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The Journal of Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of nearly 1,000 social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

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JOIN THE *JNSW* EDITORIAL BOARD

The Journal of Nephrology Social Work Editorial Board is comprised of nephrology social work experts who engage in research, policy analysis, and clinical practice. The board members include university faculty members and social work clinicians who are leaders and innovators in the field.

The Journal of Nephrology Social Work is always interested in attracting talented CNSW members to serve as Editorial Board members to help with the planning, solicitation, and review of manuscripts for publication.

If you are interested in submitting your resume for consideration to become a member of the Editorial Board, please contact Steve Bogatz, MBA, MSW, LCSW, NSW-C, by email (**SBogatz@aol.com**) or phone (203.639.2880 x24).

CALL FOR MANUSCRIPTS

The Editorial Board of *The Journal of Nephrology Social Work* encourages the submission of original manuscripts. The *JNSW* contains articles addressing contemporary issues/topics relevant to nephrology social work. Authors may wish to address any of the following topics, which are listed as guidelines:

- Social Work Outcomes
- Kidney Transplant
- Pediatric Issues
- End-of-Life Concerns
- Sleep Disorders
- Sexual Functioning
- Aging and Gerontological Issues
- Disaster Preparedness
- Comorbid Illnesses
- Home Dialysis Modalities
- Professional Roles
- Rehabilitation
- HIV/AIDS
- Quality of Life
- Ethics

Please email manuscripts to: **jnsw@kidney.org**. Questions? Contact Editor Steve Bogatz, MBA, MSW, LCSW, NSW-C, at **SBogatz@aol.com** or by phone (203.639.2880 x24).

INSTRUCTIONS FOR AUTHORS

The Journal of Nephrology Social Work (*JNSW*) is the official publication of the Council of Nephrology Social Workers of the National Kidney Foundation, Inc. Its purpose is to stimulate research and interest in psychosocial issues pertaining to kidney and urologic diseases, hypertension, and transplantation, as well as to publish information concerning renal social work practices and policies. The goal of *JNSW* is to publish original quantitative and qualitative research and communications that maintain high standards for the profession and that contribute significantly to the overall advancement of the field. The *Journal* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

ETHICAL POLICIES

Conflict of Interest. The *JNSW* fully abides by the National Association of Social Workers' (NASW) Code of Ethics, (**http://www.socialworkers.org/pubs/code/code.asp** ; see clause 5.02 (a)-(p) focused on research). This portion of the code pertains to conflicts of interest, research with human participants, and informed consent. Per the code, "Social workers engaged in evaluation or research should be alert to and avoid conflicts of interest and dual relationships with participants, should inform participants when a real or potential conflict of interest arises, and should take steps to resolve the issue in a manner that makes participants' interests primary." Authors who submit manuscripts to *JNSW* must disclose potential conflicts of interest which may include, but are not limited to, grants, remuneration in payment or in kind, and relationships with employers or outside vendors. When in doubt, authors are expected to err on the side of full disclosure. Additional information about conflicts of interest may be obtained via the International Committee of Medical Journal Editors' Uniform Requirement for Manuscripts Submitted to Biomedical Journals (URMSBJ): Ethical Considerations in the Conduct and Reporting of Research [**http://www.icmje.org/ethical_4conflicts.html**].

Human/Animal Rights. Regarding human rights, the NASW code is specific: "Social workers engaged in evaluation or research should carefully consider possible consequences and should follow guidelines developed for the protection of evaluation and research participants. Appropriate institutional review boards should be consulted…. Social workers should take appropriate steps to ensure that participants in evaluation and research have access to appropriate supportive services…. Social workers engaged in evaluation or research should protect participants from unwarranted physical or mental distress, harm, danger, or deprivation." In the unlikely event that animals are involved in research submitted to *JNSW*, per URMSBJ, "authors should indicate whether the institutional and national guide for the care and use of laboratory animals was followed."

Informed Consent. The practice of informed consent is mandatory for ethical research. In accordance with the NASW code, "Social workers engaged in evaluation or research should obtain voluntary and written informed consent from participants…without any implied or actual deprivation or penalty for refusal to participate; without undue inducement to participate; and with due regard for participants' well-being, privacy, and dignity. Informed consent should include information about the nature, extent, and duration of the participation requested and disclosure of the risks and benefits of participation in the research. When evaluation or research participants are incapable of giving informed consent, social workers should provide an appropriate explanation to the participants, obtain the participants' assent to the extent they are able, and obtain written consent from an appropriate proxy. Social workers should never design or conduct evaluation or research that does not use consent procedures, such as certain forms of naturalistic observation and archival research, unless rigorous and responsible review of the research has found it to be justified because of its prospective scientific, educational, or applied value and unless equally effective alternative procedures that do not involve waiver of consent are not feasible. Social workers should inform participants of their right to withdraw from evaluation and research at any time without penalty."

PEER REVIEW PROCESS

Manuscripts submitted to *JNSW* are peer-reviewed, with the byline removed, by at least two Editorial Board members. The review process generally takes two to three months. *JNSW* reserves the right to edit all manuscripts for clarity or length. Minor changes in style and clarity are made at the discretion of the reviewers and editorial staff. Substantial changes will only be made with the primary author's approval.

