



**END-STAGE
RENAL DISEASE
WORKGROUP
FULL REPORT**

Recommendations to the Field

PROMOTING EXCELLENCE IN END-OF-LIFE CARE
A NATIONAL PROGRAM OFFICE OF
THE ROBERT WOOD JOHNSON FOUNDATION

Completing the Picture of Excellence

In 1997, The Robert Wood Johnson Foundation launched a national program *Promoting Excellence in End-of-Life Care* with a mission of improving care and quality of life for dying Americans and their families. We soon realized that the metaphor of a jigsaw puzzle seemed apt in describing our efforts to expand access to services and improve quality of care in a wide range of settings and with diverse populations. No single approach would suffice—a variety of strategies, models of care, and stakeholders are necessary to successfully complete the picture. This monograph represents one aspect of our work and one piece of the puzzle of ensuring that the highest quality of care, including palliative care, is available to all seriously ill patients and their families.

Acknowledgements

This publication was produced by *Promoting Excellence in End-of-Life Care*, a National Program Office of The Robert Wood Johnson Foundation, directed by Ira Byock, MD.

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A special thanks to Zandra Dillon for her invaluable assistance with conducting background research, compiling the bibliography, and providing support to Workgroup members; and to Susan Jo Bumagin, Workgroup Director, for her assistance in editing this report.

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Overview of Promoting Excellence Workgroups

In 1997, a national program of The Robert Wood Johnson Foundation, *Promoting Excellence in End-of-Life Care*, received 678 Letters of Intent in response to a Call for Proposals for fewer than 25 grants. To tap this tremendous outpouring of interest and enthusiasm for extending palliative care to diverse patient populations, the *Promoting Excellence* team created a National Learning Community composed of peer workgroups. These workgroups have gathered clinicians and researchers who are working to extend palliative care to special populations of patients in various niches of medicine.

The *Promoting Excellence* team looked for realms of health care that manifested a critical patient need and openness to implementing palliative care strategies. Key stakeholder groups - including professional associations, thought leaders, and the best clinician-researchers in each field - were invited to participate.

Each workgroup was asked to assess the existing evidence base; to identify resources, gaps, and products for the field; and to develop a Research and Development Agenda. The *Promoting Excellence* theory was that recommendations developed by such workgroups, acting in good faith on behalf of their professions and patients, would have strong credibility and a good chance of implementation nationwide. Such recommendations could give policy makers and health system planners a road map for substantive change. In addition to the End-Stage Renal Disease (ESRD) Workgroup, seven others were created to include: The Children's International Project on Palliative/Hospice Services (ChIPPS); Critical Care; Amyotrophic Lateral Sclerosis (ALS); Cost Accounting; Surgeons Palliative Care; HIV/AIDS; and Huntington's Disease. While some workgroups have completed their work, other groups plan to carry forward work begun under the auspices of the *Promoting Excellence* Program.

The ESRD Workgroup was chaired by Alvin H. Moss, MD, Director of the West Virginia University Center for Health Ethics and Law and a nephrologist at West Virginia University School of Medicine. The workgroup consisted of 23 members, including nine nephrologists, four nephrology nurses, three nephrology social workers, three palliative care physicians, two end-stage renal disease (ESRD) patients (one of whom is an attorney), one ESRD network executive director, one dialysis unit administrator, and one renal dietitian (see Appendix A, also available at www.promotingexcellence.org). Meeting from March 2000 to October 2001, the workgroup completed its charge and made considerable progress in bringing palliative care issues to the attention of the nephrology community. For example, the Chair of the American Board of Internal Medicine Subspecialty Board on Nephrology invited the group to submit questions on end-of-life care for the board certification examination. For the first time, five items with palliative and end-of-life care content are included in the 2002 examination. In addition, the Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) revised their joint position statement on *Quality Care at the End of Life*, building upon resources from the ESRD Workgroup and encompassing salient workgroup recommendations.

Key accomplishments of the *Promoting Excellence* ESRD Workgroup include:

- Establishing an initial evidence base of dialysis patient and family experience;
- Expanding clinical resources available to nephrologists and dialysis clinical staff; and
- Making recommendations to correct identified deficiencies and rapidly advance the integration of palliative care within dialysis practice.

Introduction

This report describes the need for palliative care in the ESRD population and presents the methods, findings, recommendations, and products of the *Promoting Excellence* ESRD Workgroup.

Most patients with end-stage renal disease, especially those who are not candidates for renal transplantation, have a significantly shortened life expectancy. In the United States, dialysis patients live about one-third as long as non-dialysis patients of the same age and gender. The unadjusted five-year probability of survival for all incident ESRD patients on dialysis is only 39%; and for the 48% of incident ESRD patients who are 65 years of age or older, it is only 18%. Forty-five percent of new ESRD patients have diabetes. Life expectancy is also shortened by comorbid conditions, including hypertension, congestive heart failure, ischemic heart disease, and peripheral vascular disease.

According to the United States Renal Data System (USRDS) 2001 Report, over 65,000 ESRD patients die each year. The unadjusted annual death rate for ESRD patients in recent years has ranged between 20 and 22%. For some 20% of these patients, death comes after a decision to discontinue dialysis. An increasing number of patients who initiate renal replacement therapy are elderly. Based on data from the USRDS for 1993 to 1998, the highest incident treatment rates were for patients 65 years and older, with the very highest rates for patients 75-79 and 80-84 years old. Older patients have the most comorbid conditions and are at the greatest risk for developing illnesses during their subsequent course on dialysis. Older patients are also the most likely to stop dialysis.

It is clear from the foregoing information that the care of ESRD patients requires expertise not only in the medical and technical aspects of maintaining patients on dialysis, but also in palliative care - encompassing pain and symptom management, advance care planning, and attention to ethical, psychosocial, and spiritual issues related to starting, continuing, withholding, and stopping dialysis.

At its first meeting on March 27-28, 2000, the ESRD Peer Workgroup divided into three subgroups: quality of life, quality of dying, and education.

The Quality of Life (QOL) subgroup addressed the burdens ESRD patients face in living with a grave, life-shortening chronic illness while also taking advantage of the life-sustaining technology of dialysis. Discordance lies at the heart of ESRD patients' struggle for quality of life. On the one hand, dialysis creates hopeful expectations in them, their families, and their caregivers. On the other hand, at least initially, patients and families may not grasp that comorbidities and reduced life expectancy are a common aspect of ESRD. Clinicians may not have been candid about the life-limiting nature of the disease and accompanying comorbid conditions.

The Quality of Dying subgroup was created because anecdotal information and several studies suggest that the quality of the experience of dying could be enhanced for dialysis patients. Although there is a paucity of literature addressing this topic, both anecdotes and studies point to the following factors as possible contributors: inadequate treatment of pain and other symptoms; emotional stress on patient and family; insufficient attention to family dynamics, patient/family education about end-of-life care and advance care planning; and failure to address issues of religion, race, and cultural diversity as they relate to life completion and closure. The subgroup sought to better understand (1) the dimensions of quality with respect to dying, as perceived by ESRD patients, families, and caregivers; (2) the obstacles to quality; and (3) interventions that could significantly improve end-of-life care for people with ESRD.

The Education subgroup reflected the workgroup's belief that lack of knowledge about palliative care is a key barrier to change in the dialysis community. Knowledge about palliative care is perceived to be very limited among nephrologists, trainees, and dialysis staff as well as patients and their families. Beyond a lack of specific knowledge, an apparent culture of "death denial" in dialysis units needs to be addressed.

Methodology and Findings

Quality of Life Subgroup

(See Appendix B, also available at www.promotingexcellence.org for a more complete discussion and products.)

The methodology used by the Quality of Life subgroup had four components:

1. A systematic search of the medical literature on quality of life in ESRD patients;
2. Consultation with experts in research design and quality of life assessment in patients with chronic illness;
3. Discussions about assessment of quality of life in dialysis patients among members of the workgroup, and the development of an instrument to measure the quality of life of ESRD patients; and
4. Testing of a quality of life measurement instrument that explicitly addresses the psychosocial and spiritual concerns of ESRD patients.

The findings of the Quality of Life subgroup were as follows:

1. Quality of life instruments commonly in use to assess ESRD patient quality of life (e.g., SF-36 and Karnofsky Performance Scale) place considerable emphasis on physical, functional, and emotional status. Less emphasis is given to patient satisfaction and the assessment of social status and support. Very little, if any, attention is given to existential or spiritual concerns. The quality of life instruments in use are largely objective and provide little information regarding the patient's perception of his/her quality of life.
2. No accepted instrument exists for assessing spiritual concerns as they relate to quality.
3. A modified quality of life instrument for ESRD patients that measures psychosocial status, support, and spiritual domains as well as dissatisfaction with aspects of quality of life could prove beneficial in treatment and could potentially result in a reduction of the number of patients who withdraw from dialysis.

Quality of Dying Subgroup

(See Appendix C, also available at www.promotingexcellence.org for a more complete discussion and products.)

The methodology of the Quality of Dying subgroup had four components:

1. A systematic search of the medical literature on the dying experiences of ESRD patients;
2. Discussions among members of the subgroup about the need to learn about the experiences of ESRD patients and families with respect to dying;
3. An evaluation of the policies of major dialysis corporations of respect for the wishes of dialysis patients who choose not to undergo cardiopulmonary resuscitation; and
4. A review of the informational materials that hospice programs provide to patients and families; and plans to adapt these to the specifics of terminal stages of life for ESRD patients.

The findings of the Quality of Dying subgroup were as follows:

1. The available literature on the quality of the end-of-life experience and care for ESRD patients is inadequate, particularly from the perspectives of patients and families.
2. Dialysis corporations have no consistent policy to honor the preferences of dialysis patients who do not want to undergo cardiopulmonary resuscitation. More worrisome, the policies of many dialysis units are either unclear on this point or prohibit honoring a legitimate Do Not Resuscitate (DNR) directive from an ESRD patient.
3. There is a pervasive lack of correct information concerning the process of dying. This lack of correct information creates a significant obstacle to optimum end-of-life care and decision-making for ESRD patients and their families.

Education Subgroup

(See Appendix D, also available at www.promotingexcellence.org for a more complete discussion and products.)

The Education subgroup used the following methods to assess the current state of knowledge of renal palliative care among those in the nephrology community:

1. A review of the literature, including identification of articles, book chapters, and the extensive evidence-based literature search by the RPA/ASN Committee that drafted the Clinical Practice Guideline “Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis”;
2. Consensus in the group about the nephrology community’s limited knowledge of palliative care; and
3. Informal surveys of nephrology colleagues and nephrology training programs.

The Education subgroup found the following:

1. There are no ESRD-specific books or chapters on palliative care.
2. A gap in the curriculum for nephrology training programs has resulted in significant gaps in nephrologists’ knowledge, attitudes, and practice skills relating to renal palliative/supportive care. Although the major nephrology societies have recently

begun to address these issues through symposia (see Appendix D, also available at www.promotingexcellence.org) and evidence-based guidelines (i.e., RPA/ASN Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis Clinical Practice Guideline, Feb. 2000), nephrology fellowship programs generally fail to include renal palliative/supportive care in their curricula.

3. A culture of death denial prevails in dialysis units among nephrologists, staff, patients, and families.
4. The American Medical Association Education for Physicians on End-of-Life Care (EPEC) program is partially relevant to ESRD but more focused on cancer patients. The ESRD population is specialized enough that a modification of the EPEC program is needed. The subgroup named this specialized training for nephrologists, Education for Nephrologists in End-of-Life Care (ENEC).

The subgroup identified a target audience for educational interventions regarding ESRD patient end-of-life care composed of the following:

- a) Nephrologists
- b) Nephrology fellows
- c) Government agencies responsible for ESRD, including the Centers for Medicare and Medicaid Services
- d) Corporations owning multiple dialysis units
- e) Patients and families, and
- f) Dialysis nurses, social workers, dietitians, and other dialysis staff and trainees.

Recommendations to the Field

The ESRD Workgroup has endorsed these recommendations. Each subgroup prepared recommendations that were reviewed by the entire workgroup. In some cases, the recommendations were accepted as is. In most cases the workgroup revised the recommendations.

Centers for Medicare and Medicaid Services (CMS)

The *Promoting Excellence* ESRD Workgroup asks CMS to:

- Update the "Conditions of Participation" for dialysis units to include requirements for advance care planning and the provision of palliative care.
- Collect data on hospice utilization on the 2746 form.
- Allow application of the Medicare hospice benefit to ESRD patients who are certified by their physicians as terminally ill but choose to continue dialysis until they die.
- Work in conjunction with hospice and the ESRD Networks to develop manuals and training for clinicians regarding coordination and linkage of dialysis and hospice care for ESRD patients.

- Require dialysis unit staffing to provide reasonable time for social workers to counsel patients on psychosocial issues surrounding end-of-life care. At present, social workers are not using their professional skills for psychosocial support of patients because they are given other roles such as arranging patient transportation. Others might perform these functions.

National Institute of Health, National Institute of Diabetes and Digestive and Kidney Diseases

The National Institute of Health and National Institute of Diabetes and Digestive and Kidney Diseases are asked to make the following adjustments to USRDS annual reports:

- Provide more data on patient survival, including Kaplan-Meier estimates of patient survival based on ESRD diagnosis, patient age at starting dialysis, and comorbid conditions.
- Expand data regarding ages and comorbidities of patients who are withdrawn from dialysis.
- Report data on hospice utilization and identify regional differences.

Nephrology Researchers

The nephrology research community is asked to:

- Study the extent to which hospice is utilized, the barriers to utilization, and the outcomes of hospice care for ESRD patients. The possible barriers to hospice utilization by ESRD patients include the lack of data on the benefits of hospice to ESRD patients and lack of financing for hospice care for ESRD patients.
- Identify the factors associated with patient perceptions of quality of life and life satisfaction.
- Develop new health-related quality of life tools that examine ESRD patient perceptions and subjective experience of their lives and ESRD treatment. These measures would encompass psychosocial status and support, patient satisfaction, and spiritual issues.
- Evaluate the relationships between quality of life assessments and patient outcomes to determine causal factors that contribute to quality of life.
- Identify, implement, and evaluate interventions that improve quality of life.
- Apply quality of life assessment tools to distinguish patients with poor quality of life and employ specific, corresponding interventions that have been demonstrated to be effective in longitudinal outcome studies.
- Assess prevailing knowledge and attitudes among ESRD patients and bereaved family members related to end-of-life care, and identify specific misconceptions and information gaps.

Nephrology Educators

Nephrology educators are encouraged to:

- Develop a “train the trainers” course, using an adapted version of the ENEC program to train Program Directors, Network Medical Review Board Chairs, and medical directors of dialysis units.
- Include training in palliative care in nephrology fellowship programs, Nephrology Board review courses, and nephrology textbooks.
- Develop curricula on end-of-life care for dialysis patients for nephrology nurses, social workers, dietitians, and technicians to encourage multidisciplinary, comprehensive treatment. Much of this curriculum could be based on the Education for Nephrologists in End-of Life Care (ENEC) program developed by the ESRD Workgroup (see Appendix D, also available at www.promotingexcellence.org), which provides nephrologists with a "new language" on advance care planning, giving bad news, and incorporating spiritual issues into their practice. ENEC also provides new knowledge and skills in pain and symptom management.
- Include palliative care content on performance tests for knowledge and competencies/skills for all clinical dialysis staff.

