Early and Preemptive Transplant: Helping Patients and Providers Consider the Whole Picture

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ABSTRACT

This article briefly reviews a March 2007 KDOQI conference convened in 2007 to review information available regarding preemptive transplantation. Psychosocial implications as they relate to preemptive transplant are discussed. Social work assessment and psychoeduation is essential in identifying barriers in preemptive transplant that may differ from patients already on dialysis. Transplant social workers can provide collaboration and case management to improve patient outcomes through preparation.

INTRODUCTION

In March 2007, the National Kidney Foundation convened a Kidney Disease Outcomes Quality Initiative (KDOQI) conference in Washington, D.C., to review evidence and opinions regarding preemptive transplantation (transplant prior to dialysis). Fifty-two participants representing transplant centers, dialysis providers and payers were divided into three workgroups. The workgroups were divided to address the impact of early transplantation on chronic kidney disease (CKD), the educational needs of patients and professionals and finances (as they relate to providers and patients) of renal replacement therapy (RRT). Participants explored the benefits of preemptive (before RRT) and early (within the first year of dialysis) transplantation with respect to costs and outcomes, identified current barriers (at multiple levels) that hinder access to early transplantation and recommended specific interventions to overcome those barriers (Abecassis et al., 2008).

Despite emerging evidence that patients have optimum outcomes in terms of patient and graft survival when transplanted preemptively or early in the course of RRT, only 2.5% of patients who begin treatment for kidney failure undergo transplantation as their initial modality of treatment (Abecassis et al., 2008). Additionally, recommendations that CKD patients be referred for transplantation six months before beginning RRT are not widely followed (Kasiske et al., 2002). This may be due to lack of insurance for transplant at this stage of CKD. Insurance for many comes only with access to Medicare upon the initiation of dialysis. It may also be related to the practice patterns of nephrologists or to the lack of education available to patients. Nephrology social workers have a central role in preemptive transplantation and early transplantation in helping transplant candidates, potential donors and families through education, assessment, case management and counseling to overcome barriers and achieve a successful transplant.

Statistics show that preemptive transplant can provide the best survival and quality of life for patients (Meier-Kriesche & Kaplan, 2002). Statistics further show that transplant is most successful before the initiation of dialysis or within the first year of dialysis (U.S. Renal Data System, 2006). One of the reasons is that medical complications are avoided, such as dialysis exposure, cardiac events and those related to vascular access. From an economic and personal cost standpoint, preemptive transplantation is thought to be more cost-effective. For example, the cost of vascular access placement and the initiation of dialysis are avoided. From the patient perspective, the potential days of lost employment are lessened, anxiety may be reduced and destabilization of the family may be minimized. These costs are not minimal.

ENCOURAGING PREEMPTIVE AND EARLY TRANSPLANTATION: IMPLICATIONS FOR NEPHROLOGY SOCIAL WORK

Every patient is entitled to transplant referral and evaluation. A psychosocial assessment is a component of the transplant evaluation process as directed by *Medicare Conditions of Participation for Transplant Centers* (42 CFR Parts 405, 482, 488 and 498; Centers for Medicare and Medicaid Services [CMS], 2007). The transplant social work assessment not only assesses the strengths and weaknesses of the potential candidate but also educates the patient and family about what to expect in the way of needed savings, time off work, plan of care for children and the importance of beginning the work on planning for these issues *prior* to the transplant (Council of Nephrology Social Work, 2005). Rules pertaining to access to Medicare are daunting to navigate for patients and providers alike. For preemptive transplant, the problem involves the complex interplay among private and government payers, and the negotiation of these hurdles in a manner timely enough to allow preemptive transplantation to occur and patient access to medications and health care following transplant. Preemptive transplant is rarely possible for people without insurance. Some hospitals consider and can choose to approve going forth with transplant without insurance when an individual has a living donor and is Medicare eligible and entitled. The implications for medication cost and immediate post-transplant care would need to be planned for extremely carefully in this scenario.

