

New Legislation and Old Solutions: Employment Following Renal Transplantation Revisited

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Employment (i.e., return to work) and renal replacement therapy have been linked since the original discussions for the 1972 Social Security Amendment. This legislation deemed individuals with end-stage renal disease disabled for the purpose of Medicare eligibility and access to treatment. Proponents of the legislation suggested that 60% of those who received renal replacement therapy would resume employment following vocational rehabilitation, and the majority of the remaining 40% would return to work with no intervention (Kutner & Brogan, 1985; Rettig, 1984). Achieving this optimistic prediction has been elusive, and post-transplant employment outcomes have been disappointing. Nevertheless, the number of renal transplants has risen yearly, with 17,094 transplants being performed during 2006, 80.8% for individuals ages 18 to 64 (Organ Procurement and Transplantation Network, n.d.[a]). Thus, the majority of patients who undergo renal transplantation are working-age adults and many do not return to the labor force.

INTRODUCTION

Legislative action was taken as awareness increased that the current disability system is limited in returning individuals with disabilities to work. The 1999 Ticket to Work and Work Incentives Improvement Act targeted barriers to employment for individuals with disabilities (Callahan, 2005). It was also intended to supplement traditional vocational rehabilitation (VR) services, whose record of returning eligible individuals to work was less than 0.5 percent (General Accounting Office [GAO], as cited in Growick, 2001). Ohio was in the final phase of implementing the Ticket program, which began in November 2003. The Ticket program, coupled with advances in medically managing individuals following transplantation, has the potential to improve employment outcomes. To determine the current employment status of kidney transplant patients, a research study was designed to answer the following questions:

1. What is the employment status of individuals, post-transplant?
2. What is the rate of participation in the Ticket to Work Program?
3. What is the relationship between participation in the Ticket to Work Program and employment, post-transplant?
4. What factors predict post-transplant employment?

PREVIOUS LITERATURE AND THEORETICAL FRAMEWORK

Post-Transplant Employment

Employment following kidney transplantation has historically, and consistently, been lower than was pre-

dicted when the policy was enacted. Post-transplant employment in the United States ranges from 29 to 71%, although measurement of employment and sample characteristics have been quite variable (van der Mei et al., 2006). Additionally, studies have found that the percentage of individuals who claim the physical ability to work post-transplant is consistently larger than those who are actually employed (Manninen et al., 1991; Raiz, 1996).

Generalizations regarding predictors of employment are hindered by issue, such as limitations of some of the research designs (see van der Mei et al., 2006). One variable consistently associated with post-transplant employment is employment status prior to transplant (Evans et al., 1991; Jones et al., 1993; Matas et al., 1996; Raiz, 1996). Without exception, studies document that individuals who are employed prior to transplantation are more likely to be employed post-transplant. Other factors associated with post-transplant employment include age (Evans et al., 1991; Raiz, 1996), health status (Evans et al., 1991), education level (Evans et al., 1991), diabetic status (Jones et al., 1993; Matas et al., 1996) and transplant source (Jones et al., 1993). Younger recipients, non-diabetics, living donor recipients and those with higher levels of education are significantly more likely to be employed following transplantation. It has been suggested that factors beyond the clinical medical indicators (such as the creatinine level in a patient's blood) are related to employment (Callahan, 2005; Manninen et al., 1991; Matas et al., 1996; Paris et al., 1997). The biopsychosocial model provides a framework for exploring post-transplant employment from a holistic, patient-centered perspective.

The Biopsychosocial Model

In 1977, George Engel introduced the biopsychosocial model to address what he considered to be limitations of the traditional biomedical model. He noted that the biomedical model precludes acknowledging “the social, psychological, and behavioral dimensions of illness” (Engel, 1977, p. 130). Engel cautioned that because “laboratory documentation” could reflect only the potential for disease, it was necessary, though not sufficient, to assure the “human experience” of disease (p. 131). Engel concluded by challenging medicine to view disease, and its manifestations, from a holistic perspective.

To provide a basis for understanding the determinants of disease and arriving at rational treatments and patterns of health care, a medical model must also take into account the patient, the social context in which he lives, and the complementary system devised by society to deal with the disruptive effects of the illness, that is, the physician role and the health care system (p. 132).

