

Support of Renal Patients and Families Facing End-of-Life Care Decisions: A Nephrology Social Worker's Reflection

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The delivery of health care in the United States is undergoing critical change. Actualization of social work contributions to optimum healthcare is a focus. This article describes palliative care, end-of-life measures and interdisciplinary team function. The Renal Physicians Association's Ten Recommendations for Shared Decision-Making are addressed, and the recently signed Patient Protection and Affordable Care Act's section on Patient Decision Aids and Preference Sensitive Care will be referenced. A case study presentation is included with questions designed to stimulate critical thinking.

INTRODUCTION

The delivery of healthcare in the United States is rapidly evolving and the social work profession must move with changes in order to meet the needs of patients, their families, and the general health care community. With recent passage of the Patient Protection and Affordable Care Act, and subsequent state funding requirements for health care exchanges emerging, further sculpting of the roles of the nephrology social worker becomes a necessity. A significant problem to be addressed is the growing aging population (McKevitt, P., et al, 2007). The number of "baby boomers" reaching retirement age becomes greater and greater. The aged are living longer as life expectancy increases. While this is a positive testimony to the level of care provided in the nation, added responsibilities will face the social worker in the increasingly complex healthcare milieu.

Chronic illness, by its nature, is not responsive to "curative treatment." Rather, the function of clinical management and care is the alleviation of pain and symptoms, and promotion of optimal quality of life (Scham, A., 2011). The social worker's role is large. The families' needs are large. In the end, how will changes in federal legislation affect long-term goals? Answers are still being formulated. The discussion presented here will address the critical importance of shared decision-making with renal patients and families to protect autonomy and promote optimal informed consent in care.

PALLIATIVE CARE

Palliative care can be described as the relief given to a patient experiencing the symptoms of a chronic condition or that care which provides comfort for those experiencing disease from which there is no cure (Scham, A., 2011). Families have many of these same needs and they, too, must be addressed. Optimal quality of life for patients and families are the goals to be achieved. Nephrology social worker functions essential to the provision of palliative care are psychosocial assessment, patient and family counseling, and involvement of families in decision-making with the patient.

In other words, social workers are advocates in addressing optimal life functioning of the patient and family system within the overall community. Social workers are compelled in a limited time frame to find ways to practice to address the needs of many (Woods, A., et al., 1999).

Nephrology social workers are integrally involved with the outcomes of dialysis for patients, which include dialysis adequacy, vascular access patency, and adherence to treatment recommendations. Palliative care, symptom and pain management become foci for intensive psychosocial interventions (consider the Kidney Disease Quality of Life (KDQOL) Survey). The entire interdisciplinary team (IDT) works together, each member having their own specific contributions to make in the overall plans of care.

HOSPICE VERSUS PALLIATIVE CARE

Hospice Care differs from Palliative Care in that the palliation is provided for individuals identified by a physician as having a prognosis of six months or less under definition from The Centers for Medicare and Medicaid (CMS). There are seven core prognostic indicators for hospice care (Stuart, B., et al, 1995). These are: 1) physical decline; 2) multiple comorbidities; 3) dependence in most activities of daily living (ADLS); 4) weight loss; 5) serum albumin <2.5 gm/dl; 6) Karnofsky score of equal to or less than 50%; and 7) resignation to disease process. Ethical principles of beneficence (for the greatest good) and non-maleficence (do no harm) apply to patient care, even as a patient approaches end of life circumstances. The growing paradigm of palliative care and end-of-life discussion creates an environment where quality of life is taken into consideration along with quantity of life.

END STAGE RENAL DISEASE AND PALLIATIVE CARE

Chronic kidney disease (CKD) patients who have reached stage 5 (requiring either dialysis or kidney transplant) will always require a treatment option to alleviate (if not ameliorate) symptoms of kidney failure, unless they choose hospice. By their very nature, patients with ESRD qualify for palliative care, insofar that they will need relief from pain and suffering related to their condition. In separate interviews with patients, this author has become aware of the impact of patient-specific symptoms (troubled breathing, edema, feeling washed out or drained), which clearly affect the patients' perspectives of their own quality of life and their attitude towards treatment. Social workers help bridge communication among team members to address these symptoms and to provide relief—whether medication, lengthened treatment times, adherence to diet and

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treatment recommendations—all the while striving to keep the patients and families at the center of the plan of care. The principle of autonomy (self-directing) is essential in the quality care of the renal patient. And as such, when patients face end of life decisions, that patient autonomy is crucial in the conversations held with physician and interdisciplinary team (Cohen, L. M., et al., 2009).

In recent years, the principle of shared decision making has come to the forefront, with the aid of the Renal Physician Association collaboration, to promote the rights of patients to be fully informed about decisions related to their care and the ability to ultimately “choose the best health-related values that can be realized in the clinical situation” (Lelie, 2000, p. 82). Complications in communication arise when the goals of the decision-maker do not concur with the options presented by the clinical team. Patients are human beings with inherent rights and desires for an optimal quality of life. Give-and-take dialogue, active listening and intention are required for meaningful plan of care discussion to ensue.