Exclusive Publication. Manuscripts are accepted for review with the understanding that the material has not been previously published, except in abstract form, and is not concurrently under review for publication elsewhere. Authors should secure all necessary clearances and approvals prior to submission. Authors submitting a manuscript do so with the understanding that, if it is accepted for publication, the copyright for the article, including the right to reproduce the article in all forms and media, shall be assigned exclusively to the National Kidney Foundation. The publisher will not refuse any reasonable request by the author for permission to reproduce any of his or her contributions to the *Journal*.

A submitted manuscript should be accompanied by a **letter** that contains the following language and is signed by each author: "**In compliance with the Copyright Revision Act of 1976, effective January 1, 1978, the undersigned author(s) transfers all copyright ownership of the manuscript entitled ___________ to *The Journal of Nephrology Social Work* in the event this material is published.**"

To qualify as an original manuscript, the article or a version of the article must not have been published elsewhere. The author(s) must inform the editor if the manuscript is being reviewed for publication by any other journals. Once accepted for publication by the editor, the author(s) cannot make revisions to the manuscript.

TYPES OF MANUSCRIPTS BEING SOUGHT

Research and Review. The *JNSW* welcomes reports of original research on any topic related to renal social work. The editors will also consider manuscripts that document the development of new concepts or that review and update topics in the social sciences that are relevant to professionals working in the field of renal social work.

Reports and Commentary. The *JNSW* welcomes manuscripts that describe innovative and evaluated renal social work education programs, that report on viewpoints pertaining to current issues and controversies in the field, or that provide historical perspectives on renal social work. Commentaries are published with the following disclaimer: "The statements, comments or opinions expressed in this article are those of the author, who is solely responsible for them, and do not necessarily represent the views of the Council of Nephrology Social Workers or the National Kidney Foundation."

Reviews. Review articles, in traditional or meta-analysis style, are usually invited contributions; however, letters of interest are welcome.

Original Research. Full manuscript format should include: introduction, method, results, and discussion of original research. The Method section needs either a declaration of IRB approval or exemption. Length should usually not exceed 15 double-spaced pages, including references.

Clinical/Research Briefs. Abbreviated manuscript format presents clinical practice experience, preliminary research findings (basic or clinical), or professional observations in a shortened report form. Length should usually not exceed six double-spaced pages.

Practical Aspects Section. Contributions to this section are detailed protocols, forms, or other such materials that are successfully utilized for delivery of outcomes-based clinical social work services.

Case Studies. These detailed scenarios should illustrate a patient care situation that benefited from clinical social work intervention. Typically, they should consist of a brief clinical and psychosocial history, and a detailed intervention plan with discussion of recommendations focused toward practical application.

Letters to the Editor. Letters should be restricted to scientific commentary about materials published in the *JNSW* or to topics of general interest to professionals working in the field of renal social work.

MANUSCRIPT SUBMISSION PROCESS

Important Update: JNSW now has an optional MS Word template available for preparing your article. Using it will enhance the production process. To obtain this template, send an email with "Template Needed" in the subject line to **jnsw@kidney.org**.

Note: A sixth edition of the APA style guide has been published. However, there were errors in the first printing which were corrected in subsequent printings. For now, *JNSW* will adhere to the fifth edition.

Manuscript Format. Manuscripts should be formatted according to the rules laid out by the *Publication Manual of the American Psychological Association, Fifth Edition*. What follows is a brief synopsis of the broader style points used by the APA.

Manuscripts should conform to the following guidelines: Text should be double-spaced, set in 12-point type (preferably Times New Roman) and have 1-inch margins along all sides of every page. Starting with the title page, pages should be numbered in the upper, right- hand corner and should have a running head in the upper left-hand corner. The running head should be a shortened version of the manuscript's title and should be set in all uppercase letters. The first line of every paragraph in the manuscript should be indented, as should the first line of every footnote.

Order of the Manuscript Sections

1) Title page
2) Abstract
3) Text
4) References
5) Appendices
6) Author note
7) Footnotes
8) Tables
9) Figures
10) Figure captions

Title Page. The manuscript's title page should contain the title of the manuscript and the name, degree, and current affiliation of each author. Authors are generally listed in order of their contribution to the manuscript (consult the APA style guide for exceptions). The title page should also contain the complete address of the institution at which the work was conducted and the contact information for the primary author. A running head (a shortened version of the manuscript's title) should be set in the upper left-hand corner of the page, in all uppercase letters. Page numbering should begin in the upper right-hand corner of this page. With the exception of the page numbers and running heads, all text on the title page should be centered.

Abstract. The manuscript's abstract should be set on its own page, with the word "Abstract" centered at the top of the page. The abstract itself should be a single paragraph with no indentation and should not exceed 120 words. All numbers—except for those that begin a sentence—should be typed as numerals. Running heads and page numbers should continue from the title page.

Text. The text (or body) of the manuscript should begin on a new page, after the abstract. The title of the manuscript should be set at the top of the first page, centered and double spaced. Running heads and page numbers should continue from the abstract.

References. The reference list should begin on a new page, with the word "References" centered at the top of the page. Entries should be listed alphabetically, according to the primary author's last name, and should conform to APA style (see sample references provided). Running heads and page numbers should continue from the text. Do not use software functions that automatically format your references. This can cause the references or formatting to be lost when the manuscript is typeset.

