Spirituality, quality of life and the dialysis patient

Fredric O. Finkelstein, William West, Jaya Gobin, Susan H. Finkelstein and Diane Wuerth

Renal Research Institute, Hospital of St. Raphael, Yale University, New Haven, CT, USA

Keywords: dialysis; quality of life; spirituality

Spirituality refers to an attempt to understand the meaning and purpose of life; it may or may not involve organized religion and it may or may not involve a belief in a higher being [1]. The relationship between spirituality and health care has been receiving increasing attention recently [1–7]. This interest in spirituality has occurred because of a variety of reasons. Importantly, several studies have demonstrated that there is relationship between spirituality and clinical outcomes [2–7]. Moreover, the important role of addressing spiritual concerns of patients has been emphasized as the development of palliative care programmes has expanded [2].

To some extent, this interest in spirituality reflects a broader interest in quality of life issues. This is certainly the case for the patient with chronic kidney disease. The importance of assessing the quality of life of end stage renal disease (ESRD) patients, as they manage the complex demands of a chronic illness, has recently been emphasized [8]. A variety of studies have focused concern on the quality of life of ESRD patients [8–13] because of several important observations. Most importantly, it is now appreciated that quality of life measures represent valid endpoints of clinical trials that assess therapeutic advances in ESRD care [8,12]. For example, many of the primary and secondary endpoints in the National Institutes of Health Frequent Hemodialysis Trial involve selected quality of life measures [12]. Secondly, data has accumulated to indicate that various quality of life parameters are strongly correlated with morbidity and mortality of ESRD patients [9–11]. In the DOPPS studies, for example, the physical and the mental component scores of the SF-36 questionnaire and depressive symptoms have been identified as strong predictors of hospitalizations and mortality in a large international cohort of haemodialysis patients [10,11].

Numerous studies involving ESRD patients have examined selected quality of life domains. These assessments have generally been done using standardized questionnaires, which permit the rapid screening of large cohorts of patients. These questionnaires explore various domains, such as those delineated by the SF-36, Beck Depression Inventory, etc. These studies often document the impact of the medical illness on the patients’ perception of their quality of life. Moreover, the impact of quality of life domains on medical outcomes, as well as the relationships between these various domains have been noted. However, developing strategies to improve various quality of life domains has proved to be difficult. For example, although depression is documented as the most common psychological problem encountered in ESRD patients, few studies have looked at specific treatment strategies to improve the depressive symptoms of these patients [13]. And, studies that have developed strategies to treat depression have emphasized the difficulties encountered in employing successful algorithms [13]. No studies have documented that addressing or treating quality of life problems improves patient outcomes. Nevertheless, it is now recommended by K/DOQI that quality of life issues be monitored on an ongoing basis in ESRD patients [14]. The purpose of this monitoring is to define and document the quality of life status of the patient, hopefully identify therapies that can improve the patients’ quality of life, and ultimately improve patient outcomes.

Spirituality has been considered by some investigators to be an important arena to focus on in assessing the quality of life of patients. Several questionnaires have been developed to more closely examine the spirituality of patients [2–7,15,16]. These questionnaires permit an assessment to be made of an individual’s spiritual perceptions and distinguish between organized religious practices and existential spirituality. Two recent reviews have suggested that there is a significantly lower mortality rate in those individuals who attend religious services [5,6]. For example, Koenig noted that 39 of 52 studies examining the level of religiousness and mortality in a variety of patient populations observed longer survival for those patients who were more religious [6]. And, Powell et al. [5] noted a 25% reduction in mortality, after adjustment for confounders, in healthy individuals who attended religious services. The reasons for this beneficial effect are not clear;
but one can speculate on the possible associations between spirituality and the relationship of patients to health care providers, other quality of life measures, patient compliance and inflammatory markers. This latter association is of particular relevance, particularly since recent studies have suggested an association between selected quality of life domains, such as depression, and inflammatory markers, in both general medical and ESRD patients [17,18].