By applying systems theory (Borrell-Carrió et al., 2004), the biopsychosocial model recognizes that biological, psychological and social factors interact to contribute to the human experience of sickness and wellness (Suls & Rothman, 2004). Thus, it is necessary to identify and address factors within each dimension of the model to successfully understand the sickness/wellness continuum and provide appropriate services. Environmental barriers to employment for individuals with disabilities generally, and those following transplantation specifically, provide examples of the importance of a social factor. Examples of social factors that may be related to employment following renal transplantation are disability policies and time limits for Medicare coverage of immunosuppressants.

The Ticket to Work and Work Incentives Improvement Act

The Ticket to Work program was created to increase employment for individuals with disabilities (Growick & Drew, 2003). Return to work (RTW) rates of individuals with disabilities historically had been suboptimal, as reflected in the 1996 report from the GAO. It stated that beneficiaries were more likely to die or retire than to return to work (as cited in Growick & Drew, 2003). Concerns regarding the process of determining disability have been explicated. They include the requirement only in the United States that an individual is totally incapable of working at the time of disability evaluation to be considered disabled. It ignores the issue of rehabilitation

potential at the time disability is determined (Drew & Growick, 2004). The disconnect between determining disabled status and initiating RTW activities has been cited as an important area for change (Growick & Babson, 2005). Also, it has been suggested that rehabilitative services begin at the time of disability evaluation (Growick & Drew, 2003).

Another limitation of the disability and rehabilitation system is the “order of selection” created by the Rehabilitation Services Administration more than two decades ago (Growick, 2001). It established a hierarchy for receiving rehabilitation services based on the disability severity (Growick, 2001). Those with the most severe disabilities received services most quickly, leaving individuals with comparatively lesser disabilities with delayed service initiation.

Both issues—the disconnect and the order of selection—have important implications for individuals undergoing renal transplantation. Once renal replacement therapy is initiated, individuals are deemed “disabled” for the purpose of Medicare eligibility; however, an additional application for Social Security Disability is required for full disability benefits. There is variability concerning the date of eligibility, depending on the type of renal replacement therapy. Individuals who undergo transplantation are eligible for Medicare immediately upon transplantation and those who receive dialysis are eligible either immediately (in the case of peritoneal dialysis patients), or after 3 months of treatment (in the case of hemodialysis patients).

RESEARCH METHODS

Sampling

Individuals who underwent solitary renal transplantation during the five-year period from January 1, 2000 to December 31, 2004 were eligible to participate in this study. Additional eligibility criteria of having a functioning graft at the time of the study and not being lost to follow-up resulted in a final sampling frame of 734. A modified Dillman’s method for mailed survey was used to collect data. The instrument, a cover letter, consent form and self-addressed, stamped envelope were mailed to all eligible individuals. A reminder postcard was subsequently mailed, followed by a second mailing to nonresponders.

Instruments were returned by 286 individuals, for a response rate of 40.2%. The 166 respondents under age 65 with complete data who were included in the final regression analysis were compared first to all

responders ($n = 286$) and then to the total sample ($n = 734$). Diabetic status, type of donor, education level, Medicaid status, race and sex were not significantly different between the final sample and all respondents. However, those included in the final analysis were significantly ($p < 0.001$) younger and more likely to have been employed prior to transplant and at the time of study participation than those excluded. Individuals included in the final regression also had significantly higher ($p < 0.05$) self-perceived physical functioning and significantly lower ($p < 0.05$) perceived mental health functioning. Additional analyses revealed that age ($p < 0.05$) and donor status ($p < 0.01$) of the final sample were significantly different from all who met eligibility criteria ($n = 734$). The final sample was younger and composed of more individuals who received living-related donations and fewer organs from deceased donors. Diabetic status, race and sex of the two groups were not significantly different.