> "Medicare coverage can begin the month you are admitted to a Medicare-approved hospital for a kidney transplant or for health care services that you need before your transplant if you meet the following condition:

- Your transplant takes place in that same month or within the 2 following months" (CMS, 2008).

In most instances, the hospital would need to be ready to provide medications for the months until Medicare Part B was processed for anti-rejection medications (and then a Medicare Part B pharmacy could seek reimbursement from date of discharge for the same medications). Then, the hospital would need to cover the cost of other medications, including anti-viral medications, until Medicare Part D became effective. While the use of pharmaceutical assistance programs (PAPs) may be possible in this situation, it may become quite complicated for the patient and family if income documents are not readily available or income guidelines are not met or if the patient cannot cognitively manage multiple PAPs. From the experience of this author, this scenario would rarely be recommended from a psychosocial perspective.

Transplant is not a panacea, and as the renal community focuses on early and preemptive transplant, a balanced presentation of pros and cons is important. With any transplant comes the standard risks associated with immunosuppressant medications: an increased risk of cancer, hyperlipidemia, diabetes, bone disease and nephrotoxicity, to name a few. Transplant may be considered the best option available for select people with kidney failure, but it is a treatment, not a cure, and psychosocial interventions may be needed at various stages during the course of chronic illness with transplant or dialysis.

Patients who have preemptive transplantation often have a shortened period to adapt to the challenges commonly experienced by CKD patients during their initiation phase of adjustment to CKD stage 5: trauma, disruption, fear and confusion (National Kidney Foundation/Council of Nephrology Social Work, 2008). There may be fewer initial challenges post-transplant if surgery and recovery goes smoothly, but when problems occur post transplant, such as a rejection episode, cancer or a virus, the nephrology social worker can refocus interventions on the adjustment goals of Phase 1: emotional and physical stabilization, family system stabilization and support, disease knowledge, trust and hope (National Kidney Foundation/Council of Nephrology Social Work, 2008). Setbacks with transplant, such as rejection episodes, can be especially difficult. Often, there is a tendency to consider transplant a cure rather than a treatment.

DESIGNING A BALANCED EDUCATIONAL APPROACH

Sometimes, patients hear the *message* of preemptive transplant. However, they have no donor and do not want to start dialysis. Perhaps they question whether they are really sick enough to need a transplant. For these patients, the message of preemptive transplant may instill fear and despair. While transplant centers incorporate information about preemptive transplant and dialysis facilities promote early transplant in an effort to help patients understand the medical and quality-of-life benefits, programs must be mindful of the meaning of this message for those who will remain on the transplant waiting list, nearing 80,000 individuals, for five or more years.

Also, sometimes a patient may appear to be an excellent transplant candidate from a medical standpoint. However, from a psychosocial perspective, barriers exist that will create stress and are predicted to contribute to an inability to adhere to medical recommendations. The patient may need to do fundraising to save money for the costs of medication co-pays, hospital deductibles, time off work, housing at the transplant center, transportation to and from the transplant center, etc. It is sometimes very difficult for surgeons and nephrologists who see a healthy individual to understand that the necessity to save money for the needs mentioned previously means that a preemptive transplant may not be realistic. The hospital may also not be in a position to forgo some of the Medicare Part B costs that would be non-reimbursable for the candidate who is waiting for Medicare. These costs would include surgeon and anesthesiology fees for the operation, as well as post-transplant outpatient services such as clinic visits and blood draws.

A social worker's goal is to meet patients where they are, advocate for them and help them to meet their goal. This is done in collaboration with the team and the patient while seeking the best outcome for the patient. Preemptive or early transplant *may* be the ideal situation for a patient, but looking at the patient holistically, preemptive transplant may not be possible. Referral for transplant evaluation at the earliest possible time will help the patient begin preparing all areas of his or her life for post-transplant needs. The KDOQI conference provided a broad review of topics relevant to patients, as well as providers regarding preemptive transplant. Transplant social workers can provide collaboration and case management between patients and providers to promote improved outcomes for patients particularly relating to adherence.

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