.33 | <.0001 |
| Gender | | | |
| Female | 0.59 | 0.54 – 0.64 | <.0001 |
| Education | | | |
| < College degree | 1.29 | 1.18 – 1.41 | <.0001 |
| College degree + | 1.75 | 1.57- 1.95 | <.0001 |
| Ethnicity | | | |
| Black | 0.98 | 0.86 – 1.11 | 0.72 |
| Hispanic | 0.70 | 0.62 – 0.80 | <.0001 |
| Other | 0.88 | 0.74 – 1.04 | 0.12 |
| Pretransplant Employment | 3.8 | 3.5 – 4.2 | <.0001 |
| MELD score | | | |
| Missing | 1.17 | 0.95 – 1.42 | 0.13 |
| 22 - 30 | 1.02 | 0.93 – 1.11 | 0.72 |
| 31 + | 0.96 | 0.85 – 1.08 | 0.48 |
| Liver Diseases | | | |
| Cirrhosis | 1.17 | 1.06 – 1.30 | 0.0021 |
| Hepatitis | 1.63 | 1.34 – 1.95 | <.0001 |
| Biliary | 1.47 | 1.27 – 1.70 | <.0001 |
| HCC | 1.20 | 1.05 – 1.38 | 0.0075 |
| Others | 1.12 | 0.97– 1.30 | 0.13 |
| Functional Status | | | |
| Missing | 0.06 | 0.05-0.07 | <.0001 |
| Mildly Limited | 0.08 | 0.06 – 0.10 | <.0001 |
| Moderately to severely limited | 0.02 | 0.01 – 0.03 | <.0001 |
| Comorbidities | | | |
| Hypertension | 1.09 | 0.97 – 1.22 | 0.17 |

Table 6 (continued)

| | | | |
|------------------------------|------|-------------|--------|
| Diabetes | 0.84 | 0.77 – 0.93 | 0.0004 |
| Dialysis | 1.32 | 0.98 – 1.78 | 0.063 |
| Peripheral Vascular Diseases | 0.75 | 0.42 – 1.32 | 0.32 |
| Angina | 0.63 | 0.43 – 0.92 | 0.017 |
| COPD | 0.94 | 0.65 – 1.37 | 0.75 |
| Cerebro-Vascular Diseases | 0.98 | 0.51 – 1.90 | 0.96 |

Model fit: $-2 \log L = 18365.786$ **Chi-square:** Wald = 4006.2656; $p = <.0001$

Reference Categories

Reference Category for Age = 18-40

Reference Category for Gender = Male

Reference Category for Ethnicity = White

Reference Category for Education = < High school

Reference Category for MELD = < 21

Reference Category for Liver Diseases = Alcohol

Reference Category for Functional Status = No Limitation

Demographic Variables

Variables measuring demographic characteristics of the patients are included to gauge the effects of differences in post-transplant employment status. The patient's age provides an indication of the effects of changes in labor force participation over the life cycle. Race was included to measure differences in the effect of cultural differences on work behavior. Moreover, gender and pre transplant employment data were additional measures of the influence of the characteristics of labor supply. Finally, pretransplant education level (measured as years of schooling completed) was used as patient stock of human capital to measure the influence of highest education level on patient post transplant work behavior.

Age. As shown in the logistic regression, persons age 18-40 have a higher likelihood of being employed after liver transplantation than those in the other age cohorts examined.

Gender. The odds of females working post-transplant were 0.59 times less likely than for males ($p = <.0001$).

Education. The level of education attained prior to transplantation was predictive of post-transplant employment status. Patients with more than a high school education were 1.29 times more likely to be employed than patients with less than high school education. In addition, patients with a college degree education and higher education were 1.75 times more likely to be in the labor force than those who had less than high school education ($p = <0.0001$).

Ethnicity. White was chosen as the reference category. The comparisons of whites versus each of the other categories showed that there was no significant difference between whites and blacks or whites and others. On the other hand, Hispanics were 0.70 times less likely to work after transplant than whites. The possibility of an interaction between Hispanics and the effect of education was tested but did not show a significant association with the outcome.

Pretransplant Employment. Pretransplant employment had the single largest main effect on post-transplant employment status. Patients who worked pretransplant were 3.8 times more likely to be employed post-transplant than those who did not work pretransplant.

Health-Related Variables

The health capital variables are of the most significance. These variables are: MELD score at the time of transplant, etiology of liver disease, pre transplant history of comorbidities and functional status after transplant.

MELD Score. This study included the MELD score as a variable that affects the rate of depreciation, since health status decreases with a high MELD score at the time of transplantation. Table 4.3 displays the results of the logistic regression predicting employment post liver transplantation by MELD score at the time of transplant. Although the proportion of employed patients with MELD scores <21 was slightly higher compared with patients who were not employed after transplant, this did not reach significance after adjusting for all the study covariates ($p = .72$). The group of patients, who had missing values for their MELD scores, were separately compared with the reference group, and found to have effects of similar magnitude to the other comparisons.

Etiology of Liver Diseases. The etiology of liver disease for these analyses stratified patients into five diagnostic categories, with ALD as the study reference category. ALD was chosen as the referent category because of the likelihood of relapse and its influence on employment outcome. The logistic regression shows that patients whose liver condition was caused by hepatitis had better employment outcomes post transplant than did the reference category. Patients with hepatitis related liver diseases were 63% more likely to work after transplant compared to the reference category of alcoholic liver related diseases.

Patients with a diagnosis of ALD were significantly less likely to work post-transplant than those patients without ALD ($p = < 0.0001$). This was confirmed in the logistic regression. The multivariate analysis shows that patients with hepatitis-related

liver diseases (OR = 1.63), biliary liver disease (OR = 1.47), cirrhosis (OR = 1.17), HCC (OR = 1.20) and other liver diseases (OR = 1.12) were more likely to work after transplant than those patients with ALD.

Pretransplant Comorbidities. Analysis of patients' pretransplant comorbidities showed that patients with a pretransplant history of diabetes were 0.84 times or a prior history of angina were 0.63 times as likely to be employed as those without these conditions. Patients with a pretransplant history of dialysis were 1.32 times as likely to be employed as those without this history. Among the other conditions measured, none were statistically significant.

Functional Status. Patients with no functional limitations post-liver transplant were more likely to be employed than those with any such limitations. Similar effects were suggested across both mild and most limitations, and among those cases missing information on this item. Patients with mildly limited functional status were 0.08 times less likely to work post-transplant than patients with no functional limitations. Patients with even modest limitations were much less likely to be employed (OR = 0.02, $p = .0001$). Missing values were not imputed from the data, but were tested for bias in the logistic analysis.

Conclusion

A national database of patients who received liver transplants between 2002 – 2008 was utilized for this study to determine employment status after liver transplantation. The variables Michael Grossman (1972) described as demographics, health-related and external variables were utilized for this study. In summary, liver transplant patients who were employed after transplantation was mostly white (25.8%),

between the ages of 18 to 40 years (32.3%), male (27%), college educated (36%), and were employed pretransplant (54%). The most common liver disease diagnosis of the employed patients was biliary diseases (32.7%), with a MELD score of <21 and with no functional limitations (37.4%). Most of the employed patients had private insurance (31.7%).

A logistic regression of patients by likelihood of employment after transplantation revealed that employed patients were more likely to be male than female (OR = 1.0 times), between the ages of 18 to 40 years (OR = 1.0 times) and white (OR = 1.0 times). Patients with a college degree or beyond (OR = 1.75 times) or less than college degree (OR = 1.29 times) were more likely to be employed than patients with less than a high school education. Also, patients who had been employed before transplantation were more likely to be employed after transplant than patients who had not been employed before transplantation. The most common liver diseases of employed patients were hepatitis (1.63 times), biliary (1.47 times), or HCC (1.2 times) compared to alcoholic liver diseases. Employed patients were more likely to have no functional limitations. Finally, patients with a history of diabetes (0.84) or angina (0.63 times) were less likely to be employed than those without these comorbidities.

In conclusion, the characteristics of the liver transplant patients who were employed within the 2 year follow up after liver transplantation were described. Differences in age, gender, ethnicity, education level, etiology of liver disease, functional status and employment status prior to transplantation impacted employment post-transplantation. A discussion of the meaning of these findings will be presented in the following chapter.

Chapter V: Discussion

The overall intent of this research was to evaluate the employment outcomes of patients after liver transplantation, given the current system of organ allocation, implemented in 2002. This was the first population-based study done using Grossman's Health Capital Model to examine those demographic, health-related and external variables that influenced the likelihood of working for income after liver transplantation in the current acuity based allocation system (MELD). The discussion of the results of the logistic regression model for the national data will be presented first followed by discussion of the limitations of the study. In addition, the implications for future research will be addressed at the conclusion of the chapter. A summary of study conclusions completes this chapter. The meanings of the results of the study are discussed below.