Measures

Eighteen variables in this study included 1 outcome variable (employment status) and 15 predictor variables, which were used in the multivariate analysis. The two additional variables were participation in the Ticket to Work program and VR participation. Employment was measured with one item that asked about "employment status at this time." The three response options were: not employed, employed part-time and employed full-time. A single, dichotomous item asked whether respondents had ever received a Ticket to Work from Social Security and another asked whether they had ever participated in VR. The original intent was to include participation in the Ticket program and VR in the multivariate analysis to predict employment, but there was insufficient variation among the final sample to use them. Nevertheless, because they directly addressed research questions two and three, results are reported and discussed. As previously mentioned, the biopsychosocial model guided determination of variables used in the multivariate analysis. Table 1 presents the variables used in the regression analysis for employment post-transplant.

Table 1.

Variables Used in the Regression for Post-Transplant Employment

Biological	Psychological	Social
Age	Infection problems	Education completed
Creatinine	Mental Health (SF-36)	Employment status pre-transplant
Diabetic status	Physical Function (SF-36)	Medicaid status
Donor type	Sleep problems	Medicare status
Race	Stomach problems	
Sex		

Six variables comprised the biological dimension: age at the time of study participation (years and months), creatinine (average creatine of 90 days), diabetic status (no/yes), donor type (deceased, living), race (African American, Caucasian) and sex (female, male). One could debate placement of age, race and sex in the biological category as their relationship with employment may also derive from their social (cultural) importance. However, it was decided to define them as biological due to their classification, in discussions of human diversity, as primary characteristics and not within control of the individual (Lum, 2000). These visible, given traits are distinguished from traits that are within control of the individual and usually not visible (Lum, 2000).

Five variables represented the psychological domain: self-perceived physical functioning and mental health as measured by the SF-36 subscales (Cronbach's 0.943 and 0.849, respectively) and self-perceived problems with infection, sleep and stomach measured by the Memphis Survey. The Memphis Survey was created to examine the effect of immunosuppressant medications (Winsett et al., 2004). It lists a number of conditions associated with immunosuppressants and invites respondents to report whether they experience each condition and how "troubling" it is. A 5-point Likert-type scale was used. Scale scores are calculated with a 4-step process, as instructed by the survey developers. The 6 gastrointestinal items were combined to create a stomach scale with a Cronbach's of 0.701. The items were stomach pain, nausea, diarrhea, vomiting, stomach gas and indigestion. Infection and sleep were measured with single items.

Four single items represented the social domain: education completed, employment status 1 week prior to transplant (employed/unemployed), Medicaid status (no/yes) and Medicare status (no/yes).

RESULTS

Table 2 presents demographics for the final sample of 166. The majority was male, Caucasian, married and received kidneys from living donors. The mean age was 50 with a range from 22 through 64. More than 60% had education beyond high school. The overwhelming majority did not have Medicaid and a majority did not have Medicare, although the difference between those with and without Medicare was not large.

Table 2

Sample Demographics (n = 166)

Variable	Number (n)	Percentage (%)
Donor Type		
Living related	57	34.1
Living unrelated	45	26.9
Deceased	65	38.9
Education Completed		
High school	60	35.9
Some college	34	20.4
Associate/ vocational degree	23	13.8
Undergraduate degree	34	20.4
Graduate degree	15	9.0
Medicaid Insurance		
No	145	86.8
Yes	22	13.2
Medicare Insurance		
No	90	
Yes	77	
Race		
African American	20	12.0
Caucasian	146	88.0
Relationship Status		
Divorced	19	11.4
Married	113	68.1
Separated	6	3.6
Single	16	9.6
Widowed	4	2.4
Living with partner	8	4.8
Sex		
Female	59	35.5
Male	107	64.5

Nearly one-half (48.2%) of respondents reported full-time employment and another 9.6% part-time employment at the time of study participation, resulting in an employment percentage of 57.8. Participation in the Ticket to Work program was reported by 12.8% of the sample ($n = 21$). Full-time employment was reported by 2 individuals and part-time employment reported by 4 respondents who participated in the Ticket to Work program. The majority of those who indicated participating in the Ticket to Work program at some point prior to study participation (71.4%) reported being unemployed.

