

## Dialysis Social Worker Training and Knowledge Regarding Kidney Transplantation

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*Social workers are often a primary source of education for patients in the outpatient dialysis setting, requiring these professionals to have a broad knowledge base regarding many aspects of dialysis and the various treatment modalities. Social workers are expected to be able to competently educate their patients, yet this can only be done if they themselves have been properly trained. An investigation regarding the training social workers receive and their overall knowledge about transplantation was conducted. The findings noted that formal training was almost nonexistent and exceptionally brief. Many social workers had knowledge deficits and were unable to answer basic questions regarding the kidney transplantation process*

### INTRODUCTION

Social worker knowledge regarding matters such as health insurance, disability benefits, mental health, hospice care and local resources are invaluable to patients (Browne, 2006). Social workers are often a primary source of education in the dialysis clinic, which requires them to have a strong foundation of knowledge regarding many different topics. Social workers are at the forefront of issues that greatly affect the lives of patients, such as end-of-life care (Woods et al., 1999; Gwyther et al., 2005) and treatment adherence (Johnstone & Halshaw, 2003; Dobrof et al., 2000). Due to administrative and clinical responsibilities, professional roles, such as being educators and advocates for kidney transplantation, may be minimized for social workers. This is a concern for two main reasons. First, there is a large body of research noting that there is unequal access to transplantation among minorities (Furth et al., 2000; Wolfe, 2003), women (Bloembergen et al., 1997) and people with lesser socioeconomic status (Wolfe, 2006; Thomas, 2000). Second, there are numerous misconceptions that patients often have regarding the transplantation process, especially with regard to non-living donation. For example, they may believe that organs are purchased and that this is unethical, so they do not wish to pursue this treatment option. Furthermore, external sources of transplant information outside of the clinic setting, such as the Internet, are often lacking or incorrect in the material that they provide (Hanif et al., 2007). These circumstances create an environment wherein education is extremely important because patients need to be able to make informed decisions about their treatment.

Informing dialysis patients about all potential treatment modalities is not voluntary; it is a legal requirement. Federal regulation specifies that patients be advised of their suitability for transplantation (Federal Health Insurance for the Aged and Disabled, 1972). As professionals, social workers are often designated

by their employer to educate patients regarding treatment modalities (DaVita Renal Healthcare, 2007). The joint Clinical Indicators for Social Work and Psychosocial Service in Nephrology Settings was created by the National Kidney Foundation's (NKF) Council of Nephrology Social Workers (CNSW) and the National Association of Social Workers (NASW). These organizational bodies specify that social workers should provide counseling and education to pre-transplant recipients and live organ donors (National Association of Social Workers, 2007). Patient education cannot be competently provided unless social workers themselves are properly trained. The following research was conducted to determine the transplant training and knowledge level of dialysis social workers.

### METHOD

A panel of 3 hemodialysis social workers, ranging from 6 to 9 years of experience, was convened to formulate questions that tested basic knowledge regarding kidney transplantation. The panelists were chosen based on their expertise with patient and staff education, hemodialysis, peritoneal dialysis and organ donation. One of them had previously been a gubernatorial appointee and served on a state board that promoted organ donation and transplantation. A 10-item questionnaire was created that covered 3 core areas: patient evaluation, insurance issues, and medical risks and side effects. Each item was in multiple choice or true/false format. These questions were then matched with 10 more questions that inquired about the extensiveness of a social worker's initial training regarding transplantation, and how they evaluated their own knowledge regarding this topic. A random number generation computer program was then used to select 50 outpatient hemodialysis clinics in Georgia, Tennessee and North Carolina. The questionnaire was mailed to the social workers in these clinics along with a cover letter and self-addressed stamped envelope. They were asked to complete the

**Table 1****Percentage of Social Workers Who Correctly Answered Questions**

	Percent answered correctly
1. A patient can be listed for a kidney transplant at more than one hospital.	96
2. If a person obtains a kidney transplant, and their sole entitlement to Medicare is due to their kidney failure, when will their Medicare coverage terminate?	84
3. When someone is being evaluated for a kidney transplant, their specific HLA have to be identified as part of the matching process. What are HLA?	80
4. After 5 years, the majority of kidney transplants are no longer functioning.	77
5. What is the primary piece of United States federal legislation pertaining to the administration and organization of the organ transplantation process?	65
6. All solid organ transplants in the United States are matched to recipients through what organization?	61
7. What part of Medicare pays for post-transplant immunosuppressant medication once a patient is discharged from the hospital?	57
8. What is an Expanded Donor Kidney?	57
9. What are some of the common medical side effects of immunosuppressant medications?	50
10. What are the main side effects of post-transplant steroids?	15

questionnaire and return it in the envelope. Respondents were informed that their participation was voluntary and that their answers would be anonymous. Of the 50 that were mailed, 26 (52%) were returned. An analysis of the basic demographics of respondents determines that 80% of the social workers were female and they had an average of 6 years of experience in dialysis. They provided services to approximately 135 patients each (standard deviation: 42) and 92% of them worked in a for-profit clinic. Half stated that their primary clinic was in an urban area.