Meaning of National Findings

First Research Aim

Describe those who were employed within 24 months after receiving a liver transplant during the period 2002-2008 compared with those who were not employed after receiving a liver transplant during the same period.

The study population was drawn from the federally mandated UNOS database. Included were those individuals who received a deceased donor liver transplant in 2002 through 2008. In this population, those who worked after transplant were compared with those who did not work, excluding those who received a living donor liver or having a dual organ transplant (e.g., liver and kidney transplant). Also excluded were patients less than 18 years old, in acute liver failure, or who had previously received a liver transplant.

About one quarter of the liver transplant recipients (24.4%) were employed within 24 months of post transplant. The balance had not returned to employment during the same period. These findings were similar those of Moyzes (2001) and those of Saab and colleagues (2007). These results are substantially lower than those reported by Cowling et al. (2004), who reported 40% return to employment for men and 25% for women at 2 years post-transplant. The results of several other studies found employment rates varying from 53% to 70% (Levy et al., 1995; Hunt et al., 1996; Adams et al., 1995; Rongey, 2005). It is difficult to compare absolute levels of employment across liver transplant studies, because many are retrospective reports that do not control for time from liver transplant and have exclusion criteria that limit generalizability.

The latter studies involved smaller cohorts (Levy et al., 1995; Hunt et al., 1996; Adams et al., 1995; Rongey et al., 2005; Sahota et al., 2006), instead of the national registry of transplants. For example, Adams et al. (1995) (n = 203) reported a 57% employment rate for 203 liver transplant recipients who survived more than nine months after liver transplant. Sahota et al. (2006) found a 42% employment rate in 126 liver transplant recipients who survived more than one year after transplantation. However, these findings cannot simply be compared with the findings from this study, because both studies used heterogeneous samples with very broad ranges of follow-up times (9 months to 10 years). Furthermore, to this author's knowledge, no published studies have focused on the UNOS dataset. This is one of the largest cohorts (n = 23,144) evaluated for employment after liver transplantation. The published studies of employment status of transplant candidates and recipients used self-developed questions about employment or questions from quality of life scales. In addition, most of the existing literature on return

to work after liver transplantation has been conducted in single centers with small patient cohorts. The small sample sizes and heterogeneity of measurement instruments used to evaluate employment outcomes in previous studies may have contributed to the different findings in employment rates.

Second Research Aim

Examine the factors associated with those who were employed after receiving a liver transplant between 2002 and 2008, including individual demographic characteristics, health-related characteristics and external factors.

Using Grossman's theoretical framework, with guidance from the literature reviewed of studies of employment post transplantation, variables affecting employment after liver transplantation were chosen. These demographic, health-related and external variables were assessed in univariate and multivariate models for association with likelihood of employment after liver transplantation, using the logistic regression model.

Demographic variables (gender, race, age, education level, pre-transplantation employment status), health-related variables (MELD score at the time of transplant, etiology of liver disease, history of co-morbidities, functional status post transplantation), and external factors (health insurance and geographical location) were chosen for study in univariate and multivariate analyses to address the employment status of liver transplant recipients. A discussion of the results of the multivariate analysis will be presented below, organized according to those demographic, health-related and external factors previously described.

Demographic Variables

Age. Age was revealed in the logistic regression to be a statistically significant predictor of employment after transplantation. The current study illustrates that patients younger than 40 years old were significantly more likely to work after transplantation ($p = <.0001$) than patients older than 40 years. Those aged 60 to 63 years were the least likely to work after transplant (OR= 0.27, CI = 0.22 – 0.33). These findings are consistent with Michael Grossman's Health Capital Model (1972) suggesting that the depreciation rate increases with age.

These findings are consistent with prior research that age is a predictor of employment after transplantation. In a single center study from Spain, Loinaz et al. (1999) found that patients younger than 50 years old and those who had worked within 12 months pretransplant were significantly more likely to return to work ($p = .004$) than patients older than 50 years who had been unemployed for a year before transplantation. Loinaz and colleagues (1999) reported that 41% of patients returned to work an average of 2.6 months after liver transplantation. In another single center study from a Canadian medical center, Adams, Ghent, Grant and Wall (1995) concluded that age of the recipient was related to the likelihood of returning to work. The mean age of employed patients was significantly younger than that of unemployed patients (41.7 ± 1.2 years versus 49.6 ± 1.3 years, $p < .0001$). In a single center study from the Mayo Clinic, Rongey et al. (2005) conducted a study of 186 adult liver transplant recipients who survived for at least one year post-liver transplant. The study showed that age was a predictor variable for employment and suggested that individuals transplanted at an older age were less likely to be employed. Because of major differences between the operational definitions for the

current study and previous studies, exact comparisons between the studies may not be feasible. However, the findings from the previous studies (Adams et al., 1995; Loinaz et al., 1999; Rongey et al., 2005) are important as a comparative reference because age was a major variable in their models.

Another remarkable finding of this study was that the unemployment rate in the age group 41 to 55 years was higher than in the reference age group 18 to 40 years. There are two possible explanations for this phenomenon. First, given that transplant patients tend to be relatively old (age > 40 years) and need frequent medical follow-up visits, it may be difficult for them to obtain employment or to return to work after transplantation. Poor health after transplantation may play a role in returning to work. Older workers may experience a depreciation of their human capital after liver transplantation. This may affect older workers' "employability." Second, negative employer attitudes toward hiring older transplant recipients could have an impact on employment rates. However, this study did not allow for examining age-related work discrimination. Further studies are needed to better understand the barriers to successful employment for this age group and the discrimination they experience.

Gender. The current study illustrates that female transplant patients were 41% less likely to work than male patients post transplantation, which is consistent with findings from previous studies (Cowling et al., 2004b; Moyzes et al., 2001). The definition of employment may explain some of the gender work differences. This study did not include household workers in the operational definition of employment. A retrospective post-liver transplant return to work survey by Newton (1999) indicated that, after transplant, 63% of recipients were working. One reason for the significant increase in return to work

rates was the inclusion of household workers in the operational definition of work. Similarly, another study by Newton (2001), via its operational definition of work which included both employment and household work, found that 59% of the sample's female ALD transplant recipients were working post-transplant; 17% reported that they were household workers. Future studies should further explore the relationship between gender and post-transplant employment outcomes, and review interventions that may improve employment outcomes.

Race. The current study found a significant racial difference comparing Hispanics to whites. Hispanics were found to be 0.70 times less likely than whites to be employed after transplantation. There may be many reasons for this discrepancy. One of these was addressed by testing the interaction between educational level and race. No significant differences were found.

It is interesting that previous studies have found racial barriers to liver transplantation. However, none of the previous studies (Hunt et al., 1996; Saab et al., 2007) identified ethnicity as predictive of employment. Further, sample size needs to be considered. A study by Hunt and colleagues (1996) ($n = 52$) found that employed and unemployed post-transplant patients exhibited no significant difference in race. However, the sample size is likely too small to find significance. Further studies need to focus on the impact of race and ethnicity on post-transplant return to work outcomes.

The significance of racial differences is difficult to determine. Cultural issues such as language barriers and job skills (white collar vs. blue collar, income) may play a role in the lower employment rate. Socioeconomic class, including income and social class were not measured in this study. These variables may contribute to this disparity.

A means of defining income level should be identified and tested as an influencing factor in this analysis, in particular in regard to the impact income plays on this racial disparity. Perhaps there is an interaction between income and/or other measures of socioeconomic level or status that need to be considered.

Education level. The impact of education, an important human capital attribute, can be seen in comparisons against the reference level of “less than high school” education. Patients with more than high school education were 1.29 times more likely to be employed than patients with less than high school education. In addition, the study found that patients with a college degree were 75% more likely to be working after transplantation compared with patients who had not completed a high school education. This finding that employed patients were better educated has been observed in other studies also (Cowling et al., 2004a; Moyzes et al., 2001; Sahota et al., 2006; Saab et al., 2007).

Pretransplant employment. This study revealed that pretransplant employment correlated with post-transplant employment. This finding is consistent with findings from previous studies. Rongey et al. (2005) found that employment prior to transplantation (odds ratio: 5.1; CI: 1.8- 14.0) was significantly associated with employment post-transplant. Sahota et al. (2006) found that the individuals who worked during the previous five years before transplantation were more likely to return to work ($p < 0.0001$), particularly those who had held a job for longer than six months prior to transplantation. Economic status may impact employment rates but this study did not have specific financial information for the patients in this analysis because no data on wages or hours of employment were available.