Spirituality has been examined in very few studies that have explored the quality of life of ESRD patients; and the relationships between spirituality or spiritual well being and a broader array of quality of life domains have not been thoroughly examined. Kimmel, Patel and associates suggested that there is a relationship between scores on the Spiritual Beliefs Scale and global quality of life measures, satisfaction with life and perception of depression [16,19]. However, no correlation was noted between various clinical parameters and spirituality scores [16,19]. Berman et al. [15] suggested a relationship between intrinsic religious beliefs and satisfaction with life as well as between organized religious activity and satisfaction with medical care in ESRD patients. No relationships between compliance with care and religious beliefs were noted [15].

We have been interested in the quality of life of ESRD patients and have examined the relationship amongst various quality of life domains and selected medical outcomes [20–25]. We have focused attention of attempting to improve the quality of life of the ESRD patient, but have recognized the challenges presented by this effort [20]. Recently we have begun to explore the relationship between spirituality and various problems presented by the ESRD patient. Does spirituality relate to various quality of life measures in dialysis patients? Does spirituality correlate with compliance of the ESRD patient? Does spirituality impact on various quality of life domains, such as depression, perception of quality of care, etc.? And, can addressing the spiritual concerns and needs of patients impact on their quality of life and/or medical outcomes?

We decided to explore spirituality by using the Spiritual Well being Questionnaire (SWBQ), which considers both the religious and existential spiritual perceptions of the patient [26]. A cohort of ESRD patients (n=200) maintained on both haemodialysis and peritoneal dialysis was asked to complete this questionnaire in conjunction with a standard series of quality of life instruments routinely used in our dialysis units [20–25]. The preliminary results of this study have suggested that there is a strong correlation between spirituality scores on the SWBQ and several quality of life domains, including: (a) depressive symptoms as assessed by the Beck Depression Inventory (BDI), (b) the mental composite score (MCS) of the SF-36 and (c) the global assessment of the patients’ quality of life. These correlations were strongest for the existential component of the spirituality questionnaire. For example, the correlation coefficient (r²) between the existential score (ES) and BDI score was 0.43, and between the ES and the MCS was 0.45. It was of interest that there was no relationship between spirituality scores and comorbidity (as assessed by the Charlson Co-morbidity Index) and patient age. And, there was no relationship between spirituality scores and patients’ compliance, as clinically assessed by various members of the dialysis units’ staff (physician, primary nurse, dietician and social worker). Spirituality scores for PD and HD patients were similar.

How are we to interpret these preliminary findings? The relationship between spirituality and various quality of life domains is certainly worth exploring in more detail. Since it has been difficult to positively impact on the quality of life of ESRD patients, is it possible that engaging patients in discussions about their spiritual concerns and attending to their spiritual well-being may contribute to an improvement in their quality of life and medical outcome? [27]. We think that it is important to begin to explore and define specific parameters of emotional and spiritual care for ESRD patients.

Furthermore, we think that it is critically important to develop and expand palliative care programmes into the realm of ESRD care. This is particularly important as the population ages and the percent of elderly ESRD patients with various comorbidities continues to increase. The important role of spirituality in palliative care has been emphasized by several investigators [2–6]. The literature emphasizes the positive impact of spirituality on palliative care programmes and the impact of spirituality on patients and their families during this difficult time. But, as emphasized by Sinclair et al. [2], although the importance of spirituality in terminal care is recognized, much work needs to be done to better understand the spiritual experiences of the patients. This is particularly true in terms of ESRD care; little work has been done on spirituality and the terminal care ESRD patients. It is important to remember that in the United States, 20% of deaths in the ESRD population are attributed to elective discontinuation of dialysis [28]. Would it not seem reasonable then to further explore the role of spirituality in helping to support, guide and coordinate the care of these patients?

Conflict of interest statement. This work was supported by grants from the Renal Research Institute. There are no relevant conflicts of interest for any of the authors.

References