

## Post-Transplant Employment and its Relationship to Physical Status in Kidney Transplant Recipients

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*Post-transplant employment has long been considered an indication of functional benefit to the recipient and social benefit to the community. Some studies suggest that the majority of transplant recipients are physically able but remain unemployed and continue to draw disability post-transplant. In this article, the employment status and perception of 110 kidney transplant recipients from a specialty kidney transplant clinic that follows recipients from three hospital programs were compared by use of The American Medical Association's Guide to Physical Impairment (AMAGPI) and creatinine clearance. Overall, there was approximately the same number of males and females (54% vs 46%, respectively), in middle adulthood (mean = 43 years), well-educated (mean = 14 years of schooling), Caucasian (55%) and married (57%). Of those surveyed, 77% (n = 85/110) were classified as employed and 23% (n = 25/110) were disabled. After excluding those who were disabled and using AMAGPI criteria as the basis for comparison, it was found that 80% (n = 68/85) with kidney impairment ranging from 0 to 14% were employed compared with 64% (n = 16/25) for all other impairment classifications combined. When broken down by AMAGPI groups, no significant differences were found between mean creatinine clearances with regard to employment status and employment perception.*

*When employment status and patient employment perception are compared by traditional means (i.e., creatinine clearance), there is only minimal change in employment rates observed even as the lab values continue to decline and impairment level increases. Thus, use of criteria accounting for issues specifically related to kidney recipients (e.g., medication reactions, chronic pain) suggest that, unlike other solid organ transplantation, the reason for unemployment and continued perception of inability to work remains a complex phenomenon and is not directly related to organ functioning or physical impairment. These findings clearly conflict with earlier reports and indicate the need for additional study to help determine whether other physical limitations specific to the patient's continued perception of inability to work in the kidney transplant population exist or strategic rehabilitation interventions and case management (such as a structured rehabilitation program specific to outcomes) could improve employment results.*

### INTRODUCTION

Previous research has suggested that a transplant recipient's return to work post-transplant is an important indicator of functional benefit to the recipient and social benefit to the community (Paris et al., 1992). Some of the earliest research studies considered post-transplant employment feasible only for those who could return to a pre-transplant job. This body of work identified multiple barriers precluding new post-transplant employment, including changes in priorities where family and leisure activities were valued more than work; hiring discrimination based on advanced age (>56 years) or medical history; restrictive cost, including the impact on other employees or unavailability of medical insurance; poor local or regional economic conditions; and limited education and/or work skills (Evans, 1990; Harvison et al., 1988; Meister, McAleer, Meister, Riley & Copperland, 1986; Niset, Coustry-Degre, & Degre, 1988; Paris, 1990; Samuelsson, Hunt, & Schroeder, 1984; Shapiro, 1990; Wallwork & Caine, 1985). Results suggested that transplant programs (at that time) might be supportive of medical disability and were unlikely to encourage recipients to return to work (Paris et al., 1997).

In a later multi-center study of heart transplant recipients (n = 201), it was found that more than 85% of transplant recipients were assessed by their physicians as being physically able to work, but only 45% were doing so (Paris et al.,

1993). This study also found that transplant recipients who perceived few limitations responded positively to expectations for employment and returned to former jobs (if available) or attempted to secure new employment. This was supported in a later follow-up study from a single transplant program that identified a younger, better educated group who remained unemployed because they viewed themselves as physically unable to work and did not respond to employment expectations regardless of the medical or social issues (Paris, Tebow, Dahr, & Cooper, 1997).