In addition, patients who have been out of the workforce for long periods would have the greatest difficulty in returning to work. Job descriptions change, jobs disappear, and the financial and social support used during the disability period may become so entrenched that patients lose the motivation to reintegrate themselves in the workforce. This study did not have specific employment information for the patients in this analysis because no data on type/ kind of employment was available.

Health-Related Variables

MELD Score at the Time of Transplant. Although the MELD score was originally proposed as a model to predict short-term mortality in patients with end-stage liver disease, in clinical practice it is commonly used as an overall indicator of a patient's pretransplant functional health status. Individuals with high MELD scores are considered “more sick” than those with low scores. The MELD score at the time of transplant was one of the conceptually important variables in the study for predicting employment outcomes following liver transplantation. However, this study showed no correlation between MELD score and post transplantation employment status. Sahota et al. (2006) and Saab et al. (2007) have found similar results. Liver transplantation has been investigated extensively but little is known about its correlation with pretransplant liver disease severity or the effects of the pretransplant liver disease severity score (MELD score) on post-transplant outcomes such as return to work. Certainly, the role of MELD score at the time transplant in post- transplant employment outcomes must be determined and understood in order to improve post-transplant outcomes.

Etiology of Liver Diseases. The pretransplant liver disease diagnosis is associated with the rate of employment after liver transplantation. This study stratified patients into

five diagnostic categories, with ALD as the study reference category. The study found that within the first 2 years of transplant, patients whose liver condition was caused by hepatitis had better employment outcomes than transplant patients with ALD. Patients with hepatitis related liver diseases were 63% more likely to work after transplant compared to the reference category of ALD.

The possible reason for low employment rates in patients with ALD compared to hepatitis-related liver diseases could be that more transplant recipients with hepatitis may have worked before transplantation. The proportion working after transplantation was significantly different between patients with ALD and those with hepatitis. However, this issue was not evaluated in the current study. Evidence shows that pretransplant, the percentage of candidates with ALD who work is less than that of candidates with liver disease not caused by alcohol (29% vs. 59%). However, one year post-transplant there is no difference in rates of employment. Long-term employment was substantially greater in patients with non-ALD (Bravata et al., 2001).

Studies of the effects of alcohol on post-transplant employment have to date yielded conflicting results. A French study by Pageaux et al., (1999) showed that 30% of alcoholics and 60% of non-alcoholics regained employment post-transplant. However, this contradicts the findings of Hunt et al. (1996) and Cowling et al. (2004a) who found that history of alcohol use does not influence the transplant recipient's return to work. This may be explained by sample differences. These studies were not designed to directly compare rates of employment; therefore we must consider this evidence suggestive but not definitive.

Patients with biliary (cholestatic) diseases were 47% more likely to be employed after liver transplantation than the patients with ALD. This could be due to the fact that before transplantation, patients with end-stage biliary diseases have poor quality of life. These patients commonly suffered from fatigue, sleeplessness, and itching and reported considerable distress from these and other symptoms. These symptoms are more pronounced in patients with biliary liver disease than in patients with other categories of chronic liver disease. Gross et al. (1998) showed that patients with end-stage biliary disease undergoing liver transplantation experience substantial improvement in all aspects of quality of life. First, distress from symptoms of liver disease was reduced. It is notable that itching, a devastating symptom for many biliary liver disease patients is largely eliminated. Second, patients report fewer health problems and limitations to functioning in areas such as mobility, sex life, and social life.

This study showed that the post-transplant employment rate in patients with HCC is 20% and in patients with cirrhosis it is 17% higher than for patients with ALD. One possible explanation for these differences may be that since the introduction of the use of the MELD score to prioritize liver allocation, the assignment of a higher MELD score to patients with HCC increases the probability of transplantation and shortens the waiting period for patients with HCC (Sharma et al., 2004; Yao et al., 2004). On the other hand, putting HCC patients on a fast-track to transplantation may allow patients with aggressive tumor biology to be transplanted and result in an increase in the rate of HCC recurrence after transplant (Jonas et al., 2001; Zavaglia et al., 2005). This might impact patients' post-transplant employment rate.

Given the high assigned MELD score for patients with HCC plus additional points awarded the longer that they are on the waiting list, patients with cirrhosis and no HCC need to have severe decompensation to compete for transplantation. Patients with cirrhosis may develop a variety of ESLD complications, e.g., ascites, encephalopathy, while they are waiting for transplantation. These patients may need to stop working before transplant because of their advanced liver disease and its complications. This may become an obstacle to post-transplant employment status. The expectation to return to professional/occupational activities is one of the most common hopes in this population (Bravata & Keeffe, 2001). However, a significant number of patients are not able to return to work.

Functional Status. The prediction from the Health Capital Model, that decreasing involvement in the workforce is associated with health status and capacity in other functional spheres, is confirmed in this study. Patients with no functional limitation after transplant were more likely to work compared to patients with limited functional status. Our findings correlate with the results presented by Hunt et al. (1996) and Saab et al. (2007), according to whom physical functioning measuring “behavioral performance of everyday physical activities” and role physical measuring “the extent of disability in everyday physical activities” were significantly associated with post-transplant employment. A similar study (Belle et al., 1997) conducted for the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), found that 58% of liver transplant recipients prevented by their disease from working pretransplant were able to work post-transplant and all measures of physical functioning improved significantly ($P < 0.05$). This evidence raises the question: if the majority of liver transplant recipients

experience improved health, why are 60% to 70% of transplant recipients unemployed post transplant? (Belle et al., 1997; Bravata et al., 2001). This study found a high unemployment rate of 75%. The high unemployment rate issue can be understood by exploring the health problems that liver transplant recipients experience. An important contributor to poor health in many transplant recipients is non-adherence to immunosuppressive treatment which was not measured in this study. This significantly contributes to organ failure risk (Chisholm et al., 2002; Rovelli et al., 1989).

Pretransplant Comorbidities. This study found that the presence of diabetes, angina or history of dialysis were each associated with a decreased rate of employment after transplantation. In the health capital model, a negative health shock such as diabetes, angina or dialysis has several effects. The first assumed effect is an increase in the rate of depreciation due to the fact that diabetes, angina and dialysis increase mortality. The higher depreciation rate increases the cost of holding capital which results in less health capital being held. The health stock and the number of healthy days are positively correlated (Grossman, 1972). Therefore, as the stock of health increases the number of healthy days also increases and therefore the probability of labor force participation increases. Conversely, a decline in the optimal health stock will increase sick days. Hence, a history of diabetes, angina or dialysis will result in a lower optimal health stock as well as more time being lost to illness and therefore less probability of participation in the labor force.

The current study findings are consistent with those of Saab et al. (2007). The presence of diabetes was associated with a decreased rate of employment. For instance, a transplant recipient with diabetes is only 0.23 times as likely to be employed as to be

unemployed. Indeed, a cross-sectional study analysis of the Health and Retirement Study (UNOS, 2007) found that diabetes was a significant predictor of lost employment productivity, including increased number of sick days. Others have found a similar negative impact of diabetes on employment (Mayfield et al., 1999; Valdmanis, et al., 2001; Tunceli, et al., 2005).

Another issue that was not evaluated in the current study was the effect of immunosuppressive medications, particularly those of calcineurin inhibitors, on health related quality of life and employment outcomes. Diabetes mellitus, cardiovascular disease, and osteoporosis are some of the most commonly encountered adverse effects of immunosuppression (Durrbach, 2006; Kulak, et al., 2006; & Rabkin et al., 2002). Moreover, nephrotoxicity caused by immunosuppression is a major complication with approximately 25% of nonrenal solid organ recipients developing chronic renal failure and requiring dialysis (Ojo, 2007; Morard et al., 2006; & Faenza et al., 2006). Certainly, the role of immunosuppressive medication on post-transplant employment outcomes should be determined and understood in order to improve the health-related quality of life of organ transplant recipients.

Limitations of the Study

The limitations of this study should be considered when interpreting these results. First, this study included only patients who were transplanted after the adoption of acuity-based MELD scoring system, and thus may show results different from earlier findings when there was more variability in disease severity at time of transplant. Second, the study measures are limited to those included in the UNOS data set. Items that might be helpful in factors affecting employment rate, such as employer attitudes, the prevailing

unemployment rate at time of transplant were not available. Further, UNOS does not include information regarding postoperative patients' perceived physical, social or emotional health problems. Such information might strengthen understanding of the low employment rate, beyond functional status alone.

Missing data is prevalent in UNOS, particularly for the MELD score and the functional status variables. While this might introduce bias into the results, attempts were made to minimize this effect, by expressly including “missing” as a category in the analyses, comparing whether those with missing values differed from the reference category. Generally, the missing category failed to achieve a difference that was statistically significant.

