Dying Well After Discontinuing the Life-Support Treatment of Dialysis

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Background: Cessation of life-prolonging treatments precedes death in an increasing number of cases, but little attention has been accorded to the quality of dying.

Objective: To examine the quality of dying following dialysis termination.

Patients and Methods: A prospective cohort, observational study involved 6 dialysis clinics in the United States and 2 clinics in Canada, and 131 adult patients receiving maintenance dialysis who died after treatment cessation. Sixty percent (n=79) underwent patient (n=23) and/or family (n=76) interviews and follow-up with caretakers. A quality of dying tool quantified duration, pain and suffering, and psychosocial factors.

Results: The sample was 59% female, the age was 70.0±1.2 years old, the duration of dialysis was 34.0±2.8 months, and death occurred 8.2±0.7 days after the last dialysis treatment. (Data are given as mean±SE.) Thirty-eight percent of the subjects who completed the protocol were judged to have had very good deaths, 47% had good deaths, and 15% had bad deaths. During the last day of life, 81% of the sample did not suffer, although 42% had some pain and an additional 5% had severe pain. According to the psychosocial domain of the quality of dying measure, patients who died at home or with hospice care had better deaths than those who died in a hospital or nursing home.

Conclusions: Most deaths following withdrawal of dialysis were good or very good. The influence of site of death and physician attitudes about decisions to stop life support deserves more research attention. Quality of dying tools can be used to establish benchmarks for the provision of terminal care.

Arch Intern Med. 2000;160:2513-2518
PATIENTS AND METHODS

A Dialysis Discontinuation Study Group was formed by 8 dialysis clinics from the United States and Canada that were interested in participating in the study. At each site, a team consisting minimally of a nephrologist, psychiatrist, and renal social worker was established, and the study protocol and informed consent were approved by the local institutional review board. The study was described to all nephrologists in the practice, who were requested to notify the study site team when a patient had stopped maintenance dialysis treatment. Subjects were adults who had been receiving long-term dialysis for at least 3 months. The referring nephrologist provided information about the circumstances, including whether the patient was able to meaningfully participate in an interview. The site team psychiatrist or social worker would then contact the patient and/or family to describe the study and request their consent to participate. Patients underwent initial interviews and parallel interviews were conducted with families. Follow-up interviews were conducted with caretakers or family every 3 days until the death. The data collection period was from October 1, 1995, to September 30, 1997 (briefer for some of the programs).

INTERVIEW INSTRUMENT

The initial interviews were tape-recorded. A structured series of questions inquired about the dialysis, the circumstances surrounding the decision to stop treatment, and the definition of a good death. Most questions were open-ended, such as, “People sometimes speak of a ‘good death’—what would you consider to be a good death?” Information about demographics and medical history was gathered from medical chart review, while data about symptom management were obtained from the follow-up interviews with family or nurses. A final interview with caretakers provided information concerning the patient’s last 24 hours.

QUALITY OF DYING INSTRUMENT

This tool (available from the authors) represented an attempt to quantify the end of life in a manner that was similar to the one used by Virginia Apgar in measuring the condition of a newborn child.37 The instrument differentiated 3 domains, which added together represented the Dialysis Discontinuation Quality of Dying (DDQOD) score: a shorter duration of dying was assumed to be preferable to a prolonged duration, psychosocial factors surrounding the decision and death were recognized to be the most problematic to rank, and pain and suffering were relatively easily rated. Each domain was given a score from 1 to 5, with higher numbers reflecting a better death; the sum of the scores could therefore range from 3 to 15. The DDQOD scoring instructions listed the specific point scores for the duration domain, corresponding to the number of days between the last dialysis and the time of death. Pain and suffering were judged on a range from severe (a score of 1) to absent (a score of 5), while the psychosocial domain was determined according to the presence of such factors as whether the patient was alert or confused at the time of the decision to discontinue dialysis, whether family were supportive or divided by the experience, and whether the patient was alone at the time of death. Periodic meetings of each of the individual research site teams were held to review information about the deaths and to arrive at a group consensus on the subjects’ DDQOD scores.

STATISTICAL ANALYSES

A reliability study of the DDQOD was performed across the sites using a set of case descriptions that was designed to represent very good, good, or poor deaths. These case descriptions were scored by the teams at each of the 8 sites. The resulting estimate of the intraclass correlation (0.97±0.03) indicated extremely high agreement in case scores across the sites. While there was some variability among the scores for each case, the score ranges for the 3 end points were clear. This led to a delineation of very good deaths (DDQOD >12), good deaths (>8-12), and bad deaths (<8). Subsequent analysis of factors associated with quality of dying focused on the total DDQOD score. This was done to account for possible differences in scoring across the sites, since there were too few cases at some sites to allow for direct control of site in the analyses.

