

Awakening the Advocacy/Education Role of Nephrology Social Workers: The Case of the Socioeconomic And Racial Disparity in Transplant Evaluations

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Prior to the passage of the Social Security Amendment of 1972 (Public Law 92-603), which created the End-Stage Renal Disease (ESRD) Program, there was no financial guarantee that individuals with irreversible kidney failure would have access to life-sustaining hemodialysis. Around the United States, groups referred to as “Medical Advisory” (Pendras & Erickson, 1966, p. 293) and “Life or Death” committees (Weisse, 1991, p. 101) met to decide which patients would get treatment and who would be allowed to die (Alexander, 1962; Retan, Lewis, 1966; Fox & Swazey, 1974). Among the criteria used by these committees to select patients were their income, marital status and “social worth” (Evans, Blagg, & Bryan, 1981, p. 487). One of the driving motives behind the creation of the ESRD program was the desire to eliminate this moral and ethical quagmire and thus insure that all patients have equal access to all treatment options, including transplantation (Rettig, 1980).

Unfortunately, research over the last 15 years has repeatedly documented that not all patients have equal access to all treatment options. More specifically, it is found that low-income and African-American patients are less frequently referred for transplantation evaluations (Kjellstrand, 1988; Soucie, Neylan, & McClellan, 1992; Eggers, 1995; Delano, Macey & Friedman, 1997; Institute of Medicine, 1999; Epstein, Ayanian, Keogh, Noonan, Armistead, Cleary, et al., 2000; Furth, Garg, Nev, Hwang, Fivush, & Powe, 2000; Wolfe, Ashby, Milford, Bloombergen, Agodoa, Held, et al., 2000; Epstein, & Ayanian, 2001; Alexander & Sehgal, 2002; Srikaneswaran, 2003; Lurie, 2004).

A number of factors have been cited as possibly contributing to the socioeconomic and racial disparities in this area of health care. For example, some investigators (Held, Pauley, Bovbjerg, Newmann, & Salvatierra, 1988) have referred to the existence of a “strong financial incentive” (p. 2598) in large dialysis units not to refer patients because the cost per patient falls as the size of the unit increases. Giving some credence to this explanation, other researchers (Garg, Frick, Diener-West, & Powe, 1999) have documented a strong association between for-profit units and patients having a 26% less chance of being referred for a transplant evaluation.

Most recently, evidence has been increasingly pointing to inadequacy of educational information and a lack of emotional encouragement, as major contributing factors in the disparities. For example, utilizing a stratified random sample of patients, a group of investigators (Ayanian, Cleary, Weissman, & Epstein, 1999) found that African-Americans were less likely than white dialysis patients to report that their nephrologists had provided all the medical information they desired, and also that the possibility of receiving a kidney from a family member had been discussed with them. Evidence that African-American patients are less likely to be emotionally encouraged was also documented by these investigators (Ayanian et al., 1999) who found that 75.3% of white women were encouraged by their physician to consider transplantation, compared to only 59.7% of African-American women; the corresponding percentages for white and African-American men were 77.9% and 63.4%, respectively. Reinforcing the pattern of evidence in this area, King (2000) found that 44.2% of white pre-dialysis patients had been offered the option of transplantation, compared to 33.1% of African-American pre-dialysis patients. This evidence of African-American patients not being provided adequate information, or being encouraged to consider transplantation may partially explain Alexander and Sehgal’s (2001) finding that they are more likely to regress, in the steps leading to transplantation, at the step of not being able to develop a definite interest in this treatment option.