Future studies of employment status should attempt to consider additional attributes beyond the health capital items given emphasis (and the limited items available) in the present work. Among these measures, type of employment, income history, and number of hours worked prior to the transplant. Such measures might have created a better understanding of low employment rates in liver transplant recipients in general, and the relatively higher rates of employment among those previously working and those with college educations. It is possible that patients with white-collar job were more likely to return to work than the blue-collar workers. This may be due to the physical demand required for blue –collar laborers. Such specifics were not measured in UNOS. Earlier studies have found that patients who were working before transplant were more likely to hold jobs that required less physical exertion.

Implications for Future Research

There are a number of implications for future research. Health-related quality of life is recognized as an important patient-reported outcome. Solid organ transplantation is a chronic condition which can have a significant impact on the daily life and well-being of the patient (De Geest et al., 2005; Dudley et al., 2007). This study analysis of demographic, health-related and external variables demonstrates that a negative health shock, as reflected in the chronic illness of end stage liver disease and liver transplantation decreases the labor supply among liver transplant recipients. This study reaffirms knowledge about low employment rates in liver transplant recipients using a national population of recipients. This affects not only the liver transplant patients but also society in terms of costs for social insurance and lost production. It is therefore important to better understand factors affecting recovery and those affecting attainment of employment to improve employment outcomes in the liver transplant population.

Post-transplant employment rates are lower than expected for transplant recipients. The findings of this study suggest further work, but there are few conclusions that can be drawn. It is not possible to clarify whether employment itself is responsible for poor health or whether restored health due to liver transplantation allows working again. Whether or not going to work adversely affects health was not measured by this study. Some transplant recipients may not have returned to work because they would lose Medicaid and their disability income. This was not tested by the study.

Future research is needed that provides detailed descriptions of the groups of patients for whom quality of life is not improved and for whom return to satisfying employment is not possible. In addition, studies of the influence of healthcare providers

and social support interventions on transplant recipients' quality of life should be conducted to design post transplantation programs that maximize favorable outcomes for transplant recipients.

Policy Implications

The political and financial climate with regard to health care is steadily changing. Economic pressures are increasing the expectation that patients who undergo successful liver transplantation should resume full participation in the activities of the community, and this includes return to work. When the goal of liver transplantation is conceptualized as more than recipient survival and includes social-behavioral outcomes as well, then it becomes clear that the transplant team needs to have a better understanding of the post-transplant work outcomes for this vulnerable population.

Greater attention, therefore, needs to be paid to the full social rehabilitation of patients who undergo this procedure. Every effort should be made to ensure that they once again become fully productive members of society. The longer transplant recipient remains absent from work, the greater is the relative stock of claimant capital for leisure time and the greater the loss of human capital relevant to productive employment after liver transplantation. Specific interventions for liver transplant recipients should be designed to evaluate and change their health perceptions and encourage their return to work. Possible options include early occupational counseling and job referrals for post transplantation patients.

Legislation has changed over the years to help transplant patients overcome financial burdens. For example, newly established Medicaid Buy-In programs and Ticket to Work are funded programs that assist transplant patients in securing employment after

surgery. In addition to legislation, a strong and definitive policy encouraging return to work at transplant centers may influence the post-transplant employment rate. Specific interventions or programs such as early occupational counseling and job referrals should be designed to encourage transplant recipients to return to work. Transplant program coordinators are speaking with patients more often about return to work issues both before and after transplantation. Many centers have financial counselors who educate patients about employment options before and after transplantation.

At the initial pre-transplant assessment and acceptance of the patient onto the transplant waiting list, the social-work assessment should include a thorough analysis of work skills, education level, previous work history, and income/ insurance source and status. Application for permanent disability at this early stage might prove harmful and limit post transplant work options. It should be emphasized to the patient that, if considered medically able by the attending physician, he/she will be expected to seek employment post-transplant. Consideration should be given, and plans should be made, at this early stage for a return to work after the transplant has been performed. Post transplantation, if the patient does not return to work by approximately 6 months (depending on his/her medical progress), referral for full vocational-rehabilitation evaluation should be made to assess the patient's ability to return to work.

With increasing attention on how the United States allocates money for health care, questions continue to arise about whether the U.S. government can continue to fund liver transplantation for alcoholic liver disease, especially since public support for it has been lacking (Evans, Manninen & Dong, 1991). The liver transplant team, however, can have a positive effect on the public's perception of liver transplantation for patients with

alcoholic liver disease. In order for liver transplantation to survive and prosper in the 21st century, the transplant teams who care for recipients must be able to document the outcomes attained as a result of their actions as well as how those actions impact important post transplant outcomes, including work outcomes.

There is no federal mandate for liver transplant recipients to return to work post transplantation. Numerous financing, education, and manpower and health care organization programs need to be introduced with that objective in mind. It may be well, then, to characterize health policy as the starting point for consideration of the post transplant return to work concept. The barriers to employment post transplantation should be remediable through health policy interventions at the state or federal level.

Conclusion

Liver transplantation is a widely accepted treatment for ESLD. Research has shown that people with ESLD experience improved survival and health-related quality of life after transplantation. However, the unemployment rate among liver transplant recipients remains high. The reasons for this were the subject of a study that was used as the secondary dataset for this policy analysis. The findings from this study contribute significantly to the body of knowledge because the results provide corroborating evidence at the national level of findings from earlier studies done at the local level. This study shows that liver transplant recipients are more likely to be employed if they are young, educated, have private insurance, do not have comorbidities, worked prior to transplantation, and have high physical functioning.

Policy solutions to the problem of unemployment among liver transplant recipients may arise from the examination of health outcomes. Such analysis is necessary

for the formulation of policies that improve outcomes. When employment is considered as a health outcome, it is important in an era of evidence based medicine to ensure that healthcare interventions such as liver transplantation produce improved health outcomes. Therefore, the high unemployment rate among liver transplant recipients is a poor health outcome that should be addressed. Examining health outcomes after medical intervention allows the public health community to find ways to improve outcomes and to ensure that medical interventions are worthwhile. Continued research will be required to further understand the employment outcomes of liver transplant patients. Perhaps this research contribution will help provide guidance to future researchers in their quest to understand the role of health policy in evaluating a framework for employment outcomes.

References

- Aadahl, M., Hansen, B., Kirkegaard, P., & Groenvold, M. (2002). Fatigue and physical function after orthotopic liver transplantation. *Liver Transplantation*, 8(3), 251-259.
- Adams, P., Ghent, C., Grant, D., & Wall, W. (1995). Employment after liver transplantation. *Hepatology*, 21(1), 140-144.
- Belle, S., Porayko, M., Hoofnagle, J., Lake, J., & Zetterman, R. (1997). Changes in quality of life after liver transplantation among adults. *Liver Transplantation and Surgery*, 3(2), 93-104.
- Berlakovich, G., Steininger, R., Herber, F., Barlan, M., Mittlbock, M., & Muhlbacher, F. (1994). Efficacy of liver transplantation for alcoholic cirrhosis with respect to recidivism and compliance. *Transplantation*, 58(5), 560-565.
- Best, J., Veenstra, D., & Geppert, J. (2001). Trends in expenditures for Medicare liver Transplant recipients. *Liver Transplantation*, 7(10), 858-862.
- Blanch, J., Sureda, B., Flavia, M., Marcos, V., Pablo, J., Lazzari, E., et al. (2004). Psychosocial adjustment to orthotopic liver transplantation in 266 recipients, *Liver Transplantation*, 10(2), 228-234.
- Bravata, D., Olkinn, I., Barnato, A., Keeffe, B., & Owens, D. (1999). Health-related quality of life after liver transplantation: A metaanalysis. *Liver Transplantation and Surgery*, 5(4), 318-331.
- Bravata, D., & Keeffe, B. (2001). Quality of life and employment after liver transplantation. *Liver Transplantation*, 7(11), S119-123.
- Caccamo, L., Azara, V., & Dogila, M. (2001). Longitudinal perspective measurement of

