

# Withdrawal from Dialysis: The Literature, DOPPS, and Implications for Practice

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Summary: Withdrawal from dialysis is a common occurrence in the United States, although withdrawal rates vary throughout the world. DOPPS data focusing on withdrawal and the similarities and differences among various countries are reported. Literature related to withdrawal is explored and includes the decision-making process, the reasons underlying the decision, patient characteristics, and the dying experience. Finally, practice suggestions to enhance the delivery of care during the decision-making process and at end of life are offered.

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## **INTRODUCTION**

According to the U.S. Renal Data System (USRDS) 2005 Annual Data Report, there were 324,826 individuals receiving dialysis therapy in the United States at the conclusion of 2003. During that same year, slightly more than 100,000 new individuals began dialysis, while approximately 69,000 people who were on dialysis expired. Although there are a multitude of causes of death, 22% (14,352) resulted from dialysis withdrawal during 2001 to 2002. In addition, Tigert et al. (2005) reported that 56.6% of people on hemodialysis in their study had considered withdrawal at one time.

The number of patients who withdraw from dialysis in the United States is increasing. The USRDS 1996 Annual Data Report showed that 17.6% of dialysis deaths from 1991 to 1993 resulted from dialysis withdrawal, and that percentage has steadily increased over the past decade. This increase underscores the importance of understanding the factors associated with dialysis withdrawal. This knowledge will aid caregivers in assessing those at risk for treatment withdrawal and in assuring that those individuals receive compassionate, competent care both during the difficult decision-making process and at the end of their lives.

### **BACKGROUND**

There are existing legal and ethical principles that support a person's right to make a decision to withdraw medical treatment. The Renal Physicians Association (RPA) and American Society of Nephrology (ASN) document "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis" (2000) highlighted these principles: patient autonomy or self-determination, justice, beneficence, nonmaleficence, and the right to make an informed decision to refuse treatment. The Patient Self-Determination Act of 1990 established the legal right of competent individuals to determine their own health care decisions and to appoint a durable power of attorney for health care to make decisions for them if they are mentally unable to

do so. Although the number of Americans who have formally completed advance care planning documents is low (Emanuel et al., 1991; LaPuma et al., 1991), many individuals have exercised their right to make treatment decisions. McCloskey (1991) reported that the American Hospital Association estimated that approximately 70% of all deaths in the United States occurred as a result of withdrawal or withholding of medical treatment.

Neu and Kjellstrand (1986) reported that physicians were more likely to initiate the decision-making process that resulted in termination of dialysis for both competent and incompetent patients (66%) in the 1970s, whereas dialysis patients and/or their family members were more likely to initiate the process (70%) in the 1980s. This trend toward increased patient and family involvement has continued. Sekkarie and Moss (1998) documented that 63% of the subjects in their study had decision-making capacity and that only 14% of withdrawal discussions were initiated by the physician in such cases. However, when the person lacked capacity, these discussions were initiated by nephrologists 62% of the time.

A wealth of data (Kelner et al., 1993; Emanuel & Emanuel, 1992; LaPuma et al., 1993; Mower & Baraff, 1993) has documented that physicians do not routinely honor advance directive instructions. However, dialysis withdrawal appears to be an area in which physicians are more inclined to follow a patient's wishes, especially if the patient has decision-making capacity. Singer and the End-Stage Renal Disease Network (ESRD) of New England (1992) found that 88% of nephrologists in their study would respect a competent individual's request to withdraw from dialysis. Although 90% of these same physicians would honor family members' requests to withdraw dialysis from incapacitated patients if patients' wishes were clear, only 63% would do so if they were not. The RPA and ASN (2000) reported that nephrologists' decisions about treatment withdrawal were impacted by patient age, neurological status, comorbid conditions, physical functioning, and by fam-







ily request. Other factors that affected nephrologists' decisions to withdraw dialysis were medical benefit and quality of life (Rutecki et al., 1997).

According to Singer and the ESRD of New England (1991), nephrologists reported that social workers participated in the decision to withdraw from dialysis in 95% of withdrawal cases. They were the team member assessed as the most frequently involved, followed by the primary physician and primary nurse. Ethics committee consultation was sought in less than 15% of withdrawal situations. This may be attributable to the fact that freestanding dialysis facilities having minimal access to ethics committees.

Dialysis treatments may be withdrawn for a variety of reasons. The USRDS 2005 Annual Data Report lists failure to thrive, which typically includes symptoms of decline in function, depression, and/or dementia as the cause of 42.9% of withdrawals. This cause is followed by the categories of acute medical complications and "other."