Appendices. Each appendix should begin on a new page and should be double spaced. The word "Appendix" and the identifying letter (A, B, C, etc.) should be centered at the top of the first page of each new appendix. Running heads and page numbers should continue from the references.

Author Note. *JNSW policy is to include an Author Note with Disclosure Information at the end of the article.*

It should begin on a new page with the words "Author Note" centered at the top of the page. Each paragraph should be indented. Running heads and page numbers should continue from the last appendix. Consult the APA style guide for further details on the structure of an author note.

Authors must include a two-sentence disclosure. The author note should include this disclosure (source of funding, affiliation, credentials) and contact information: "address correspondence to" primary author.

Footnotes. A footnote should be indicated in the text of the manuscript with a superscript Arabic numeral to the right of the pertinent material. The footnotes should be listed on a separate page with the word "Footnotes" centered at the top of the page. They should be listed sequentially, with the first line of each note indented. Running heads and page numbers should continue from the author note. Do not use software functions that automatically format your footnotes. This can cause the footnotes or formatting to be lost when the manuscript is typeset.

Tables. All tables should be double spaced and each should begin on a separate page. Tables are numbered sequentially according to the order in which they are first mentioned in the manuscript (Table 1., Table 2., etc.) and are given an appropriate title that is centered at the top of the page. Table Notes should be a single, double-spaced paragraph, set after the last line of data. The first line should be flush and begin with the word "Note." Please submit all table files in black and white (grayscale), high resolution format.

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Figures. Figures are also numbered consecutively, according to the order in which they appear in the manuscript. The convention Figure 1., Figure 2., Figure 3., etc. should be followed. In cases where the orientation of the figure is not obvious, the word TOP should be placed on the page, well outside the image area, to indicate how the figure should be set. If any figure has been previously published, the author is required to submit a copy of a **letter of permission** from the copyright holder, and must acknowledge the source of the figure in the manuscript's reference section. Running heads and page numbers should continue from the tables. Please submit all figure files in black and white (grayscale), high-resolution format.

Figure Captions. Each figure in the manuscript must have a caption, formatted as follows:

Figure 1. Exemplary formatting for all figure captions.

All figure captions should be listed on a separate page, according to the order in which they appear in the manuscript. Multi-line captions should be double-spaced.

Reference Examples

Journal Article, Two Authors

Wassner, S. J., & Holliday, M. A. (1989). Protein metabolism in chronic renal failure. *Seminar in Nephrology, 9*, 19–23.

Journal Article, Three to Six Authors

Gartner, J., Larson, D. B., & Allen, G. D. (1991). Religion commitment and mental health: A review of the empirical literature. *Journal of Psychology and Theology, 19*, 6–25.

Journal Article, More Than Six Authors

Larson, D. B., Sherrill, K. A., Lyons, J. S., Craigie, F. C., Thielman, S. B., Greenwold, M. A., et al. (1992). Associations between dimensions of religious commitment and mental health reported in the *American Journal of Psychiatry* and *Archives of General Psychiatry*: 1978–1989. *American Journal of Psychiatry, 149*, 557–559.

Journal Article in Press

Odaka, M. (in press). Mortality in chronic dialysis patients in Japan. *American Journal of Kidney Diseases*.

Complete Book, Edited

Levine, D. Z. (Ed.). (1983). *Care of the renal patient*. Philadelphia: Saunders.

Chapter of an Edited Book

Nixon, H. H. (1966). Intestinal obstruction in the newborn. In C. Rob & R. Smith (Eds.), *Clinical surgery* (pp. 168–172). London: Butterworth.

Article from a Journal Supplement

Paganini, E. P., Latham, D., & Abdulhadi, M. (1989). Practical considerations of recombinant human erythropoietin therapy. *American Journal of Kidney Diseases*, *14*(Suppl. 1), 19–25.

Abstract

Bello, V. A. O., & Gitelman, H. J. (1990). High fluoride exposure in hemodialysis patients [Abstract]. *American Journal of Kidney Diseases, 15*, 320.

Editorial

Piantadosi, S. (1990). Hazards of small clinical trials [Editorial]. *Journal of Clinical Oncology, 8*, 1–3.

ACCEPTANCE PROCESS

If a manuscript is accepted for publication, the author will be required to send the following to the editorial office:

- An electronic copy of the final version of the manuscript. All components of the manuscript must appear within a single word processing file, in the order listed previously. Any features that track or highlight edits should be turned off; do not forget to hit the "accept all changes" function first. Do not use automatic numbering functions, as these features will be lost during the file conversion process. Formatting such as Greek characters, italics, bold face, superscript, and subscript, may be used; however, the use of such elements must conform to the rules set forth in the APA style guide and should be applied consistently throughout the manuscript.
- Art, tables, figures, and images should be high-resolution TIFF or EPS file formats only. Most other file formats (PowerPoint, JPG, GIF, etc.) are not of sufficient resolution to be used in print. The resolution for all art must be at least 300 d.p.i. A hard copy of each figure should accompany the files. These images should be black and white (grayscale) only. They should be high-resolution TIFF or EPS file formats only.
- In addition to the images that appear in your word processing file, it is also important to send the images separately as individual files. These images should be black and white (grayscale) only, 300 d.p.i. minimum.