Historically, the literature has explored the issue of recipient employment after organ transplant by identifying variables associated with employment and comparing the number of recipients who are able (or want) to return to work with the number who actually do. For example, Evans (1986) found that 58% of American recipients were assessed by their physician as able to work but only 32% returned to employment. Wallwork and Caine (1985) reported that only 56% of European transplant recipients were employed, although 97% indicated a desire to work. It should be emphasized, however, that these numbers identified only those recipients who returned to their former employment and did not use any standardized measure of employment ability or capacity, nor were patients asked their plans for returning to work. Rather, they were asked if they "wanted" to return to work. As later research revealed, virtually all patients will say they

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“want” to return to work, especially when asked at the time of the pre-transplant assessment (Cooper & Paris, 1993). However, in reality, the number that return to work varies greatly from the stated intention and is thought to depend on the strength of expectations from the health care team and family and the rehabilitation-focused interventions and case management available post-transplant.

Some authors go so far as to say that the most difficult aspect of a recipient’s rehabilitation is the psychological barrier that prevents them from deriving a perception of their full physical potential (Andrews et al., 1992). As with other chronic illnesses, transplant recipients may not be totally disabled but may have specific physical limitations and complaints that preclude only certain types of work (Paris et al., 1993).

Kidney patients, in particular, may often not work for long periods of time pre-transplant. Dialysis, which often precedes a kidney transplant, is an “automatic qualification” for Social Security Disability (SSDI). This reality increases the chances the individual patient will be less likely to work while on dialysis, if dialysis precedes kidney transplantation. Receiving SSDI may become a financial disincentive after receiving their kidney transplant (Callahan, 2005). Additionally, although SSDI is helpful, the reality is that being maintained on dialysis for long periods of time may ultimately result in work skills or educational certifications becoming obsolete. Also, medical complications may arise that will lessen the chances of employability with even the most motivated of patients.

Clearly, numerous issues determine whether a patient will return to work after his or her kidney transplantation. Vocational rehabilitation has shown some potential with kidney transplantation patients resulting in a 45% success rate in helping them return to work (Paris et al., 1997). Regrettably, the same positive vocational rehabilitation numbers have not been achieved with other transplanted organs. However, the most recent clinical research findings with heart and liver transplant recipients suggest that it may not be disability *per se* that influences a patient’s employment potential or perception as much as his or her measured level of impairment (Paris, 2006). By “level of impairment” it is meant that there are agreed upon standardized factors that limit the individual’s ability to carry out activities of daily living.

This work with kidney transplant recipients was the first attempt to more clearly delineate the extent to which employment decisions and perceptions may be influenced by very subtle physical, medication-induced and/or emotional factors that previously were not quantifiable with standardized assessment criteria. New findings with heart and liver transplant recipients show that use of the The American Medical Association’s Guide to Physical Impairment (AMAGPI; American Medical Association, 1993) helped explain why patients who do not meet SSDI criteria and had been determined by their physician as “not being disabled” were

influenced in their employment and employment perception by multiple mechanisms that limited their ability in ways that had not been previously quantifiable (e.g., heat, sun exposure, medication reactions). The current study was designed to determine whether these same factors are found to influence the kidney transplant patient’s employment perceptions and decisions and hopefully provide the basis for the development and testing of alternative interventional paradigms.

## METHODOLOGY

This study was designed specifically to explore whether or not the traditional form of physical disability or “impairment” best explained the employment decisions and perceptions of kidney transplant patients. This study was funded in part by grants from the National Kidney Foundation’s Council of Nephrology Social Workers and the Society for Transplant Social Workers.

After approval by both the hospital and university Internal Review Boards (IRBs), survey packets were mailed to adult kidney transplant patients. Two hundred post-kidney transplant patients were chosen through random sampling from a five-year (October 2001–2006) log of 1,306 patients admitted to Dallas Transplant Institute. Patient selection criteria included ability to speak English, competency and a valid U.S. contact address. Additional people excluded were those who had returned to dialysis. After randomization, patients (kidney transplant recipients between the ages of 18 and 55) were contacted only once via mail and asked to complete a short data sheet and return in an enclosed, addressed and stamped envelope. A cover sheet was included describing the proposed study, its aims, the mechanism to be used to maintain anonymity and their right of refusal without jeopardizing their medical care. The data sheet requested demographic, perceptual and historical information. There was a 55% (110/200) response rate. The design did not allow for follow-up for those who did not respond.