An earlier study by Neu and Kjellstrand (1986) found that the mean duration of treatment prior to dialysis withdrawal was 30 months, with 10% of the study population withdrawing after 3 years and 3% withdrawing after 9 years. A later study by Cohen et al. (1995) documented that the mean duration of treatment prior to withdrawal for their dialysis population was 43.6 months. Leggat et al. (1997a) found that patient age may play a factor (i.e., patients 65 or older were more likely to withdraw from dialysis during their third month of treatment).

Multiple research studies have explored dialysis patient characteristics that are associated with withdrawal. Past research (Leggat et al., 1997a, 1997b) has shown that Caucasians are more likely to withdraw than other races, as are females versus males. While Cohen et al. (2002) reported that most individuals who elected to discontinue dialysis did not appear to be affected by major depression, McDade-Montez et al. (2006) found that depression was a highly predictive risk factor (P < 0.05). Bajwa et al. (1996) reported that those who were widowed or divorced were more likely to stop treatment than those who were married. Living situation may also be associated with withdrawal decisions; Sekkarie et al. (1998) found that patients who resided in nursing homes were more likely to withdraw from dialysis. Elderly patients, who may be more likely to lack significant others or to be nursing home residents, were also more likely to withdraw, according to Cohen et al. (2000). The mean age at time of withdrawal was approximately

74 (USRDS, 2005), with the withdrawal rate beginning to increase after age 50 (Leggat et al., 1997a). Bajwa et al. (1996) found that individuals with comorbidities were twice as likely to withdraw from dialysis. Diabetes was a comorbidity associated with withdrawal (Leggat et al., 1997a, 1997b). Terminally ill patients were also more likely to discontinue dialysis (Conneen et al., 1998). Leggat et al. (1997a) found that patients who had a chronic rather than an acute health problem were much more likely to withdraw from dialysis. They also reported that individuals dying of dementia were more than four times likely to discontinue dialysis than those dying of other causes. Research by Bajwa et al. (1996) documented that a low score on the Karnofsky Performance Scale, a staff-reported subjective assessment of patient physical functioning, and spending less time outdoors were additional factors associated with increased likelihood of dialysis withdrawal. It could be assumed that those who are depressed or have poor physical functioning may also be more likely to spend time indoors and be less active overall. Leggat et al. (1997a) found that individuals on hemodialysis who performed their own treatment either at home or in a facility had a 27% higher likelihood of withdrawing from dialysis than those who depended on staff for their treatment. Patients who performed any type of peritoneal dialysis were at no greater risk of withdrawal than those who dialyzed conventionally in a facility.

The USRDS 2005 Annual Data Report documented that, overall, individuals who withdrew from dialysis were more likely (49.2%) to expire in the hospital than at home (25.3%). Approximately 42% of those who withdrew used hospice prior to their death, with 10.1 mean days of hospice services. Patients who used hospice were twice as likely to die at home (45.3%) as in the hospital (22.5%), whereas 68.5% of patients who were not involved with hospice after withdrawal expired in the hospital.

If dialysis treatment had been terminated because of medical deterioration associated with a progressive, chronic disease, Cohen et al. (1995) found that a multidisciplinary team was more likely to view a patient's death as "good," as assessed by the length of the dying experience, the discomfort experienced during the dying process, and the patient's psychological and social situation. According to Cohen et al. (2000), patients and families characterized a good death as a short, pain-free, peaceful dying process. Of patients who died after stopping dialysis, 85% were evaluated as having had either a very good or good death. Families indicated that 81% of patients did not suffer in the last 24 hours of their







Withdrawal from Dialysis

lives. Although pain was identified as the most common symptom after dialysis withdrawal, it was assessed as being severe in only 5% of cases. Cohen et al. (1995) suggested that dialysis patients' dying experiences could be enhanced by decreased suffering and delirium and improved pain control if they were offered appropriate palliative care.

## DIALYSIS OUTCOMES PRACTICE PATTERNS STUDY (DOPPS) FINDINGS ON WITHDRAWAL

DOPPS is an international, longitudinal study that focuses on the impact of clinical practice patterns on hemodialysis patient outcomes (University Renal Research and Education Association, 2002). Phase I of DOPPS began in 1998 and involved seven countries: France, Germany, Italy, Japan, Spain, the United Kingdom, and the United States. In 2002, DOPPS was expanded and began data collection under Phase II in six additional countries: Australia, Belgium, Canada, New Zealand, and Sweden. DOPPS provides the opportunity to compare practice patterns, such as hemodialysis withdrawal rates, across countries. Termination of dialysis, compared with the other issues studied by DOPPS, may be particularly influenced by the cultural and religious values, beliefs, and practices of individual countries.