The results of the hierarchical regression analysis are presented in Table 3. The biological variables entered in the first step contributed 6.8% of the variance in employment status post-transplant. Only the -0.272 coefficient for diabetic status was significant at the 0.01 level. The coefficient indicated that individuals with diabetes were significantly less likely to be employed. The second step resulted in an F change of 12.72 ($p < 0.001$) with 31.9% of the variance explained. Of the 5 psychological variables, perception of physical functioning was the only one that contributed significantly to the model. Diabetes retained its importance in the second step. The final step, which introduced the social variables, explained 66.6% of the variance and resulted in an F change of 40.90 ($p < 0.001$).

Table 3

Regression of Biological, Psychological and Social Variables on Employment Status Post-Transplant

Variables	B	SE B	β
Step 1			
Biological			
Age	-0.009	0.007	-0.095
Creatinine	-0.113	0.095	-0.092
Diabetic status	-0.602	0.172	-0.272**
Donor type	0.171	0.157	0.088
Race	-0.083	0.122	-0.057
Sex	0.126	0.152	0.064
Adjusted R ² = 0.068			
F Change = 3.016**			

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Table 3 Continued

Step 2			
Biological			
Age	-0.001	0.007	-0.015
Creatinine	0.011	0.084	0.009
Diabetic status	-0.316	0.160	-0.143*
Donor type	0.128	0.136	0.066
Race	-0.068	0.106	-0.047
Sex	0.150	0.139	0.076
Psychological			
Physical functioning	0.015	0.003	0.460***
Mental health	0.006	0.004	0.128
Infection problems	-0.098	0.073	-0.101
Sleep problems	-0.033	0.052	-0.047
Stomach problems	0.032	0.019	0.129
Adjusted R ² = .319			
F Change = 12.716***			
Step 3			
Biological			
Age	0.000	0.005	-0.005
Creatinine	-0.015	0.059	-0.012
Diabetic status	0.022	0.116	0.010
Donor type	0.009	0.099	0.004
Race	0.046	0.075	0.032
Sex	0.204	0.099	0.103*
Psychological			
Physical functioning	0.008	0.002	0.246***
Mental health	0.004	0.003	0.087
Infection problems	-0.0052	0.051	-0.053
Sleep problems	-0.020	0.037	-0.028
Stomach problems	0.042	0.013	0.167**
Social			
Education completed	0.040	0.032	0.059
Employment status	1.065	0.110	0.560***
Pre-Transplant			
Medicaid status	-0.008	0.155	-0.003
Medicare status	-0.354	0.103	-0.186**
Adjusted R ² = .666			
F Change = 40.897***			

*P<0.05; **P<0.01; ***p<0.001.

The final model identified factors related to post-transplant employment status. The most important was employment status 1 week before transplantation (0.560) followed by patient perception of physical functioning (0.246). Medicare status was next in importance (-0.186), followed by patients perceiving stomach problems (0.167) and respondents' sex (0.103). In this sample of patients, important predictors of employment

following transplantation were employment prior to transplant, perception of better physical functioning, lack of Medicare insurance, report of less trouble due to stomach problems and being male.

Because employment status 1 week prior to transplant was such an important predictor of post-transplant employment, further examination was conducted. Table 4 presents the relationship between employment status prior to transplant and prior to onset of end-stage renal disease (ESRD) and employment at the time of study participation. Significant differences ($p < 0.001$) in current employment were related to employment status both 1 week prior to transplantation and pre-ESRD.

Table 4

Relationship Between Prior Employment Activity and Current Employment Status

Current Employment Status	If Employed Pre-ESRD (n = 95)	If Employed Pre-Transplant (n = 89)	If Employed Pre-ESRD and Pre-Transplant (n = 72)
Not employed	24 (25.3%)	7 (7.9%)	5 (6.9%)
Employed part-time	8 (8.4%)	10 (11.2%)	8 (11.1%)
Employed full-time	63 (66.3%)	72 (80.9%)	59 (81.9%)

The group of individuals who were employed prior to the onset of ESRD and 1 week prior to transplantation presented with the largest percentage of post-transplant employment. Their combined full- and part-time employment was 93.0%. However, only employment 1 week prior to transplant resulted in post-transplant employment (combined full- and part-time) of 92.1%. Finally, nearly three-fourths of those employed pre-ESRD were employed post-transplant.