- the quality of life before and after liver transplantation among adults. *Transplant Proceedings*, 33(1-2), 1880-1881.
- Chisholm, M. (2002). Enhancing transplant patients' adherence to medication therapy. *Clinical Transplantation*, 16(1), 30-38
- Cicutto, L., Braidy, C., Moloney, S., Hutcheon, M., Holness, D., & Downey, G. (2004). Factors affecting attainment of paid employment after lung transplantation. *The Journal of Heart and Lung Transplantation*, 23(4), 481-486.
- Commander, M., Neuberger, J. & Dean, C. (1992). Psychiatric and social consequences of liver transplantation. *Transplantation*, 53(5), 1038-1040.
- Cowling, T., Jennings, L., Goldstein, R., Sanchez, E., Chinnakotla, S., Klintmalm, G., et al. (2004a). Societal reintegration after liver transplantation: Findings in alcohol related and non-alcohol related transplant recipients. *Annals of Surgery* 239(1): 93-98.
- Cowling, T., Jennings, L., Goldstein, R., Sanchez, E., Chinnakotla, S., Klintmalm, G. et al. (2004b). Liver transplantation and health related quality of life: scoring differences between men and women. *Liver Transplantation*, 10(1), 88-96
- Cowling, T., Jennings, L., Jung, G., Goldstein, R., Molmenti, E., Gonwa, T., et al. (2000). Comparing quality of life following liver transplantation for Laennec's versus non-Laennec's patients. *Clinical Transplantation*, 14(2), 115-120
- Currie, J., Madrian, B.C. (1999), Health, health insurance and the labor market, in Ashenfelter, O., Card, D. (1st ed.), *Handbook of Labor Economics*, Elsevier, London, Volume 3C, pp.3309-3415.
- DeGeest, S. Dobbels, F., Fluri, C., Paris, W., Trooster, T. (2005). Adherence to the

- therapeutic regimen in heart, lung, and heart-lung transplant recipients. *Journal of Cardiovascular Nursing*, S88-98
- Dudley, T., Chaplin, D., Clifford, C., & Mutimer, D. (2007). Quality of life after liver transplantation for hepatitis C infection. *Quality of Life Research*, 16(8), 1299-1308
- Evan, R. (1990). The demand for transplantation in the United States. *Clinical Transplantation*, 319-327.
- Evans, R., Manninen, D., & Dong, F. (1993). An economic analysis of liver transplantation. *Gastroenterology Clinics of North America*, 22(2), 451-473.
- Evans, R. (1995). Liver transplantation in a managed care environment, *Liver Transplantation and Surgery*, 1(1), 61-75
- Evans, R. (1995). Social, vocational and financial consequences of liver transplantation. *Liver Transplantation and Surgery*, 1(5) 116-123.
- Faenza, S., Santora, A., Mancini, E., Pareschi, S., Siniscalchi, A., Zanzani, C., & Pinna, A. (2006). Acute renal failure requiring renal replacement therapy after orthotopic liver transplantation. *Transplant Proceedings*, 38(4), 1141-1142
- Folland, S., Goodman, A.C., & Stano, M. (2004). *The economics of health and health care* (4th ed.). Upper Saddle River, New Jersey: Prentice Hall.
- Gross, C., Malinchoc, M., Kim, R., Evans, W., Wiesner, R., Petz, J., et al. (1999). Quality of life before and after liver transplantation for cholestatic liver disease. *Hepatology*, 29(2), 356-364.
- Grossman, M. (1972). On the concept of health capital and the demand for health. *The Journal of Political Economy*, 80, 223-255.

- Heylink, J., Tymstra, T., Sloof, M., & Klompmaker, I. (1990). Liver transplantation: Psychosocial problems following the operation. *Transplantation* 49(4), 1018-1019
- Hunt, C., Tart, J., Dowdy, E., Bue, B., Williams, D., & Clavien, P. (1996). Effect of Orthotopic liver transplantation on employment and health status. *Liver Transplant Surgery*, 2(2), 148-153.
- Jonas, S., Steinmuller, T., Settmacher, U., Langrehr, J., Muller, A., & Neuhaus, P. (2001). Liver transplantation for recurrent hepatocellular carcinoma in Europe. *Journal of Hepato-Biliary-Pancreatic Surgery*, 8(5), 422-426
- Karam, V., Castaing, D., Danet, C., Delvart, V., Gasquet, I., Adam, R., et al. (Azoulay, D., Samuel, D., & Bismuth, H.) (2003). Longitudinal prospective evaluation of quality of life in adult patients before and one year after liver transplantation. *Liver Transplantation*, 9(7), 703-711.
- Kavanagh, T., Yacoub, M., Kennedy, J., Austin, P. (1999). Return to work after heart Transplantation: 12- year follow-up. *Journal of Heart and Lung Transplantation*, 18(9), 846-851.
- Keeffe, E. (2000). Liver transplantation at the millennium: Past, present and future. *Clinics in Liver Disease*, 4(1), 241-255.
- Kulak, C., Borba, V., Kulak, J., Shane, E. (2006). Transplantation Osteoporosis, *Endocrinology and Metabolism*, 50(4), 783-792
- Levy, M., Jennings, L., Abouloud, M., Mulligan, D., Goldstein, R., Husberg, B., et al. (1995). Quality of life improvement at one, two, and five years after liver transplantation. *Transplantation*, 59(4), 515-518.

- Leyendecker, B. Bartholomew, U., Harold, M., Klapp, B. & et al., (1993). Quality of life of liver transplant recipients. *Transplantation*, 56(3), 561-567.
- Loinaz, C., Clemares, M., Marques, E., Paserio, G., Gomez, R., Pinto, I., et al. (1999). Labor status of 137 patients with liver transplantation. *Transplant Proceedings*, 31(6), 2470-2471.
- Matas, A., Lawson, W., McHugh, L., Gillingham, K., Payne, W., Dunn, D., et al. (1996). Employment patterns after successful kidney transplantation. *Transplantation*, 61(5), 729-733.
- Mayfield, J., & Whitecotton, L. (1999). Work disability and diabetes. *Diabetes Care*, 22(7), 1105-1109.
- Morard, I., entha, G., Spahr, L., Majno, P., Hadengue, A., Huber, O., Morel, P. & Giostra, E. (2006). Long-term renal function after liver transplantation is related to calcineurin inhibitors blood levels. *Clinical Transplantation*, 20(1), 96-101
- Moyzes, D., Walter, M., Rose, M., Neuhaus, P., & Klapp, B. (2001). Return to work 5 years after liver transplantation. *Transplant Proceedings*, 33(5), 2878-2880.
- Mueller, K. (1989). National Organ Transplant Act of 1984: Congressional response to changing technology. *Policy Studies Review*, 8, 346-356.
- Munro, B. H. (2005). *Statistical Methods for Health Care Research*, 5th ed. Philadelphia, PA: Lippincott Williams and Wilkins.
- Newton, S. (1988). Renal transplant recipients' and their physicians' expectations regarding return to work post transplant. *ANNA Journal*, 26(2), 227-232.
- Newton, S. (1997). Return to work post liver transplant: A theoretical explanatory model

- with sense of coherence, conception of health, and hardiness. *Unpublished doctoral dissertation*, University of Michigan, Ann Arbor, MI.
- Newton, S. (1999a). Relationship of hardiness and sense of coherence to post liver transplant return to work, *Holistic Nurse Practice*, 13(3), 71-79.
- Newton, S. (1999b). Recidivism & return to work posttransplant: Recipients with substance abuse histories. *Journal of Substance Abuse Treatment*, 17(1), 103-109.
- Newton, S. (2001). Work outcomes for female liver transplant recipients with alcohol related liver disease. *Gastroenterology Nursing*, 24(6), 288-293.
- Newton, S. (2003). Relationship between depression and work outcomes following liver transplantation: The nursing perspective. *Gastroenterology Nursing*, 26(2), 68-72.
- Nicholas, J., Oleske, D., Robinson, L., Switala, J., & Tarter, R. (1994). The quality of life after orthotopic liver transplantation: An analysis of 166 cases. *Archives of physical medicine and rehabilitation*, 75(4), 431-435.
- Ojo, A. (2007). Renal diseases in recipients of non renal solid organ transplantation. *Seminars in Nephrology*, 27(4), 498-507
- Pageaux, G., Michel, J., Perney, P., Possoz, P., Perrigault, F., Navarro, F., et al. (1999). Alcoholic cirrhosis is a good indication for liver transplantation, even for cases of recidivism. *International Journal of Gastroenterology and Hepatology*, 45(3), 421-6.
- Paris, W., Woodbury, A., Thompson, S., Levick, M., Nothegger, S. Hutkin-Slade, L., et al. (1992). Social rehabilitation and return to work after cardiac transplantation--a multicenter survey. *Transplantation*, 53(2), 433-438.
- Paris, W., Woodbury, A., Thompson, S., Levick, M., Nothegger, S., Arbuckle, P., et al.