Fissell et al. (2005) conducted a study of 8,615 adult hemodialysis patients, representing 304 dialysis facilities, which were randomly selected from DOPPS I data. The number of hemodialysis treatment withdrawals per 100 patient-years of observation was used to determine withdrawal rates. The unadjusted rate of withdrawal was 1.9, with the Unites States reporting the highest rate and Germany and Italy having the lowest rates other than Japan, which reported no dialysis withdrawals. Approximately 79% of the study population expired within 10 days of terminating dialysis. The average person lived 7.8 days after withdrawal.

Those at higher risk of withdrawing were older and non-black (P < 0.0001 for each). Comorbidities that were associated with withdrawal were any type of cancer other than skin cancer, HIV/AIDS, coronary artery disease, cardiovascular disease, and psychiatric illness. There was a 9% lower adjusted risk of withdrawal from dialysis per 3-point higher score on both the physical and mental component summaries of health-related quality of life summary measures (P < 0.0001). Although not highly significant, individuals who had less than 12 years of education were more likely to withdraw from dialysis (P = 0.06). Patient living situation and income were not associated with an increased risk of withdrawal.

Of the 8,615 patients, 326 (38%) had a do not resuscitate (DNR) order. When patients had DNR orders, the relative risk of dialysis withdrawal was significantly higher than for individuals who did not have DNR orders (P < 0.001). Non-blacks and females were more likely to have DNR orders. Those with congestive heart failure, cardiovascular disease, and cancer other than skin cancer were also more likely to have DNR orders (P = 0.06). Patients with higher adjusted odds of having DNR orders resided in nursing homes rather than with friends or family (P = 0.003) and had incomes greater than \$75,000 (in U.S. currency; P = 0.06). Educational level was not associated with having a DNR order.

47

Another analysis using DOPPS II data by Kerr et al. (2005) found that Japan and Germany each had the lowest dialysis withdrawal rate (2 per 100 patient-years) compared with Belgium, which had the highest (9 per 100 patient-years). They found that being black, male, or having hypertension resulted in a reduced likelihood of withdrawal. Other factors that were not significantly associated with withdrawal were pulmonary disease, diabetes, coronary artery disease, cardiovascular disease, or reoccurring gangrene or cellulitis. Those significantly more likely to terminate dialysis were older, had congestive heart failure, peripheral vascular disease, cancer, HIV/AIDS, neurological disease, gastrointestinal bleeding, a recent reduction in serum albumin or psychiatric disease. Failure to thrive was the strongest predictor of withdrawal. The data also documented that new events such as being diagnosed with cancer or having a cerebral vascular accident or myocardial infarction predicted dialysis withdrawal.

Lambie et al. (2006) used DOPPS I data from 20 dialysis units in France, Italy, Spain and the United Kingdom, 21 units in Germany, and 141 units in the United States to study the associations between practice patterns relating to initiating and withdrawing dialysis and nephrologists' opinions and patient characteristics. They also conducted a subanalysis of data in DOPPS II from corresponding units. Medical director and nurse manager responses from questionnaires about their practice patterns were analyzed to obtain further information.

Nurse managers were less likely than physicians to encourage, assist, or allow patients to withdraw from dialysis. Not surprisingly, units had lower rates of withdrawal (0.8 per 100 patient-years) in which physicians did not encourage termination of dialysis than did those in which physicians encouraged or were neutral about withdrawal (1.4 per 100 patient-years). Similarly, if physicians agreed to allow patients to withdraw from dialysis at their request, there was a higher relative risk







of withdrawal than when physicians did not agree or were neutral about granting patient requests.

Nephrologists and nurse managers in the United Kingdom and the United States were significantly more likely to agree to patient withdrawal from treatment than were their counterparts in other countries. Physicians were also asked to respond to the statement, "We attempt to initiate dialysis on almost every patient with advanced renal failure, regardless of age, other medical problems, or degree of independence." The majority of physicians in the United Kingdom either strongly disagreed or disagreed with the statement and those in the United States responded neutrally, while the physicians in the other countries either agreed or strongly agreed.

