THE RENAL PALLIATIVE CARE INITIATIVE

DAVID M. POPPEL, M.D., LEWIS M. COHEN, M.D., and MICHAEL J. GERMAIN, M.D.

ABSTRACT

Despite ongoing technological advances, patients with end-stage renal disease (ESRD) have a mortality rate of approximately 23% per year, and comorbid cardiovascular, cerebrovascular, and peripheral vascular disorders often make life on dialysis an ordeal. This patient population needs an improved approach to symptom assessment and control, as well as advance care planning and high-quality palliative care. Families need support during the lifetime and after the death of their loved ones. To address these needs, the Renal Palliative Care Initiative (RPCI) was instituted at Baystate Medical Center, a large tertiary care hospital, and at eight dialysis clinics in the Connecticut River Valley. With the cooperation of a large nephrology practice, the Western New England Renal and Transplant Associates, a core group of physicians, nurses, and social workers were trained in palliative medicine, and charged with the goals of developing and implementing innovative interventions. The RPCI’s programs include symptom management protocols, advance care planning, and bereavement services for families and staff. The Initiative is increasing completion of formal advance directives by the patient population, while staff and families are particularly pleased with annual renal memorial services. The RPCI experience has much to offer the practice of nephrology, and it is relevant to ongoing efforts to extend palliative medicine beyond the traditional focus on cancer and AIDS.

BACKGROUND

For many years, nephrologists and the renal care community focused their attention primarily on the creation of sophisticated technology to extend life in the face of end-stage renal disease (ESRD). Such an approach has had considerable success but it has also tended to direct attention away from the physical, emotional, and spiritual suffering that complicates the lives of many of these patients and their families. It has deprived them of palliative interventions that have the potential to alleviate distress and to improve quality of life. The Renal Palliative Care Initiative (RPCI) was instituted to address the integration of palliative medicine into the practice of nephrology.

The RPCI developed from a set of descriptive studies done in the early 1990s at Baystate Medical Center. These studies prospectively examined the clinical experience of patients who discontinued dialysis. Retrospective studies had suggested that an increasing number of dialysis patients were making this choice, and between 1990 and 1995, more than 20,000 deaths in the United States were preceded by dialysis termination. In 2000, data from New England clinics found that 28% of patient deaths from ESRD were preceded by decisions to stop dialysis.

The Baystate investigators reported that 75% of a sample of patients from eight dialysis clinics in the United States and Canada were quite ill, with between three and seven comorbid conditions, half of the subjects experienced inanition or fail-
ure-to-thrive, and many patients had neuropathies (34%), blindness (18%), gastroparesis (14%), and malignancies (12%).

Forty-eight hours after withdrawal from dialysis, less than half the sample was alert and approximately 10% were in comas. Families reported that terminal care was satisfactory for most subjects (85%), but that pain (42%) and agitation (30%) were common during the final day of life.

Additional studies were conducted with patients who had not terminated dialysis, but were receiving technically adequate dialysis treatments. Patients maintained with dialysis were found to experience a wide variety of chronic and, at times, disabling conditions. These included: fatigue (41%), insomnia (38%), cramping (36%), pruritus (35%), neuropathy (29%), poor spirits (24%), and nausea and vomiting (20%).

Cardiomyopathy, congestive heart failure, progressive blindness from diabetes, and peripheral vascular disease leading to amputations, were common complications facing the population with ESRD. Recognition of the suffering, added to revelations concerning symptoms in the terminal hours of the subgroup of patients who discontinued treatment, prompted the investigators of these epidemiologic studies to develop and propose a demonstration project, the RPCI. The overarching goal of the RPCI has been to integrate palliative medicine into the care of all patients with ESRD.

THE RPCI POPULATION AND INTERVENTIONS

Approximately 80,000 Americans develop ESRD each year, and approximately 300,000 people currently receive maintenance dialysis in the United States. More than 40% of the prevalent population has diabetes, while other comorbid conditions include congestive heart failure (34%), coronary artery disease (25%), peripheral vascular disease (15%), and cerebrovascular disease (10%). The annual mortality rate of dialysis patients in the United States is approximately 23%, with cardiovascular disease responsible for approximately half the deaths. Despite improved technology in dialysis care, 5-year survival remains low. Only 29% of the 1990 cohort of patients were alive after 1995. Despite technically “adequate” control of uremia, the life expectancy for dialysis patients is markedly diminished and remains between 16% and 37% that of age and sex matched controls.