- (1993). Returning to work after heart transplantation. *The Journal of Heart and Lung Transplantation*, 12(1), 46-53.
- Pomfret, E., Fryer, J., & Sima, C. (2007). Liver and intestine transplantation in the United States, 1998-2005. *American Journal of Transplantation*, 7(5), 1376-1389.
- Rabkin, J., Rosen, H., Corless, C., & Olyaei, A. (2002). Tacrolimus is associated with a lower incidence of cardiovascular complication in liver transplant recipients. *Transplant Proceedings*, 34(5), 1557-1558
- Reid, A, Resnick, & MChang, Y. (2004). Disparity in use of orthotopic liver transplantation among blacks and whites. *Liver Transplantation*, 10(7), 834-841.
- Rongey, C., Bambha, K., Vanness, D., Pedersen, R., Malinchoc, M., Therneau, et al. (2005). Employment and health insurance in long term liver transplant recipients. *American Journal of Transplantation*, 5(8), 1901-1908.
- Rovelli, M., Palmeri, D., Vossler, E., Bartus, S., Hull, D., Schweizer, R. (1989). Noncompliance in renal transplant recipients: evaluation by socioeconomic groups. *Transplant Proceedings*, 21(6), 3979-3981
- Saab, S., Wiese, C., Ibrahim, A., Peralta, L., Durazo, S., Yersiz, H., et al. (2007). Employment and quality of life in liver transplant recipients. *Liver Transplantation*, 13(9), 1330-1338.
- Sahota, A., Zaghla, H., Adkins, R., Ramji, A., Lewis, S., Moser, J., et al. (2006). Predictors of employment after liver transplantation. *Clinical Transplantation*, 20(4), 490-495.
- Salyer, J., Flattery, M., Joyner, P., & Elswick, R. (2003). Lifestyle and quality of life in

- long term cardiac transplant recipients. *The Journal of Heart and Lung Transplantation*, 22(3), 309-321.
- Sharma, P., Balan, V., Hernandez, J., Harper, A., Edwards, E., Rodriguez-Luna, H., Byrne, T., Vargas, H., Mulligan, D., Rakela, J., & Wiesner, R. (2004). Liver transplantation for hepatocellular carcinoma: the MELD impact. *Liver Transplantation*, 10(1), 36-41
- Shih, F., Hu, H., Ho, M., Lin, H., Lin, M., & Lee, P. (2000). Change in health related quality of life and working competence before and after liver transplantation. *Transplant Proceedings*, 32(7), 2144-2148.
- Showstack, J., Katz, P., & Lake, J. (1999). Resource utilization in liver transplantation: Effects of patient characteristics and clinical practice. *Journal of the American Medical Association*, 281(15), 1381-1386.
- Starzl, T., Iwatsuki, S., & Van Thiel, D. (1982). Evolution of liver transplantation. *Hepatology*, 2, 614.
- Tarter, R., Switala, J., Arria, A., Plail, J & Van Thiel, D. (1991). Quality of life before and after orthotopic liver transplantation. *Archives of Internal Medicine*, 151(8), 1521-1526.
- Thomas, D. (1996). Returning to work after liver transplant: Experiencing the roadblocks. *Transplant Coordinator*, 6(3), 134-138.
- Tunceli, K., Bradley, C., Nerenz, D., Williams, L., & Pladevall, M. (2005). The impact of diabetes on employment and work productivity. *Diabetes Care*, 28(11), 2662-2667.
- United States Department of Human and health Services. (1990). Assessment of liver

- transplantation. *Health Technology Assessment Reports*, 1990, 3-7.
- United States Department of Health and Human Services. (1991). Medicare program: Criteria for Medicare coverage of adult liver transplants. *Federal Register*, 56, 15006-15018.
- United Network for Organ Sharing (UNOS) (2004). Retrieved February 26, 2008 from: <http://www.unos.org/data/about/uses.asp>
- United Network for Organ Sharing (UNOS) (2007). Retrieved June 20, 2007 from: <http://www.unos.org/data/about/uses.asp>
- United Network for Organ Sharing (UNOS) (2008). Retrieved February 2003 from: <http://www.unos.org/data/about/uses.asp>
- Valdamanis, V., Smith, D., & Page, M. (2001). Productivity and economic burden associated with diabetes. *American Journal of Public health*, 91(1), 129-130.
- Yao, F., Bass, N., Ascher, N., & Roberts, J. (2004). Liver transplantation for hepatocellular carcinoma: lessons from the first year under the Model of End-Stage Liver Disease (MELD) organ allocation policy. *Liver Transplantation*, 10(5), 621-630
- Zavaglia C., De Carlis L., Alberti A., Minola E., Belli L., Slim AO., Airoidi A., Giacomoni A., Rondinara G., Tinelli C., Forti D., Pinzello G. (2005). Predictors of long-term survival after liver transplantation for hepatocellular carcinoma. *Journal of Gastroenterology*, 100(12), 2708-2716

Appendix A: UNOS Database: Tiedi

Adult Liver Transplant Candidate Registration (TCR) Form

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 10/31/2010

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI® application.

Currently in the worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through the online TIEDI® application, additional fields that are dependent on responses provided in these required fields may become required as well.

However, since those fields are not required in every case, they are not marked with a red asterisk.

Provider Information

Recipient Center:

Candidate Information

Organ Registered: Date of Listing or Add:

Last Name: First Name: MI:

Previous Surname:

SSN: Gender: Male Female

HIC: DOB:

State of Permanent Residence:

Permanent ZIP Code: -

Is Patient waiting in permanent ZIP code: YES NO UNK

Ethnicity/Race:

(select all origins that apply)

American Indian or Alaska Native

American Indian

Eskimo

Aleutian

Alaska Indian

American Indian or Alaska Native: Other

American Indian or Alaska Native: Not

Specified/Unknown

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |

Asian

Asian Indian/Indian Sub-Continent

Chinese

Filipino

Japanese

Korean

Vietnamese

Asian: Other

Asian: Not Specified/Unknown

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |

Black or African American

African American

African (Continental)

West Indian

Haitian

Black or African American: Other

| | |
|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |
| <input type="checkbox"/> | <input type="checkbox"/> |

Hispanic/Latino

Mexican

Puerto Rican (Mainland)

Puerto Rican (Island)

Cuban

Hispanic/Latino: Other

Black or African American: Not Specified/Unknown Hispanic/Latino: Not Specified/Unknown

Native Hawaiian or Other Pacific Islander

Native Hawaiian

Guamanian or Chamorro

Samoan

Native Hawaiian or Other Pacific Islander: Other

Native Hawaiian or Other Pacific Islander: Not Specified/Unknown

White

European Descent

Arab or Middle Eastern

North African (non-Black)

White: Other

White: Not Specified/Unknown

Citizenship:

U.S. CITIZEN

RESIDENT ALIEN

NON-RESIDENT ALIEN, Year Entered US

Year of Entry to the U.S.

Highest Education Level:

NONE

GRADE SCHOOL (0-8)

HIGH SCHOOL (9-12)

ATTENDED COLLEGE/TECHNICAL SCHOOL

ASSOCIATE/BACHELOR DEGREE

POST-COLLEGE GRADUATE DEGREE

N/A (< 5 YRS OLD)

UNKNOWN

Medical Condition at time of listing:

IN INTENSIVE CARE UNIT

HOSPITALIZED NOT IN ICU

NOT HOSPITALIZED

Patient on Life Support: **YES** **NO**

Ventilator

Artificial Liver

Other Mechanism, Specify

Specify:

Functional Status:

Physical Capacity:

- CV VH: Continuous Venous/Venous Hemofiltration
- Dialysis Status Unknown
- Dialysis-Unknown Type was performed

Peptic Ulcer:

- No
- Yes, active within the last year
- Yes, not active within the last year
- Unknown

Angina:

- No
- Yes, and documented Coronary Artery Disease
- Yes, with no documented Coronary Artery Disease
- Yes, but Coronary Artery Disease unknown
- Status Unknown

Drug Treated Systemic Hypertension: YES NO UNK

Symptomatic Cerebrovascular Disease: YES NO UNK

Symptomatic Peripheral Vascular Disease: YES NO UNK

Drug Treated COPD: YES NO UNK

Pulmonary Embolism: YES NO UNK

Any previous Malignancy: YES NO UNK

Specify Type:

- Skin Melanoma
- Skin Non-Melanoma
- CNS Tumor
- Genitourinary
- Breast
- Thyroid
- Tongue/Throat/Larynx
- Lung
- Leukemia/Lymphoma
- Liver
- Other, specify

Specify:

Most Recent Serum Creatinine: mg/dl ST=

Liver Medical Factors

Variceal Bleeding within Last Two Weeks: YES NO UNK

Previous Upper Abdominal Surgery: YES NO UNK

Spontaneous Bacterial Peritonitis: YES NO UNK

History of Portal Vein Thrombosis: YES NO UNK

History of TIPSS: YES NO UNK

Adult Liver Transplant Recipient Registration (TRR) Form

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 10/31/2010

Note: These worksheets are provided to function as a guide to what data will be required in the online TIED® application. Currently in the worksheet, a red asterisk is displayed

by fields that are required, independent of what other data may be provided. Based on data provided through the online TIED® application, additional fields that are dependent

on responses provided in these required fields may become required as well. However, since those fields are not required in every case, they are not marked with a red

asterisk.