Do Not Resuscitate Orders for Adults with Developmental Disabilities: Ethical Considerations in the Dialysis Center

Renata Sledge, LCSW, Cancer Support Community of Greater St. Louis, St. Louis, MO

Each discipline in the nephrology community has a specific code of ethics with clearly defined principles, values, and standards of practice. Reconciling these often similar values and principles with differences in professional language (jargon) and perspectives is a challenge experienced by all members of the interdisciplinary team. The following is a brief discussion of four principles of medical ethics defined by Beauchamp and Childress (1994) and the relationship of these principles to those in the National Association of Social Workers (NASW) Code of Ethics (2008). A model for resolving ethical conflicts is described and a case study using the model is presented.

Each discipline in the nephrology community has a specific code of ethics with clearly defined principles, values, and standards of practice. Reconciling these often similar values and principles with differences in professional language (jargon) and perspectives is a challenge experienced by all members of the interdisciplinary team. Social workers are trained in resolving ethical dilemmas using models such as those created by Loewenberg, Dolgoff, and Harrington (2000), Reamer (2006), and Congress (1996). These models are effective but may not be familiar or accessible for the interdisciplinary team. The “So Far No Objections” or SFNO Model developed by DuBois (2008) offers an opportunity to explore social work values and medical principles in resolving ethical differences.

Case One illustrates how end of life issues were addressed without the use of a model to help the interdisciplinary team members explore appearances of conflicting values and principles.

CASE ONE: INTRODUCTION TO THE PROBLEM

Michael was a 35-year-old male with diabetes, hypertension, and multiple cardiac issues on in-center dialysis for 3 years. Michael was diagnosed with mild mental retardation (I.Q. approximately 60) and was residing in a skilled care facility. Michael participated in recreational activities in the skilled care facility. He had limited family interaction, because his parents died many years before and his siblings were only peripherally involved in his care. Michael had the same state guardian for five years. Michael continued to present to dialysis with uncontrolled blood pressure and slept through most of his treatments. Dialysis staff had limited interaction with Michael due to the sleeping; however, their interaction with Michael was mostly positive as he seemed eager to please and answered almost all questions from staff with attempts to mollify.

The dialysis center staff was invited to participate in a care conference at the skilled care facility to discuss Michael’s status and treatment options; the nephrology social worker attended on behalf of the interdisciplinary team. During the meeting, Michael’s guardian, a Qualified Mental Retardation Professional (QMRP), the Director of Nursing, and a primary care doctor indicated they would like to change Michael’s resuscitation status in the skilled care facility to a do not resuscitate (DNR) order and requested Michael’s status be changed in the dialysis center as well. The phrase, DNR is used here, as opposed to the phrase allow natural death (AND), because this is the language used in state documentation for physician orders. When later presented with the request, Michael’s nephrologist as a concurring doctor refused to sign the Office of Guardianship and Advocacy Consent Request, consenting to the change in resuscitation status. In other words, Michael would maintain a full resuscitation status at the dialysis center and the guardian would need to find another doctor to sign for a change in resuscitation status at the skilled care facility. The nephrologist wanted to discuss the DNR decision with Michael to ensure he was comfortable with the decision. She stated Michael was in “too good of health” to have a change in resuscitation status. The nephrologist asked Michael during her next rounds at the dialysis center if he wanted “CPR” (cardiopulmonary resuscitation). The patient replied, “Yes,” and the nephrologist refused to designate Michael a DNR for the dialysis facility or complete the consent request as a concurring doctor.

An uneasy agreement was reached between the two facilities to have separate orders and to revisit Michael’s resuscitation status should he be admitted to a hospital. Approximately three months later, Michael “coded” at the skilled care facility, resuscitation was not performed, and he died at the skilled care facility.

The compromise reached between the stakeholders left both treatment teams uncomfortable and made further communication between them difficult. The skilled nursing facility felt the dialysis center staff were not cooperative in coordinating Michael’s care; the dialysis team felt the skilled nursing facility staff was simply “waiting for Michael to die”; and the social worker was left to mediate between the two. The management of this case was based on stakeholder value and a desire for a quick resolution, rather than on a framework or model that would have facilitated an evaluation of norms, facts, and consideration of other options.

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What follows is a brief discussion of four principles of medical ethics defined by Beuachamp and Childress (1994) and the relationship of these to the principles included in the National Association of Social Workers (NASW) Code of Ethics (2008). A description of a model for resolving ethical conflicts is described and a case example using the model is presented.

Reconciliation of Principles

The first principle articulated by Beauchamp and Childress (1994) is the principle of "beneficence." "Beneficence" requires the practitioner to consider potential benefits and harms of an action, and positive steps to help others and do good in general. The value of service and the NASW stated ethical principle that "social workers' primary goal is to help people in need and to address social problems" speaks to the proactive expectation of social workers (NASW, 2008).

"Non-maleficence," the second principle, is generally understood to refer to the obligation to avoid the causation of harm. Medical intervention often includes some pain on the part of the patient; therefore, the medical professional should provide the least invasive intervention first and the most aggressive intervention to prevent and treat pain. The NASW encourages social workers to provide competent service with integrity. The focus on ethics in social work training and some state licensure mandate for continuing education ethics training further demonstrate the expectation to be aware of and minimize potential harm in social work interventions (Beauchamp & Childress, 1994; NASW, 2008).