Nephrology Certifying Boards

Nephrology certifying boards are encouraged to:

- Include palliative care content on certifying examinations for Nephrology Board certification examinations.
- Include palliative care content on specialty certifying examinations for nephrology nurses, social workers, and technicians, and all clinical disciplines associated with care of ESRD patients.

Dialysis Corporations

Corporations that own and operate dialysis units are called upon to:

- Incorporate palliative care policies and practices into dialysis unit services.
- Adopt policies regarding CPR in the dialysis unit that respect patients’ rights of self-determination, including the right to refuse CPR and to have a DNR order issued and honored.
- Implement bereavement programs for the benefit of other patients, patients’ families, and dialysis staff.

- Support the development of peer mentoring in their dialysis units to enhance patient education and support.
- Foster the role of social workers in providing psychosocial support in their dialysis units, ensuring that dialysis social workers have sufficient time to offer psychosocial guidance and support for dialysis patients and their families.

Dialysis Units

The *Promoting Excellence* ESRD Workgroup recommends that Dialysis Units:

- Educate patients and families about palliative and end-of-life care.
- Institute palliative care programs that include pain and symptom management, advance care planning, and psychosocial and spiritual support for patients and families.
- Adopt policies regarding CPR in the dialysis unit that respect patients' rights of self-determination, including the right to refuse CPR.
- Support the development of peer mentoring in their facilities.
- Develop and implement bereavement programs.

ESRD Networks

ESRD Networks can:

- Incorporate end-of-life/palliative care concepts into educational outreach programs.
- Conduct educational sessions for dialysis providers on the medical, ethical, legal, and practical issues surrounding CPR in the dialysis unit.

ESRD Patient Advocacy Organizations

Organizations providing patient education and advocacy organizations, such as the American Association of Kidney Patients (AAKP) and the National Kidney Foundation (NKF), are asked to:

- Develop patient-centered, sensitive, culturally relevant educational materials that are candid about the life-limiting nature of ESRD. These materials would convey the importance of patient choice about control over treatment, especially as complications of ESRD and comorbid conditions arise. These choices include advance directives, Do Not Resuscitate (DNR) orders, palliative care, and hospice as well as considerations related to dialysis withdrawal.

- Work with nephrology educators to distribute brochures and information about common symptoms, treatment, and available resources for ESRD patients and their families relative to the patients' final days/hours of life.
- Promote the use of peer mentors to assist patients in their adjustment to ESRD and its treatment and to help them become knowledgeable about a full range of options as they prepare for the end of life.

Nephrology Health Care Professionals

To enhance the quality of life, nephrologists and other members of the renal care team are asked to:

- Incorporate interventions found to be effective in improving quality of life of ESRD patients into their own clinical practice and into routine care on dialysis units in which they practice.
- Routinely invite patients to express their end-of-life care preferences in the required semi-annual short-term and annual long-term care planning meetings.
- Encourage patients to communicate their preferences to family and to complete written advance directives.
- Refer dying ESRD patients to hospice and/or adopt a palliative care approach to their management.

Public and Private Funders of Research

The *Promoting Excellence* ESRD Workgroup calls upon funders of research in nephrology to:

- Support research in pain and symptom management for ESRD patients.
- Support research on patient perceptions of quality of life in ESRD, including research that identifies reasons for the high dialysis withdrawal rates.
- Support research on the impact of interventions that result in improved patient satisfaction with dialysis.
- Support research on the impact of peer mentoring on psychosocial measures of ESRD patient quality of life and research on end-of-life care planning among renal patients.

Workgroup Products

(Full report including all appendices are available at www.promotingexcellence.org)

- Quality-of-Life Assessment Instrument (see Appendix B)
- Day-long Program, American Society of Nephrology Annual Meeting, End-of-Life Care in Nephrology, Oct. 13, 2001, San Francisco, CA (see Appendix D)
- Nephrology version of the American Medical Association's Education Program for Physicians on End-of-Life Care (see Appendix D for learning objectives of ENEC)
- Half-day seminar, Renal Physicians Association Annual Meeting, End-of-Life Care in Nephrology, March 23, 2002, Washington, DC (see Appendix D)
- Focus Groups in Colorado, Missouri, and North Carolina of ESRD Patients and Bereaved Family Members of ESRD Patients regarding Attitudes and Experiences with Quality of Dying in ESRD (see Appendix C)
- Model Policy for Do Not Resuscitate Orders in Dialysis Units (see Appendix C)
- Revision of the Renal Physicians Association and American Society of Nephrology Statement on Quality Care at the End of Life (see Appendix D)
- Comprehensive Bibliography on End-of-Life Care and Palliative Care in Nephrology (see Appendix D)
- Grant Proposal for Peer Mentoring in Dialysis Units for Advance Care Planning

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(See Appendix A, also available at www.promotingexcellence.org for contact information.)

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APPENDIX A

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APPENDIX B

Quality of Life Subgroup

Quality of Life Subgroup Methodology

Search of the Medical Literature

From a computerized search of the medical literature using multiple databases, the group concluded that assessment of quality of life in ESRD patients treated with hemodialysis has been a concern for nephrologists for almost two decades. However, the proper method of measuring quality of life in ESRD patients remains controversial. Many standard instruments are generalizable but focus heavily on patients' functional status. The Karnofsky Performance Status Scale and the Medical Outcomes Study 36-Item Short Form Health Survey have been the most widely studied in the ESRD population. The Karnofsky Performance Status Scale largely evaluates quality of life from the perspective of functional status.

Studies using these instruments have shown that ESRD patients' functional status is significantly below that of normal and chronically ill populations. The subgroup found that measures of satisfaction with life are often uncorrelated with functional parameters. Interestingly, satisfaction-with-life measures (assessments of happiness) generally do not predict survival of patients with ESRD. The subgroup knew of no studies to examine the relationship between ESRD patient satisfaction with life measures and patient withdrawal from dialysis. It is not known if dialysis patients' satisfaction with life can be improved with more comprehensive care.

The subgroup considers better renal palliative care to be part of comprehensive care. Renal palliative care includes pain and symptom management, advance care planning, psychosocial support, and attention to spiritual issues. A search of the medical literature highlighted the significant contributions of Paul Kimmel, MD to the literature on ESRD patient quality of life. Dr. Kimmel subsequently joined the workgroup and participated in subgroup conference calls from December 2000 through the completion of the project.

Subgroup Discussions and Development of an Instrument

Subgroup members were quite diverse: at one time or another, there were three nephrologists, Drs. John Leggat, Paul Kimmel, and Alvin Moss; a palliative care physician, Dr. Gary Reiter; three nephrology nurses, Sharon McCarthy, Cathy Greenquist, and Susan Pfetscher; a nephrology nurse-renal administrator, Helen Danko; a renal dietitian, Lori Lambert; and a health policy analyst and ESRD patient, John Newmann. In its first meeting, the subgroup agreed that patients' perceptions may be more important than objective measures. The subgroup concluded that it was important to "get inside patients' heads," i.e., to become patient-centered, in order to learn why so many patients grow dissatisfied with their QOL on dialysis.

Subgroup members cited their clinical experience with ESRD patients who expressed a strong desire to discuss beliefs or spiritual concerns as a way to help them adjust to and live with

ESRD. As one article identified in the literature search noted, “...many patients believe spirituality plays an important role in their lives, that there is a positive correlation between a patient’s spirituality or religious commitment and health outcomes, and that patients would like physicians to consider these factors in their medical care.” As a conclusion of the literature scan, the subgroup noted minimal attention in the nephrology quality of life literature to spiritual concerns. The subgroup also concluded that there has been insufficient attention to ESRD patient psychosocial support and status as it relates to patients’ ratings of quality of life.

The subgroup determined that a useful contribution to the care of ESRD patients would be to develop an improved quality of life instrument. Such an instrument would need to include measures of psychosocial status and support, patient satisfaction with life, patient satisfaction with their nephrologist and dialysis staff relationships, existential issues, and the role of faith in their lives. The goals of developing this instrument were:

- 1) to measure psychosocial and spiritual variables in addition to many other variables commonly measured in assessments of ESRD patient quality of life;
- 2) to determine if these psychosocial and spiritual variables proved to be significant factors in patients’ perceived quality of life, and if so, how they related to markers of adequacy of dialysis treatment and patient functional status; and
- 3) to recommend the use of this instrument in dialysis practice to incorporate attention to parameters that patients report as important to improving their quality of life into their care.

Among the quality of life instruments found in the literature scan, the subgroup selected for their instrument the McGill Quality of Life Questionnaire, the Diener Satisfaction with Life Scale, questions from the KDQOL instrument by the RAND Corporation and from the DiMatteo and Hays Patient Satisfaction with Care questionnaire, and spirituality questions developed by subgroup chair John Newmann, PhD, MPH (see below). The subgroup chose these measures recognizing that a mix of instruments would probably be necessary to appreciate the concerns it had identified.

Consultations

In the choice of instruments, the subgroup consulted with Robin Cohen, PhD, the principal developer of the McGill Quality of Life Questionnaire; Karen Steinhauser, PhD, a nationally recognized investigator of factors important to patients and families at the end of life; and Ira Byock, MD, a nationally recognized expert in end-of-life care who has experience in quality of life instrument design and validation. These individuals concurred that the McGill instrument was the best choice among those available and validated in a chronic disease population.

The subgroup also consulted with Melanie Merriman, PhD, a specialist in outcome measurement. Dr. Merriman recommended that the subgroup adopt a three-phase approach to evaluating the instrument they had developed. The first phase would determine if the instrument identified concerns that were very important to patients; in other words, did the instrument ask the right questions? If so, the second phase would validate the instrument against other validated instruments. If the instrument performed well in the validation study, then the third phase would develop a process for implementing the use of the instrument by those caring for ESRD patients.

The subgroup asked Seth Emont, PhD, and Ronald Althouse, PhD, both social scientists with experience in research methodology, to review the design of the instrument to be sure that it lent itself to analysis for the types of questions the subgroup was asking. Both were favorably impressed with the instrument and agreed to serve as consultants for data analysis once interviews were completed using the instrument.

Testing of the Instrument

The subgroup secured \$10,000 in funding from the *Promoting Excellence in End-of-Life Care* program to pay for the first phase in instrument evaluation, and contracted with West Virginia University to carry out the work. The consultants recommended that 200 to 300 interviews be conducted for the first phase in instrument evaluation. After obtaining approval from their respective Institutional Review Boards for the Protection of Human Subjects, subgroup members Danko, Kimmel, Leggat, Moss, and Pfetscher each agreed to oversee the interviews of 50 to 60 patients in dialysis units to which they had access. The Survey Research Center at West Virginia University was responsible for data entry and analysis. Dr. Althouse, Director of the Survey Research Center, worked with Dr. Moss to develop a scannable interview form that would facilitate data entry. At the time of this report, interviews and data analysis were completed. The following Quality of Life Questionnaire for Dialysis Patients was developed by the QOL subgroup.

QUALITY OF LIFE QUESTIONNAIRE FOR DIALYSIS PATIENTS

| | |
|--|---|
| ID Numbers | Date |
| □□□□ □□□□□□ □□□□□□ □□□□□□ | □□/□□/□□ |
| Interviewer _____ | Site _____ Time interview started _____ |
| 1. In general, how would you rate the patient's overall health; would you say that it is: | |
| <input type="checkbox"/> Excellent <input type="checkbox"/> Good <input type="checkbox"/> Fair <input type="checkbox"/> Poor <input type="checkbox"/> Very Bad <input type="checkbox"/> Terrible <input type="checkbox"/> Don't Know | |

| 2. DEMOGRAPHICS <input type="checkbox"/> Male <input type="checkbox"/> Female Date of Birth: _____ <u>Racial/Ethnic Group:</u> <input type="checkbox"/> American Indian or Alaska Native <input type="checkbox"/> Asian <input type="checkbox"/> Black or African American <input type="checkbox"/> White <input type="checkbox"/> Native Hawaiian or other Pacific Islander <input type="checkbox"/> Other : _____ Of Hispanic or Latino origin? <input type="checkbox"/> Yes <input type="checkbox"/> No | 4. THE KARNOFSKY RATING SCALE Instructions: Darken the bubble corresponding to the patient's current disease stage. <table style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="text-align: left; width: 10%;"><u>%</u></th> <th style="text-align: left;"><u>Description</u></th> </tr> </thead> <tbody> <tr> <td>100</td> <td>Normal; no complaints; no evidence of disease.</td> </tr> <tr> <td><input type="checkbox"/></td> <td></td> </tr> <tr> <td>90</td> <td>Able to carry on normal activity; minor signs or symptoms of disease.</td> </tr> <tr> <td><input type="checkbox"/></td> <td></td> </tr> <tr> <td>80</td> <td>Normal activity with effort; some signs or symptoms of disease.</td> </tr> <tr> <td><input type="checkbox"/></td> <td></td> </tr> </tbody> </table> | <u>%</u> | <u>Description</u> | 100 | Normal; no complaints; no evidence of disease. | <input type="checkbox"/> | | 90 | Able to carry on normal activity; minor signs or symptoms of disease. | <input type="checkbox"/> | | 80 | Normal activity with effort; some signs or symptoms of disease. | <input type="checkbox"/> | |
|---|--|----------|--------------------|-----|--|--------------------------|--|----|---|--------------------------|--|----|---|--------------------------|--|
| <u>%</u> | <u>Description</u> | | | | | | | | | | | | | | |
| 100 | Normal; no complaints; no evidence of disease. | | | | | | | | | | | | | | |
| <input type="checkbox"/> | | | | | | | | | | | | | | | |
| 90 | Able to carry on normal activity; minor signs or symptoms of disease. | | | | | | | | | | | | | | |
| <input type="checkbox"/> | | | | | | | | | | | | | | | |
| 80 | Normal activity with effort; some signs or symptoms of disease. | | | | | | | | | | | | | | |
| <input type="checkbox"/> | | | | | | | | | | | | | | | |

| | |
|---|---|
| <p><u>Geographic Area of Residence:</u> ≡ Urban Area (Densely settled area with a population of 50,000 or more) * ≡ Urban Cluster (Densely settled area with a population of 2,500-49,999) * ≡ Rural (All other areas) * "Densely settled" is defined as having at least 1,000 people per square mile in the core area, and at least 500 people per square mile in the surrounding area.)</p> <p>Does the patient receive professional health Care services in the home? ≡ Yes ≡ No Source: _____</p> <p>Does the patient receive assistance in daily living activities in the home? ≡ Yes ≡ No Source: _____</p> <p>3. MEDICAL INFORMATION</p> <p>Cause of ESRD (HCFA 2728): _____</p> <p>Diabetes Present? ≡ Yes ≡ No</p> <p>Length of time on dialysis: _____</p> <p>Current dialysis modality: _____</p> <p>Biochemical Markers (average past 3 months): Hemoglobin _____ Albumin _____ URR or KT/ V _____</p> | <p>70 Cares for self; unable to carry on normal activity or to do active work. ≡</p> <p>60 Requires occasional assistance but is able to care for most of own needs. ≡</p> <p>50 Requires considerable assistance and frequent medical care. ≡</p> <p>40 Disabled; requires special care and assistance. ≡</p> <p>30 Severely disabled; hospitalization indicated although death not imminent. ≡</p> <p>20 Very sick; hospitalization necessary; active supportive treatment necessary. ≡</p> <p>10 Moribund, fatal processes progressing rapidly. ≡</p> <p>0 Dead. ≡</p> |
|---|---|

McGILL QUALITY OF LIFE QUESTIONNAIRE

Instructions

The questions in this questionnaire begin with a statement followed by two opposite answers.