Nephrologists in the United Kingdom, the United States, and France reported they were more likely to maintain a waiting list for patients to initiate dialysis, had delays in beginning hemodialysis, and were more likely to start patients on other treatment modalities such as peritoneal dialysis because hemodialysis units were at capacity. It was speculated that this may have influenced the willingness of U.K. and U.S. physicians to more readily consider withdrawal as an option.

Lopes et al. (2004) analyzed DOPPS II data from 12 countries for 9,382 people on hemodialysis specifically assessing associations correlated with depression. Although depression has been identified as the most common psychological problem experienced by individuals on hemodialysis, there is speculation that it may also be underdiagnosed and undertreated among this population. They found that physicians were more likely to diagnose depression in patients in Sweden, followed by the United States, with Japan having the lowest physician diagnosis rate. However, when patients completed the Center for Epidemiological Studies Depression (CES-D) screening index, 43% had scores of 10 or higher (indicating symptoms of depression) compared with 13.9% who had a physician diagnosis of depression. Using the scores from the CES-D, Japan's rate of depression was similar to the overall prevalence rate of 43%. Overall, females, unemployed individuals, those with lower levels of serum albumin, and patients with congestive heart failure, peripheral vascular disease, lung disease, neurological disease, or gastrointestinal bleeding were significantly more likely to be diagnosed as depressed, using both measures of depression. Antidepressants were more likely to be prescribed if physicians diagnosed the depression than when patients were diagnosed as depressed, according to their responses on the CES-D. Swedish patients (52.8%), followed by Canadian patients (44.1%), were

more likely to be prescribed antidepressants when physicians diagnosed the depression. Patients in the United States who scored 10 or higher on the CES-D (28.9%) were the most likely to be prescribed antidepressants, followed by Swedish patients (28.8%).

Even when adjusted for age, sex, socioeconomic factors, length of time on dialysis, and country, there was a 55% higher relative rate of dialysis withdrawal for patients who scored 10 or higher on the CES-D. When physicians diagnosed depression, there was also an independent and significant association with a higher relative risk of dialysis termination.

Kurella et al. (2006) analyzed DOPPS data from 16,694 people on hemodialysis in an attempt to determine correlates and outcomes of dementia. Four percent of their study population had been diagnosed as having dementia. Age, black race, low educational level, malnutrition, anemia, diabetes, and cardiovascular disease were all independent risk factors for dementia. Dementia was associated with an increased risk of both death and withdrawal from dialysis.

### IMPLICATIONS FOR PRACTICE

Treatment withdrawal has received considerable attention not only from the American public and general medical community but also within the field of chronic kidney disease. Documents on withdrawal from dialysis have been developed by the National Kidney Foundation (NKF), as well as by the RPA and ASN. Both documents are intended to provide guidance to dialysis professionals as they address the issue of treatment withdrawal with their patients and family members.

The NKF document "Initiation and Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team" (1996), is a consensus statement that was based primarily on expert opinion. It specifies that the patient's values, preferences, and goals should be major factors in deciding whether to terminate dialysis. The health care team should be involved in the decision-making process by offering medical, educational, and emotional support to patients (and their families or surrogates, if applicable). However, if individuals are competent to make their own health care decisions, the final decision about whether to terminate dialysis should ultimately be theirs.

When a patient expresses a desire to terminate dialysis, it is suggested that the health care team first assess whether the patient is competent to make the decision. If the patient is not competent and has a durable power of attorney for health care, that person is responsible







Withdrawal from Dialvsis

for the decision. If no one has been appointed to act in this capacity, the health care team has the responsibility to determine who has the legal right to act on behalf of the patient. Once competency has been determined, the document clarifies that the health care team's role is to assess the factors underlying the patient's or surrogate's decision to stop dialysis. If appropriate, interventions should be initiated to attempt to deal with the identified issues.

The document suggests that if there is disagreement or uncertainty about the benefits and burdens of dialysis, treatment should be continued for a 30-day period, at which time there should be re-evaluation of the situation by the health care team, including the patient or the surrogate as an active member. After the 30-day period, a recommendation should be presented to the patient or surrogate, with the final decision about whether to continue dialysis ultimately being his or hers. The document recognizes physician rights to refuse to provide treatment that is determined to be futile. However, mandatory withdrawal standards based on such factors as age, life expectancy, quality of life, or intellectual or physical functioning were rejected.

The guidelines specify that the health care team has continued responsibilities if patients elect to withdraw. Education about what to expect during the course of dying is imperative. In addition, the team must assure that bereavement counseling is offered. Where and how patients desire to die should be determined, with preferences honored when possible. The document also stresses that it is imperative that patients understand that the decision to terminate dialysis is reversible. It concludes by specifying that the facility should anticipate and address staff issues that may arise as a result of patient withdrawal from dialysis. These may include such feelings as anxiety, guilt, sadness, and grief.