Recipient Information

Name: DOB:

SSN: Gender:

HIC: Tx Date:

State of Permanent Residence:

Permanent Zip: -

Provider Information

Recipient Center:

Surgeon Name:

NPI#:

Donor Information

UNOS Donor ID #:

Donor Type:

Patient Status

Primary Diagnosis:

Specify:

Date: Last Seen, Retransplanted or Death

Patient Status:

 LIVING DEAD RETRANSPLANTED

Primary Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Transplant Hospitalization:

Date of Admission to Tx Center:

Date of Discharge from Tx Center:

Was patient hospitalized during the last 90 days prior to the transplant admission:

 YES NO UNK

Medical Condition at time of transplant:

 IN INTENSIVE CARE UNIT HOSPITALIZED NOT IN ICU NOT HOSPITALIZEDPatient on Life Support: YES NO Ventilator Artificial Liver Other Mechanism, Specify

Specify:

Functional Status:

Physical Capacity:

 No Limitations Limited Mobility Wheelchair bound or more limited Not Applicable (< 1 year old or hospitalized) UnknownWorking for income: YES NO UNK

If No, Not Working Due To:

If Yes:

 Working Full Time Working Part Time due to Demands of Treatment Working Part Time due to Disability Working Part Time due to Insurance Conflict Working Part Time due to Inability to Find Full Time Work Working Part Time due to Patient Choice Working Part Time Reason Unknown Working, Part Time vs. Full Time Unknown

Academic Progress:

 Within One Grade Level of Peers Delayed Grade Level Special Education Not Applicable < 5 years old Status Unknown

Academic Activity Level:

- Full academic load
- Reduced academic load
- Unable to participate in academics due to disease or condition
- Not Applicable < 5 years old/ High School graduate
- Status Unknown

Source of Payment:

Primary:

Specify:

Secondary:

Clinical Information : PRETRANSPLANT

Height: ft. in. cm %ile ST=

Weight: lbs kg %ile ST=

BMI: kg/m2 %ile

Previous Transplants:

Previous Transplant Organ Previous Transplant Date Previous Transplant Graft Fail Date

The three most recent transplants are listed here. Please contact the UNet Help Desk to confirm more than three previous transplants by calling 800-978-

4334 or by emailing unethelpdesk@unos.org.

Viral Detection:

HIV Serostatus:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

CMV IgG:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

CMV IgM:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV Core Antibody:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HBV Surface Antigen:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

HCV Serostatus:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

EBV Serostatus:

- Positive
- Negative
- Not Done
- UNK/Cannot Disclose

Any tolerance induction technique used: YES NO UNK

Pretransplant Lab Date:

SGPT/ALT: U/L ST=

Malignancies between listing and transplant: YES NO UNK

This question is NOT applicable for patients receiving living donor transplants who were never on the waiting list.

If yes, specify type:

- Skin Melanoma
- Skin Non-Melanoma
- CNS Tumor
- Genitourinary
- Breast
- Thyroid
- Tongue/Throat/Larynx
- Lung
- Leukemia/Lymphoma
- Liver
- Other, specify

Specify:

Clinical Information : TRANSPLANT PROCEDURE**Multiple Organ Recipient****Were extra vessels used in the transplant procedure:****Surgical Procedure:** ORTHOTOPIC HETEROTOPIC**Procedure Type:** Whole Liver Partial Liver, remainder not Tx or Living Transplant Split Liver Whole Liver with Pancreas (Technical Reasons) Partial Liver with Pancreas (Technical Reasons) Split Liver with Pancreas (Technical Reasons)**Split Type:****Preservation Information:****Warm Ischemia Time (include anastomotic time): min ST=****Total Cold Ischemia Time (if pumped, include pump****time): hrs ST=****Risk Factors:****Did Patient receive 5 or more units of packed red blood cells within 48 hours prior to transplantation due to spontaneous portal hypertensive bleeding:** YES NO UNK**Spontaneous Bacterial Peritonitis:** YES NO UNK**Previous Abdominal Surgery:** YES NO UNK**Portal Vein Thrombosis:** YES NO UNK**Transjugular Intrahepatic Portacaval Stint Shunt:** YES NO UNK**Incidental Tumor found at time of Transplant:** YES NO UNK

If yes, specify tumor type:

 Hepatocellular Adenoma Hemangioma Hemangioendothelioma Angiomyolipoma Bile Duct Cystadenocarcinoma Cholangiocarcinoma Hepatocellular Carcinoma Hepatoblastoma Angiosarcoma Other Primary Liver Tumor, Specify

Specify:

Clinical Information : POST TRANSPLANT**Pathology Conf. Liver Diag. of Hospital Discharge:****Specify:****Graft Status:** Functioning Failed**If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.****Date of Graft Failure:****Causes of graft failure:**Primary Graft Failure YES NO UNKVascular Thrombosis YES NO UNKBiliary Tract Complication YES NO UNKHepatitis: DeNovo YES NO UNKHepatitis: Recurrent YES NO UNKRecurrent Disease (non-Hepatitis) YES NO UNKAcute Rejection YES NO UNKInfection YES NO UNK

Other, Specify:

Discharge Lab Date:**Total Bilirubin: mg/dl ST=****SGPT/ALT: U/L ST=****Serum Albumin: g/dl ST=****Serum Creatinine: mg/dl ST=****INR: ST=****Did patient have any acute rejection episodes between transplant and discharge:** Yes, at least one episode treated with anti-rejection agent Yes, none treated with additional anti-rejection agent No**Was biopsy done to confirm acute rejection:** Biopsy not done Yes, rejection confirmed Yes, rejection not confirmed**Treatment**

Biological or Anti-viral Therapy: YES NO Unknown/Cannot disclose

- Acyclovir (Zovirax)
- Cytogam (CMV)

If Yes, check all that apply:

- Gamimune
- Gammagard
- Ganciclovir (Cytovene)
- Valgancyclovir (Valcyte)
- HBIG (Hepatitis B Immune Globulin)
- Flu Vaccine (Influenza Virus)
- Lamivudine (Epivir) (for treatment of Hepatitis B)
- Other, Specify
- Valacyclovir (Valtrex)

Specify:
Specify:

Other therapies: YES NO

If Yes, check all that apply:

- Photopheresis
- Plasmapheresis
- Total Lymphoid Irradiation (TLI)

Immunosuppressive Information

Are any medications given currently for maintenance or anti-rejection: YES NO

Did the patient participate in any clinical research

protocol for immunosuppressive medications: YES NO

If Yes, Specify:

Immunosuppressive Medications

View Immunosuppressive Medications

Definitions Of Immunosuppressive Medications

For each of the immunosuppressive medications listed, select **Ind** (Induction), **Maint** (Maintenance) or **AR** (Anti-rejection) to indicate all medications that were prescribed for the recipient during the initial transplant hospitalization period, and for what reason. If a medication was not given, leave the associated box(es) blank.

Induction (Ind) immunosuppression includes all medications given for a short finite period in the perioperative period for the purpose of preventing acute rejection. Though the drugs may be continued after discharge for the first 30 days after transplant, it will not be used long-term for immunosuppressive maintenance. Induction agents are usually polyclonal, monoclonal, or IL-2 receptor antibodies (example: Methylprednisolone, Atgam, Thymoglobulin, OKT3, Simulect, or Zenapax). Some of these drugs might be used for another finite period for rejection therapy and would be recorded as rejection therapy if used for this reason. For each induction medication indicated, write the total number of days the drug was actually administered in the space provided. For example, if Simulect or Zenapax was given in 2 doses a week apart, then the total number of days would be 2, even if the second dose was given after the patient was discharged.

Maintenance (Maint) includes all immunosuppressive medications given before, during or after transplant *for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug* (example:

Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes, or for induction.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode during the initial post-transplant period or during a specific follow-up period, usually up to 30 days after the diagnosis of acute rejection (example: Methylprednisolone,

Atgam, OKT3, or Thymoglobulin). When switching maintenance drugs (example: from Tacrolimus to Cyclosporine; or from Mycophenolate Mofetil to Azathioprine) because of rejection, the drugs should not be listed under AR immunosuppression, but should be listed under maintenance immunosuppression.

If an immunosuppressive medication other than those listed is being administered (e.g., new monoclonal antibodies), select Ind, Maint, or AR next to Other

Immunosuppressive Medication field, and enter the full name of the medication in the space provided. **Do not list non-immunosuppressive medications.**

Ind. Days ST Maint AR

Steroids

(Prednisone, Methylprednisolone, Solumedrol, Medrol, Decadron)

Atgam (ATG)

OKT3 (Orthoclone, Muromonab)

Thymoglobulin

Simulect - Basiliximab

Zenapax - Daclizumab

Azathioprine (AZA, Imuran)

Adult Liver Transplant Recipient Follow-Up (TRF) Form

FORM APPROVED: O.M.B. NO. 0915-0157 Expiration Date: 10/31/2010

Note: These worksheets are provided to function as a guide to what data will be required in the online TIEDI® application.