Numbers extend from one extreme answer to its opposite.

Please circle the number between 0 and 10 which is most true for you.

There are no right or wrong answers.

Completely honest answers will be most helpful.

EXAMPLE:

I am hungry:

not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

- **If you are not even a little bit hungry, you would circle 0.**
 - **If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.**
 - **If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.**
 - **If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.**
 - **If you are extremely hungry, you would circle 10.**
-

BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

PART A

Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two (2) days the quality of my life has been:

very bad 0 1 2 3 4 5 6 7 8 9 10 excellent

PART B: Physical Symptoms or Physical Problems

- (1) For the questions in Part "B", please list the PHYSICAL SYMPTOMS OR PROBLEMS which have been the biggest problem for you over the past two (2) days. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary)
- (2) Circle the number which best shows how big a problem each one has been for you **OVER THE PAST TWO (2) DAYS.**
- (3) If, over the past two (2) days, you had NO physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days, one troublesome symptom has been: _____

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

2. Over the past two (2) days, another troublesome symptom has been: _____

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

3. Over the past two (2) days, a third troublesome symptom has been: _____

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous problem

4. Over the past two (2) days I have felt:

physically terrible 0 1 2 3 4 5 6 7 8 9 10 physically well

12. Over the past two (2) days, I have felt that I have:

| | | | | | | | | | | | | |
|--|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|--|
| no control over my life | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | complete control over my life |
|--|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|--|

13. Over the past two (2) days, I felt good about myself as a person.

| | | | | | | | | | | | | |
|--------------------------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|-----------------------------|
| completely disagree | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | completely agree |
|--------------------------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|-----------------------------|

14. To me, the past two (2) days were:

| | | | | | | | | | | | | |
|-----------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|---------------|
| a burden | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | a gift |
|-----------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|---------------|

15. Over the past two (2) days, the world has been:

| | | | | | | | | | | | | |
|--|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|--|
| an impersonal unfeeling place | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | caring and responsive to my needs |
|--|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|--|

16. Over the past two (2) days, I have felt supported:

| | | | | | | | | | | | | |
|-------------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|-------------------|
| not at all | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | completely |
|-------------------|----------|----------|----------|----------|----------|----------|----------|----------|----------|----------|-----------|-------------------|

A minister, priest, rabbi, cleric, or religious person:

rarely 1 2 3 4 5 6 7 8 9 10 always

A doctor or other knowledgeable health professional:

rarely 1 2 3 4 5 6 7 8 9 10 always

7) **When I need to speak to someone, I don't know whom to turn to:**

rarely 1 2 3 4 5 6 7 8 9 10 always

8) **How much would you like to talk to someone about your illness and life's meaning and purpose:**

Not at all 1 2 3 4 5 6 7 8 9 10 very much

SATISFACTION WITH LIFE SCALE (SWLS)

Diener, Emmons, Larson & Griffin

Below are five statements with which you may agree or disagree. Using the 1-7 scale below, indicate your agreement with each item by circling the number that corresponds to it.

1 – Strongly Disagree

2 – Disagree

3 – Slightly Disagree

4 – Neither

Agree Nor

Disagree

5 – Slightly Agree

6 – Agree

7 – Strongly Agree

| | Strongly Disagree | | | Strongly Agree | | | |
|--|------------------------------|----------|----------|---------------------------|----------|----------|----------|
| 1. In most ways my life is close to my ideal. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 2. The conditions of my life are excellent. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 3. I am satisfied with my life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 4. So far I have gotten the important things I want in life. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| 5. If I could live my life over, I would change almost nothing. | 1 | 2 | 3 | 4 | 5 | 6 | 7 |

| |
|--|
| <p>PATIENT SATISFACTION <i>Newmann and Pfettscher (adapted from KDQOL)</i></p> |
|--|

1. Think about the care you receive for kidney dialysis. In terms of your satisfaction, how would you rate the interest shown in you as a person?

| | <i>(Circle One Number)</i> <u>By your doctor</u> | <i>(Circle One Number)</i> <u>By your dialysis staff</u> |
|--------------|---|---|
| Very poor... | 1 | 1 |
| Poor... | 2 | 2 |
| Fair... | 3 | 3 |
| Good... | 4 | 4 |
| Very good... | 5 | 5 |
| Excellent... | 6 | 6 |
| The best... | 7 | 7 |

2. How TRUE or FALSE is each of the following statements?

| | <u>Definitely True</u> | <u>Mostly True</u> | <u>Don't Know</u> | <u>Mostly False</u> | <u>Definitely False</u> |
|--|------------------------|--------------------|-------------------|---------------------|-------------------------|
| a. My doctor encourages me to be as independent as possible | 1 | 2 | 3 | 4 | 5 |
| b. My doctor supports me in coping with my kidney disease | 1 | 2 | 3 | 4 | 5 |
| c. Dialysis staff encourages me to be as independent as possible | 1 | 2 | 3 | 4 | 5 |
| d. Dialysis staff supports me in coping with my kidney disease | 1 | 2 | 3 | 4 | 5 |

| |
|---|
| <p>PATIENT SATISFACTION <i>(adapted from DiMatteo and Hays)</i></p> |
|---|

| |
|---|
| <p>To what extent do you agree with the following statements:</p> |
|---|

| | Strongly Disagree | Slightly Disagree | Neutral | Slightly Agree | Strongly Agree |
|---|----------------------|----------------------|---------|-------------------|-------------------|
| <p>This doctor really cares about me as a person. I'm not just part of his/her job.</p> | 1 | 2 | 3 | 4 | 5 |
| <p>This staff really cares about me as a person. I'm not just part of their job.</p> | 1 | 2 | 3 | 4 | 5 |
| <p>This doctor always treats me with a great deal of respect and never "talks down" to me.</p> | 1 | 2 | 3 | 4 | 5 |
| <p>This staff always treats me with a great deal of respect and never "talks down" to me.</p> | 1 | 2 | 3 | 4 | 5 |

Final Questions

Please write your answers to the following two questions on the lines below. You may continue on the back if you wish.

1. Were there any questions in this questionnaire that were irrelevant to your quality of life?

2. Is there anything important to your quality of life that was not asked about in this questionnaire?

Time interview ended _____

Dialysis shift patient on _____

Interviewer's assessment

Was the patient cooperative? Yes No

Were family members present during the interview? Yes No

Were there frequent interruptions during interview? Yes No

How would you rate the patient's level of function?

Poor

Fair

Good

Very Good

Excellent

Executive Summary of Findings from the ESRD Quality of Life for Dialysis Patients Questionnaire Study

Background

The purpose of this study was to investigate the impact of physiological, psychosocial, and spiritual factors on the quality of life (QOL) among end-stage renal disease (ESRD) patients receiving dialysis treatment.

Methods

Patients receiving treatment (n=165) were asked to respond to a series of questions focusing on various dimensions of QOL. Questions asked by interviewers included the McGill Quality of Life Questionnaire (MQOL), the Satisfaction with Life Scale (SWLS), and two patient satisfaction scales, including an adaptation from the Kidney Disease QOL instrument. In addition, a new scale was administered for the purpose of exploring the effects of spiritual beliefs and patient supports on overall quality of life. Demographic information also was collected on each patient to determine variations in outcomes based on these factors. And finally, medical information was also collected. This information included length of time on dialysis, the clinician's Karnofsky rating, and average level of hemoglobin, albumin, and Kt/V ratio.

The analysis strategy had two main objectives. The first objective was to document in an exploratory analysis, the relationship between various medical and psychosocial characteristics and self-perceived QOL among dialysis patients. The second objective was to explore the development of a new scale that could be used to measure additional dimensions of QOL.

Results

Although biomarkers such as levels of albumin and hemoglobin and Kt/V have been traditionally used by nephrologists to assess QOL, this study clearly indicated that other factors such as psychosocial factors play a significant role in defining overall QOL. The study also indicated that two factors – spiritual beliefs and support network – could be assessed to define overall patient QOL. Factor analysis and reliability analysis (as a measure of internal consistency) of the scale items were conducted to determine the factors and explore the overall stability of the measures, respectively. The two resulting factors accounted for 45% and 19% of the variance, respectively, for a total of 64%. The final standardized item alpha was .84. In addition, a split-half reliability analysis indicated strong correlations between one half of the variable set and the other (correlation = .80). The “spiritual belief” subscale was significantly associated with the following subscales/scales and other variables: The MQOL overall score, the MQOL Existential and Support Subscales, the MQOL single item measure, the SWLS, and a number of indices related to patient interactions with dialysis staff, including encouragement from dialysis staff. The “support network” subscale was significantly associated with the following subscales/scales and other variables: The MQOL Existential subscale and the MQOL Support subscale, and the average level of satisfaction with doctors and staff. Whites compared to minorities were likely to score significantly lower on the support network subscale, while minorities scored significantly lower on the MQOL Psychological subscale compared to whites.

It is also interesting to note that neither the total score on the “spiritual belief” nor “support network” scales was associated with number of symptoms reported by patients on the McGill QOL Questionnaire, or with the various biomarkers that were studied. However, there was a significant inverse dose-response relationship between the MQOL total score, the MQOL physical subscale, the single item global measure of QOL and patient’s report of symptoms. The total score on the SWLS also was significantly and inversely associated with the number of symptoms reported.

Further analysis of patients reporting symptoms revealed additional interesting findings. For the spiritual beliefs subscale, 67.7% of responses associated with pain-related symptoms fell below the median score on the “spiritual beliefs” subscale compared to only 46.6% and 49.3% of the “no symptom” and “other symptom” groups, respectively. The same pattern was identified for the support network subscale: 64.5% of responses in the pain category fell below the median score of the support index compared to 47.8% and 48.7% of the “no symptom” and “other symptom” categories. These results point to the potential association between symptom and quality of life and points to pain management as a particularly important focus of intervention for clinicians.

The results of this study are promising and indicate potential points of intervention for improving the quality of life among dialysis patients. In addition, the lack of any significant association between the various biomarkers studied and quality of life indicate that clinicians need to consider the relative importance of other dimensions from the patient’s perspective. The results also indicate the utility of a brief, 9-item scale that can be used to document the patient’s spiritual beliefs and support network. Although more research is needed to further validate this scale, when administered in conjunction with other QOL scales, it can provide a more comprehensive assessment of a patient’s psychosocial needs.

Statistical Summary of Quality of Life for Dialysis Patients Questionnaire Study Findings

Methods

Patients with end-stage renal disease (ESRD) receiving dialysis treatment (n=165) in three different dialysis units (50 patients in Washington, DC; 55 patients in Morgantown, WV; and 60 patients in Mineola, NY) were asked to respond to a series of questions focusing on various dimensions of quality of life (QOL), satisfaction with life, and satisfaction with the care they received from clinical staff while receiving dialysis treatment. Questions asked by interviewers included the 16-item McGill Quality of Life Questionnaire (MQOL) plus the single item overall measure of QOLⁱ, the Satisfaction with Life Scaleⁱⁱ (SWLS), and two patient satisfaction scales, including an adaptation from the Kidney Disease QOL instrumentⁱⁱⁱ and the DiMatteo and Hays patient satisfaction instrument.^{iv} In addition, a series of questions was administered for the purpose of exploring the impact of other psychosocial dimensions on overall QOL among individuals with kidney disease. Demographic information also was collected for each patient to determine variations in outcomes based on these factors. And finally, medical information was collected, including length of time on dialysis (in months), physical symptoms experienced, presence of pain-related symptoms, the clinician's Karnofsky rating^v, and average level of hemoglobin (in gm/dl), albumin (in gm/dl), and the patient's Kt/V ratio.

Statistical Methods

The analysis strategy had two main objectives. The first objective was to document, in an exploratory analysis, the relationship between the patients' various medical and psychosocial characteristics and the QOL indices. Total scores for each of the QOL and patient satisfaction scales were calculated and used to test associations with other factors. In addition, total scores from each of the four McGill QOL subscales (i.e., physical, psychological, existential, and support domains) were calculated and tested against other factors. Pearson correlations, independent sample t-tests, one-way ANOVAs with *a posteriori* contrast tests (i.e., least-significant difference), and χ^2 tests were used as appropriate, using 2-sided significance levels $\leq .05$.

The second objective of the analysis was to explore the development of a new scale that could be used to document the impact of other potential dimensions on QOL, including spiritual beliefs and support networks. Patients were asked to respond to twelve questions on issues focusing on the meaning and value of spiritual beliefs and level of support and comfort in talking about their illness to family or friends, other patients, a social worker or therapist, a priest, rabbi, or other religious person, or their clinician. To explore the potential underlying dimensions associated with the 12-item questionnaire, subjects' responses to the questionnaire were subjected to a principal components analysis (PCA). Bartlett's test of sphericity and the Kaiser-Meyer-Olin statistic were used to further test the strength of the association among variables. Reliability analysis using Cronbach's alpha was also conducted on the reduced scale to test the internal consistency of scale items. Further reliability analysis was conducted using a split-half analysis and interpreted by the Spearman-Brown coefficient. After the final solution was reached with the PCA and reliability analyses, regression-method factor scores were calculated using the factor score coefficients. The resulting subscales were then correlated with the other validated

QOL indices, biomarkers, and patient satisfaction scales (described above) to determine the associations among the scales and subscales. Further differences by patient characteristics were also explored using statistical tests, as appropriate.

Results

Although nephrologists have for the most part traditionally relied upon one-dimensional measures of physical functioning (for example, by examining levels of albumin and hemoglobin and Kt/V ratio) to assess QOL among patients with end stage renal disease, the findings clearly indicate the importance of psychosocial factors in defining a patient's overall QOL. The results also indicate interesting associations between measures of QOL and various patient characteristics. Results of the PCA are presented first since these results are incorporated into the subsequent analyses on associations with other measures of QOL.

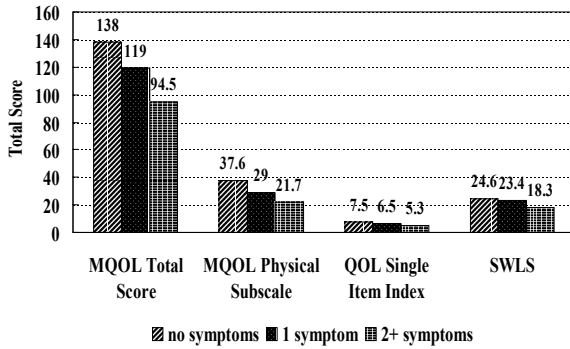
The PCA and reliability analyses resulted in two constructs: spiritual beliefs and patient support network. These two resulting factors accounted for 45% and 19% of the variance, respectively, for a total of 64%. The final standardized item alpha for the reliability analysis was .84. In addition, the split-half reliability analysis indicated strong correlations between one half of the variable set and the other (correlation = .80) and a strong Spearman-Brown coefficient of .89. The final "spiritual beliefs" construct consisted of four items and the "support network construct" consisted of five items (from the original 12-item questionnaire).