The employment status of those unemployed prior to ESRD and/or transplant also was examined. Table 5 presents the employment status for those with no employment pre-ESRD and/or pre-transplant. More than 80% of those unemployed during any time prior to the transplant remained so following transplantation.

Table 5

Current Employment Status for Individuals Reporting No Employment Pre-ESRD and/or Pre-Transplant

Current Employment Status	If Not Employed Pre-ESRD (n = 49)	If Not Employed Pre-Transplant (n = 77)	If Not Employed Prior to ESRD or Transplantation (n = 46)
Not employed	41 (83.7%)	63 (81.8%)	39 (84.8%)
Employed part-time	5 (10.2%)	6 (7.8%)	4 (8.7%)
Employed full-time	3 (6.1%)	8 (10.4%)	3 (6.5%)

STUDY LIMITATIONS

Surveys were sent to all eligible individuals, but the final sample was self-selected. It consisted only of those individuals who completed and returned questionnaires. As previously mentioned, the final sample had characteristics significantly different from all individuals who completed the survey and all 734 eligible to participate in the study. Further, the final sample included only those under age 65 with a functioning graft. Thus, representativeness of the final sample and generalizability must be evaluated with these caveats (Rubin & Babbie, 2005).

The outcome of interest—employment—is dynamic, as are some of the predictor variables. Respondents were asked about employment status only at the time of study participation. Thus, only a point-in-time representation of employment is provided. This estimate may be too high, or low, as individuals transition in and out of the labor force. However, this potential concern may be diminished by disability policies related to employment and eligibility criteria for Medicare and Medicaid that constrain frequent changes in employment status for those receiving disability. However, the cross-sectional nature of this design limits examination of causal relationships. Longitudinal research, ideally at multiple points along the ESRD process, will address this limitation.

Finally, it was not possible to examine fully the relationship between participation in the Ticket to Work program and employment status due to the low number of respondents who reported participation in the program. Perhaps this resulted from the relatively recent implementation of the program in Ohio. Future research

should revisit participation in the Ticket to Work program and associated outcomes, ideally with a longitudinal time dimension.

DISCUSSION

Two unexpected results emerged in this study, which was largely intended to investigate the relationship between participation in the Ticket to Work program and post-transplant employment. The first was the dismal participation in the Ticket to Work program. The second was the dramatic demonstration of the importance of pre-transplant employment.

The low rate of participation in the Ticket to Work program precluded meaningful investigation of its relationship with employment. However, the low rate of participation, itself, was a disconcerting finding. One explanation could be the relatively recent implementation of the program in Ohio. Data for this study were collected nearly 3 years after the 2003 rollout in Ohio. An area for future research is the extent of participation by individuals with ESRD. If the findings are consistent with those of this study, investigation of contributors to low participation is warranted. Because one explanation of the low participation rate could be the somewhat recent implementation of the Ticket to Work program, participation in traditional VR by respondents in this study was examined. Once again, only 12.1% of the final sample received VR. Eight individuals participated in both VR and Ticket to Work. Thus, an additional 12 individuals participated in only VR. This, too, presents a disturbing picture, one that requires further exploration. It appears that almost all respondents in this study did not participate in the Ticket to Work program or VR and the few who did so did not achieve the desired outcome of employment.

The percentage of those in this study with full- or part-time employment following transplantation (57.8%) was larger than the previously reported 35.8% full- or part-time employment of 636 individuals with a functioning renal graft post-transplant (Matas et al., 1996). It also was greater than the 43.4% employed reported by Evans et al. (1991). The weight of employment status prior to transplantation cannot be overstated. It echoes findings in studies dating back 25 years. Evans et al. (1991) found that age, health status, education level and employment status during the year pre-transplant were related to post-renal transplant employment. Jones et al. (1993) reported that pre-transplant employment was an important predictor of employment following transplantation and suggested that employment status often remains consistent following transplant. Pre-transplant

employment and diabetic status were the only factors predictive of post-transplant employment for 636 individuals 1 to 9 years following renal transplantation (Matas et al., 1996). In the previously mentioned studies, individuals employed prior to transplantation were more likely to be employed following the transplant. The importance of employment status prior to transplant becomes even more compelling when one examines the consistency of employment status throughout the course of ESRD.