Educating Patients About Treatment Options: The Emergent Role of Nephrology Social Workers

Patient education has historically been a primary responsibility of the physician (McClellan, 1986). Over the last 30 years, other health care professionals with expertise in different areas (e.g., nurses, nutritionists, pharmacists, and social workers) have been increasingly involved in patient education (Rankin & Stallings, 2001; Snella, Trewyn, Hansen, & Bradberry, 2004; Buchanan, 2004; Bailly & DePoy, 1995). Nephrology social workers’ involvement in educating ESRD patients was given impetus by the enactment of the Patient Self-Determination Act of 1991, which emphasized patient choice in every aspect of care

(Breckenridge, 1997). In the ensuing years, research shows (Grumke & King, 1994) that nephrology social workers were involved in a variety of patient education issues. Most recently, shortages in the nephrology work force have compelled increasing numbers of nephrologists to delegate additional patient education tasks to social workers and nurses (Renal Physician Association, 2000). Further research reveals that for some time now these disciplines have actually been filling an education void in providing information about treatment options. In this case, a group of investigators (Holley, Barrington, Kohn, & Hayes, 1991) earlier documented that patients identified social workers, along with nurses, as the professionals who “best disseminated information and influenced choices about information and influenced choices about dialysis modality” (p. 110). Emphasis is given to the fact that the education information on transplantation, typically provided by these professionals in a dialysis unit, is only of a preliminary nature. Being preliminary, it is an initial but critical first step in the patient education process, to be more thoroughly covered by the interdisciplinary team at a transplant center (Wolfe, 2003a).

Discussing Treatment Options at More Frequent Intervals

The Centers for Medicare and Medicaid Services, in conjunction with the End Stage Renal Disease Networks, require dialysis providers to annually review treatment options with patients and record the results on care plans. Although this mandate is ostensibly complied within 100% of the cases, disparities continue to exist regarding low-income and African-American patients being equitably referred for renal transplant evaluations. Several lines of converging evidence point to the need to discuss treatment options at more frequent intervals, and that nephrology social workers may be in one of the most strategic positions to do this. Among the reasons options need to be discussed more often is that many patients are frightened and distressed at the start of treatment and are not able to absorb initial information that may be provided. Secondly, the validity of the transplant status code information on patients, provided to the ESRD Networks by dialysis providers, has been questioned (Sehgal, Coffin, & Cain, 2000). As to the reasons for nephrology social workers’ strategic position in discussing treatment options at more frequent intervals, it has been suggested that it results from: (a) their day-to-day problem-solving involvement with patients and the spontaneous opportunities this presents for reproaching the subject; (b) the qualitative

difference in their interactions with patients, which allows for a better sensitivity to timing and the readiness to learn; and (c) nephrology social workers may be more readily able to see patients away from the treatment experience, given that hemodialysis can cause dysfunctions in patients’ ability to process information (Wolfe, 2003b).

The Impending Crisis in Patient Education About Transplantation: The Indispensable Role of Nephrology Social Workers

Analysts are predicting that the number of individuals requiring dialysis will double by 2010 (Xue, Ma, Louis, & Collins, 2001). Studies are also projecting a serious shortage of nephrologists by that year as well (Kletke, 1997; Chevalier, 1997; Hoffart & Nissenson, 1998; Luke & Galla, 2000). Additional research is projecting that the current ratio of one nephrologist for every 40 to 60 patients will increase to one for every 120 patients by 2010 (Nissenson & Rettig, 1999). Given these impending developments and the current deficiencies in information and encouragement provided to low-income and African-American patients, it probably means that these patients’ chances of being adequately informed and encouraged will be even more diminished in the near future. With this as a likely scenario, nephrology social workers, along with nurses, will have to take a much more active (and even proactive) role in educating and encouraging patients about treatment options.

CONCLUSIONS

This article has endeavored to briefly highlight some salient issues on renal transplantation currently confronting nephrology social work which are likely to become even more of a concern in the not-too-distant future. Established patterns of professional practice and research clearly show that nephrology social workers have a role to play in educating patients about treatment options. The limited research in this area suggests, however, that not all see this as an integral part of their role. This was evident in King’s (2000) study of factors affecting modality selection, which found that 46.1% of patients reported receiving information about treatment options from nephrology nurses, but only 19.1% from social workers. This is unfortunate because the profession has a unique opportunity to distinguish itself in terms of helping to eliminate a socioeconomic and racial disparity in health care. Given social work’s long

history of advocacy and sensitivity to economic and racial inequalities (Kittredge, 1988; Solomon, 1976), practitioners should bring a special passion to this pressing issue.

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