Spiritual beliefs were significantly and positively associated with the following subscales/scales: The MQOL overall score ($r(138) = .25, p < .01$), the MQOL Existential and Support Subscales ($r(150) = .34$ and $r(148) = .30$, respectively, $p < .001$), the MQOL single item measure ($r(157) = .18, p < .05$), and the SWLS ($r(155) = .21; p < .01$). In addition, spiritual beliefs were significantly associated with patients' perceived support from dialysis staff ($r(155) = .22, p < .01$). Age was significantly and positively associated with spiritual beliefs ($r(153) = .21, p < .01$), while women compared to men ($t(149) = 3.57, p < .001$) and racial/ethnic minorities compared to whites ($t(150) = 3.68, p < .001$) were likely to have higher scores on the spiritual beliefs construct.

Patients who were more likely to speak about their illness to others in their support network and to gain comfort from this (i.e., support network construct) also were significantly more likely to score higher on the following QOL measures compared to patients that scored lower on the support network measure: The MQOL Existential subscale ($r(150) = .21, p = .01$) and the MQOL Support subscale ($r(151) = .29, p < .001$). Patients scoring higher on the support network construct also were more likely to be satisfied with their doctors and staff ($t(136) = 2.61, p = .01$).

Whites compared to racial/ethnic minorities were likely to score significantly lower on the support network subscale ($t(97) = 2.28, p < .05$), while minorities scored significantly lower on the MQOL Psychological subscale compared to whites ($t(85) = 2.28, p < .05$). In addition, women were significantly more likely than men to score higher on the McGill Support subscale ($t(136) = 2.61, p = .01$), while minorities were significantly more likely to report greater overall average satisfaction with doctors and staff compared to whites ($t(157) = 2.50, p < .05$).

Association Between Reports of Troublesome Symptoms and Quality of Life Measures



Note: All results statistically significant, p values <.01

The relationships between the number of troublesome symptoms reported, presence of pain-related symptoms reported by patients and QOL scores were also explored. Fifty-five percent of patients reported having no troublesome symptoms, while 28% and 17% of patients reported having one, or more than one, troublesome symptom, respectively. There was a significant inverse dose-response relationship between the MQOL total score ($F(2, 138) = 38.8, p < .0001$), the MQOL physical subscale ($F(2, 158) = 180.3, p < .0001$), the single item global measure of QOL ($F(2, 162) = 12.5, p < .0001$) and the number of symptoms reported by patients. The total score on the SWLS also was

significantly and inversely associated with the number of symptoms reported ($F(2, 158) = 6.3, p < .01$) (see Figure). Neither the total score on the spiritual belief construct nor the support network construct was associated with the number of troublesome symptoms reported by patients.

Further analysis of the type of symptom reported by patients revealed additional interesting findings. Types of symptoms were categorized into the following three groups: no symptoms, pain-related symptoms (e.g., chest pain, stomach pain, pain in extremities), and other types of troublesome symptoms (e.g., lack of appetite, trouble sleeping, dyspnea). For the spiritual beliefs construct, 67.7% of responses associated with pain-related symptoms fell below the median score compared to only 46.6% and 49.3% of the “no symptoms” and “other symptoms” groups, respectively. The same pattern was identified for the support network construct: 64.5% of responses in the pain category fell below the median score compared to 47.8% and 48.7% of the “no symptoms” and “other symptoms” categories. These overall results point to the potential association between symptom reduction – and particularly, pain management – and QOL, and represent a point of intervention for clinicians.

It is interesting to note that none of the biomarkers (i.e., hemoglobin, albumin, and Kt/V) was significantly associated with the patient’s QOL, including both the spiritual beliefs and support network constructs. In fact, the only significant association between physical functioning and QOL was found between the Karnofsky rating and overall score on the SWLS ($r(160) = .17, p < .05$).

The results of this study are promising and indicate potential points of intervention for improving the QOL among dialysis patients. Better assessment and treatment of patients’ symptoms would seem to have a very positive effect on ESRD patients’ QOL. Since pain was the most frequently reported symptom, better pain management for ESRD patients appears to be a priority to improve ESRD patient QOL. In addition, the lack of any significant association between the various biomarkers studied and quality of life underscores the relative importance of

psychosocial and spiritual dimensions from the patient's perspective. The results also indicate the utility of a brief, 9-item scale that can be used to document the patient's spiritual beliefs and support network. Although more research is needed to further validate this scale, when administered in conjunction with other QOL scales, it can provide a more comprehensive assessment of a patient's psychosocial needs.

APPENDIX C

Quality of Dying Subgroup

Quality of Dying Subgroup Methodology and Findings

Dimensions of Quality

The available literature that addresses the dimensions of quality of end-of-life experience and care, particularly from the perspectives of patients and families, is inadequate. Several studies that assign values to certain dimensions of dying seem to derive these standards from the perspectives of the clinicians and authors of the studies, and are thus limited and probably faulty.

The subgroup felt strongly that far more worthwhile benchmarks that would ultimately define protocols for care of dialysis patients should be derived from a clearer understanding of what patients and families themselves perceive as indicators of quality. Consequently, the subgroup opened discussions with Michael Perry and Susan Kannel of Lake Snell Perry & Associates, Inc., to pursue the possibility of conducting focus groups among dialysis patients as well as the families of dialysis patients who were deceased. After considerable exchange of ideas between members of the subgroup and the focus group moderators, a format for such groups was developed, and efforts were made to provide funding for the project. The Robert Wood Johnson Foundation was most generous in contributing toward some of the costs involved, as was the Missouri Kidney Program, in association with the University of Missouri at Columbia.

The subgroup wanted to hold focus groups in several diverse geographic locations in the United States in an attempt to have diverse populations represented. Focus groups were conducted in Missouri, North Carolina and Colorado, and a summary of the findings was prepared by Susan Kannel and Michael Perry of Lake Snell Perry & Associates (see below). Two focus groups were conducted in each location, one group of current patients, and the other of family members of deceased patients.

It is hoped that the data provided by these groups will serve as the nucleus of a clearer understanding of how patients and families view the process of dying with ESRD, as well as their expectations for care. Such information will fuel more appropriate and insightful research about the current state of affairs. It will also make a powerful contribution to the development of procedures for caring for terminally ill dialysis patients as it works to eliminate the obstacles of ignorance and supposition that now interfere with delivery of high quality care to ESRD patients in the final stages of their lives.

Advance Care Planning and DNR Orders

The subgroup was also aware of the inadequate state of advanced care planning among dialysis patients, which has been cited in several studies. A particular area that caught the interest of the subgroup was the potential obstacle to honoring advance directives, and particularly Do Not Resuscitate (DNR) orders, within the confines of dialysis units. When the subgroup attempted to

review the policies of dialysis units and dialysis corporations with respect to honoring patients' refusals of cardiopulmonary resuscitation, it became apparent that no consistent policy applied. More worrisome, policies of many units are either unclear on this point or prohibit honoring a legitimate DNR directive. Such prohibitions violate the principles of patient autonomy as well as those of beneficence and non-maleficence. Many states have specific laws and statutes governing out-of-hospital DNR orders, and it was apparent to the subgroup that the policies of many dialysis units did not comply with such statutes. Thus, in addition to the moral and ethical considerations, an institutional policy obstacle was identified that inhibits delivery of optimal care through the end of life in dialysis care settings.

In response to this issue, the subgroup formulated a model policy statement for dialysis unit DNR orders, as well as a proposed model procedure that could be incorporated into the practices of dialysis units. The subgroup intends to publish this policy statement along with a review article detailing the dimensions of the DNR issue, in a major nephrologic journal in the near future. In this manner, the subgroup hopes to enhance another aspect of the care of the ESRD patient who may become critically ill. (See Appendix C, also available at www.promotingexcellence.org for the model DNR policy for dialysis units.)

Hospice Care and Support of Caregivers

Finally, the subgroup perceived a need for improved guidance for patients and their families as they anticipate the terminal stages of life. A lack of information or incorrect perceptions about dying are further obstacles to optimum end-of-life care and decision-making for ESRD patients and their families. Recognizing the considerable benefits often derived from the involvement of hospice care programs, the subgroup reviewed informational materials that hospice programs provide to patients and families. The group concluded that hospices would do well to provide a dialysis-specific booklet to ESRD patients. Such a booklet could provide "anticipatory guidance" to patients as well as those who will care for terminally ill dialysis patients, often in their own homes. Such guidance would reduce the stress and burden on both patients and families as they confront the symptoms and suffering of advanced illness, the tasks of caregiving, and issues of life completion and life closure.

ESRD Patients and Family Members on Death and Dying

Summary of Findings from the ESRD Quality of Dying Work Group Focus Group Project

Conducted by
Lake Snell Perry & Associates
Authored by Susan Kannel

As part of its Quality of Dying Project, the ESRD Workgroup hired Lake Snell Perry & Associates (LSPA) to conduct a series of focus groups with ESRD patients and family members of deceased ESRD patients about end-of-life issues. Group participants discussed their feelings and experiences around planning for and talking about death and dying. They also explored what role healthcare professionals and institutions – and dialysis units in particular – can and should play in helping ESRD patients and families deal with these issues. Lastly, participants discussed the concept of palliative care and explored what factors contribute to quality of dying.

A total of six groups were held in three diverse sites, as shown in Table One. In each site, one group was conducted with ESRD patients and another with family members of recently deceased ESRD patients. The groups were racially and ethnically diverse; the voices of African-Americans, Hispanics, and Caucasians were all included. The patient groups were composed of people of different ages and varying medical conditions. Likewise, the family groups were composed of a range of spouses, parents and children of ESRD patients.

Table One

| Location | Date | Participant Description |
|-----------------------------|-------------|--|
| Columbia, Missouri | 7.24.01 | White Family Members |
| | 7.25.01 | Mixed Race (mostly White) ESRD Patients |
| Carrboro, North Carolina | 9.20.01 | African American Family Members |
| | 9.20.01 | African American ESRD Patients |
| Denver, Colorado | 11.28.01 | Hispanic (English Speaking) Family Members |
| | 11.29.01 | Hispanic (English Speaking) ESRD Patients |

This executive report summarizes the findings of this research effort. More detailed findings, as well as additional quotes from participants, are available in the individual site reports on file with the *Promoting Excellence in End-of-Life Care* office in Missoula, Mont.

The report begins by reviewing some important contextual factors including participants' general opinions about the disease and the healthcare that they (or their loved-ones) received. Then, we discuss their experiences with and feelings about end-of-life planning issues and what role they feel healthcare providers can and should play in end-of-life planning. Lastly, we discuss hospice care, palliative care, and participants' views of what factors contribute to quality of dying.

A Note about Education, Experience, and Priming

One of the major underlying findings of this study is that education level and personal experience strongly affect how participants think and feel about these issues. Specifically, these factors shape people's willingness to discuss end-of-life issues, and their openness to the involvement of healthcare professionals in end-of-life planning.

Education, in this case, entails both education generally – that is, the amount of schooling – as well as more issue-specific knowledge. Relevant knowledge areas include knowledge about ESRD specifically – its prognosis and treatments – and familiarity with the workings of the healthcare system more broadly.

Experience also shapes attitudes. Older and sicker patients, and those who have had setbacks, tend to be more comfortable talking about end-of-life issues. Family members, by virtue of having gone through the death of a loved-one, also tend to be receptive. In general, participants who have had very positive or negative experiences with a loved-one's death are especially attuned to the topic at hand. For example, those who have witnessed a difficult end-of-life situation in which the patient's preferences were unknown felt more urgency about these issues than others. Lastly, participants' familiarity with hospice care and its tenets influence their mind-set.

Another factor that seems to have shaped these findings has to do with self-selection and priming. Ideally, focus group participants are selected at random and given little information about the group topic. That way, those who are resistant to a topic are less likely to decline, and participants are not able to “prime” themselves by thinking about the topic before the group session.

But given the sensitive nature of these focus groups, participants were informed about the subject matter during recruitment. This was done differently, and to different extents, in the three sites. In the first groups in Missouri, participants – and patients in particular – were given relatively little information. They were simply told they would be discussing “issues about their care, including death and dying.” Participants in North Carolina were given more detailed information about the group topic. In Colorado, an experienced nephrology social worker recruited the participants. Thus, many Colorado participants had extended conversations about the issues at hand during recruitment, and thus were primed.

This dynamic – that education level, experience and priming correlate strongly with opinions and attitudes about end-of-life issues – runs throughout the study findings. One of the strongest positive findings from the focus group study is that patients and families who are better educated about the life-limiting nature of ESRD are more prepared to discuss and seek out the type of end-of-life care that they desire. Indeed, some apparent group differences might actually be a function of the preparedness of the participants. Specifically, the Hispanic participants in Denver were among the most savvy and progressive participants on many of the issues discussed. However, this seems to be more a function of education, experience, self-selection, and priming than of ethnicity.

Well, I'm comfortable with it because I know that's what's going to happen, you know... And I've dealt with it besides myself. I dealt with my brother's passing away; I took care of him. And I took care of my father when he passed away. I took care of my mother when she passed away.

- Patient, CO

Context

Limited Awareness about the Life-Limited Nature of ESRD

A lack of understanding, or at least acknowledgement, of the fact that ESRD is degenerative and will eventually lead to death seems to be widespread among ESRD patients. Many seem to assume they can be kept alive indefinitely on dialysis. This lack of understanding was particularly evident in Missouri and North Carolina.

The Colorado participants, on the other hand, seem much more aware of the seriousness of ESRD, and also aware that this is not common knowledge. They say that not everyone who should know does, in fact, know that renal failure will eventually lead to death and that dialysis is not a cure for ESRD. They stress the importance of informing patients and families about these basic facts. As one Colorado family member who is a nurse at a dialysis clinic explains: “I can’t tell you how many [new] patients come into our unit that think that their kidneys are going to start working again...[They think] that this is just a temporary thing.”

Many Unanswered Questions

Participants vary widely as to how informed they are about their illness. Some participants say they are, and do seem to be, quite well informed. Others admit they know very little about ESRD, dialysis, or the specifics of their own (or their loved one’s) condition and prognosis. A few cannot even name what kind of dialysis they are on, and are even unaware that there are different types.

Whatever their level of knowledge, most patients say they want to know more. Even those who are knowledgeable have many questions. Participants differ in terms of how aggressive they are about getting their questions answered. Some make a great effort to educate themselves and participate in medical decision-making. Others seem to just go along with whatever their doctors recommend. In discussions about how well-informed they feel about their disease, treatment and prognosis, it is clear that proactive patients and families get more information. Many participants also believe proactive, informed patients get better care.

With kidney disease, it's not something that's going to go away. I mean, it's going to progressively get worse. It doesn't get better, it gets worse.

- Patient, CO

We really liked [my mom's doctor]. He kept us informed ... [But] we just didn't know anything about renal failure or glucose dialysis, nothing... We just didn't know enough about what was going on with her.