Simple frequencies of responses to interview questions, medical chart reviews, demographic data, and quality of dying scales were produced, along with the means, SEs, and percentiles for continuous scale data. Association of the quality of dying scale with continuous scale factors, such as age and duration of dialysis, was examined via Spearman correlations owing to skewed distributions of these factors. χ² or Fisher exact test (2-tailed) was used to examine the association of factors with the total DDQOD score, as well as the Mantel-Haenszel χ² test for ordered trends.

End-stage renal disease death certificates were obtained, and the regional ESRD Networks independently supplied information about all deaths that occurred at the American clinics during data collection. These measures provided an opportunity to assess the completeness of reporting and potential bias in selection of study cases.

RESULTS

There were 131 deaths preceded by dialysis discontinuation at the 8 clinics. The average of the clinics’ dialysis discontinuation rates (percentage of deaths preceded by treatment termination) was 23.4%. Table 1 shows the distribution of cases according to the sites. The clinics were both freestanding and hospital-based, academic and private. They had widely disparate discontinuation rates and varied markedly in patient load. Consequently, there was large variability in the number of cases contributed per site.

Seventy-nine subjects (60%) completed the study protocol: they or their families had initial interviews, follow-up interviews were conducted, and quality of dying scores completed. Forty-nine subjects (37%) were not re-
ferred or were referred too late to be interviewed, and 3 (2%) refused to participate. The only significant difference between the group of patients who were referred in time to complete the full study protocol and those who were not was the sex distribution, with significantly higher referral of women than men (were not was the sex distribution, with significantly higher referral of women than men (χ² = 6.9, P = .008).

The demographic characteristics of patients are reported according to referral status in Table 2. The major causes of renal failure were diabetes (46%) and hypertension (29%). Common (≥50%) comorbid conditions included neurological disorders, cardiovascular disorders, coronary artery disease, and peripheral vascular disease. The chief reasons for stopping dialysis were deterioration due to long-standing diagnosis of a chronic disease (66%), an acute intercurrent disorder (22%), and inanition or “failure to thrive” (9%).

INTERVIEW RESULTS

According to the referring physicians, most patients were unable to participate in the interviews because of diminished mental status or physical frailty. At the time of referral, only 23 (29%) of the 79 subjects who subsequently completed the study protocol could be meaningfully interviewed. Interviews were conducted with 76 families (96%), and in 20 cases (25%) both patient and family were separately interviewed.

The patients reported that the characteristics of a good death are that it is pain-free (53%), peaceful (37%), and brief (26%). This was echoed by families, who described good deaths as being pain-free (67%), peaceful (41%), and brief (32%), as well as having loved ones present at the end (15%).

After death, follow-up interviews with caretakers and/or families concerning the last 24 hours of life revealed that suffering was not evident in 81% of cases. Pain was the most common symptom: it was present in nearly half (47%) of cases during the last day of life, but was judged to be severe in only 5% of patients. Families and/or staff were present at the time of death in 71% of cases.

DDQOD RESULTS

According to the DDQOD, 38% of subjects were judged to have had very good deaths, 47% had good deaths, and 15% had bad deaths. Scores ranged from 4 to 15, with a mean (± SE) among all 79 patients of 11.4 (± 0.3). Each of the 3 subscores ranged from a low of 1 to a high of 5. The mean duration score was highest at 4.2 (± 0.1), the psychosocial component mean was 3.5 (± 0.1), and the suffering score mean was 3.7 (± 0.1).

No significant associations were found between the total DDQOD scores and ethnicity, education, religion, marital status, reason for stopping dialysis, or primary cause for renal failure. Using Spearman correlations, a positive association was found between age and quality of dying. Older patients were seen as having had better deaths (P = .03). Female sex was significantly associated with better quality of dying (P = .03), and a smaller proportion of women (9%) than men (28%) had bad deaths.

The individual domains of the DDQOD score were analyzed separately. In the psychosocial domain, site of care was the factor that showed the strongest association. Terminal care was provided in the hospital (61%), a nursing home (24%), a hospice unit (2%), or at home (13%). Once the decision to discontinue dialysis was made, two thirds of 21 patients who were in nursing homes had a low psychosocial score, 41% of 44 patients in hospitals had a low score, while only 1 of 11 patients in hospice, home hospice, or family care had a low psychosocial score. Not surprisingly, in the suffering domain there were significant associations with various symptoms, such as pain (P = .02), while a negative association was apparent with the use of effective analgesics. In the duration domain, the mean (± SE) survival time from the last date of dialysis among 126 patients with data available was 8.2 (± 0.7) days, with half the patients dying within 6 days. Five patients lived between 30 and 46 days.