The third principle of "respect for autonomy" refers to the right of the individual to make choices, be informed, consent to treatment, and accept responsibility for the choices made. This principle is often cited in the context of discussing surrogate decision making, versus decision making capacity of patients. In order to understand autonomy, the NASW Code of Ethics includes values emphasizing the importance of human relationships, and the impact of those relationships on clients and their decisions. Social workers are also expected to respect the dignity and worth of a person, which includes the client's right and ability to make decisions (Beauchamp & Childress, 2001; NASW, 2008).

Finally, the principle of "justice" generally describes the responsibility to distribute risks and benefits fairly. The principle of justice is often referred to when discussing access to treatment by privately-insured versus publicly-funded patients, or distribution of solid organs for transplant. The ethical values of social justice, dignity, and worth of the person often challenge social workers to consider the impact of their intervention on those within the patients' immediate system and in the larger system (Beauchamp & Childress, 1994; NASW, 2008).

Identifying Ethical Disagreements

Ethical disagreements arise when there is uncertainty between stakeholders, facts or norms. These uncertainties and dilemmas are sometimes called "volitional," "cognitive" and "social" differences. The "volitional" or "stakeholder" dilemma refers to challenges faced when stakeholders have different and competing interests (DuBois, 2008). Dialysis patients with a high spenddown would benefit from state-funded transportation to and from dialysis, but states must manage their limited resources. In this case, there is an ethical disagreement between dialysis patients and the State because their goals are divergent—that is, patients would like to benefit from subsidized transportation, but the State must exercise fiscal responsibility and prioritize allocations based on the greatest needs of all stakeholders.

"Cognitive" disagreements refer to uncertainty about the next step (DuBois, 2008). Often stakeholders with cognitive disagreements do not share the same understanding of relevant facts, probability of benefits, or magnitude of harm. For instance, a patient or family may refuse home dialysis options given reports from friends that home options are less favorable than in-center dialysis.

Social disagreements occur when stakeholders are confronted with different ethical norms and values (DuBois, 2008). Staff may not understand the cultural tendency of a particular group to pursue all treatment options when the staff believes quality of life is so poor, the patient should withdraw from dialysis (Dubois, 2008).

Possible Framework for Resolution

There are multiple frameworks available to interdisciplinary teams to aid in addressing ethical conflicts. The "So Far No Objections" or SFNO model uses a root cause analysis approach to explore the dilemma or conflict, and then reviews options for resolving the issue. The root cause analysis process is often used in clinics for the Quality Assurance Performance Improvement (QAPI) process and can be easily adapted to dialysis clinic culture. The SFNO model asks the following questions:

1. **S**takeholders: Who has a stake in the decision being made? That is, who will be significantly affected by the decision made?
2. **F**acts: What factual issues might generate disagreement? What facts are relevant to a solution?
3. **N**orms: What ethical principles, norms, and values are at stake? Which do you think are relevant, and which might appear to conflict or generate disagreement?
4. **O**ptions: What actions or policies deserve serious consideration? If the ethical ideal is not possible, what compromise solutions are most attractive? (Dubois, 2008)

Once an option has been selected by a team, there are five criteria for evaluating whether a recommended solution to an ethics case is justified. The five criteria and questions to consider include:

1. Necessity: Is it necessary to infringe on the values or norms under consideration in order to achieve the intended goal?
2. Effectiveness: Will the action be effective in achieving the desired goal?
3. Proportionality: Is the desired goal important enough to justify overriding another principle or value?
4. Least Infringement: Is the policy or action designed to minimize the infringement of the principle or value that conflicts with it?
5. Transparency: Has the decision been made using proper processes? (Dubois, 2008)

The next case example uses the "So Far No Objections" or SFNO approach to case analysis.

CASE TWO: A SNFO-BASED RESOLUTION

Steven was a 38-year-old male diagnosed with end stage renal disease (ESRD), diabetes, and hypertension. Steven was also diagnosed with mild mental retardation and metabolic encephalopathy. An uncle, who lived several states away, had guardianship of Steven since his parents' death ten years before. Steven was on dialysis for approximately three months and continued to present with uncontrolled blood pressure and diabetes. Steven continued to work full time and participated in group home activities. The group home doctor and staff were concerned about Steven's high blood pressure and the potential for stroke or heart attack. In the last care planning meeting at the group home, the home's Qualified Mental Retardation Professional (QMRP), director of nursing (DON), and primary care doctor recommended that Steven's resuscitation status be changed to DNR. Based on group home reports of an increase in fatigue, decreased activity, change in mood, and family reports of malaise for Steven, the guardian agreed to change the resuscitation status to DNR. The guardian contacted the dialysis center and requested Steven be designated DNR at the dialysis center as well.

Based on the dialysis interdisciplinary team experience with Michael and citing a value of respect of dignity and worth of the person (NASW, 2008), the social worker's recommendation was to honor the guardians request for a change in resuscitation status, citing the principle of respect for autonomy as the primary justification. The nephrologist at the dialysis center stated her concern that this change was inappropriate at the time as Steven was in "too good of health." The SFNO model was used by the social worker and reviewed with the interdisciplinary team and guardian to discuss options for Stephen's resuscitation status.