- Family Member, MO

Healthcare Professionals are often Inaccessible

Participants say one reason they have so many unanswered questions is that healthcare professionals, and doctors in particular, are inaccessible, busy, and unapproachable. Most complain that doctors never have time to talk with them and address their concerns. There are exceptions of course; a number of participants talked about doctors who made themselves very available and some that are even proactive about talking with patients and family members.

Participants have mixed feelings about getting information and advice from providers other than doctors. Some have had very good experiences with nurses, social workers and technicians. Indeed, some say these providers are a better source than doctors since they are usually more accessible and sometimes more knowledgeable. Other patients are hesitant to go to other providers for help. Some have had negative experiences doing so or just do not have close enough relationships with any nurses or social workers to make them feel comfortable approaching them with questions. Others simply feel that doctors are the best source.

Alternative Resources are in Short Supply

Some participants have looked to outside resources for information about ESRD. Some have learned from other patients or support groups. Others collect and read all the pamphlets available at doctors' offices and clinics. Some more educated participants have done their own research on the Web. In general, participants feel there are not enough resources for patients and families and that much of the existing information is too technical.

Mixed Ratings of Dialysis Clinics

Patients have mixed opinions about their dialysis clinics. In Missouri and Colorado, most participants are pleased with both the medical and personal care provided. Participants in North Carolina are less pleased. Some North Carolinians say the technicians and other staff lack compassion. Some feel the technicians are inadequately trained, and a few even question the quality of the care provided.

Patient and family members' assessment of their dialysis clinic is important. If clinics are to engage and educate people on end-of-life issues, people must feel that clinic personnel are educated, competent, and compassionate.

My experience with getting support from dialysis staff has been more from nurses than it has from doctors. There's some good RNs out there that can really answer a lot of questions, and are really knowledgeable. I've learned more from nurses, more than I ever learned from the doctor...

- Patient, CO

Lack of Continuity of Care

Whatever their experience with their individual dialysis clinics, there seems to be a lack of connection between patients' dialysis unit and their other healthcare providers. For many it seems the clinic is simply where they go for dialysis, and it is only tangentially connected to their other healthcare resources and providers.

Moreover, participants note that patients rarely die in the dialysis unit. Rather, they die at hospitals or nursing homes. This is important because it shows that participants, even if they appreciate the care they or their loved-ones have received in their dialysis clinic, do not necessarily see the clinic and its personnel playing a role in end-of-life care or planning.

Talking and Planning around End-of-Life Issues

Starting Point: Tough Terminology

One of the challenges in exploring this issue is participants' varied levels of familiarity with the terminology used. Many participants are unfamiliar with the term "advance directive" (see discussion below). There is also confusion around the term "end of life." For example, some participants interpret "end-of-life planning" to mean making funeral arrangements and completing a will.

Stopping Dialysis

Participants have mixed opinions about whether and when it is acceptable to terminate dialysis (or other life-sustaining treatment). Many participants, and patients in particular, say they can imagine a point at which they would consider stopping. Both the Missouri and Colorado family member groups had participants whose loved-ones had discontinued dialysis. Beyond that, quite a few participants know of patients who had stopped. In general, people seem supportive of that decision, provided the person is very ill and elderly.

A few patients say they would not stop dialysis under any circumstances. Some feel a religious duty to continue, and believe stopping is tantamount to suicide. As a Missouri patient says, "I think religion has a lot to do with all of us staying on our dialysis. I really do. I think the man up there, he's taking care of us."

I think if I was real bad, I would [stop dialysis]. Like, if I was in the bed and I couldn't do nothing for myself anymore. If I was completely dependent on my son or whoever. I think I would quit... because I wouldn't want to live that way.

- Patient, CO

Talking about and Planning for the End of Life

Despite having dealt with a terminal condition for a long time, many participants have done very little thinking or talking about end-of-life issues. Some seem unable or unwilling to address the subject. A few worry that talking about death is defeatist or may be self-fulfilling; they prefer to focus on staying alive. Others point out that it is not they but their loved-ones who are unable to tackle the topic. As one Colorado patient explains, "[My siblings] don't want to hear it, they are real distant... When I tell them, 'Well this is what I want to happen if it comes,' they are like, 'Let's talk about something else.'"

There are exceptions of course. Some participants, in Colorado especially, say they or their loved-one have done a great deal of talking with family members and healthcare providers about end-of-life issues. Some family members say their deceased loved-one had asked questions about what to expect during death and made their end-of-life wishes clear.

I think that it was one thing for us to prepare all the material things and have the house in order and paperwork and everything done.... But to verbally discuss it was kind of like saying, "I've given up." So you don't. You don't really stand around and say, "This is what's going to happen."

- Family Member, MO

Focus group results suggest that some end-of-life issues are easier to talk about – and make decisions about – than others. Completing a will and making funeral arrangements seems easier for many participants than deciding whether they want a DNR or what end-of-life wishes would be in different circumstances. It seems easier to talk about concerns associated with when a person has died than when he or she is dying.

Often, end-of-life issues, if discussed at all, are only touched on indirectly. While many of the participants say their conversations about end-of-life issues have been limited, there is a sense of preparedness nevertheless. In the family groups, many caregivers – especially spouses – say they felt well prepared and knew their loved-one’s end-of-life wishes, despite relatively little discussion. As a Missouri widow explains, “Well, [we just knew] just through the different illnesses that we got we really [knew]. It was really never discussed but it’s just something that [we knew from] comments that would be made so those decisions were made a long, long time ago.”

Advance Directives: Limited Knowledge

While some have heard of advance directives, only a few participants are really familiar or comfortable with the term. Almost half had never heard the term prior to the focus group they attended. Even among participants who have an advance directive of some sort, few use that label.

After a brief discussion to gauge knowledge about advance directives, participants read the following definition before exploring the topic further.

Advance Directives

An advance directive is a document, such as a living will, that tells a patient’s healthcare providers what kind of care the patient would like to have if he or she became unable to make medical decisions. An advance directive describes the kind of treatment a person would want to receive for different levels of illness. For example, a directive would describe what kind of care the patient would want if they had a critical illness, a terminal illness or permanent unconsciousness.

A Do Not Resuscitate Order or DNR is one type of advance directive. A DNR is an order, signed by a doctor, which instructs other healthcare providers not to perform cardiopulmonary resuscitation (CPR) if a patient stops breathing.

I got that [thing that says] if I get so sick, don't hook me up to that machine to try to keep me alive... I'm talking about that report. I've got them all in the doctor's office where I go to so they won't hook me up to that machine...I done signed the papers.
- Patient, NC

Most Think Advance Directives Are Important...

Most participants agree having an advance directive is important. They recognize that it allows a person to make decisions about his or her life and death while they are still able to do so. Most agree that advance directives lessen the possibility that their loved-ones will have to make, and possibly fight over, difficult decisions. Participants who have had formative experience with the death of a loved-one are the most strongly in favor of advance directives. Several spoke of deaths in which the lack of an advance directive made an already difficult time more difficult. Others told how an advance directive had lessened the stress and sorrow of a loved-one’s passing.

[It's about] making decisions about your life while you can still make that decision and not wait until it happens and then somebody in the court has to decide for you and your family.
- Patient, MO

...But “Have Not Gotten Around to It”

Although most participants agree that having an advance directive is a good idea, relatively few have one. Even in Colorado, where patients and family members were the most aware and forward thinking, only about half the patients and slightly fewer of the family members have an advance directive. Many of those who do not have one explain that, while they know it is important to fill one out, they “just haven’t gotten around to it” or “aren’t ready.”

Some Simply Do Not Want an Advance Directive

Some participants actively resist having an advance directive. Some say they feel that completing an advance directive would be premature; they are not “that ill.” Just as some fear that talking about their death will hasten it, others fear that filling out an advance directive may become a self-fulfilling prophecy. A few object to advance directives because they want all possible measures taken to keep them alive (few are aware that an advance directive can stipulate that all necessary means be taken to sustain life). Some do not want to put their wishes in writing for fear they may change. As one patient explains, “You may think you might want to be in the hospice. You may think you want to be home or whatever. But, when it comes to that time, still having the ability to say ‘No, this is what I want for the last few hours’ - is somebody going to honor those last wishes?”

The nurse talked to me about it one time, but I told her that I wasn’t ready to have one... because you never know, there’s miracles.

- Patient, CO

For some participants, especially those in Missouri, the problem may in part stem from the way they first learned about advance directives. Some patients were only told about advance directives when presented with a form by a hospital admission clerk with little or no explanation. Even participants who had gotten advance directive forms from social workers seem to have received very little explanation about them.

The Role Of Providers In End-Of-Life Planning

Many Do Not See a Role for Healthcare Providers...

Many participants feel dialysis clinics, as places one goes for life-sustaining treatment, are an inappropriate venue for discussions about death and dying. In the words of one Missouri patient, “If you came to the center and they said, ‘Now, we’re going to talk to you about dying,’ I think that would be a low blow.”

*He’s the doctor
he’s supposed to
keep us alive.*
- Patient, CO

More generally, some participants are uncomfortable with the idea of any healthcare provider engaging patients and families around end-of-life issues; those with less experience and education are especially unlikely to see providers in this role. Some feel providers should focus on sustaining life, and that they cannot simultaneously make preparations for death. Some feel death and dying are outside the medical realm, either because these issues are intensely personal or spiritual or because they do not see what role providers would play or what knowledge they could share. Some patients are explicit in their rejection of provider involvement in end-of-life planning. Others had never thought about healthcare providers in this capacity; it simply would never cross their minds to discuss preparing for end of life with doctors, nurses or social workers.

...But Some Participants Do Recognize the Benefits of Provider Involvement

Although some are reluctant to embrace this idea, the most sophisticated and experienced participants unquestionably see a role for providers in end-of-life planning. After some discussion, most concede that there is a role for healthcare providers – including dialysis clinic staff – in helping patients and families prepare for the end of life. In the words of a Colorado patient, “Yes [there is a role for healthcare providers], because we – I don’t think we all know all this. And I think if, when you first go in, they ask you these [kinds of questions] ... Then you could make your own decisions on what you wanted ... I mean, it doesn’t come into your mind, to have all this.”

*But, you know,
when they’ve
tried everything
under the sun,
you know. They
have to be – they
have to lay it out
for you.*
- Patient, CO

Which Healthcare Providers Should Take on End-of-Life Issues?

Participants have mixed feelings about which healthcare providers should engage patients and families on these issues. Some feel if anyone is going to play this role, it should be the doctor. After all, he or she is the main caregiver and the most knowledgeable, trusted figure. Others feel better about talking with providers other than doctors, such as nurses and social workers, noting that they may take more time or discuss aspects that doctors would not cover.

Discussions about which healthcare providers should broach this topic offer a revealing example of how education and experience affect participants' views. In Missouri and North Carolina, many participants express discomfort with the idea of discussing death with social workers. Some even question whether this is in a social worker's job description. Participants in Colorado (who tended to be more educated) are more willing to see social workers in this role. They are aware that dialysis social workers are trained specifically to deal with these issues.

Mixed Experiences Discussing End-of-Life with Providers

Focus groups participants report mixed experiences in talking about end-of-life issues with healthcare providers. Many have had very positive experiences. They describe doctors, nurses and social workers that have helped them and their loved-ones tackle these issues. Those who were especially likely to report positive experiences working through end-of-life issues with healthcare providers included family members whose loved-one had chosen to end dialysis as well as participants from both groups with hospice experience.

Why would we speak to [the social worker] about something like that? Because they don't know. They don't know no more about it than you do.

- Patient, NC

Unfortunately, some participants report unsuccessful interactions with healthcare providers in this vein. In Colorado, several patients tell of experiences in which they had talked with a provider about stopping dialysis and the provider's only response was to recommend anti-depressants. In some cases, these were fairly young, healthy patients, so perhaps the providers' reactions were appropriate – that is, ending dialysis might have been premature – but these patients were upset that their concerns were brushed off. At the very least, it seems the providers missed an opportunity to talk to patients about end-of-life issues.

Perhaps most important is that many participants have no experiences to report. Even among the family members of deceased ESRD patients, many say healthcare providers never approached them about end-of-life issues or did so only at the very end of their loved-one's life. Likewise, many patients who have been on dialysis for years have never discussed these issues with any of their providers.

Tact and Timing are Critical to These Discussions

Participants differ in terms of their openness to talking with healthcare professionals about end-of-life care, and in their views about whether and to what extent dialysis clinics are the appropriate venue for this intervention. Even those who are most open feel that this topic must be approached carefully, at the right time, and with the clear understanding that the ultimate decisions rest with patients and their families. One Missouri patient's comment demonstrates participants' ambivalence about being approached on this topic and the care that should be taken: "I'd like to at least know that there was somebody here that you could go to, to do that when you wanted. You don't have to shove it down people's throat."

Hospice Care, Palliative Care and Quality in Dying

Participants explored the concept of "quality in dying" in a number of ways. Family members talked about what went well with their loved-one's death, and what they wish had been different. Patients were asked similar questions about the deaths of fellow patients. Next, participants in both groups discussed hospice care. They also read and discussed a description of palliative care (see below). Lastly, participants listed all the aspects of a dying experience they would use to measure quality, and then listed the five they feel are most important.

Hospice Care has Mostly Positive Connotations, Some Gaps in Knowledge

Almost all the participants have heard of hospice care, and most know at least a little about what it entails. Most have positive notions about the care patients and families receive in hospice. There are some gaps in their knowledge. Many think hospice care is only available to cancer patients and not an option for people with ESRD. A few believe hospice is only available in hospice facilities, not in patients' homes. Some are uncomfortable even discussing hospice because it is seen as a last resort.

Palliative Care: Sounds Good, but Lacks Familiarity

Few participants had heard the term "palliative care." When they read and discussed the following description, they had mostly positive reactions. Most feel that it describes the kind of care they would want for themselves and their loved-ones. Many equate palliative care with hospice care.

I never heard of [palliative care], and I worked in medical field. Well, I'm not a nurse but I mean, I worked at the health services center for 35 years and I never heard the word.
- Family Member, CO

Palliative Care

Palliative care means care which focuses on easing pain and making life better for people who are dying and for their loved-ones. Palliative care means taking care of the whole person - not just their physical symptoms, but also their emotional and spiritual needs. It looks at death and dying as something natural and personal. The goal of palliative care is to keep dying people as pain-free and comfortable as possible, to help them maintain their dignity, and to provide them the best quality of life until the very end of life.

Downsides and Misinterpretations of Palliative Care

In discussion about palliative care and hospice care, participants do voice some concerns. In general, those who are less comfortable with end-of-life issues are more restrained in their enthusiasm about palliative and hospice care. As one North Carolina patient puts it, “I don't know, to tell you the truth, I don't know of any ‘good death.’” Beyond this general uneasiness with the notion of a good death, participants have more specific concerns about palliative care.

I don't know, to tell you the truth. I don't know of any “good death.”
- Patient, NC

Questions about Availability and Probability

Participants question the availability of this kind of care; they doubt that it is the norm. Many family members doubt their loved-one got this kind of care. As a daughter in Missouri complained, “I felt like she’s an old person and that’s exactly how they [were] treating her...If one of us kids were not there, I don’t think she was getting very good quality care and I don’t think they were concerned about pain.” Some participants stress that palliative care – and pain control in particular – should be a focus of care for all patients, not just those who are near death.