Once returned, the surveys were then compared to most recent creatinine clearance. This measure was chosen because it is consistent with the American Medical Association’s view that creatinine clearance “...is the most accurate reflection of renal function and will quantitate the degree of functional impairment of the upper urinary tract” (American Medical Association, 1993, p. 250). A physician assistant was then asked to evaluate the patient’s current medical status by use of the third edition of the AMAGPI.

All data analysis was done by use of Chi-Square or Mann-Whitney U comparisons with SPSS statistical software. If one of the variables was continuous with an  $n$  less than 30, the Mann-Whitney U, non-parametric test was used and the Chi-Square procedure was used for comparison of frequency data per guidelines, as suggested in Rubin and Babie (2008).

There were two measures of physical ability used. The patient’s physical status was determined by physician cat-

egorizations based on objective scales that measured physical impairments from the AMAGPI (1993). The AMAGPI is the result of an agreed upon set of guidelines developed by 11 medical specialty societies, the Social Security Administration, U.S. Department of Veterans Affairs and the American Bar Association. The patient's perception of his or her physical capacity was determined by his or her answer to a very simple question, "In your opinion, are you currently physically able to work?"

An impairment, according to the AMAGPI definition, represents an informed estimate of the degree to which an individual's capacity to carry out daily activities have been diminished. Impairments are conditions that interfere with an individual's activities of daily living. It is recognized that "normal" is not a fine point or an absolute in terms of physical and mental functioning and good health. More often, normality is a range or a zone, as with vision and hearing. Normal can vary with age, gender and other factors. Disability refers to an activity or task that an individual cannot accomplish and may be thought of as the gap between what a person *can* do and what the person *wants* or *needs* to do. Accordingly, an impairment, although restrictive, may not necessarily result in disability.

None of the previous employment research had a tool that allowed physicians to make such an informed decision as to a patient's physical status. The use of this tool allows a flexibility that did not previously exist. Until now, there were no standardized comparisons available that allowed for medication reactions and complications. Previous studies have been very direct in stating that an inability to account for this problem raised questions about the existing physical assessments (Meister et al., 1986; Paris, 1990; Paris et al., 1992; Paris, Tebow, Dahr, & Cooper et al., 1997; Paris, Muchmore, Pribil, Zuhdi, & Cooper, 1994).

For the purposes of this study, patients were categorized in a manner consistent with previous research: employed, unemployed, medically disabled or retired (Paris, 1992; Paris et al., 1993; Paris, Tebow, Dahr, & Cooper et al., 1997; Paris et al., 1998). Employed meant working full- or part-time. Students and homemakers were included as employed if they had returned to their pre-transplant role post-transplant. Unemployed meant not working and not meeting SSDI criteria. Medically disabled meant meeting SSDI criteria. A recipient was not placed in this category unless identified as such by a physician. Retired meant the recipient was over age 65 or electively retired if under 65. These recipients were not receiving any form of disability income.

**RESULTS**

The random sample pool was surprisingly smaller than expected due to a higher amount of post-kidney transplant patients over the age of 55 and a fairly large number of patients that did not speak English. The demo-

graphic profile of those surveyed could be characterized, in general, as married Caucasians adults in middle adulthood with slightly more than a high school education and an equivalent number of males and females (see Table 1). When compared on the basis of employment and employment perception, demographic variables did not explain whether someone was employed post-kidney transplantation or perceived he or she was/was not able to work (not significant; data not shown).