Stakeholders

The primary stakeholder in this case was Steven as the decision and discussion affected his body and health and any ambiguity regarding resuscitation status would affect his medical care. Conflict between group home staff and dialysis center staff may also fragment Steven's care. The staff in the group home was invested both personally and professionally in Steven. The uncertainty of resuscitation status for Steven may increase anxiety during treatments for the dialysis center staff working with Steven. They also were working to preserve Steven's life and may have experienced some ambivalence about not continuing that action through CPR. The statement referring to Steven being in "too good of health" suggested the nephrologist, who had been his nephrologist for ten years, had hope for Steven and perceived a change in resuscitation status as "giving up" on him. Steven's uncle was given the task of making decisions for another human being and was cognizant of the responsibility associated with that task. A contentious battle regarding resuscitation status may lead to resentment or guilt on the part of the guardian.

The decision made by the nephrologist, group home team, dialysis center team, and guardian would affect how resuscitation status was evaluated in the future for other dialysis patients and group home residents. Advocacy groups could closely monitor this and other cases to ensure appropriate change in resuscitation status for persons with disabilities. The residents of the state and other taxpayers might have concerns about the cost of ongoing care should Steven experience further physical challenges from resuscitation.

Facts

Facts that may have influenced decision making or recommendations in this situation included understanding the process for changing resuscitation status for a ward of the state, dialysis center's policy for changing resuscitation status, the patient's likelihood for cardiac arrest, and understanding Steven's current health and prognosis.

From a dialysis perspective, Steven was stable and thriving; he was alert and interacted positively with staff. Steven regularly achieved good clinical outcomes, tolerated dialysis without cramping or significant changes in blood pressure, and historically tolerated medical procedures well. Steven was new to dialysis and the expectation by the nephrologist was the concern of the group home staff and guardian would resolve itself. The perspective of the group home staff differed, as they believed Steven was more tired and less active. They were concerned that Steven's quality of life was negatively impacted by the strict diet and fluid restrictions. Steven was still able to work and participate in activities at the group home, but did not have as much enthusiasm as he exhibited before starting dialysis.

Steven's uncle and the group home staff evaluated a change in resuscitation status by considering the potential quality of life post-resuscitation, including ventilator dependency and decreased participation in activities meaningful to Steven. Steven's uncle and group home staff discussed the resuscitation status with Steven, who agreed that he did not want CPR. According to his family, Steven's parents stated prior to their death that they did not want Steven to ever be placed on a vent for an "extended period of time"; however, this was not documented in the form of an advance directive. Steven's uncle did not know anyone on dialysis and the group home staff reported having only one other patient on dialysis who died within the first year.

Because Steven lived and was treated in Illinois, the dialysis and group home staff reviewed the state requirements for changing resuscitation status. The State Office of Guardianship and Advocacy required the attending physician and a concurring physician to determine if the patient lacked decisional capacity. The physicians' documentation of the last physical exam must include a description of the medical condition that supports the consent request, available treatments, and recommendations if these treatments should be continued. The physician has the option of consulting an ethics committee; if consulted, a representative of the committee must include a consult note and signature (IGAC, 2006). The Illinois Health Care Surrogate Act (Illinois Guardianship & Advocacy Commission, 1998) also requires that a "qualifying condition" exists prior to changing the resuscitation status. A qualifying condition would include a terminal condition, permanent unconsciousness, or an incurable or irreversible condition. ESRD would be considered an incurable or irreversible condition under the Illinois Health Care Surrogate Act.

The dialysis center policy required the social worker to review advance directives, including resuscitation status, with all patients or their surrogates at least once a year. The dialysis center accepted the Illinois Department of Public Health Uniform Do Not Resuscitate (DNR) Advance Directive (Illinois Department of Public Health, 2006) if it had been signed at another center and also accepted the Office of Guardianship and Advocacy Consent Request as documentation regarding resuscitation status. The dialysis center did not have a policy regarding a nephrologist's refusal to concur with a decision to allow natural death because physicians are not employees of the dialysis center. Only two of the 100 patients at the dialysis center had a DNR status.

While reviewing the facts, it became clear the dialysis interdisciplinary team and group home team had a different understanding of the facts regarding Steven's health; the nephrologist and interdisciplinary team felt Steven was thriving, while the group home felt Steven was dying.

Norms

The nephrologist's resistance to signing the consent form as a concurring physician was likely founded on a principle to do good (keeping Steven alive) while not causing unnecessary harm (preserving bodily integrity). Steven's uncle also had a legal responsibility to protect Steven from prolonged, unnecessary suffering. However, when considering treatment options, the guardian must remember the patient's right to receive medical care in order to preserve health, minimize and relieve pain, or otherwise promote well-being (McKnight & Bellis, 1992). Therefore, the interdisciplinary team was presented with a need to balance the principles of beneficence and non-maleficence with autonomy. In this case, autonomy referred to the decisions the guardian made for Steven. This means the guardian would be accountable for considering Steven's wishes, despite his impaired abilities.

With the absence of a traditional protective network of friends and family, clear guidelines were needed to protect Steven while considering treatment options. Through the Illinois Health Care Surrogate Act, Steven's uncle was given clear guidelines for considering treatment options. Three approaches to surrogate decision making were available: "substituted judgment," "pure autonomy," and "best interest." Case law generally focuses on formerly competent patients, or competent but disabled patients when recommending the "substituted judgment" approach. Family members had reported to Steven's uncle, the state guardian, that Steven's parents had said they did not wish to have him dependent on a ventilator for breathing. However, this was never formally documented as an advance directive.