The RPA/ASN document, "Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis" (2000), is a clinical practice guideline based on both a systematic literature review and expert opinion. Its ultimate goal is to promote shared decision-making in the patient-physician relationship around the issue of withdrawal from dialysis. Informed decisions and full disclosure are integral components of shared decision making.

This clinical practice guideline states that it is appropriate to withdraw dialysis from patients who have decision-making capacity, are informed, and make a voluntary choice. The importance of assessing patients for depression and other psychiatric problems during this process is stressed. Withdrawal is also appropriate

when a person no longer has capacity and has either indicated previously in an advance directive that dialysis should be stopped in this circumstance or when the person's legal agent requests dialysis termination. Finally, withdrawal is acceptable if a patient has irreversible, profound neurological impairment, lacking signs of thought, sensation, purposeful behavior, and awareness of self and the environment. These guidelines further elaborate that it is reasonable to consider withdrawal if a patient has a terminal illness due to a non-renal cause with a life expectancy of less than 6 months and is not a candidate for organ transplantation. Other reasons that withdrawal should be considered include: having medical conditions that interfere with the performance of dialysis; an irreversible inability to relate to others in a purposeful manner; significant, ongoing access problems; failure to thrive; and inability to cooperate with dialysis. There is clarification that nonadherence with the medical regimen is not a reason for staff to consider withdrawing dialysis.

As with the NKF document, the RPA/ASN guidelines also suggest a time-limited dialysis trial if there is uncertainty about the prognosis or if there is a lack of consensus on how to proceed. This trial of approximately 1 to 3 months may offer patients and their families an enhanced understanding of dialysis and its benefits or burdens. It may also provide the team with a more informed assessment of the likelihood of the benefits of dialysis outweighing its burdens for the individual. Ultimately, a trial period of dialysis can further promote shared decision making.

The document stresses that while palliative care should be offered to all patients throughout the course of their illness, everyone who withdraws from dialysis should be offered this type of care. It should include pain and other symptom management, attention to psychosocial and spiritual concerns, and identifying and addressing what matters most to the individual during the dying process. Bereavement support should also be made available.

Beyond these guideline documents, there are additional issues, such as when to discuss withdrawal from dialysis, that should be addressed. When individuals begin dialysis, they should be offered every treatment option—center and home hemodialysis, peritoneal dialysis, and kidney transplantation—for which they are medically suited. In addition, they should be offered the option of not beginning dialysis. They should be informed that even if they elect to initiate dialysis, the option of withdrawing from dialysis remains available to them at any time should they decide the burdens of





49



dialysis outweigh the benefits. Discussing withdrawal early on gives patients "permission" to discuss it with the health care team in the future should the need arise. In one study, 19% of patients were not aware they could terminate dialysis and 92% had never been approached about this issue by their nephrologists (Leggat et al., 1997b).

Social workers are often involved with patients who elect to withdraw from treatment. As a result, social workers, as well as all dialysis team members who deal with the issues of death and dying, must be aware of their own feelings and values related to patient withdrawal from dialysis and death. This awareness assists staff members in not transferring their values and beliefs about these subjects onto patients, and thus unduly influencing their decisions. If any staff members are unable to deal with patients around these issues in an objective, supportive manner, it is their responsibility to refer patients to others who are able to do so.

If a patient is contemplating termination of dialysis, one of the social worker's main roles is to conduct a thorough psychosocial assessment of factors underlying the consideration. Changes that have occurred in the patient's physical or mental health status, family situation, social or vocational environment, finances, or quality of life, as well as current stressors should be considered. Factors known to be associated with dialysis withdrawal should be assessed to determine whether they might be contributors to the specific patient situation. Although patients have a right to self-determination, they also have the right to be informed about interventions that may have an impact on their unique situation and, ultimately, their decision to withdraw from life-sustaining treatment.

Dialysis withdrawal should not automatically lead to the conclusion that a patient is depressed or suicidal, although the literature supports that depressed patients are more likely to withdraw from dialysis. If a patient is determined to be depressed, it is appropriate to discuss psychotherapy or antidepressant medications that may be beneficial. If unacceptably decreased physical functioning or increasing dependence is contributing to a patient's decision to terminate dialysis treatment, an intervention such as physical and/or occupational therapy may be appropriate. Because individuals who have reduced social support, such as those who are widowed or divorced, are more likely to withdraw, attempts to expand their support network through extended family, friends, support groups, or other activities may be beneficial.