**Table 1**  
*Kidney Recipient's Demographic Profile*

	<b>Kidney Recipients</b> <i>N = 110</i>
Mean Age (SD)	43 (8)
Mean Education (SD)	14 (3)
Gender	
Male	60 (54%)
Female	50 (46%)
Ethnicity*	
Caucasian	60 (55%)
African American	27 (25%)
Hispanic	10 (9%)
Native American	2 (2%)
Other	11 (10%)
Marital status	
Married	63 (57%)
Single	26 (23%)
Divorced	21 (19%)

\*(n = 5 missing)

Of the 110 who completed the survey, 85 (77%) were employed and 25 (23%) were disabled (see Table 2). Ninety-three percent (n = 79/85) of those employed and 28% (n = 7/25) of those who met SSDI criteria viewed themselves as physically able to work. When the employed and unemployed were compared on the basis of their perception of physical ability, significantly more (p < 0.01) of the employed patients viewed themselves as physically able.

**Table 2**  
*Chi-square Comparison of Post-Transplant Employment Status by Patient Employment Perception*

	<b>Employed</b> <i>n = 85</i>	<b>Disabled</b> <i>n = 25</i>
Physically Able	79*	7
Not Able	6	18

\*p < 0.01

Employed patients who believed themselves physically able to work had significantly higher organ functioning (see Table 3). Disabled patients who believed themselves physically able to work had higher mean creatinine clearance, although the difference was not significant.

**Table 3**

*Mann-Whitney U Comparison of Post-Transplant Employed and Unemployed Kidney Patients Compared by Employment Perception and Mean Creatinine Clearance*

	All Patients <i>n</i> = 110	Employed <i>n</i> = 85	Disabled <i>N</i> = 25
<b>Physically Able</b> Mean creatinine clearance	66.2	67.2*	62.8
<b>Not Physically Able</b> Mean creatinine clearance	58.4	53.8	55.6

\**p* < 0.05

Employment perception was compared on the basis of physician assessment by use of AMAGPI (see Table 4). The numbers are reported in frequencies because the nature of the data was not amenable to collapsing of AMAGPI categories for non-parametric comparison. This would have required an attempt to compare impairment levels ranging from 15 to 100% in the same category. The findings suggest that patient employment and perception of work ability is not always consistent with the physician assessment of their level of medical impairment. When the patients were compared on the basis of employment perception and AMAGPI impairment level, 84% (*n* = 70/83) with 9–14% impairment, 86% (*n* = 6/7) with 15–34% impairment, 58% (*n* = 7/12) with 35–59% impairment and 83% (*n* = 5/6) with 60–95% impairment believed they were physically able to work.

**Table 4**

*Chi-square Comparison of Post-Transplant Patient Employment Perception by Physician Assessment of AMAGPI (*n* = 2 missing)*

	Class 1 0–14% Impairment <i>n</i> = 83	Class 2 15–34% Impairment <i>n</i> = 7	Class 3 35–59% Impairment <i>n</i> = 12	Class 4 60–95% Impairment <i>n</i> = 6
Physically Able	70*	6*	7	5*
Not Able	13	1	5	1

\**p* < 0.05

Patient perception of their ability to work post-transplant is very strongly related to their level of impairment. There were significantly (*p* < 0.05) more (*n* = 13) who perceived an ability to work with in Class 1, 2 and 4. Only those patients with 35–59% (Class 3) did not have a significant difference based on their individual perception of work ability.

When employment status was compared with AMAGPI categories, there were significantly more of those who were employed in the 0–14% impairment. Two of the three remaining categories had nearly twice as many employed for each impairment level, but the differences were not significant (see Table 5).

**Table 5**

*Chi-square Comparison of Post-Transplant Patient Employment Status by Physician Assessment of AMA Impairment Level (*n* = 2 missing)*

	Class 1 0–14% Impairment <i>n</i> = 83	Class 2 15–34% Impairment <i>n</i> = 7	Class 3 35–59% Impairment <i>n</i> = 12	Class 4 60–95% Impairment <i>n</i> = 6
Employed	68*	4	8	4
Disabled	15	3	4	2

\**p* < 0.05

When compared by *t*-test on the basis of mean creatinine clearance with employment status or employment perception there were no significant differences found (see Table 6). In all but three cases, those who were employed perceived themselves as physically able and had better organ functioning for each impairment level (e.g., Classes 2 and 4).