COMMENT

This study of dialysis discontinuation serves to highlight issues that are relevant to the cessation of all types of life-prolonging treatment. It used to be relatively simple when physicians reflexively determined and prescribed the course of treatment with the best survival rate. In recent years as the principle of patient autonomy has risen in importance, the process has become more complex. Medical practitioners are being confronted by the neces-

<table>
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<th>Home Hemodialysis</th>
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*Discontinuation rate is the percentage of end-stage renal disease deaths preceded by dialysis discontinuation during study.
sity to arrive at a clear vision of their responsibilities toward dying patients. Physicians now need to better describe how different courses of treatment will influence quality of life and quality of dying. Dying well has become a goal for many individuals. Whether there are 3, 6, or 10 domains, what is important is that a good death need not be a quixotic, nebulous vision beyond reach. End-of-life measures can assist in establishing a standard of care and facilitate continuous quality improvement for the treatment of terminally ill patients.

In the literature, deaths following dialysis discontinuation have generally been described as involving little associated suffering and progressive impairment of consciousness from uremia. In this study, many family and medical personnel in attendance during the last day of life agreed that suffering was controlled and treatment was effective. According to the quality-of-dying measure, 85% of subjects had good or very good deaths. We have introduced the concept of the very good death because many of these deaths were not merely good. In the best of cases, dialysis discontinuation provided an opportunity to spend the final days candidly communicating, reliving meaningful past interactions, laughing, and crying. It was a chance that most of us will not have to bring closure in an orderly fashion to relationships and business affairs. While the presence of dementia, coma, or other organic brain syndromes detracted from these situations, families were still grateful for the opportunity to express affection and bid final farewells.

The study also touched on the nature of the patients who decide, or whose families decide, to stop life support. This was a severely ill patient population. The sample conformed to the demographic profile in the retrospective literature—white, elderly, and diabetic—who were most likely to use this option. The ESRD population has increasingly grown older and sicker, and even with continued improvement in dialysis technology, the 23% adjusted annual mortality rate for patients with ESRD is greater than that of HIV or many cancers. As our society struggles over physician-assisted and physician-hastened deaths, it seems important to note that the study subjects were not cavalier about dialysis and did not make the decision hastily. It is striking that the sample underwent an average 3 years of renal replacement therapy before physical deterioration and inattention finally prompted them to discontinue treatment.

Another general issue highlighted by the data is the question of what determines whether life support is to be withdrawn. While we would like to believe that these decisions are made on the basis of hard, prognostic facts combined with patient/family preferences, physician willingness to consider this practice may be an essential factor. Although the research sites were united by a common interest in the topic, there was considerable variation in discontinuation rates, with a greater than 7-fold difference between 2 of the clinics. While this disparity may reflect variance in patient populations, it is more likely that the determining factor was physician attitudes and the culture of their dialysis facilities. By extension, it is just as likely that physicians’ beliefs about decisions to hasten death are major influences in withholding or removing ventilators, refraining from cardiopulmonary resuscitation, recommending against aggressive chemotherapy regimens, and other medical practices that have the potential to accelerate dying.

This has been a sensitive topic for nephrology since Neu and Kjellstrand reported that, between 1966 and 1983, 9% of patients in a large regional program in Minnesota stopped dialysis, accounting for 22% of all ESRD deaths. The seminal article was followed by a flurry of...
There were several statistically significant associations that warrant further study and replication. The issue of site of care after termination of life-support treatment is raised by the DDQOD psychosocial domain data. We believe it is fortunate that, despite increasing consolidation of managed care, most patients are able to choose between dying in the hospital, extended care nursing facilities, or home. The finding that dying at home can be a salutary choice is intriguing. Patients with greater family resources may have selectively remained at home, and the association may have also been influenced by bias in the psychosocial scoring. Nevertheless, it makes intuitive sense to provide people with the option of early referral to home hospice care when they are pondering their decision. Last, while the associations between age, female sex, and quality of dying were interesting, we leave to others whether they reflect societal influences, instrument bias, or objective truth.