"Pure autonomy" typically applies exclusively to previously competent patients with the use of advance directives or statements. As the state had declared Steven incompetent, the pure autonomy approach would not apply even though Steven had stated to his uncle and the group home staff that he did not want CPR. Steven tacitly consents to dialysis treatments three times a week, because he allowed dialysis to be performed without objections or negative behaviors. Cea and Fisher (2003) reported adults with mild mental retardation were able to balance the risks and benefits of treatment, and partially or fully understand medical information provided to them. As Brock (1995) suggests, while Steven may not have procedurally consented to the change in resuscitation status, he may have been able to give informed consent and act with self-determination.

The "best interest" standard requires the surrogate when to consider making treatment decisions for the relief of suffering, preservation or restoration of functionality, quality and duration of life, satisfaction of present desires, opportunities for future satisfaction, and opportunity to regain self-determination (Beauchamp & Childress, 2001; McKnight & Bellis, 1992). Steven's uncle and the group home staff believed, given the risk of intubation, anoxic injury and further pain associated with CPR, that allowing natural death would be acting in Steven's best interest (Kidney End of Life Coalition, n.d.; Robert Wood Johnson Foundation, 2004).

Steven had previously been declared incompetent by the State of Illinois and assigned a guardian, his uncle, by the Office of Guardianship and Advocacy. It was required that the guardian must be consulted before any medical or financial decision was made for Steven. However, neither the staff at the group home nor the dialysis staff regularly consulted the guardian for minor issues, such as confirming a headache and authorizing the use of an appropriate analgesic.

Beauchamp and Childress (2001) offer a schema to understand the competing standards of competence. The schema evaluates the person's ability to:

1. state a preference;
2. understand information; and
3. appreciate one's situation.

Research by Cea and Fisher (2003) and staff observation of decisions made by Steven demonstrated that, with an IQ of 69, Steven was capable of stating a preference and understanding information provided to him. However, he was limited in appreciating situations and the consequences of his decisions.

The nephrologist has the obligation to respect autonomy, but must also honor the principles of beneficence and non-maleficence, and has the obligation to provide benefits balanced against risks to a patient's health. These principles guided each decision the nephrologist made regarding Steven's dialysis. Dialysis is an intrusive procedure that involves needles, changes in blood pressure, and cramping. However, these risks come with a potentially improved quality of life, and increased quantity of life. Steven was monitored consistently throughout dialysis procedures and any changes in blood pressure, heart rate or respiration were monitored and addressed by the staff at the center. CPR if it was needed during dialysis sessions could have potentially "restored and preserved" Steven's life (McKnight & Bellis, 1992).

The beneficent act in this case may have been to also to question the best interest decision reached by the guardian and the group home treatment staff. It is reasonable to question the rationale for changing Steven's resuscitation status, given the low number of DNR designations at the dialysis center and Steven's diagnosis of mental retardation.

Goal and Options

Before contacting the group home and Steven's uncle, the social worker needed to clarify the goal. The goal was not to advocate for autonomy, which was the social worker's initial inclination; the goal was to facilitate an environment with the dialysis interdisciplinary team and group home staff that allowed Steven to thrive through his desired activities, minimizing physical intrusions, and maintaining his bodily integrity.

The social worker listed five options for meeting the above goal. These included:

1. Transfer Steven to another doctor or to request a new guardian
2. The nephrologist could cooperate in the change in resuscitation status despite her reservations
3. The guardian could withdraw the DNR request
4. The resuscitation status could be modified to allow for a DNR at the group home and a full resuscitation status at the dialysis center (as illustrated previously in Michael's case)

The group home staff and dialysis center staff could arrange another consultation in which Steven, his guardian, the group home staff, and dialysis center staff would discuss resuscitation with the nephrologist present.

Given the basic disagreement of facts about Steven's general health, the social worker proposed a meeting with the nephrologist, group home staff, primary care physician and Steven's uncle/guardian to discuss the matter. General education was provided to the group home staff, Steven and his guardian regarding dialysis, dialysis treatment options and expectations regarding Steven's quality of life. This provided insight into the behavioral changes that had been observed since Steven had started on dialysis. The group home team and guardian provided more information regarding the observed behavioral changes in Steven. Based on this, changes were made to Steven's dialysis prescription, fluid management, and dietary guidelines to address the concerns of the group home staff. In return, the nephrologist, primary care physician, Steven, and his guardian agreed to reconsider a change in resuscitation status on an annual basis or if there was a dramatic change in Steven's health.

Justification

Effectiveness

The proposed action plan was effective in ensuring that all stakeholders involved in the case participated in treatment planning. The proposed action respected the shared autonomy of Steven and his uncle, while maintaining the uncle's accountability as Steven's surrogate. The proposed plan was effective in achieving the goal of creating an environment that allowed Steven to thrive and created an ongoing channel of communication among his treatment professionals.

Proportionality

The proposed plan facilitated an opportunity for Steven's uncle to communicate with the nephrologist regarding a change in Steven's resuscitation status, and created an opportunity to coordinate treatment goals. The plan supported the guardian's rights to autonomy while giving the state the burden of justifying the decision. This burden of proof is proportional to the need to protect the more vulnerable Steven.