ESRD AND SHARED DECISION MAKING.

In 1999, the Renal Physician Association and the American Society of Nephrology’s working group, the RPA/ASN Group, formed an expert consensus opinion called the Shared Decision-Making in Dialysis Opinion. This consensus has grown and evolved into the publication, *Shared Decision-Making in the Appropriate Initiation and Withdrawal from Dialysis, Clinical Practice Guideline, Second Edition* (RPA, 2010). The authors outlined ethical considerations in dialysis decision-making, to include: medical indications, patient preferences, quality of life and the contextual features. For nephrology social workers, the contextual features outline the precise areas of concentration for the growth of the role of the renal social worker: “when medical needs are embedded in larger social, institutional, economic context...decisions to be made with respect to psychological, emotional, financial, legal, scientific, educational and spiritual assessment” (RPA, 2010, p. 20).

Giving consideration to the contextual features of shared decision-making, this author finds the RPA’s Ten Recommendations for Establishing a Shared Decision-Making Relationship useful:

1. Develop physician-patient relationship for shared decision-making.
2. Fully inform acute kidney injury (AKI), stage 4 and 5 chronic kidney disease (CKD) and end stage renal disease (ESRD) patients about their diagnosis, prognosis and all treatment options.
3. Give all patients with AKI, stage 5 CKD or ESRD an estimate prognosis specific to their overall condition. Consider the “surprise” question (Moss, A., et al., 2008): “Would I be surprised if this patient died in the next year?” Risk factors with poor prognosis: age, comorbidities, severe malnutrition and poor functional status (consider core indicators for hospice referral)
4. Institute advance care planning.
5. If appropriate, forgo (withhold initiating or withdraw ongoing) dialysis for patients with AKI, CKD 5 or ESRD in certain well-defined situations.
6. Consider forgoing dialysis for AKI, CKD or ESRD patients who have a very poor prognosis or for whom dialysis cannot be provided safely (consider risk factors for poor prognosis, clinician’s response of “No, I would not be surprised” to the surprise question).
7. Consider a time-limited trial of dialysis for patients receiving dialysis, but who have an uncertain prognosis, or for whom a consensus cannot be reached without providing dialysis.
8. Establish a systemic due process approach for conflict resolution if there is disagreement about what decision should be made with regard to dialysis.
9. To improve patient-centered outcomes, offer palliative care services and interventions to all AKI, CKD and ESRD patients who suffer from burdens of their disease.
10. Use a systemic approach to communicate about diagnosis, prognosis, treatment options and goals of care.

In the dialysis setting, social workers have the opportunity to facilitate these recommendations in the roles they perform on a daily basis with patients. They assist patients in their preparedness for shared decision making discussions by advocacy on patients’ behalf with the interdisciplinary team. While the physician-patient relationship is respected, often patients may pose questions requiring clarification of language and context. Social workers engage patients and families in meaningful discussion, especially with regard to advance care planning (Yuscak, 1999). Social workers help patients feel comfortable in identification of persons who may serve as health care proxies. They provide education to patients and families about advance directives, and they promote clarity and understanding to help patients identify their wishes. Even in those cases where patients may opt not to have an advance directive, open dialogue may generate thoughts in patients about what truly constitutes a meaningful quality of life. The involvement of family in discussion with the patients and the surrogates are crucial, as they will lend support to surrogates in their roles, and promote acceptance of the patient’s wishes for care. Also, social workers explore with patients their goals for an ideal quality of life, and what strengths and coping mechanisms patients possess in order to attain the ideal lifestyle. They provide a quality of life survey (KDQOL) to help patients identify areas where perhaps their lifestyle may be enhanced and function may be restored or modified to meet changing needs. From a psychosocial perspective, they can also help patients delineate strengths, thoughts and behaviors which

may modify the patients' perception of care and their role as a partner in the process.

An especially difficult task is to navigate communication where there is a conflict of wishes in the plan of care. There are situations where a patient may wish not to initiate dialysis, even when referred from physician or admitted in an acute care setting with renal failure (Davison, S., 2010). In a critical acute care setting, a family may wish to continue a treatment that is no longer considered clinically sound (deemed "futile care"). Having served on a hospital Palliative Care Team for eight years, this writer has reviewed many patient situations which have required examination of clinical, fiscal and emotional facets involved. Answers are difficult to create when such conflicts arise; often, patient care and patient wishes meet a standstill.