The RPCI is a collaboration between eight dialysis clinics and Baystate Medical Center, the largest tertiary care hospital in western New England. The geographic area served extends along the Connecticut River Valley from southern New Hampshire and Vermont, through western Massachusetts and into northwest Connecticut. It includes both urban and rural areas, and has considerable racial and ethnic diversity. The dialysis units are directed by a large, private nephrology physician and mid-level practitioner group, the Western New England Renal and Transplant Associates (WNERTA). All of the facilities are owned and operated by Fresenius Medical Care, Inc., a publicly traded, for-profit corporation. The dialysis clinics range in size, some having 6 or 7 “stations,” while others have up to 30. Baystate Medical Center has a dedicated renal unit, an entire floor where hospitalized dialysis and transplant patients are located, and a nursing staff skilled in the care of ESRD. Baystate Health System also includes a hospice care program, and there are several other hospitals and hospices in the region that are available to provide service to the population. Approximately 650 patients annually receive long-term dialysis care in the outpatient dialysis units; approximately 90% undergo in-center hemodialysis, and approximately 10% are maintained with home peritoneal dialysis.

Dr. Lewis Cohen, a psychiatrist at Baystate, has been instrumental in organizing and directing the Initiative. Volunteers from the existing staffs of Baystate, WNERTA and Fresenius Medical Care were organized into a core RPCI team. This core team comprised nephrologists, nurses, and social workers, each discipline represented by three members. Team members were encouraged to develop and refine ideas for appropriate interventions (Table 1), and to guide their application into the dialysis, transplantation, and hospital settings. During the first year of the program, the RPCI team underwent didactic training from a palliative care physician and nurse. In subsequent years the educational efforts were directed toward all of the dialysis and transplant staff.

Symptom assessment and treatment protocols

A renal symptom assessment tool was developed to allow for evaluation of patients’ symp-
toms, as well as monitoring the success of interventions meant to control or eliminate symptoms. In view of the unique profile of symptoms prevalent in the population with ESRD, the symptom assessment tools already available for patients with cancer and for patients with acquired immune deficiency syndrome (AIDS) were judged to be inadequate, and the RPCI group has been developing a new instrument. It was hoped that the assessment tool and protocols would become part of routine care, along with those established protocols that address adequacy of dialysis and metabolic control.

After review of the medical literature, treatment guidelines to address common ESRD symptoms, such as pruritus, insomnia, pain, and fatigue were crafted by the team. The guidelines have been distributed to the clinic nursing stations and are available as a resource for all rounding nephrologists, nurse practitioners, and nurses.

Renal morbidity and mortality conferences: continuing education and quality improvement

Borrowing and modifying an idea from surgery, a formal morbidity and mortality (M&M) review process was designed to focus on issues relevant to palliative and end-of-life care. The M&M conference fits within the existing framework of monthly team meetings in the dialysis units, during which patient care and other issues relevant to quality improvement are routinely discussed by the clinical staff. To assist in preparation for the M&M conferences, a data collector conducted chart reviews in the dialysis units, hospitals, and nursing homes. This provided details of the clinical course leading up to death. It was supplemented by further information obtained through a family post-death questionnaire. This tool was sent to loved ones approximately 6 weeks after the death of the patient. The M&M conference allowed further input from members of the care team, emphasizing advance care planning, control of pain and other symptoms, and review of the overall character of the patient’s last days and hours. It is to be hoped that review of adverse outcomes in this educational and quality improvement context will increase staff sensitivity to palliative care. Presently, more than 320 patient deaths have been reviewed using an M&M quality of dying tool. A physician reviewer has scored the characteristics of each death, including domains of pain and other symptoms, level of advance care planning, involvement of family and additional support systems, and the duration of dying.

Bereavement support

It has been our observation that contact by the renal care team with a patient’s family often ceases abruptly after the patient dies. Staff and fellow patients are often left unsure as to whether individuals have died or merely moved to another shift. Consequently the first step taken by the RPCI was to discuss ways in which individual clinics can acknowledge deaths. These practices vary and have included notices in the waiting room, posting obituaries, and placement of a ritual flower arrangement and card by the nursing station.

