Peer Mentoring: A Culturally Sensitive Approach to End-of-Life Planning for Long-Term Dialysis Patients

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• ***Background:*** **This study is designed to explore the impact of peer mentoring on end-of-life decision making.** ***Methods:*** **A controlled randomized intervention study with 203 patients from 21 dialysis centers across Michigan explored the impact of peer mentors, dialysis patients trained to help other patients, on end-of-life planning.** ***Results:*** **Communicating information on advance directives (ADs) through peer mentoring significantly influenced the completion of ADs overall compared with distributing standard printed material or no specific designed intervention. However, the influence was most prominent among African Americans, not only increasing actual completion of ADs ($P < 0.001$) and comfort discussing ADs ($P < 0.01$), but also improving subjective well-being ($P < 0.05$) and anxiety ($P < 0.05$) during the study period. These effects of peer mentoring did not appear among white patients, although printed material on ADs decreased reported suicidal ideation ($P < 0.05$).** ***Conclusion:*** **These results suggest the importance of addressing specific cultural factors in the process of AD education. Common practice assumes that printed materials are effective in educating patients about health care and decision making. However, peer mentoring, a relationship-centered person-to-person approach, may be more effective in some cultural groups because it partakes of oral, rather than written, traditions. Acknowledging cultural differences and tailoring our approach could be powerful in enhancing trust and participation and decreasing potential disparities in health care outcomes. *Am J Kidney Dis* 46:111-119.**

INDEX WORDS: Quality of life; end-stage renal disease (ESRD); health care disparity; peer mentors; race; African American; advance directives (ADs).

OF MORE THAN 450,000 patients with end-stage renal disease (ESRD) in the United States, more than 79,000 died in 2004.[1] Patients beginning dialysis therapy are older and sicker than ever before. Because of the high mortality rate, death and end-of-life discussions are critical issues for the dialysis community.

The Patient Self-Determination Act of 1990[2] mandates end-of-life education by offering advance directives (ADs) to all patients admitted to Medicare-participating hospitals. This legislation was intended to ensure the possibility of patient input for medical decisions concerning end-of-life care. In practice, patients being admitted to hospitals usually are offered printed materials and given the opportunity to execute AD papers, often by personnel unfamiliar to the patient. The act did not address the outpatient setting or maintenance dialysis units. Several articles question the effectiveness of ADs, pointing out that ADs often are not taken into account during acute hospital care,[3-7] ADs may be too vague to be of use in specific clinical situations or may lead caregivers to give up prematurely,[4,7,8] execution of ADs does not always foster increased discussion between the patient and family or caregivers,[5,9,10] and ADs may have cultural biases that do not address the needs of such groups as African Americans.[11,12] However, other research suggested that patients who discussed their end-of-life wishes with family and staff had an increased likelihood of experiencing "a good death" irrespective of cultural background.[10] In addition, AD completion is increased when a trusted health care staff member broaches the subject, particularly when contact is recurring[9,13] and takes place in such settings as family meetings. In the final analysis, the process

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of end-of-life discussion, rather than the document itself, may be most important in determining successful and reconciled outcome in terminally ill patients with ESRD.[9,10,13]

Our standard methods, such as written materials or interactive Internet programs, do not always address cultural differences, and a people-to-people approach might be more effective. A prominent example in the United States is African Americans, who are 4 times more likely than whites to develop ESRD, face a similar 15% annual mortality rate,[1] and often are reluctant to complete ADs.[14] This reluctance comes as no surprise because there is well-recognized disparity in both availability and access to health care,[15,16] and African Americans often are distrustful of the medical system[16-19] because of such experiences as the Tuskegee Syphilis Experiment.[20,21] Furthermore, there are cultural differences, such as family-oriented decision making and oral traditions,[22,23] that we have failed to take into account when designing health care or, more specifically, AD education.

An important people-to-people method now used in the long-term dialysis setting is peer mentoring, training of selected patients to support and empower other patients. Peer mentoring has proved beneficial not only to patients on long-term dialysis therapy,[24,25] but also in several other medical settings, including patients with breast and prostate cancer, breastfeeding women, women with postpartum depression, and patients with acquired immune deficiency.[26-39] In Michigan, peer mentoring for patients with ESRD is a statewide clinical service program fostered by the National Kidney Foundation of Michigan. A 16-hour training program teaches active listening and problem-solving skills combined with focused discussion on human development and mental health. Peer mentors have been highly effective in helping alleviate patient's fears about renal transplantation and helping adolescents cope while on dialysis therapy and after renal transplantation.[24,25,40-46] Because they often have faced multiple complications with the potential of dying during their own medical experiences, peer mentors are in a unique position to broach discussion of end-of-life and AD issues with other patients.

The present study is designed to explore the impact of peer mentoring on end-of-life decision making. We propose to address the following questions: (1) Is peer mentoring more effective than other methods for increasing patient comfort in discussing end-of-life issues and completing ADs? (2) Are there demographic differences in the effectiveness of peer mentoring? (3) Is AD education through peer mentoring associated with worsened or improved psychosocial outcomes for patients?

METHODS

Participants

Two hundred eighty patients from 21 dialysis units (units of varying size selected on the basis of social worker availability and willingness to participate) across the state of Michigan met initial eligibility criteria: patients needed to speak English, be assessed as competent, be older than 18 years, and not yet have completed an AD. All patients were recruited by unit social workers, and signed consent forms were approved, along with other study materials, by the Investigational Review Board of the University of Michigan Health System (Ann Arbor, MI). Subjects were largely (>95%) naive to peer-mentor intervention before this study and were asked to participate in a study of both peer intervention and ADs.

Study Design

Experimental Conditions. Patients were assigned by random lots to receive AD information in 1 of 3 ways: (1) through peer mentoring (group 1; peer intervention), (2) through printed material prepared by the National Kidney Foundation ("Advance Directives: A Guide for Patients and Families," question-and-answer format, targeted at 8th-grade reading level) distributed approximately at the midpoint of the 2- to 4-month study period (group 2; printed material), or (3) through no additional means other than that routinely provided by the dialysis unit (group 3; control). No other study-related intervention was planned, but unit social workers performed their usual intake interview for all patients starting dialysis therapy and were free to answer questions that came up during the study period regardless of randomized study assignment.

Survey. Patients responded to a baseline survey and follow-up survey 2 to 4 months later. Surveys were distributed and collected by dialysis unit social workers and contained psychosocial measures that included the following: depression, subjective well-being, death acceptance, anxiety, and suicidal thinking. Depression (6 questions assessing such symptoms as dysphoria, somatic symptoms, and hopelessness), anxiety (2 items measuring such symptoms as feeling trapped), and suicidal ideation (1 question) were assessed by using a modified version of the Hopkins Symptom Checklist.[47] The severity of each symptom during the previous 2-week period was rated on a scale varying from 1 (not at all) to 5 (extremely). Subjective well-being was assessed based on patient ratings by using 5 statements from the Diener scale[48] assessing current level of life satisfaction, including "the conditions of my life are excellent" and "I am