Just as patients have a right to learn of possible therapeutic interventions that might affect their decisions about withdrawal, they also have a right to have accurate information upon which to base their decision. Patients may struggle with whether terminating a life-saving treatment such as dialysis is considered suicide. Approximately 12% of dialysis patients in the study by Cohen et al. (2002) were either uncertain or believed that stopping dialysis equated with suicide. Although this decision must be made by the individual, it may assist the patient to know that according to the NKF (1996) document, Western ethical and most religious traditions recognize a person's right to terminate heroic or aggressive medical treatment that delays the dying process. Staff should also be prepared to provide information on such issues as whether patients should continue with dietary, fluid and medication regimens, if death after withdrawal is painful, and regarding life expectancy without dialysis treatment. Typically, patients are advised to avoid fluid overload that could lead to pulmonary distress. In their study, Cohen et al. (2000) found that nonpalliative, unnecessary medications and laboratory tests were stopped for most patients who decided to terminate dialysis. The same study reported that 85% of deceased dialysis patients' families rated the dying experience of patients who had withdrawn from dialysis as either very good or good, with a "good" death being described as having no pain, being at peace, and of short duration. Death from dialysis termination also typically involves an increased lack of consciousness due to uremia. Sekkarie et al. (1998) reported that the mean number of days post-withdrawal from dialysis until the time of death in their study was 12 days, while others (Cohen et al., 2000) found that the mean rate was 8.2 days. It is important for patients to be aware of the average length of survival after stopping dialysis to allow them to appropriately plan for their final days.

The NKF guidelines state that patients and their families should have assistance in preparing for death after dialysis withdrawal. Social workers can play an important role in this preparation. It should be suggested to patients that completing both a living will and appointing a durable power of attorney for health care, if they have not already done so, may help assure that their final wishes are carried out. Patients should also be encouraged to complete a will for distribution of their financial assets and personal items. If appropriate, organ and tissue donation should be explored. Patients should be asked if they desire support from a religious or spiritual advisor during this time. The idea of making an audio or videotape or writing letters to family







Withdrawal from Dialysis



and friends to allow for expression of their feelings and sharing their thoughts should be suggested. It is also important to determine where and how patients desire to die. The social worker may assist by arranging medical equipment, home health care, and/or hospice services, if appropriate. Hospice services are underutilized by dialysis patients, as the USRDS 2005 Annual Data Report points out. Only 41.9% of those who withdrew from dialysis had hospice care during 2001 to 2002. Additionally, family members need to be informed in advance about the protocol to follow if patients expire at home. Patients may also want to consider their preferences for a funeral or memorial service.

It is important for dialysis staff to realize the important role they have played in the lives of their patients and family members and understand that it is crucial that they not abandon them during this critical period. Although patients will no longer be receiving dialysis treatment at the facility, the social worker and other staff who have played major roles in providing care should maintain contact with both patients and their families during the dying process to offer them the opportunity to deal with unfinished issues, have questions answered, and either provide counseling or refer them to counseling resources. Families should also be informed of bereavement support that is available after patients expire. The social worker should consider contacting family members to offer support at certain times, such as the 6-month or 1-year anniversary of the death.

Any patient death has an emotional impact on the staff and other patients in the dialysis unit. This is especially true when the death is due to dialysis withdrawal. Staff may express ambivalence, guilt, anger, or sadness. Fellow patients may feel depressed or vulnerable. Social workers can play significant roles in offering support to staff during patients' decision-making processes, as well as to both staff and patients who have been impacted by the withdrawal from treatment and the ensuing death. The Kidney End-of Life Coalition (Mid-Atlantic Renal Coalition) offers suggestions to facilitate the patient and staff grieving process that include devoting a portion of staff meetings for discussion of patient deaths; posting obituaries or funeral or memorial notices once they have become public; maintaining a journal for staff to share their feelings about expired patients; providing a sympathy card for the patient's family that staff, patients, and their family members can sign; and holding annual nondenominational memorial services that staff, patients, and families can attend.

#### **CONCLUSION**

Not only do people on dialysis have a right to know they can terminate dialysis treatment at any time, they and their families also deserve information, support, and counsel if they face such a decision. If the decision to withdraw from dialysis is made, they have a further right to expect that they will not be abandoned and will receive quality care at the end of their lives. Social workers are not only uniquely trained to play an integral role in each of these areas, it is their professional obligation to do so.

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53



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