The second approach to bereavement involved initiating annual renal memorial services, modeled after those that are commonly held in hospices. An organizing committee was created to plan and prepare annual services. The committee is composed of social workers, nurses, dietitians, clergy, and family members. Names of the deceased are read during a candle-lighting ceremony, and the services also include brief speeches, poems, and inspirational readings. Musical interludes are provided by local musicians, and the services are designed to bring together the community in an ecumenical celebration of life.

Advance care planning

The level of symptoms, comorbidities, and risk of dying in patients with ESRD mandates advance care planning. It is apparent that many patients and families have not been addressing these issues, and the RPCI team has been seeking ways to increase awareness of staff, patients, and families to the importance of advance directives. The Five Wishes™ format (www.agingwithdignity.org) has been selected for use in the dialysis units. An educational video is periodi-
cally played over the dialysis unit televisions for patients. The medical staff, physicians, nurse practitioners, and nurses encourage advance care planning with patients and families, and the Five Wishes document is being incorporated into medical records.

**Collaboration with area hospices**

Hospices are involved in less than 10% of patient deaths. Accordingly, an RPCI task force has been trying to increase awareness and access to area hospices. At the request of the RPCI team, the director of one of the area hospice programs called on representatives from all of the other community hospices to develop a plan for educating the dialysis staff concerning hospice admission criteria and also informing hospice staff about the care of ESRD patients. Medicare guidelines for admission to hospice care have been summarized and communicated to WNERTA physicians and dialysis clinics staff. A hospice director is now a regular participant in all meetings of the RPCI planning team. These efforts are intended to create a better understanding of services offered by hospice and the referral process. Reasonable goals are being set to increase referrals by 10% and to have all patients who discontinue dialysis offered hospice services.

**Spiritual care**

The RPCI is appreciative of the spiritual needs of patients and their families. Chaplains are increasingly involved in meetings, and the team has been exploring ways to increase the presence of spiritual counselors in the dialysis units. Chaplains are closely involved in the preparation and content of the memorial services.

**RESULTS**

Perhaps the greatest success of the RPCI thus far is having helped stimulate interest on the part of the nephrology community to integrate palliative medicine. In our dialysis units and hospitals the vocabulary of advance care planning, symptom assessment and treatment, and hospice care have all become a definite part of “business as usual.” This was certainly not the case prior to the inception of the RPCI. Nephrologists and nurses have become much more adept in the control of pain and suffering, and find themselves more comfortable with discussions of dialysis withdrawal and care for dying patients. End-of-life care is a constant and high priority agenda item at monthly interdisciplinary dialysis unit team meetings. There has been an evolution in the attitude of staff, their sensitivities to palliative care related issues, and, most importantly of all, a programmatic change in the practices of the dialysis units and the care teams. For example, before the RPCI introduced symptom assessment tools and treatment protocols, attention to patients’ symptoms was somewhat haphazard and idiosyncratic. Access to evidence-based protocols of care has offered the potential to facilitate acute relief of symptoms and to provide treatment on a consistent basis.

There has been a considerable shift in quality improvement. The impact has not been quantified, but is nevertheless apparent. In particular, we have seen expansion of outcome assessment and quality improvement beyond the traditional viewpoint of interdisciplinary team meetings that once focused primarily, if not exclusively, on adequacy of dialysis, control of anemia and hyperparathyroidism and other medical issues, to now include symptom control, palliative care, and end-of-life issues. Staff at the dialysis facilities have become sensitized to the issues of palliative medicine and conversant in the techniques. A 2-year review of more than 300 deaths at team meetings is testimony to the dimensions of this “routine” and the manner in which the focus of clinical practice has been expanded.

Additional evidence of the success and value of the initiative is the increasing number of invitations received by members of the RPCI to make presentations at national and international meetings and to write articles and book chapters. Members of the RPCI are actively involved in a Robert Wood Johnson Foundation national work group to develop educational materials and standards of palliative care for ESRD. Other indicators and results are listed in Table 2.