### RESULTS

As a whole, the sample participants answered 64% of the transplant knowledge questions correctly. When the data were collapsed, those with 5 or more years working in dialysis scored only slightly better than those with 4 or less (66 vs 62%). When scores were factored together with years of experience, a mild correlation was noted with  $r = 0.24$ . That is to say that scores somewhat improved as years employed in dialysis increased. No significant findings were found between the 2 groups (i.e., those with less than 5 years of experience vs. those with 5 or more years of experience),  $t(25) = 0.02$ , *ns*. Four of the 10 questions were answered correctly by only 57% or less of the social workers. See Table 1 for the percentage of social workers who were able

to answer each question correctly. When analyzed by category, questions regarding the transplant process and evaluation were more likely to be answered correctly as compared to those that focused on medical risks and side effects.

When asked if they were provided with training regarding transplantation when they were initially hired, only 3 (11.5%) of social workers stated "yes." They received approximately 20 minutes of training on this topic and they rated the overall quality of the information to be "fair." It is worth noting that all 3 of these social workers scored higher on the knowledge portion of the questionnaire as compared to the group average. When asked who was the primary source of patient education in their clinic regarding kidney transplantation only 8 (30.7%) of social workers identified themselves. The majority noted that this task was handled by nursing staff or the nephrologist. However, many of these social workers stated that they were in charge of completing the transplant referral paperwork (42%) and for providing written educational materials to patients (50%) regarding transplantation.

One exceptionally notable aspect of the results was that every social worker (100%) stated that they believed that they need further training regarding kidney transplantation. However, only 10 (38.4%) reported

frequently reading research articles regarding transplantation, and only 1 (3.8%) reported receiving information about changes and updates regarding this topic from their employer. When asked to rate their overall knowledge level regarding kidney transplantation on a 5-point Likert Scale, the average response was "fair." There was a low correlation ( $r = 0.27$ ) between social worker scores on the questionnaire and their overall perceived knowledge level. Thus, even though most social workers believed that they had a high knowledge level regarding transplantation, this was not reflected in their actual scores on the questionnaire.

## DISCUSSION

The social work roles of being an educator and advocate are vital in the dialysis setting. Patients often have questions about kidney transplantation, along with many misconceptions, which social workers need to be able to address. The results of the research with this sample show that training for dialysis social workers regarding transplantation is almost nonexistent, which is ironic because employers often identify them as being responsible for relaying transplant information to patients. Nearly 4 out of every 10 respondents could not identify the name of the organization that matches non-living organs to recipients; any discussion with patients about how the transplant waiting list functions would require this information. Years of experience did not appear to be a major factor in the sample; scores did not greatly improve when the number of years employed in dialysis increased. This is a unique finding because one might expect that knowledge would expand over time.

Over the last several years there have been efforts to improve the predialysis education that patients receive and this has greatly reduced hospitalizations and emergent care, while also increasing rates of continued employment (Golper, 2001). However, large-scale studies continue to show that many patients are still not presented with information about all of the various treatment modalities (Mehrotra et al., 2005). Fortunately, there are some clinics that have created systematic educational programs specifically regarding transplantation and these warrant further investigation to determine their impact (Malarcher, 2006).

Research has shown that there are racial and perceptual biases among physicians and patients that greatly impact access to transplantation; this research makes it particularly important that nephrology social workers join their teams in providing patients with education

and information about kidney transplantation. A survey of nearly 300 nephrologists noted a general view that transplantation was less beneficial for African Americans (Ayanian et al., 2004). Another study found that African Americans were less likely to be referred for kidney transplantation or to be listed for transplantation within 18 months of initiating dialysis as compared to Caucasians (Ayanian et al., 1999). There are also many myths, misconceptions and cultural beliefs that patients may have that make them less likely to seek transplantation (Navaneethan & Singh, 2006). For example, some minority racial groups may believe that the organ-matching process is purposely and unfairly biased toward providing transplants to Caucasians. Also, there are many urban legends about people being tricked into providing donor organs, or even having them stolen. This can potentially taint a patient's view about the safety or legality of the process. The NKF generated a press release in April 2000 to address an urban legend because it had become so rampant (NKF, 2008). On a general knowledge level, some people may not seek transplantation because they think it is a rare or experimental procedure.

Learning does not end when a social worker obtains his or her degree, it should be a constant element of continual practice. The NKF and the CNSW provide several useful online and written informational/educational materials, such as the Kidney Learning System (KLS) and Clinical Indicators for Practice, to aid in professional education. The field of transplantation is constantly evolving. New medications, surgical techniques, evaluation requirements, insurance benefits and other changes need to be known so that this information can be relayed to patients. Every social worker who completed the questionnaire believed that they needed further information regarding this topic. A unique aspect regarding dialysis social worker training is its lack of formality. Nurses, patient care technicians and machine technicians are often provided with weeks of detailed training and have to complete examinations to make sure that they have absorbed the content provided to them. Social worker training appears to be much more "word of mouth" and informal, thus an individual's knowledge is only as valid as what is provided by the person who trains them. A study by Merighi and Ehlebracht (2004) noted a similar finding in that nearly two-thirds of employers did not provide renal-specific in-service training to their social workers. It should be noted that the deficits identified in this research were found in all types of dialysis settings—rural or urban, profit or nonprofit and across several major corporations. Thus, this is a systemic issue.

There may be a tendency for social workers to shy away from discussing the kidney transplant option with patients because they do not perceive this as being part of their role. A review of NKF/NASW guidelines contradicts this view, and it appears that many social workers are already responsible for providing written literature to patients about this topic. It is also a very limited view because social workers are often called on to deal with a myriad of educational issues regarding other aspects of dialysis, such as treatment adherence and health insurance. There is a professional and ethical responsibility to learn more about this topic so that patients can be better served.

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