**Table 6**

*Post-Transplant Patient Employment and Employment Perception by Physician Assessment of AMA Impairment Level and Most Recent Mean Creatinine Clearance*

	Class 1 0–14% Impairment <i>n</i> = 83	Class 2 15–34% Impairment <i>n</i> = 7	Class 3 35–59% Impairment <i>n</i> = 12	Class 4 60–95% Impairment <i>n</i> = 6
<b>Employment Status</b>				
Employed	71.8	48.8	37.5	17.3
Disabled	69.7	51.5	30.0	26.0
<b>Employment Perception</b>				
Physically Able	71.6	49.7	36.4	19.0
Not Able	70.1	45.0	34.6	19.0

## DISCUSSION

It has been widely documented that employment is an important component in the reestablishment of a transplant recipient's identity, self-esteem and quality of life (Callahan, 2005). However, one of the primary assumptions associated with this research has been that there is, in fact, little or no relationship with employment, perception of ability to work and medical status (Raiz & Monroe, 2007). Given that 77% of the current cohort of patients were employed and believed they were physically able to work, often despite significant kidney dysfunction, this would challenge such an assumption. However, this does not mean that patients do not have medical "complications," because they do. But those same reports have also indicated that by one year post-transplant, most patients are functioning fairly normally again. Given the current findings, that may be open to debate and closer scrutiny. For example, as early as 1993, published research reported that transplant recipients may not be totally disabled but may have specific physical limitations and complaints that preclude only certain types of work (Paris et al., 1993). It was not until use of the AMAGPI that there has been an agreed upon mechanism or standardized criteria by which to evaluate or compare patients on multiple levels (AMAGPI, 1993).

Comparisons of functional disability and subjective perceived health status from pre- to post-kidney transplantation have revealed improved health status and physical function from one to three years (Gross, Limwattananon, Matthees, Zehrer, & Savik, 2000) with relatively low death or graft loss at one and five years (Cardinal et al., 2005), near normal rates of volunteer work, going out, socializing and leisure activities up to seven years post-transplantation when compared to the general population (Mei et al., 2007) and increased participation in daily activities and improved quality of life (Niu & Li, 2005).

With regard to employment post-kidney transplantation, there are multiple studies that have addressed this issue specifically. Employment rates have ranged from 29–76%, depending on the definition and age group under study (Gross et al., 2000; Taber, Lee, & Slapak, 1982) and with time frames for collecting data from 6 months to 8.6 years (Griva et al., 2002; Hathaway et al., 1998). There has also been a great deal of variation in the methodology used from standardized tools (Griva et al., 2002; Gross et al., 2000; Johnson, McCauley, & Copley, 1992) to self-constructed questionnaires absent documented reliability and validity (Flechner, Novick, Braun, Popowaniak, & Steinmuller, 1983; Russell, Beechcroft, Ludwin, & Churchill, 1992; Simmons, Abress & Anderson, 1998).

Sorting through these studies to try and clarify whether support for the current findings of some correlation between physical impairment and continued perception of disability exists is difficult. It is made more challenging because the above studies seldom mention employment in relation to the patient's physical status. However, reading closely, one

finds comments such as "moderately impaired," "generally similar physical function," "mild limitations of daily activities." In other words, significant improvement does not imply being without limitations or complications.

The discrepancy between medical assessment of employability and the patient's continued perception of being unable to work that was suggested by previous employment research was not found in this study. In that regard, the current work is consistent with the most recent employment research from heart and liver transplantation, which links employment perception with impairment rather than overall disability status. There is heart transplantation quality of life research that also supports the current findings. Grady, Jalowiec and White-Williams (1999) found that a recipient's perceived quality of life is consistent with their perceived health status and functional ability. Given that 17% ( $n = 19$ ) of the disabled patients were either employed and/or perceived themselves as physically able to work, it is logical to assume that even in the face of significant physical limitations some patients will have the perception of physical ability to meet the demands of certain types of full-time post-transplant employment and focused rehabilitation interventions, and that case management could improve employment outcomes.