Some question whether this kind of care is even possible. As one North Carolina family member says, “You have no control over [death]...Yes, we want to make it as comfortable as we can. We don't want people to lose their dignity. We don't want people to do all of these things. But we do this when it is in our power to do this. There are some areas, maybe some cases, where it may not be in your power.”

Does Palliative Care Mean Euthanasia?

One North Carolina family member feared palliative care might be akin to euthanasia or even assisted suicide. This was only one individual, but if this definition of palliative care reminds this man of euthanasia, it might raise the same concern with others.

Too Much Ado

In Colorado, a few participants feel palliative care (and hospice care specifically) prolongs the dying process. For example, when asked if she would ever want hospice care, one Colorado patient replied, “I wouldn’t feel comfortable with it. Well, only because I feel it’s prolonging what’s going to take place anyway.”

Further conversation suggests patients’ misgivings have less to do with concerns about prolonging death than with feeling it is “too much ado.” In the words of one patient, “My personal feeling about it is: just let me go.... I think you’re only creating more pain for [your family] because the bottom line is you’re going to leave.... They make you as comfortable as possible and let you leave...this world in dignity, but I wouldn’t want it. I wouldn’t choose it for myself.” Another Colorado patient’s objection seemed to have more to do with involving outsiders: “If I’m going to go, I’d like my wife can take care of me. I wouldn’t like anybody else to come in or do anything for me.” These ambivalent feelings about hospice and palliative care seem more prevalent among men, though one woman in the Colorado patient group seemed to share the feeling.

Measuring Quality In Dying

The items listed in the description of palliative care – pain control, dignity, the meeting of emotional and spiritual needs, maintaining quality of life – resonate strongly with participants. In this final discussion and exercise, they added a few other aspects they feel are important to measuring quality in dying. The most important aspects, and participants’ feelings about them, are explored below.

It important to note that a number of the aspects participants deemed most important in this exercise were not raised earlier in the group discussions. This suggests that neither patients nor family members had thought much about some of those elements which, upon reflection, they consider vital.

They gave [my father] pain medication and everything before when he was on dialysis, but if he had some pain then, they weren’t nearly as concerned about it. Then, once he went into hospice care, that was their primary concern – to keep him pain free. And I think it would have been nice if they had started to worry about that a little more before he went into hospice care, you know, to help him be more pain free as much as possible.

-Family Member, CO

If I’m to go, I [just] want to go. I don’t want all that. I know they are not prolonging it. I know they are not feeding me all this stuff, but I’d rather not have all that, you know?

- Patient, CO

Controlling Pain and Being as Comfortable as Possible

Participants feel controlling pain is vital; many feel it is the single most important element of palliative care. Some even see it as a given that suffering is kept to a minimum, and thus they assume pain control is always a major concern of those who care for the dying. On the other hand, some participants, especially family members, feel doctors are not concerned enough about pain.

Along with pain control, another important concern is ‘not lingering.’ As a Missouri family member succinctly puts it: “A good death is just quick.” Participants also stress the importance of being treated with compassion by those around you – be they healthcare providers or family members.

For some participants, concerns about pain are complicated by worries about over-medication. They feel it can be difficult to balance the need for pain control with a desire to be mentally alert.

Spiritual Needs

Another major area of concern is spiritual preparedness. Interestingly, this element was seldom mentioned in group discussions but struck a nerve when mentioned as part of the palliative care definition. It is worth noting that some participants think spiritual matters are beyond the medical realm; thus they may not feel it is an appropriate concern for healthcare providers.

For some participants, especially those in the North Carolina group, being “right with God” is the most important – even the only – concern. Indeed, some seem to use this as a justification for not thinking about other aspects of the end of life. They feel that whatever happens is God’s will. As one such North Carolina patient explains, “I don’t think the pain would bother me that much. When my time is up that is the way He meant for me to go.”

Where...and with Whom

Another major concern for patients is being where they want to be when they die. Most say they want to die at home; some say they would prefer to be in a nursing home or hospice facility in order to lighten the burden on their loved-ones. Quite a few had not given this much thought. One patient in Missouri mused that he might prefer not to die in his own bed. As he explained, “I haven’t really thought about it that much, but I’m not sure I’d really want to die in my own bed. I mean, that’s something for [my wife] to deal with every time she sleeps on it.”

Another important issue is with whom patients want to be at the end. Most say they want to be surrounded by family. A few say they prefer to be alone because they want to spare their loved-ones. As a Colorado family member explains, “I wouldn’t want to tell my pains to my wife or to my children. I want to hold them for myself. I want to suffer myself because I don’t [want] them to suffer.” Others would prefer to be alone simply because they prefer the solitude.

A couple hours of pain is no problem. But it’s the ongoing pain and misery that’s what I really don’t want, is sustained pain and misery. I don’t want that.

- Patient, MO

His main concern was his soul, spiritual. The only thing he told me is, you know, just don’t forget about me, make sure you have masses said, pray for me every night and all this kind of stuff, but he was ready...

- Family Member, CO

My dad always said that when he died he didn’t want to die in the hospital with strangers ... or in an old age home, he wanted to die at home. So we saw to it that he did.

-Family Member, CO

Concern About Loved-Ones During Death and After

Participants worry about the effect their death will have on their loved-ones. Patients, in particular, do not want to be a burden on their families either financially or emotionally. Many stress that they want support available to help their families cope not just during their death, but also during the mourning period. On that note, some family members are angry that neither their loved-one's doctor nor the dialysis clinic kept in touch after their loved-one's death. As a Colorado family member laments, "I didn't get anything from the doctors, the nurses, the social worker. Nobody ever called after he passed away. They were wonderful right before, you know, calling or answering the questions...but once he passed away, I never heard from a single person."

Participants also want to ensure their loved-ones will be okay in the months and years following their death. They want to know that their children, especially, will be in good shape emotionally and financially. As one North Carolina family member explained in reference to her mother's death, "I think knowing that your loved-one left behind is going to be well taken care of...[that] they are going to be okay.... For instance, my mom knew that my little sister was going to be well taken care of...She wasn't worried about that."

Expressing Love and Saying Goodbye

Participants feel it is important to have a chance to say goodbye to their family and friends and to express their love. Bereaved family members who had the opportunity to have this kind of conversation with their loved-ones say these conversations were very important and speak of them with great reverence.

Being Prepared

Another major concern for both patients and family members is being prepared. Preparation means different things to different people. For some, being prepared means having funeral arrangements planned and paid for, or having made out their will. For only a few does being prepared mean having an advance directive.

Some participants talk about being prepared in a more emotional or psychological sense. They talk about knowing that death is imminent and being ready and "at peace." Some also discuss being prepared in terms of knowing what to expect – that is, "what is going on and what is going to happen." Participants who are concerned about this kind of preparedness say that straight-talk from healthcare providers, and doctors in particular, is vital.

I'd want to be able to say goodbye to everyone and tell them how much they all meant, how much they all mean to me and that I appreciated being in, being in their family, being with them. I'd want to be with my family and say goodbye because when you don't get to say goodbye to someone who has passed away, it's hard. It's harder to accept that death.

-Patient, CO

One thing that helped me...was the doctor came to me towards the end and just kind of laid it on the line. [He said], 'I don't think he's going to make it.' I appreciated that... Some of them are kind of evasive they don't want to just come right out and tell you what's really going on.

- Family Member, MO

Wishes Honored

Another important factor for some participants is having their end-of-life wishes followed – whatever those wishes might be. Some stress that they would not want to be kept alive on a machine or “be a vegetable.” Some have more specific requests, such as who they would, or would not, want at their side during their last hours. As important as these wishes are to some participants, they do not always make the connection between having their wishes fulfilled and making those wishes known. Furthermore, many do not recognize the importance of not just communicating their wishes verbally, but actually putting them in writing.

It is worth noting that a few participants say they do not really care about this element. Basically, they feel that since they are going to be dead, or close to it, they would prefer to have their families decide what is best.

What if you don't have a choice, if your kidneys did fail so bad that you go into a coma and you, and nobody knows about [your wishes]? What I'm saying [is] this way you have a chance. You have a choice to respond to something

- Patient, CO

Maintaining Dignity

Participants stress the importance of helping patients maintain their dignity. In this vein, they stress the importance of allowing dying patients some measure of privacy. Some also say that patients should not be pitied or treated disrespectfully by those around them – be they family members or healthcare providers.

Model Policy and Procedure for DNR Orders in Dialysis Facility

I. Policy

It is the policy of [the name of the dialysis unit] to respect the informed oral or written refusal of cardiopulmonary resuscitation (CPR) in the dialysis unit by patients with decision-making capacity or the health care agents for patients who lack decision-making capacity. In response to an informed refusal of CPR, [the name of the dialysis unit] will issue and honor a do-not-resuscitate (DNR) order for such patients.

II. Rationale for the Policy

CPR is not a successful therapy for most dialysis patients who undergo it. Patients who undergo and survive CPR may have major complications. Because dialysis patients already often bear considerable burdens as a result of dialysis and the frequent occurrence of co-morbid conditions, such as diabetes, congestive heart failure and peripheral vascular disease, many dialysis patients elect to limit the extent of life-prolonging medical care. Such limitations may include a decision to refuse CPR in the dialysis unit and request a DNR order. Honoring the decision of a patient with decision-making capacity (or the decision of a health care agent for a patient who lacks decision-making capacity) not to undergo CPR is ethically justified by the principle of respect for patient autonomy and legally justified by the doctrine of informed consent and the patient's right to self-determination. Furthermore, the performance of CPR on dialysis patients with significant co-morbid conditions who have an extremely poor prognosis with CPR violates the ethical principle of non-maleficence.

III. Definitions

Advance Directive An oral or preferably written statement by a patient with decision-making capacity expressing his/her preferences for a health care agent and/or for future medical care in the event he/she becomes unable to participate in medical decision-making. All 50 states have one or more laws or regulations recognizing written advance directives and the rights of patients to have their wishes respected. There are two types of written advance directives: a living will (an instruction directive in which the patient gives directions for future medical care in the event of particular medical conditions, such as a terminal illness or a persistent vegetative state); and a health care proxy (a proxy directive in which the patient designates a person to make decisions for him/her when the patient loses decision-making capacity). In some states, the health care proxy is referred to as a medical power of attorney or a durable power of attorney for health care. In some states, both instruction and proxy directives may be combined into one advance directive form. All advance directives must comply with applicable state procedural and substantive laws.

Attending Physician A licensed physician with staff privileges in the dialysis facility selected by or assigned to the patient who has primary responsibility for treatment of the patient. (In the case of dialysis patients, this physician is likely to be the nephrologist primarily assigned to the supervision of the patient's dialysis and related care.) If more than one physician shares the responsibility for care of the patient, any of those physicians may act as the attending physician under this policy.

Cardiopulmonary Resuscitation (CPR) A procedure performed to attempt to support and restore ventilation and circulation in a patient experiencing cardiac arrest (systole, ventricular fibrillation, or pulseless electrical activity) or respiratory arrest (cessation of respiratory effort). It includes establishment and maintenance of an airway, assisted ventilation, chest compressions, establishment of intravenous access, cardiac monitoring, administration of medications, defibrillation or other control of arrhythmias, and immediate care after resuscitation.

Decision-Making Capacity The capacity of a patient to 1) understand his/her medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including non-treatment; 3) judge the relationship between the treatment options and his/her personal values, preferences and goals; 4) reason and deliberate about his/her options; and 5) communicate his/her decision in a meaningful manner. Assessment of decision-making capacity is a clinical judgment made by the patient's attending physician.

Do Not Resuscitate (DNR) Order An order written in an appropriate document (medical record, specially formulated advanced care directive, standardized form according to applicable state law or regulation, etc.) that indicates the patient's (or health care agent's) decision to refuse CPR in the event of cardiac or respiratory arrest in the dialysis unit. This order does not restrict the provision of standard measures in dialysis treatment such as fluid resuscitation for intradialytic hypotension, nor does it preclude other forms of care meant to provide comfort and to relieve suffering. A DNR order only becomes effective when the patient has experienced a cardiac or respiratory arrest.

Health Care Agent, Proxy, Surrogate, Guardian, Medical Power of Attorney, or Durable Power of Attorney for Health Care A person who, in accordance with applicable state laws, has been selected by a patient, or who, in accordance with applicable state laws, has been appointed, and has been given the authority to make informed health care decisions for the patient in the event the patient loses decision-making capacity. The appropriate terminology may vary from state to state, but the intent to allow an individual to pre-assign decision-making authority to another person is common among all such instruments. To the extent permitted by applicable state law, the health care agent may have the opportunity to be guided in his/her decision-making by prior knowledge of the patient's wishes through conversations and/or the stipulations in a written advance directive.

Living Will The living will, also known as an instruction directive, indicates a patient's wishes to be followed if he/she loses decision-making capacity. Wishes may refer to care in the event of particular medical conditions such as a terminal illness or a persistent vegetative state. The patient may indicate that he/she wishes under certain circumstances to have or continue treatments such as dialysis or CPR or to discontinue or refrain from such treatments.

Patients Without Decision-Making Capacity A patient who in accordance with the clinical judgment of the attending physician, clinical practice guidelines, and applicable state laws, has been declared to lack the capacity to: 1) understand his/her medical condition; 2) appreciate the consequences (benefits and burdens) of various treatment options including non-treatment; 3) judge the relationship between the treatment options and his/her personal values, preferences and goals; 4) reason and deliberate about his/her own options; and 5) communicate his/her decision in a meaningful manner.

IV. Statement of Principles

1. Patients with decision-making capacity have the same legal and ethical right to request DNR orders in dialysis facilities as they do in hospitals, nursing homes, and other medical or custodial facilities. Patients can better ensure that their legal and ethical rights are secured if they subsequently lose capacity to make medical decisions by executing an advance directive in which they designate a health care agent and state their preferences, including a preference for a DNR order in the dialysis unit if that is their wish. (See Appendix A, also available at www.promotingexcellence.org)

1. For patients with decision-making capacity who have not appointed a health care agent, dialysis units should learn from them whom they wish to choose for a health care agent so that this person can participate in medical decisions for the patient in the event the patient loses decision-making capacity. When a patient has not designated a health care agent and temporarily or permanently lacks decision-making capacity to designate a health care agent, the dialysis facility must determine who has the legal authority to make medical decisions for the patient and take such actions as are necessary to secure the designation of the health care agent according to applicable state laws.

2. There is no legal or ethical difference between a patient requesting a DNR order in a dialysis facility or deciding to forgo dialysis therapy, each of these actions being legitimate manifestations of patient self-determination and the right to refuse therapy. On a clinical basis, a DNR order may be an entirely appropriate decision by a patient who recognizes that his/her quality of life may be quite adversely affected by even a “successful resuscitation” in the face of varying degrees of co-existing morbidity. Requesting a DNR in a dialysis facility may mean that the patient considers his or her quality of life to be adequate to continue dialysis treatment until cardiac or respiratory arrest occurs, even if this occurs while on dialysis, and possibly as a complication of the dialysis treatment itself.

3. Education of dialysis patients and their legal agents about the outcomes of CPR for patients with end-stage renal disease and other co-morbid conditions is essential for patients to make informed decisions about CPR.