**CONCLUSIONS**

A few lessons may be derived from the RPCI experience. It is desirable to use existing staff in the organization and implementation of new programs. Because the medical staff (nephrologists and nurse practitioners) direct patient care, their
involvement in the integration of palliative care into the routine of the units is absolutely crucial. The whole-hearted support of the unit medical directors is necessary before interest in palliative medicine interventions can spread throughout the entire staff. The RPCI has been most fortunate in having had this support for the past 3 years, and the core team has “passed along” its knowledge of palliative care to the other nephrologists, and to the directors of nursing and charge nurses at the dialysis facilities.

Education is a wonderful stimulus for medical staff, and an event as simple as a conference at which modalities of pain control are discussed may lead to important changes in practice. This is especially so when combined with emotionally rich experiences, such as the renal memorial services. A list has been generated of 20 dialysis facilities from around the country that are requesting RPCI assistance to help them establish services of remembrance. These clinics will hopefully form the nucleus of a national dissemination program.

Developing strategies to heighten awareness of the protection afforded to patients and families by advance care planning will be crucial to the future success of renal palliative care programs. Nephrologists, mid-level practitioners, and social workers must find time in their already demanding schedules to incorporate discussions of advance care planning with patients and families. Clinicians must be trained in the vocabulary of presenting in a sensitive, yet realistic fashion, the implications of ESRD as a life-limiting disease.

New directions in patient education need to be developed, and these may include Web-based programs of patient and family self-education. An additional strategy may be to develop teams of peer counselors and use their perspectives as active or former dialysis patients to help individuals better address advance care planning.

A number of papers are being written by RPCI staff. One will deal with the results of the post-death family questionnaires, while another will look at the quality of death indicators reviewed in the M&M conferences. The RPCI core group is in the process of seeking further funding for investigations based on the interventions, and it intends to conduct an analysis of the role of depression in decisions to discontinue dialysis.

Last, this is a highly symptomatic patient population, and one that has a high mortality rate. Patients and their families are beginning to expect improved symptom management and more attention to the quality of care at the end-of-life. We firmly believe that the field of nephrology is poised to integrate the innovations of palliative medicine. We are hopeful that renal palliative care will continue to evolve, and that the work begun in this demonstration project will become an ordinary part of dialysis and transplantation.

**Table 2. Indicators and Findings**

| In 1994–1995, 6% (n = 121) of our dialysis clinic population had completed an advance directive.\(^a\) In 2001, an RPCI interview study found that 32% of patients now report having health care proxies, and 21% living wills (n = 618). This is well above the national average. The 16 program nephrologists and surgeons were surveyed about the effect on various RPCI interventions on their practices. The didactic course and bereavement memorial service were endorsed as being most helpful. Memorial service feedback surveys are overwhelmingly positive. Attendance has ranged between 40 and 180 people, depending on the location and number of clinics included. In the 3 months after initiation of the RPCI-hospice task force there were seven patients referred to the Visiting Nurse Association & Hospice; this equaled the total for the previous year. Renewed efforts to uncover barriers and devise solutions to increase these referrals are being conducted. With the cooperation of the ESRD Network of New England, the RPCI is following potential changes in the population’s mortality and dialysis discontinuation rates. As anticipated, there are no significant deviations. Interventions that are mainly aimed at end-of-life issues would not predictably alter factors measured by quality of life tools. A baseline quality of life battery (including the SF-36 and the Missoula Vitas QOL) completed by 618 patients showed no significant differences in quality of life between the program population and patients treated at a control clinic (Berkshire Medical Center). Quality of dying forms have been collected for 319 deaths, and are reviewed at morbidity & mortality meetings. The measure has been published,\(^b\) and data are currently being analyzed. Postdeath questionnaires have been completed by 86 families, in order to elicit their perspective on end-of-life care. Among other findings, respondents found staff to be sensitive to spiritual/religious (73.2%) and to cultural/ethnic (73.8%) concerns.


REFERENCES


Address reprint request to:
David M. Poppel, M.D.
Western Massachusetts Kidney Center
2000 Main Street
Springfield, MA 01103

E-mail: dmpoppel@yahoo.com
This article has been cited by:


3. Fliss E.M. Murtagh, Irene J. Higginson. 2007. Death from Renal Failure Eighty Years On: How Far Have We Come?. *Journal of Palliative Medicine* **10**:6, 1236-1238. [Citation] [PDF] [PDF Plus]