Consider the following patient care scenario:

Mr. A presented as a 79-year-old married gentleman with past medical history significant for hypotension, hyperlipidemia, laryngeal cancer, carotid endarterectomy, abdominal aortic aneurysm, Type II diabetes, insulin dependent, GI bleed, peripheral vascular disease, COPD, CKD stage 5 hemodialysis-dependent, and dementia. Past surgical history is significant for repair of abdominal aortic aneurysm, carotid endarterectomy, IVC filter placement, laryngeal CA, status post resection. Mr. A was nonverbal and poorly responsive. He responded only to pain stimuli. Patient also had a PEG tube for feedings. Blood pressure ranged from 80-to-90 systolic, with a mean blood pressure of 51-to-62. Mr. A required norepinephrine to support blood pressure within the confines of the critical care unit of the hospital. Though Mr. A was not intubated, but on a rebreather oxygen mask, at that time, Mr. A could not be weaned from norepinephrine.

Mr. A had been a hemodialysis patient for several years in a dialysis unit located within the hospital setting. Mr. A's dementia preceded initiation of dialysis, so his wife, Mrs. A, primary proxy and decision-maker, made the decision with the physician to initiate hemodialysis treatment, and signed all appropriate consents. Prior to this CCU admission, Mr. A had been bedbound, living in his daughter's home with support from his wife to perform all personal care and activities of daily living (including feeding). Mr. A required stretcher transportation for dialysis, and he required a one-to-one sitter during dialysis treatments. Mr. A had been prone to bouts of combativeness and agitation, often pulling out his AVF needles and lines. He had been at risk for exsanguination on four occasions within one calendar year. Mrs. A acknowledged the problem of such agitation. She did not agree to a sedative, but sat one-to-one with her husband at bedside during dialysis. Many attempts to counsel and support Mrs. A were made, yet she maintained her "I'm not going to let him die" decision. Despite all discussions with the critical care team, the palliative care team, the Biomedical Ethics Committee and the dialysis IDT team, Mr. A died in critical care, without order for Hospice, with-

out order to stop dialysis, and without comfort or resolution for wife and family. All therapeutic interventions offered failed. The wife's unwavering pursuit of full aggressive treatment did not appear to improve her husband's quality of life or longevity. This author reviewed the events, analyzing how this scenario might have had a different outcome, if the RPA Shared Decision-Making Guidelines were utilized at initial engagement phase of the clinical relationship. This author will delineate a view of how the relationship may have taken a different course after the next section.

Recent Legislative Changes.

The Patient Protection and Affordable Care Act of the Legislative Council of the 111th Congress, 2nd session addresses these important shared decision-making facets in Section 936 [42U.S.C. 299b-36].

Program to Facilitate Shared Decision-making.

"(a) Purpose. – The purpose of this section is to facilitate collaborative processes between patients, caregivers or authorized representatives, and clinicians that engages the patient, caregiver or authorized representatives with information about trade-offs among treatment options, and facilitates the incorporation of patient preferences and values in the medical plan" (PPACA, § 936 [42 U.S.C., 299b-36] p. 450).

There is particular mention of the necessity of the Patient Decision Aid (educational tool) and the Preference Sensitive Care, meaning "medical care for which the clinical evidence does not clearly support one treatment option such that the appropriate course of treatment depends on the values of the patient or the preferences of the patient, caregivers or authorized representatives regarding the benefits, harms, and scientific evidence for each treatment option, the use of such care should depend on the informed patient choice among clinical appropriate treatment options" (PPACA, § 936 [42 U.S.C., 299b-36] p. 450). While there is no clear cut answer to the issue of futile care, the Preference Sensitive Care appears to support the right of the family to decide a course of treatment despite the absence of empirical clinical indication.

Federally funded agencies will be mandated to create patient decision aids to help patients, families and authorized representatives to clearly comprehend all treatment choices, risks and benefits involved in choosing a plan of care. This is particularly important with regard to Preference Sensitive Care, where choices may not appear congruent with clinical indications and project uncertain outcomes for care. (See RPA's Ten Recommendations, Recommendation No. 8.) The authors of the RPA Manual have great vision, and time will tell how the authors of the Patient Protection and Affordable Care Act will be able to protect the autonomy and well-being of the aging renal patient.

This author wishes to outline a possible scenario which may have helped Mrs. A and her family to grapple with the difficult decisions facing them in the care of Mr. A, and how the

nephrology social worker may have evolved her clinical practice to better engender family participation and agreement on goals for Mr. A, following the Ten Recommendations for Establishing a Shared Decision-Making Relationship:

1. **Recommendation No. 1:** Establishing the relationship with the patient and family and identifying concerns. Mr. A, who was unable to engage in detailed discussion about his plan of care, was dependent upon his wife, Mrs. A, who had order of priority for making decisions on his behalf. She has the right of decision for her husband, and clear communication about the concept of Shared Decision-Making may have helped her feel as an equal partner in this process. Her views needed to be clearly appreciated and validated.
2. **Recommendation No. 2:** The nephrology social worker intervenes here to ask, “What have you been told about your husband’s condition? Do you have any questions which need clarification by the physician? How did you handle being given this information? Are you aware of all options available to you?” Perhaps an approach such as this might have stimulated the consideration of alternative options for care of the patient.
3. **Recommendation No. 3 (The Surprise Question):** Explore Mrs. A’s expectations of care. Does she feel they correspond with information given to her by the treatment team? Are there any unspoken emotions about her husband’s condition, and is Mrs. A safe enough to reveal them in the relationship? Here, the Gestalt “I and Thou, Here and Now” would possibly create an atmosphere of resonance—and trust. Be willing to stay with the emotions and to help Mrs. A to experience the feelings in a safe, therapeutic environment of acceptance. “Gestalt Therapy places great importance on the chewing up or integration of experience. It is assumed that once an experience is assimilated, it recedes into the background, freeing up energy for a new figure to emerge. Once closure has been reached and can be fully experienced in the present, the preoccupation with the old incompleteness is resolved and one can move on to current and future possibilities” (Melnick and Roos, 2007, p. 97) It is this author’s opinion that Mrs. A may have greatly benefited from a Gestalt encounter in the therapeutic alliance with the social worker.
4. **Recommendations No. 4 and No. 5:** A detailed discussion about advance directive education may have been initiated with a question about Mrs. A’s beliefs and values regarding treatment at the end-of-life. Here the Contextual Features of Shared Decision-Making can be explored in more detail to help Mrs. A to create a conceptualization of end-of-life care which she may find acceptable (RPA, 2010, p.19). She should be given the opportunity to include all family members in later discussion to clarify their views and identify common goals for care.
5. **Recommendations No. 6 and No. 7:** The nephrology social worker would provide ongoing support to Mrs. A and her family as they review all available options for care. Here the proposed Patient Decision Aids can help the family communicate more effectively with their treatment team and have a greater understanding of treatment options available, including initiation of palliative care, hospice care and/or consideration of withdrawal from treatment with full informed consent. The Preference Sensitive Care option should also be fully examined with the patient’s family, with full disclosure of risks and benefits of care in a futile situation, in order to help the family come closer to making a decision that they would want for their loved one (PPACA, § 936 [42 U.S.C., 299b-36] p. 450).
6. **Recommendations No. 8, No. 9 and No. 10:** The family and treatment team need to seek mediation when conflicts of opinion arise. The nephrology social worker needs to advocate for the family and help support them in their views—but also strive to clarify language to enhance the family’s understanding of the what treatment can be provided effectively in the given clinical situation. Once a decision is reached, the family needs to be supported in their right of decision on behalf of the patient.

Families and authorized representatives have a great stake in the decision-making process, as often these persons are entrusted with the responsibility of carrying out the patient’s wishes for care and to clearly communicate their needs with all involved clinicians in this process (Melhado, L., & Fowler-Byers, J., 2011). Even when an advance directive exists, such as a Power of Attorney document or a Do Not Resuscitate order, the moment that one needs to give authorization for a treatment (or to withhold it) can prove to be extremely challenging to the bearer of the responsibility. Family dynamics play significant roles in the assignation of responsibility to the appointed loved one and facilitation of the decision-making process. These moments, where family members reach back and remember how their loved one would wish to be treated in medical crisis can stir many emotions and transference issues (Wood, A., et al., 1999). Depending upon the family structure, myths, and code of conduct and roles ascribed to all members within the family system, coming to clear, agreed-upon choices in care can be challenging without emotional support and mediation among the patient, the family and the IDT team (King, K., 2007; Weiner, S., 2008). Nephrology social workers need to take time with the patient and family, to establish trusting rapport and a safe haven for patient and family. All perspectives need to be evaluated and reality tested with each other in order to determine a clear pathway for communication.

VISION FOR NEPHROLOGY SOCIAL WORK IN THE 21ST CENTURY

Nephrology social workers have a great number of tasks as they move into the 21st century. They need to be ever aware of patients' and families' rights to exercise autonomy and choice in decisions affecting plan of care. However, as fiscal and legislative changes are brought forth, how much leverage would an individual or family have in selection? The recent Supreme Court decision to uphold the Patient Protection and Affordable Care Act may hold great promise for patients who wish to retain their autonomy as the final decision-makers in their plans of care. The sections describing the Patient Decision Aids and the Preference Sensitive Care clearly highlight the importance of patient decision in end-of-life care, and would suggest an atmosphere which supports self-determination. The litmus test of efficacy of the new legislation began January 1, 2014. This author's vision of nephrology social work is one of enhancement of patient advocacy, clinical sensitivity, and integral involvement in change on the national level for sufferers of kidney disease. No matter what circumstances they face, nephrology social workers possess multifaceted skill sets which will serve them effectively in the years and generations to come.

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