4. Dialysis units are obligated to identify and respect the informed preferences of patients regarding performance of CPR. Education about CPR and inquiry about patients’ preferences may be conveniently conducted during required semi-annual long-term care planning meetings, though the process of advance care planning should begin as soon as medically indicated. Patients who request a DNR order in the dialysis facility should be encouraged to make advance preparations for their death to relieve the burden on their health care agent and family (see Appendix B, also available at www.promotingexcellence.org).

5. To accommodate patients who refuse CPR in the dialysis unit and subsequently die there, dialysis units are obligated to have a procedure for treating such patients at and after the time of cardiorespiratory arrest with comfort, dignity, and respect (See V. Procedure on following page).

7. A patient or the patient's health care agent has the right to revoke a DNR order at any time.
8. If the patient requests an in-facility DNR order, the dialysis facility is obligated to continue to provide the patient with the normal range of dialysis treatment and supportive services provided to all other patients.
9. Inherent in quality end-of-life care is the provision of bereavement support to the patient's family. Dialysis units should arrange for such support to be made available to the family either through the dialysis unit or through services available in the community.

V. Procedure

1. The dialysis unit personnel (physicians, nurses, social workers, dietitians, and patient care technicians) are to identify patients who want a DNR order in the dialysis unit through the long-term care planning process and/or in conversations that are appropriate as medical complications arise. Patients who request a DNR order in the dialysis unit are to be encouraged to complete an advance directive for a DNR order in the dialysis unit (see Appendix A, also available at www.promotingexcellence.org), especially if they have not been issued DNR identification (card or bracelet) applicable under state law.
2. Attending physicians are to issue DNR orders for patients with decision-making capacity who want them or at the request of health care agents for patients who lack decision-making capacity. The DNR order is to be recorded in the patient's medical record, a DNR label is to be attached to the inside front cover of the chart, and the notation "DNR" is to appear in the special directions section of individual dialysis treatment sheets.
3. When a patient with a DNR order has a cardiorespiratory arrest in the dialysis unit, dialysis personnel are to screen the patient from other patients and move the patient to a private area of the facility as soon as possible and proper.
4. The dialysis nurse in charge is to notify the attending physician and follow the physician protocol to pronounce the death of the patient.
5. The dialysis nurse in charge and/or the social worker should reassure other patients and staff that everything possible is being done to respect the affected patient's wishes and to promote his/her comfort and dignity.
6. The attending nephrologist, the nurse in charge, or the social worker is to notify the health care agent of the patient's death and to inquire about funeral home preferences, if not previously determined (see Appendix B, also available at www.promotingexcellence.org).
7. Dialysis unit personnel are to notify the funeral home of the patient's death and request immediate pick-up of the body.

8. If required by state law, dialysis unit personnel are to notify the Medical Examiner (Coroner) and to inform him/her that the attending physician has been notified and the patient has been pronounced dead using the physician protocol for pronouncement of death. (The Medical Examiner telephone number is to be readily available in the dialysis unit.)
9. The nurse in charge is to document the death and procedures followed in the patient's progress notes and prepare an incident report, if appropriate, according to dialysis unit policy and procedure.

Addendum A to Model Policy and Procedure for
DNR Orders in Dialysis Facility

Advance Directive for a Do Not Resuscitate Order in the Dialysis Unit

Having considered the things that are important to me in life, my current medical condition, the probability that my medical condition will not improve in the future, and my feelings about life and the quality of my life, I hereby state my wishes.

I request that I not have cardiopulmonary resuscitation (CPR) performed on me when my heart or lungs stop functioning.

I understand that CPR will probably not be successful in prolonging my life, or if it is, that my quality of life will probably not be satisfactory to me.

Based on the above reasons and after discussion with family, friends, and health care professionals to the extent to which I wish to have such discussions, I've come to the conclusion that I do not want CPR, even though I still want to continue my dialysis treatments.

In this regard, I hereby direct that if my heart or my breathing stops while being treated in the dialysis unit, I do not want to undergo CPR regardless of whether the stoppage of my heart or lungs is due to my underlying medical condition or a complication of the dialysis treatment.

Signature or Mark

Date

Witness

Date

Witness

Date

Notary (if required by state law)

Addendum B to Model Policy and Procedure for DNR Orders in Dialysis Facility

Recommendations for Advance Preparation for Death*

Patients who request a DNR order in the dialysis unit are encouraged to provide the following information to their health care agent, family, close friends, and executor (where applicable):

1. A will.
2. Signed advance directive (living will, health care proxy, durable health care power of attorney, and/or an out-of-hospital DNR order) in accordance with applicable state law (provided also to dialysis unit, physician, and hospital).
3. A durable power of attorney complying with applicable state law (one that survives incompetence and death) designating someone to act on the patient's behalf on all matters other than medical, including legal, financial, banking and business transactions. The power of attorney can be made effective immediately or upon the occurrence of a defined set of circumstances.
4. An inventory, including the location of her/his bank, brokerage and other financial accounts, stock and bond holdings not in brokerage accounts, real estate and business records and documents, medical and other insurance policies, pension plans, and other legal documents.
5. A list giving the names, addresses and telephone numbers of the attorney, accountant, family members, close friends, and/or business associates who should be notified of the death or may have information that will be helpful in dealing with estate affairs.
6. Documentation and instructions concerning burial or cremation, including choice of funeral home, preferences for the funeral ceremony, and any decisions about organ, tissue, or body donation.
7. Written or video or audio taped message to the family, close friends, or business associates.

* Adapted and reprinted with permission from "Initiation or Withdrawal of Dialysis in End Stage Renal Disease: Guidelines for the Health Care Team" © National Kidney Foundation, Inc.

The Renal Palliative Care Initiative Memorial Service

The Renal Palliative Care Initiative was a demonstration project to integrate palliative care into the dialysis and transplantation settings. It was supported by the *Promoting Excellence in End-of-Life Care* national program of The Robert Wood Johnson Foundation, and its medical director was Lewis Cohen, MD. This report was composed by Anne Woods, LICSW.

Introduction

The Service of Remembrance is an annual non-denominational program designed to remember the patients who have died during the year. It unites members of the renal community: family members, doctors, nurses, social workers, dietitians, technicians, van drivers, fellow patients and others impacted by the death. It is a collaborative effort to meet the bereavement needs of all. Remembrance can be simple or elaborate. It can be confined to one unit or area or cover a broader area. It should be designed in whatever format is thought to be appropriate for the needs of the bereaved community.

The following outline briefly describes components of the Service of Remembrance that is held in the Greater Springfield Area. This annual program includes participation of both a hospital-based dialysis facility and six freestanding treatment centers in the Connecticut River Valley region of New England. The service is intended to be an avenue of support for all that attend. Diversity of culture, ethnicity, religious belief, professional identity, age, and connectedness to the deceased is taken into consideration in developing the program. It is intended to be inclusive and welcoming.

Beginning

Once the participating facilities have been defined, committees can be formed and program planning can begin. An effort was made to include committee members representing each of the participating facilities. For the program to be a success, all members of the renal community need to feel a part of the process. It is also necessary at this point to consider resources. A budget is needed.

Committee Decisions: Planning the Event

Once a committee is formed, there are a number of decisions that are best made by the committee as a whole. First the population needs to be determined. Location is another major consideration. The facility needs to be large enough to accommodate the potential number of attendees, including loved ones, staff and patients. The final committee decision before breaking up into smaller task groups involves the consideration of symbols that touch upon remembrance. Some examples are candles, roses, rosemary, and bittersweet. Lists of patients to be remembered need to be obtained from whatever facilities are involved. The invitation needs to be drafted so it can be printed and mailed in a timely fashion. Printing arrangements for the programs need to be considered. Finally, evaluations and their stamped, addressed envelopes need to be prepared.

The Service

Program Committee decisions will be key in establishing the tone and content of the remembrance service. Inclusion of pastoral care, social work, administrative and nursing disciplines provide a balanced cross section of education and work experiences to contribute diversity of included elements. Drawing upon the various religious, ethnic and racial backgrounds of members establishes the basis of a program with meaning to all participants and invitees.

Room Set Up

The room designated for the service should be media equipped if large enough to require microphones for speakers and musicians.

Equipment

Podiums are helpful for the readers so that they may have a place to put script to maximize eye contact with the audience. Table coverings, candleholders for large tapers, matches and a candle lighter and snuffer will be needed.

Service Participants

All service participants should arrive approximately 1½ hours before the scheduled time of the service. Participants will have their rehearsal during this time period. A group will also be needed to ensure that resources are collected and the facility is secure, neat, and clean after the event.

Welcome

As guests enter the facility, greeters and escorts should be available. The hospitality greeters' welcome will help to put guests at ease and set the tone for participants. If family members have a photograph for the **Collage of Loved Ones**, greeters take the photograph at this time. A quick check to make sure the name of the loved one is on the back of the picture will ensure its safe return. Family members are encouraged to retrieve their pictures at the close of the service. The guests may then be directed or assisted to the **Welcome Table** to sign the **guest books**. Guests requiring assistance can then be seated in the main room by a hospitality greeter. An ample number of greeters for the expected number of guests insure that people are transitioned smoothly.

The **welcoming speech** that begins the service is an important mechanism to bring together participants and guests by highlighting the role of the remembered loved ones in uniting the group.

Music will be a key piece of the service.

Readings - scripture, prayer, poetry, quotations may be interspersed with the musical selections to vary the tempo of the service.

Candle lighting as names of loved ones remembered are read provides a powerful symbol of love and hope.

At the conclusion of the service, program greeters are again stationed at exit doors to provide each family with an **evaluation form** in a self-addressed stamped return envelope.

The **Resource Table** requires staffers to assist families in selecting the materials most helpful for them.

The first Renal Palliative Care Initiative Service of Remembrance took place in Springfield on October 24, 1999. Anne Woods, LICSW, chaired the Organizing Committee, and the committee met repeatedly over the year. Deborah Hayes, LICSW, had organized earlier versions of a memorial service in Greenfield, MA during the previous several years.

APPENDIX D

Education Subgroup

One-Day Postgraduate Education Course for ASN Renal Week 2001

"Supportive Care for the Renal Patient: Modern Palliative Care Principles Applied to the ESRD Patient"

Course Objectives

The goal of this program is to present a "renal" version of the American Medical Association's Education for Physicians on End-of-Life Care Program. At the completion of this program the participant should be able to:

- 1) explain what renal palliative care is and how it differs from routine ESRD patient care;
- 2) communicate more effectively to discuss difficult issues with patients and families;
- 3) use evidence-based protocols and algorithms for palliative care;
- 4) discuss current literature in this field;
- 5) utilize a comprehensive list of resources on palliative care including journal references, Web sites, etc.;
- 6) employ a patient/family-centered approach to palliative care; and
- 7) develop a Renal Palliative Care program in his or her dialysis unit.

Course Co-Chairs

Richard Dart, MD, Marshfield Clinic, Marshfield, WI
Michael Germain, MD, Tufts University, Springfield, MA
Alvin Moss, MD, West Virginia University, Morgantown, WV

Session One: Introduction to Palliative Care; Communication Issues

| | |
|--------------|---|
| 7:00-8:00 am | Registration and Breakfast |
| 8:00-8:30 am | What is Palliative (Supportive) Care and Why is it Important to Nephrologists <i>(Ira Byock, MD, University of Montana, Missoula, MT)</i> |
| 8:30-9:00 am | Advanced Care Planning-Discuss Early and Often with Patients and Families <i>(Jean Holley, MD, University of Rochester, Rochester, NY)</i> |
| 9:00-9:30 am | Improving Palliative Care in Your Practice and Renal Care Program - A Simple Incremental Approach <i>(Marilyn Pattison, MD, Franciscan Health System, Tacoma, WA)</i> |

- 9:30-10:00 am **How to Incorporate Palliative Care into Your Practice and Dialysis Unit**
(Lewis Cohen, MD, Tufts University, Baystate Medical Center, Springfield, MA)
- 10:00-10:30 am **BREAK**
- 10:00-12:00 pm **Case-Based Interactive Workshop in Groups of Ten**
- Communication Skills** Videotape of nephrologist discussion with the patient/family. Examples of successful and unsuccessful interviews
- How to Break Bad News** Videotape of patient discussions will be shown. Role playing for different scenarios:
- 1) telling a patient they have ESRD and must start dialysis;
 - 2) asking for an advance directive from a dialysis patient;
 - 3) discussing discontinuation of dialysis; and
 - 4) reaching agreement on the goals of care for the dying ESRD patient.
- 12:00-1:30 pm **LUNCH**

Session Two: Practical Skills in Renal Palliative Care: Providing Comfort and Support to the ESRD Patient

- 1:30-2:00 pm **Principles of Pain Management in Patients with Renal Insufficiency: Pharmacokinetic Considerations**
(Richard Dart, MD, Marshfield Clinic, Marshfield, WI)
- 2:00-2:30 pm **Symptom Assessment and Management of Dialysis and Non-Dialysis Related Symptoms**
(Michael Germain, MD, Tufts University, Springfield, MA)
- 2:30-3:00 pm **Management of the Patient Who Withdraws from Dialysis**
(Carl Kjellstrand, Chicago, IL)
- 3:00-3:30 pm **Personalizing End-of-Life Discussions: The Role of Peer Counseling**
(Erica Perry, Richard Swartz, University of Michigan, Ann Arbor, MI)
- 3:30-4:00 pm **BREAK**

4:00-5:30 pm

**Case-based Discussions - What We Know about End-of-Life
Issues in Dialysis Patients: Ethical and Palliative Care
Principles - Review of the Literature**

*(Alvin Moss, MD, West Virginia University, Morgantown, WV and
faculty)*

*This course is sponsored by an unrestricted educational grant from The Robert Wood Johnson
Foundation.*

ENEC Learning Objectives

Education for Nephrologists in End-of-Life Care (ENEC)

Learning Objectives

Module 1: Gaps in End-of-Life Care

1. Describe the current state of dying in America
2. Contrast this with the way people wish to die
3. List the 3 most common causes of death in ESRD patients
4. List the most common characteristics of ESRD patients who elect to withdraw from dialysis and factors that most influence their decisions

Module 2: Giving Bad News

1. List 3 reasons why communication of bad news is important
2. List the clinical events in the course of ESRD that are most often considered “bad news”
3. Identify the 6-step protocol for delivering bad news and what to do at each step

Module 3: Advance Care Planning

1. Define advance care planning and why it is important
2. List the steps of advance care planning
3. List events in the course of ESRD when advance care planning should be updated
4. Identify pitfalls and limitations of advance care planning

Module 4: Pain Management

1. Identify different pain types (nociceptive and neuropathic) and common clinical presentations
2. How to assess pain to initiate intervention, using simple bedside methods
3. Factors that alter pain therapy in ESRD patients
4. How to adjust dosage based on re-assessment for effective management and toxicity

Module 5: Symptom Management

1. How to identify and manage adverse direct (toxic) and indirect analgesic side-effects
2. Identify variety of secondary symptoms that arise from pain therapy
3. How to manage the usual complications
4. How to identify symptoms that may be related to inadequate pain therapy