While the current work does not facilitate the development of a universal definition of employability post-kidney transplantation, the findings from the use of AMAGPI in this population suggests the need to consider the development of such a comparison with later studies. In fact, comparisons with the AMAGPI suggest the need for a closer examination of the traditional measure of creatinine clearance as a valid measure of a kidney transplant recipient's employment ability. Current findings would suggest an inverse relationship between impairment and employment perception. In other words, as the percentage of physical impairment increases the individual patient's perception of employment ability declines. Because the AMAGPI are very standardized assessment categorizations, the potential for value-based judgments is lessened and the notion that these numbers must be taken seriously is supported. As kidney transplant professionals, we must look at a 15–34% level of functional disability with a new vision and a renewed sense of how to intervene with this particular segment of our transplant population.

Within the context of the broader transplant community, the question of whether creatinine clearance is the best measure of physical outcomes remains an important one. Disability may be too narrowly defined by organ functioning when the transplant patient's physical ability is impacted by multiple underlying medical problems. This may help to explain why transplant patient comparisons regarding employment and disability vary widely. Virtually every study has used primarily Social Security determinations, based on automatic qualification with the onset of dialysis as medical criteria, as the basis for stating a patient's employ-

ment ability. Yet, each transplant patient has some residual deficit or underlying disease process, the cause of which could be multi-factorial. We know, for example that more than 40% of incident and prevalent end stage renal disease patients have kidney failure due to diabetes (U.S. Renal Data System, 2008). Additionally, according to Sulanc et al. (2005), the incidence of new-onset diabetes after transplantation ranges between 2 and 50%. Further, the current study did not separate kidney-pancreas transplants from kidney transplants. This disease process alone may alter patient and staff perceptions about employment ability.

Creatinine clearance is a reliable measure of the medical status of the kidney. However, there are limitations associated with this study because of the limited number of participants, which means the statistical findings may be open to question and should be used more as a suggestion of significance rather than specific significance. Even so, the use of the AMAGPI may help the evaluation process in two ways: first, it moves patient claims from being merely subjective patient perceptions to one of objective physician assessments using agreed upon criteria; second, it opens the door to a new way for transplant staff to conceptualize individual patient employability potential. Although not addressed or part of the logic for the AMAGPI, it may be that ultimately employment perception is based on the cumulative effect of various forms of impairment the kidney patient may experience. Plus, one should never underestimate the value of dialysis in helping to take care of poor kidney functioning, which allows individual patients to function at a higher level when compared with other organs.

### LIMITATIONS

There are limitations associated with this descriptive study. These include limitations associated with the use of a mailed survey, which narrowed the potential response rate. The survey instrument itself used by the investigators could have been a more in-depth analysis and potentially provided greater insight into barriers to employability. A more exhaustive survey was not chosen because of the narrow focus of the work, which was to address the question of organ functioning and patient employment and perception of employability. Given the question of the population's literacy level served, it was also important to keep the instructions and questions as simple as possible. In addition, the use of this survey allowed for comparison with previous work done with other organs for wider comparison with the existing literature. Also, sample size was lower than anticipated, partly due to the choice of using a mailed survey and design constraints that did not allow for contacting patients who did not initially respond. As with any employment study, it would be of interest to understand the work status of those who did not respond, as the investigators theorize that those who were employed were the most likely to respond. However, again, design protocol did not allow for this or any follow-up to occur.

Whether the conclusions of this work, given its limitations, are justified will need to rely on additional research that explores these questions and helps determine the reliability of the findings from such a small patient cohort. But, given the significant success with current employment rates from the current patient cohort, one is also left to ponder whether there is really any way in which to improve upon the results currently being reported, or whether only those more likely to have worked completed the survey about employment. Only additional studies will help to clarify the most likely answer. Regardless, the findings are important enough to justify the exploration of additional medical and psychosocial paradigms with the goal of continuing to improve overall patient employment.

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