Although the multicenter design of the research represents an improvement over the pilot study, the results should be generalized with appropriate caution. It would have been preferable, for example, to have a comparison group—such as patients who die without dialysis having been discontinued—but this proved impractical to implement. Likewise, quality of dying measures could ideally have been completed from patient and family perspectives and thereby enriched the assessments of medical personnel, but this also was not attempted in the present study. When one enlists clinics from both the United States and Canada, there are well-known national differences in the practice of dialysis that need to be considered. In the latter country, for example, there may be decreased referral of older and sicker patients for dialysis initiation and a lower mortality rate. The sample was similarly influenced by the absence of sites from the western and southwestern United States. The largest proportion of subjects was drawn from western Massachusetts, as this was not only the base of the principal investigators but also had the longest enrollment period.

While the study’s quality of dying tool was a useful prototype, it still needs modification and refinement. For instance, although the duration dimension of the DDQOD is the easiest to calculate, briefer is not always better than longer. According to our system, 3 weeks of pain-free, socially uncomplicated survival would receive a poorer rating than that of a comparable individual who only lived 4 days. Another problem comes in trying to determine whether suffering precedes or follows discontinuation, and our approach does not answer the basic question of whether there is pain and distress caused by the physiological processes that unfold when one terminates dialysis. Likewise, one can quibble about our choice of descriptive terms and ask whether what we call “good” is actually “fair,” and is “very good” merely “good?” As discussed previously, our inclination to use the term “very good” was shaped by the remarkable and sometimes transcendental deaths that were witnessed.

CONCLUSIONS

Sir Thomas Browne was correct in his remark that, “Many have studied to exasperate the ways of Death, but fewer hours have been spent to soften that necessity.” The major finding of this study—that the great majority of deaths were good or very good—should be comforting to patients, family, and staff who grapple with these difficult decisions. On the other hand, dialysis discontinuation or the cessation of any type of life-support treatment should ideally be preceded by comprehensive advance care planning and followed by the provision of maximum palliative care. So far, they are not. Nearly half the patients during their final days were reported to have at least some pain, 1 in 20 had severe pain, and 1 in 7 were judged to have had bad deaths. These observations need further attention if we are to fulfill the goals to not only extend life and ameliorate symptoms but also to help people die well. It is our belief that the use of tools, such as the DDQOD, can contribute to altering the culture of medicine and improving the standard of care of dying patients.

Accepted for publication March 17, 2000.

This study was funded by grants from the Greenwall Foundation, New York, NY; and from the Project on Death in America, Open Society Institute, New York. Dr. Cohen is a fellow of the Faculty Scholars Program of the Project on Death in America, and an investigator in the Promoting Excellence in End-of-Life Care National Program of the Robert Wood Johnson Foundation.

Preliminary data from this study were presented at the International Conference of Psychonephrology, September 18, 1998, New York, and as a poster at the Annual Meeting of the American Society of Nephrology, October 26, 1998, Philadelphia, Pa.

We thank the members of the Dialysis Discontinuation Study Group. They include: Berkshire Medical Center, Pittsfield, Mass: Henry Rose, MD; Steve Nelson, DO; Mark Pettus, MD; Steven K. Dobscha, MD; Richard Berlin, MD; Kathy Duquette-Penna, LICSW; Jack McCue, MD, Greenville Dialysis Center, Greenville, NC: M. J. Barchman, MD; Kathy Shy, MD; Tracey Correa. Toronto Hospital, Toronto, Ontario: Dimitri Oreopoulos, MD; David Mendelsohn, MD; Jose Mederos, MSW; Lillian Mierzwa, BSW. Yankee Family Dialysis, Greenfield, Mass: Jeffrey W. Blomstedt, MD; Deborah J. Hayes, LICSW. Southern Maine Dialysis Facility, Portland: Jonathan E. Morris, MD; Donald Lecher, MD; Nancy Lord, LICSW; Betty Jarratt, LCPC, MMH. University of Alberta Chronic Renal Failure Program, Alberta, Canada: Kathy Collinson, MD; Irene James, MSW, RSW. Albert Einstein Medical Center, Philadelphia, Pa: Kevin Hails, MD; Rasis Raja, MD; Marcia Gold-

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yte, RN, MSN. Baystate Medical Center, Springfield, Mass. Steven V. Fischel, MD, PhD; Coney Island Hospital, Brooklyn, NY: Norman Levy, MD.

We also thank Jenny Kitsen and Cindy Andrzejewski of the End-Stage Renal Disease Network of New England, which is funded by contract 500-97-E019 from the Health Care Financing Administration, as well as Neal Wenger, MD, for editorial assistance, and Peg Madden-Butorac for coordinating the study.

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