Module 6: Incorporating Palliative Care into your Dialysis Unit

1. Identify 3 reasons why palliative care must be incorporated into dialysis units as a standard of care
2. Discuss the ASN/RPA Guidelines for end-of-life care
3. List the major barriers to incorporating palliative care into dialysis units
4. List potential members of the team responsible for incorporation of palliative care and their distinctive roles

End-of-Life Care in Nephrology Seminar
Renal Physicians Association Annual Meeting
March 23, 2002 Washington, DC

AGENDA

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|----------------|--|
| 8:00-8:15 am | Introductions <i>Alvin Moss, MD</i> |
| 8:15-9:00 am | Communication and Advanced Care Planning in the Dialysis Unit <i>Jean Holley, MD</i> |
| 9:00-10:00 am | Incorporating Palliative Care into Your Dialysis Unit <i>Michael Germain, MD</i> |
| 10:00-10:30 am | BREAK |
| 10:30-11:30 am | Pain Management in ESRD <i>Richard Dart, MD</i> |
| 11:30-12:30 pm | Symptom Management in ESRD <i>Michael Germain, MD</i> |
| 12:30-1:00 pm | Q & A <i>All Faculty</i> |
| 1:00 pm | LUNCH |

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RPA/ASN Position on Quality Care at the End of Life

Initially adopted by RPA/ASN Boards of Directors, 4/14/97

Approved as revised by RPA/ASN Boards of Directors, 1/19/02

Executive Summary

The Renal Physicians Association (RPA) and the American Society of Nephrology (ASN) believe there is substantial need to educate all members of the medical community, including patients, families, physicians, and other health care professionals regarding what constitutes quality care at the end of life. This is an especially important concern for nephrologists, because nephrologists often treat patients with end-stage renal disease (ESRD) that either decline or withdraw from dialysis and wish to die naturally. The RPA/ASN believe that competent patients have the right to forgo dialysis based on the ethical principle of respect for patient autonomy and the legal right of self-determination, and that withholding or withdrawing dialysis of a competent patient at the request of the patient does not constitute physician-assisted suicide. It is the opinion of the RPA/ASN that after a decision is made to forgo dialysis, a palliative care approach is the optimal method of patient care. Palliative care includes pain and symptom management, advance care planning, and psychosocial and spiritual support to the patient and family. Nephrologists are encouraged to obtain education and skills in palliative care, so that they are comfortable addressing end-of-life issues with their patients. Dialysis facilities are also urged to develop protocols, policies, and/or programs to ensure that palliative care, including advance care planning, is conducted with their patients.

Background

Over 60,000 ESRD patients die per year with approximately 20 % of these deaths following a decision by the patient or the patient's surrogate to stop dialysis. The RPA/ASN believe that care at the end of life is an especially important concern for nephrologists, because nephrologists often treat patients with end-stage renal disease who either decline dialysis or withdraw from dialysis. In so doing, these patients express the wish to die naturally. The RPA/ASN believe that care of the dying renal patient is best provided by a multidisciplinary team, and for this reason, the RPA/ASN asked the American Nephrology Nurses' Association, the National Kidney Foundation Council of Nephrology Social Workers, and the Forum of ESRD Networks to work with them in preparing the initial version of this position statement. Similarly, because identifying and respecting patients' wishes is central to providing quality end-of-life care, the RPA/ASN invited the American Association of Kidney Patients to provide input to this position statement.

Definitions

Advance Care Planning A process of communication among the patient, his/her family and friends, and the health care team in which the patient's preferences for a surrogate and for future medical care are determined prospectively (preferably including the completion of a written advance directive), updated periodically, and respected when the patient no longer has the decision-making capacity to participate in medical decisions.

Advance Directive An oral or preferably written statement by a patient with decision-making

capacity expressing his/her preferences for a surrogate and/or for future medical care in the event he/she becomes unable to participate in medical decision-making. All 50 states have one or more laws recognizing written advance directives and the rights of patients to have their wishes respected. There are two types of written advance directives: a living will (an instruction directive in which the patient gives directions for future medical care); and a health care proxy (a proxy directive in which the patient designates a person to make decisions for him/her when the patient loses decision-making capacity). In some states the health care proxy is referred to as a medical power of attorney or a durable power of attorney for health care. In some states, both instruction and proxy directives may be combined into one advance directive form. All advance directives must comply with applicable state procedural and substantive laws.

Cardiopulmonary Resuscitation A procedure performed to attempt to support and restore ventilation and circulation in a patient experiencing cardiac arrest (asystole, ventricular fibrillation, or pulseless electrical activity) or respiratory arrest (cessation of respiratory effort). It includes establishment and maintenance of an airway, assisted ventilation, chest compressions, establishment of intravenous access, cardiac monitoring, administration of medications, defibrillation or other control of arrhythmias, and immediate care after resuscitation.

Hospice A team approach to treatment of the terminally ill patient, usually in the home, that uses the principles of palliative care to help meet the physical, psychological, social, and spiritual needs of the patient and family. Hospice treats the person, not the disease; considers the entire family the unit of care; and provides bereavement counseling for the family after the patient's death. Occasionally hospice is available in a residential facility when the patient is unable to receive hospice in the home because of the lack of a caregiver in the home.

Palliative Care Comprehensive, interdisciplinary care of patients and families facing a chronic or terminal illness focusing primarily on comfort and support. It affirms life and regards dying as a normal process. It neither hastens nor postpones death. It includes relief from pain and other distressing physical symptoms, and advance care planning. It integrates the psychological and spiritual aspects of patient care, and offers a support system to help the family cope during the patient's illness and in their own bereavement. The goals of palliative care are relief of suffering and maximization of quality of life.

Surrogate A person who has the legal authority to make decisions for a patient who lacks decision-making capacity. A surrogate is usually a family member, but may be a close friend. A surrogate should make treatment decisions for a patient based on either the patient's expressed wishes, or upon the patient's known values and beliefs (a process known as "substituted judgment"), or when these are unknown, upon the patient's best interests.

Terminal Illness Illness in which death is expected within six months.

RPA/ASN Position on Quality Care at the End of Life, Cont'd

Analysis

Most patients with ESRD who refuse dialysis or choose to stop it usually die in less than a month. Patients who stop dialysis die on average eight to twelve days later. By definition, these patients are terminally ill. It is generally agreed that the optimal method of providing end-of-life care for terminally ill patients is a palliative care approach. Nephrologists need to know how to incorporate a palliative approach into their treatment of patients to provide them with the best care possible. This statement describes this approach as it relates to nephrological care under three components: ethical and legal issues, treatment issues, and advance care planning.

Ethical and Legal Issues

Competent patients have the right to forgo dialysis based on the ethical principle of respect for patient autonomy and the legal right of self-determination. To exercise this right, patients need to have decision-making capacity, be fully informed about and understand the alternatives and the consequences of each, and be free from coercion. When a patient refuses dialysis, nephrologists should also consider whether there are reversible factors such as depression or dissatisfaction with one or more aspects of dialysis that are leading to the patient's request and that could be addressed. If, after examination of these factors and responding to them, when appropriate, and the nephrologist is satisfied that the patient's refusal of dialysis is informed and uncoerced, the nephrologist is obligated to respect the patient's wishes.

Withholding or withdrawing dialysis from a competent patient at the request of the patient or of an incompetent patient at the request of the surrogate does **not** constitute physician-assisted suicide. Inherent in the legal doctrine of informed consent is the right of competent patients to refuse unwanted treatments. This doctrine is firmly grounded in common law, constitutional law, and federal statute. Physicians are legally required to honor competent patients' treatment decisions. To do otherwise--for example, to force unwanted dialysis on a competent patient--constitutes medical battery.

Treatment Issues

The wishes of an informed and capable patient or, if the patient lacks decision-making capacity, his/her surrogate, are pivotal concerning dialysis treatment decisions. In responding to an ESRD patient/surrogate decision to forgo dialysis, the nephrologist is obligated to determine why the patient/surrogate is refusing dialysis to be sure the patient/surrogate correctly understands the information that has been presented to him/her and the consequences of the decision.

Questions that may be helpful in this evaluation are as follows:

- 1) Does the patient have decision-making capacity or is the patient's cognitive capacity diminished by depression, encephalopathy, or other disorder?
- 2) Why does the patient want to not initiate or stop dialysis?
- 3) Are the patient's perceptions about the technical or quality-of-life aspects of dialysis accurate?
- 4) Does the patient sincerely mean what he/she says or is the decision to refuse dialysis made to get attention, help, or control?

- 5) Can any changes in treatment or treatment modality be made that might improve life on dialysis for the patient?
- 6) Has the patient discussed this request with family, close friends, and/or clergy? What do they think about the patient's request? Is the patient cognizant of the implications of his/her requests on his/her family and close friends?
- 7) Would the patient be willing to continue dialysis while the factors responsible for the patient's request are being addressed?

Once a decision is made to forgo dialysis, the dialysis team should refer the patient to a hospice or adopt a palliative care approach to patient care. Patients and surrogates should be informed that death from uremia usually takes 8 to 12 days (or occasionally longer) depending on the circumstances, that death from uremia is usually a comfortable one in which the patient becomes increasingly somnolent and then dies, and that if dialysis is not initiated or is withdrawn it will be necessary to maintain salt and fluid restrictions so that pulmonary edema does not occur and mar the comfort of the dying process. Nephrologist/renal team involvement is strongly encouraged to maintain continuity in patient care. The team should take the following steps:

- encourage the patient to review his/her advance directive for any change that the patient may wish to make;
- institute whatever means are necessary to ensure patient comfort, including medications and measures for pain, nausea, agitation, myoclonus, pruritus, and dyspnea;
- encourage the patient to express his/her preferences with regard to the dying process, including site of death, persons desired to be present, funeral arrangements, etc;
- issue a Do-Not-Resuscitate order that applies to whatever setting the patient chooses to spend his/her final days;
- discuss with the patient and family contingencies for the final hours of the patient's life so that family or caregivers do not panic and call emergency medical services when the patient experiences a cardiopulmonary arrest; and
- address the needs of the family with regard to coping and grieving during the patient's dying process and bereavement after the patient's death.

Advance Care Planning

There is a presumption in favor of starting or continuing life-sustaining treatment, including dialysis, for patients who cannot and have not expressed their wishes. Hence, patients' preferences (and rights) to forgo dialysis in certain situations are usually difficult to respect unless patients have explicitly stated their preferences in advance or named surrogates to speak on their behalf. Therefore, the best way to be sure that a patient's wishes are known and can be respected after the patient loses decision-making capacity is to discuss with the patient (and his/her surrogate) in advance his/her preferences for medical treatment in the future. This discussion is called advance care planning. The product of this discussion is a patient's advance directives which are preferably given in writing but may include oral instructions about a patient's wishes for end-of-life care and designation of a surrogate. If the patient or surrogate

gives oral advance directives, it is often helpful for the physician to document them in the progress notes in the patient's chart.

In the process of advance care planning, some of the issues that need to be specifically discussed are the following:

- circumstances when advance directives should be followed or ignored; and the degree of leeway the patient would wish to give his surrogate and physician in following or not following the advance directive explicitly, particularly when a new treatment becomes available;
- wishes for withdrawal or continuation of dialysis under various medical conditions;
- medical decisions surrogates are likely to face during the patient's incapacity such as whether to use cardiopulmonary resuscitation, mechanical ventilation, and tube feedings;
- the patient's values about independence, control, quality of life, suffering, additional treatment to reduce uncertainty about prognosis, and being a burden on the family; and
- the setting and circumstances under which the patient would prefer to die, i.e., at home versus in the hospital, a palliative care approach versus an aggressive approach, etc.

Because advance directives are needed to be able to respect incompetent patients' wishes, dialysis facilities have been strongly encouraged to develop protocols, policies, and/or programs for providing advance care planning to their patients. To be sure that advance care planning has occurred prior to a medical crisis, dialysis facilities are urged to incorporate advance care planning into the ongoing discussion with patients of their long-term care plan and to update the planning, as needed, whenever patients' medical conditions change. Patients generally expect that their nephrologist will introduce the topic, but other members of the renal team need to be involved in the educational process necessary to prepare the patient and surrogate for the discussion. For advance care planning to be effective, research has shown that the renal team must be educated so that they are comfortable in addressing end-of-life issues.

To respect the wishes of patients who prefer not to undergo cardiopulmonary resuscitation, nephrologists shall issue Do-Not-Resuscitate (DNR) orders for their patients who request them. These orders shall be issued in the dialysis unit in a manner that respects patient confidentiality and yet ensures that those treating the patient are aware of them. As noted above, physicians are legally required to honor competent patients' treatment decisions. To do otherwise, i.e., to perform unwanted cardiopulmonary resuscitation on a competent patient, constitutes medical battery. It is important to note, however, that a DNR order does not preclude other standard measures in dialysis treatment such as fluid resuscitation for intradialytic hypotension. A DNR order only becomes effective when the patient has experienced a cardiac or respiratory arrest (see Definitions section under cardiopulmonary resuscitation). When a patient with a DNR order is hospitalized or admitted to a nursing home, the existence of the DNR order shall be communicated to the ambulance transport team and to the receiving facility to ensure respect for the patient's wishes.

Research studies of cardiopulmonary resuscitation in patients with renal disease, including ESRD, have indicated that the outcomes of cardiopulmonary resuscitation for these patients are usually poor. Many dialysis patients are misinformed about the outcomes of cardiopulmonary resuscitation because of what they have seen on television. Therefore it is necessary for nephrologists and other members of the renal team to educate dialysis patients about the likely outcome of cardiopulmonary resuscitation based on patients' particular medical conditions.

Recommendations

- 1. All members of the renal health care team including nephrologists, nephrology nurses, nephrology social workers, and renal dietitians should obtain education and skills in the principles of palliative care to ensure that ESRD patients and families receive multidimensional, compassionate, and competent care at the end of life.**
- 2. In responding to an ESRD patient/surrogate decision to forgo dialysis, the nephrologist is obligated to determine, if possible, why the patient/surrogate has decided to forgo dialysis to be sure the patient/surrogate correctly understands the information that has been presented to him/her and the consequences of the decision. Once the nephrologist is satisfied that the patient's decision to forgo dialysis is informed and uncoerced, the nephrologist should respect the wishes of the patient/surrogate.**
- 3. After a decision is made to forgo dialysis, the renal team should refer the patient to a hospice or adopt a palliative care approach to patient care. In either case, the nephrologist and other members of the renal team should remain active in the patient's care to maintain continuity of relationships and treatment.**
- 4. Nephrologists and other members of the renal team should obtain education and skills in advance care planning so that they are comfortable addressing end-of-life issues with their patients.**
- 5. Dialysis facilities should develop protocols, policies, and/or programs to ensure that advance care planning is conducted with their patients.**
- 6. Nephrologists should explicitly include in their advance care planning with patients/surrogates information about the outcomes of cardiopulmonary resuscitation for patients with ESRD and a discussion of patients' preferences regarding cardiopulmonary resuscitation if cardiac arrest were to occur while patients are undergoing a dialysis treatment. The RPA/ASN encourages dialysis facilities to develop policies and procedures for respecting the wishes of dialysis patients with regard to cardiopulmonary resuscitation in all settings including in the dialysis unit.**

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End Notes

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