When examining those employed prior to transplant and prior to renal failure, employment percentages are even more impressive. In fact, they actually approach estimates of post-transplant employment offered by proponents of the original legislation in 1972. This suggests an important consideration for research and practice. Researchers must attend to the heterogeneity that exists with regard to employment status prior to transplant, even prior to renal failure. At a basic level, when simply describing employment status post-transplant, researchers (and transplant centers) should identify which group of individuals they are examining. Data should be collected that informs not only pre-transplant employment status, but also employment pre-ESRD. One would not anticipate the same employment outcomes for those working until transplantation and those detached from the labor force for longer periods of time.

Further, attempts to identify factors related to employment should consider when the individual ceased employment during the ESRD disease process. There are multiple contributors to detachment and attachment to the labor force, which may affect those at various stages of the ESRD/transplant continuum differently. In fact, some factors important at one stage may decrease in importance, or even disappear, at another stage. For example, biological factors may take precedence when an individual begins dialysis. At that time, physical adjustment to treatment as well as symptoms related to the disease and side effects of dialysis may have an important role. However, psychological and social factors may become more important to individuals with a functioning graft following transplantation.

The biopsychosocial model guided analysis of contributors to employment following renal transplantation. Interestingly, the dimension that made the least contribution to the final model was biological. While this may appear counterintuitive at first glance, these findings, once again, suggest that individuals post-transplant are not a homogenous group. The individuals in this study had well-functioning grafts, as reflected in their creatinine levels. It appears that those whose kid-

neys are functioning well post-transplant may benefit from interventions that address more holistic issues. The one biological variable, diabetes, that significantly contributed to employment initially, lost its importance in the final model that included psychological and social variables. Patient perception of physical functioning was the second most important predictor of post-transplant employment. Another psychological variable, the trouble individuals perceived related to stomach problems, also was important. These factors suggest that it is the experience of illness and wellness, as perceived by the patient that is important versus an objective clinical indicator, such as a lab value.

Social work interventions should be initiated to address factors appropriate for individual circumstances. Dialysis and transplant social workers should develop protocols to direct assessment and intervention based on whether an individual is employed at the time of first contact and the point in time the individual became detached from the labor force. A standard employment assessment tool could be a distinct component of the psychosocial assessment, and include biological, psychological and social dimensions known to be associated with employment. Social workers, in this field of practice, have unique training in investigating the patient experience of ESRD and its relationship to employment, particularly at different points in the illness/wellness continuum. Thus, the services provided for a patient who had not been employed for months, or years, prior to the onset of ESRD may be quite different from services for an individual detached from the labor force while undergoing hemodialysis.

Dialysis social workers also can appreciate the importance of maintaining employment for those working at the time of ESRD. Labor force detachment may occur during the days one waits for a kidney from a deceased donor, considering that the median waiting time, during 2001 to 2002 was 1,636 days for individuals between the ages of 18 and 64 (Organ Procurement and Transplantation Network, n.d.[b]). Therefore, dialysis social workers should educate patients about the importance of maintaining employment, if possible; help patients understand their rights and protections under the Americans with Disabilities Act; and most certainly advise patients about RTW services, such as Ticket to Work. Social workers should also advocate for patients within the dialysis center (for schedules that promote employment) and in the community (for receipt of VR in a timely fashion). It is incumbent upon nephrology social workers to be knowledgeable about the Ticket to Work services in their communities, initi-

ate the appropriate referrals and advocate for receipt of RTW services, despite barriers such as the order of selection.

While the biopsychosocial model provides a sound framework from which to study important outcomes in transplantation, such as employment, each component of the model needs further specification. The component that currently may be most developed, biological, may not be the most important to employment. Researchers should include all biological variables previously shown to be associated with non-biological outcomes of interest (e.g., employment and quality of life). Additionally, theory and previous findings should advise utilization of variables from the psychological and social dimensions. These are the domains in which social workers possess expertise and the ability to advocate toward the desired outcomes.

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