Currently in the

worksheet, a red asterisk is displayed by fields that are required, independent of what other data may be provided. Based on data provided through

the online TIEDI® application, additional fields that are dependent on responses provided in these required fields may become required as well.

However, since those fields are not required in every case, they are not marked with a red asterisk.

Recipient Information

Name: DOB:

SSN: Gender:

HIC: Tx Date:

Previous

Follow-Up:

Previous Px Stat

Date:

Transplant Discharge Date:

State of Permanent Residence:

Zip Code: -

Provider Information

Recipient Center:

Followup Center:

Physician Name:

NPI#:

Follow-up Care Provided By:

- Transplant Center
 Non Transplant Center Specialty Physician
 Primary Care Physician
 Other Specify

Specify:

Donor Information

UNOS Donor ID #:

Donor Type:

Patient Status

Date: Last Seen, Retransplanted or Death

Patient Status:

- LIVING
 DEAD
 RETRANSPLANTED

Primary Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Contributory Cause of Death:

Specify:

Hospitalizations:

Has the patient been hospitalized since the

last patient status date: YES NO UNK

Number of Hospitalizations: St=

Noncompliance:

Was there evidence of noncompliance with immunosuppression medication during this follow-up period that compromised the patient's recovery:

YES NO UNK

Functional Status:

Physical Capacity:

- No Limitations
 Limited Mobility
 Wheelchair bound or more limited
 Not Applicable (< 1 year old or hospitalized)
 Unknown

Working for income: YES NO UNK

If No, Working Due To

- Working Full Time
- Working Part Time due to Demands of Treatment
- Working Part Time due to Disability
- Working Part Time due to Insurance Conflict

If Yes:

- Inability to Find Full Time Work
- Working Part Time due to Patient Choice
- Working Part Time Reason Unknown
- Working, Part Time vs. Full Time Unknown

Academic Progress:

- Within One Grade Level of Peers
- Delayed Grade Level
- Special Education
- Not Applicable < 5 years old
- Status Unknown

Academic Activity Level:

- Full academic load
- Reduced academic load
- Unable to participate in academics due to disease or condition
- Not Applicable < 5 years old/ High School graduate
- Status Unknown

Primary Insurance at Follow-up:

Specify:

Clinical Information

Height: ft. in. cm %ile St=

Weight: lbs. kg %ile St=

BMI: kg/m² %ile

Pathology confirmed liver diagnosis at hospital discharge:

Specify:

Graft Status: Functioning Failed

If death is indicated for the recipient, and the death was a result of some other factor unrelated to graft failure, select Functioning.

Date of Failure:

Contributory causes of graft failure:

Primary Graft Failure

YES NO UNK

Vascular Thrombosis YES NO UNK

Biliary Tract Complication: YES NO UNK

Denovo Hepatitis YES NO UNK

Recurrent Hepatitis: YES NO UNK

Recurrent Disease: YES NO UNK

Acute Rejection: YES NO UNK

Chronic Rejection: YES NO UNK

Infection: YES NO UNK

Patient Noncompliance: YES NO UNK

Other, Specify:

Discharge Lab Data:

Lab Date:

Total Bilirubin: mg/dl St=

SGPT/ALT: U/L St=

Serum Albumin: g/dl St=

Serum Creatinine: mg/dl St=

INR (ratio): St=

Most Recent Lab Data:

Lab Date:

Total Bilirubin: mg/dl St=

SGPT/ALT: U/L St=

Serum Albumin: g/dl St=

Serum Creatinine: mg/dl St=

INR (ratio): St=

Diabetes onset during the follow-up period: YES NO UNK

Insulin dependent: YES NO UNK

Did patient have any acute rejection episodes during the follow-up period:

Yes, at least one episode treated with anti-rejection agent

Yes, none treated with additional anti-rejection agent

No

Unknown

Was biopsy done to confirm acute rejection:

Biopsy not done

Yes, rejection confirmed

Yes, rejection not confirmed

Unknown

Post Transplant Malignancy: YES NO UNK

Donor Related: YES NO UNK

Recurrence of Pre-Tx Tumor: YES NO UNK

De Novo Solid Tumor: YES NO UNK

De Novo Lymphoproliferative disease and

Lymphoma: YES NO UNK

Treatment

Biological or Anti-viral therapy: YES NO Unknown/Cannot disclose

Acyclovir (Zovirax)

Cytogam (CMV)

Gamimune

Gammagard

Ganciclovir (Cytovene)

If Yes, check all that apply:

Valgancyclovir (Valcyte)

HBIG (Hepatitis B Immune Globulin)

Flu Vaccine (Influenza Virus)

Lamivudine (Epivir) (for treatment of Hepatitis B)

Valacyclovir (Valtrex)

Other, Specify

Specify:

Specify:

Other therapies: YES NO

If Yes, check all that apply:

Photopheresis

Plasmapheresis

Total Lymphoid Irradiation (TLI)

Immunosuppressive Information

Previous Validated Maintenance Follow-Up

Medications:

Were any medications given during the followup period for maintenance:

Yes, same as previous validated report

Yes, but different than previous validated report

None given

Did the physician discontinue all maintenance

immunosuppressive medications: YES NO

Did the patient participate in any clinical research protocol for immunosuppressive medications:

YES NO

Specify:

Immunosuppressive Medications

View Immunosuppressive Medications

Definitions Of Immunosuppressive Follow-Up Medications

For each of the immunosuppressant medications listed, check **Previous Maintenance (Prev Maint)**, **Current Maintenance (Curr Maint)** or **Anti-rejection (AR)** to indicate all medications that were prescribed for the recipient during this follow-up period, and for what reason. If a medication was not given, leave the associated box(es) blank.

Previous Maintenance (Prev Maint) includes all immunosuppressive medications given during the report period, which covers the period from the last clinic visit to the current clinic visit, *for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance*

drug (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes.

Current Maintenance (Curr Maint) includes all immunosuppressive medications given at the current clinic visit to begin in the next report *for varying periods of time which may be either long-term or intermediate term with a tapering of the dosage until the drug is either eliminated or replaced by another long-term maintenance drug* (example: Prednisone, Cyclosporine, Tacrolimus, Mycophenolate Mofetil, Azathioprine, or Rapamycin). This does not include any immunosuppressive medications given to treat rejection episodes.

Anti-rejection (AR) immunosuppression includes all immunosuppressive medications given for the purpose of treating an acute rejection episode since the last clinic visit (example: Methylprednisolone, Atgam, OKT3, or Thymoglobulin). When switching maintenance drugs (example: from Tacrolimus to Cyclosporine; or from Mycophenolate Mofetil to Azathioprine) because of rejection, the drugs should not be listed under AR immunosuppression, but should be listed under maintenance immunosuppression.

Note: The Anti-rejection field refers to any anti-rejection medications since the last clinic visit, not just at the time of the current clinic visit.

If an immunosuppressive medication other than those listed is being administered (e.g., new monoclonal antibodies), select Previous Maint, or Current Maint, or AR next to Other Immunosuppressive Medication field, and enter the full name of the medication in the space provided. **Do not list non-immunosuppressive medications.**

Prev

Maint

Curr Maint AR

Steroids

(Prednisone, Methylprednisolone, Solumedrol, Medrol, Decadron)

Atgam (ATG)

OKT3 (Orthoclone, Muromonab)

Thymoglobulin

Simulect - Basiliximab

Zenapax - Daclizumab

Azathioprine (AZA, Imuran)

EON (Generic Cyclosporine)

Gengraf (Abbott Cyclosporine)

Other generic Cyclosporine, specify brand:

Neoral (CyA-NOF)

Sandimmune (Cyclosporine A)

Mycophenolate Mofetil (MMF, Cellcept, RS61443)

Tacrolimus (Prograf, FK506)

Modified Release Tacrolimus FK506E (MR4)

Sirolimus (RAPA, Rapamycin, Rapamune)

Myfortic (Mycophenolate Sodium)

Other Immunosuppressive Medications

Prev Maint Curr Maint AR

Campath - Alemtuzumab (anti-CD52)

Cyclophosphamide (Cytosan)

Leflunomide (LFL, Arava)

Methotrexate (Folex, PFS, Mexate-AQ, Rheumatrex)

Other Immunosuppressive Medication, Specify

Rituximab

Investigational Immunosuppressive Medications

Prev Maint Curr Maint AR

Everolimus (RAD, Certican)

FTY 720

Other Immunosuppressive Medication, Specify

UNOS View Only

Comments:

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Author Signature

3/31/10
Date