Least Infringement

Because the plan did not require the nephrologist to consent to a change in resuscitation status the plan did not infringe on the nephrologist's concerns regarding beneficence and non-maleficence. The burden of justification for the guardian's decisions infringed least on the state and Steven's autonomy, when compared to outright refusal by the nephrologist to consent to the change in status. The goal was also to maintain Steven's bodily integrity. His surrogate, considering in Steven's "best interest," regarded performing CPR as violating Steven's bodily integrity. Therefore, the DNR plan infringed least on the goal of maintaining bodily integrity.

Steven's uncle arrived at the decision to change Steven's resuscitation status following the group home staff expressing concern about a potential stroke or cardiac arrest due to Steven's uncontrolled hypertension and given his perceived changes in mood and activity level. The nephrologist continued to believe that Steven was in "too good of health" to change his resuscitation status. The proposed plan respected the guardian's autonomy in decision making as well as the team's responsibility to the principles of beneficence and non-maleficence. Participation of the family, Steven's age and comorbid conditions, and community setting were all factors that could change the outcome of this case.

CONCLUSION

The first case, Michael's, was resolved and managed based on stakeholders' values and a sense of urgency of team members. The interdisciplinary team and skilled nursing team were certain of a conflict, but unable to articulate the reason for the conflict beyond a difference in values. The resolution was tenuous and required further peacekeeping by the social worker between the dialysis team and skilled nursing facility team.

Using the SFNO framework, the resolution of Steven's case allowed the stakeholders to explore the facts, values and norms influencing the initial request for change in resuscitation status and collaborate in resolving the conflict. Use of this model illustrated three distinct differences between the cases of with Michael and Steven: first, in Steven's case, the social worker was able to help the stakeholders identify the disagreement of facts; second, Steven's group home and dialysis center interdisciplinary team was able to work with a clear and positive goal; and finally, the cooperation between the two teams created an environment of collaborative treatment and continuity of care between facilities, Steven and his guardian.

Further study of ethics in the nephrology community could explore the question and bias regarding appropriate patients for whom to allow natural death. Ethical reviews at the institutional level regarding the use of advance directives and end-of-life planning for dialysis patients could also be explored. As evidenced by the two case studies, an evaluation of the relationship between patient and provider, as well as communication and ethical conflicts would also be interesting avenues for exploration.

Social workers are a resource for the interdisciplinary team in considering ethical conflicts in the dialysis clinic. It is important for the social worker to be aware of the values and principles of other professionals in the clinic, as well as tools to facilitate efficient exploration of differences. A framework that is familiar to the team, such as a root cause analysis (SFNO) of a conflict, can help them consider options and develop a plan to resolve issues when an ethics committee is not available.

REFERENCES

Asch, A. (2005). Recognizing death while affirming life: Can end-of-life reform uphold a disabled person's interest in continued life? *Hastings Center Report, Special Report, 35*(6), 31–36.

Beauchamp, T. L. (1994). The "Four-Principles" approach. In R. Gillon (Ed.), *The principles of health care ethics* (pp. 3–12). New York: John Wiley and Sons.

Beauchamp, T. L., & Childress, J. F. (2001). Respect for autonomy. In *Principles of biomedical ethics* (5th ed.) (pp. 57–112). New York: Oxford University Press.

Bouvia v. Superior Court, 179 Cal. App. 3d 1127, 225 Cal. Rptr. 297 (California Court of Appeals, 1986).

Brock, D. W. (1995). Surrogate decision-making for incompetent adults: An ethical framework. In D.C. Thomasma & P.A. Marshall (Eds.), *Clinical medical ethics cases and readings*. Lanham, MD: University Press of America.

Cea, C., & Fisher, C. (2003). Health care decision-making by adults with mental retardation. *Mental Retardation, 41*(2), 78–87.

Congress, E. P. (1996). *Social work values and ethics*. Chicago: Nelson-Hall.

DuBois, J. M. (2008). Solving ethical problems: Analyzing ethics cases and justifying decisions. In *Ethics in Mental Health Research* (pp. 46–57). New York: Oxford University Press.

Illinois Guardianship and Advocacy Commission (IGAC). (1998). *Illinois Health Care Surrogate Act*. Retrieved from **http://gac.state.il.us/hcsa.html**

Illinois Guardianship and Advocacy Commission (IGAC). (2006). *A guide to adult guardianship in Illinois.* Retrieved July 7, 2008, from **http://gac.state.il.us/pdfs/GTAGII/GuideAdultGuardianship2006.pdf**

Illinois Department of Public Health. (2006, June 27). *Illinois Department of Public Health uniform do-not-resuscitate (DNR) advance directive.* Retrieved July 7, 2008, from **http://www.idph.state.il.us/public/books/guide_individual.htm**

Kidney End-of-Life Coalition. (n.d.). *What happens if my heart stops beating?* Retrieved July 7, 2008, from **http://www.kidneyeol.org/CPR_DNR.pdf**

Loewenberg, F. M., Dolgoff, R., & Harrington, D. (2000). *Ethical decisions for social work practice* (6th ed.). Itasca, IL: FE Peacock.

Lohiya, G., Tan-Figueroa, L., & Crinella, F. (2003). End-of-life care for a man with developmental disabilities. *Journal of the American Board of Family Practice, 16*(1), 58–62.

McKnight, D., & Bellis, M. (1992). Foregoing life-sustaining treatment for adult, developmentally disabled, public wards: A proposed statute. *American Journal of Law and Medicine, 18*(3), 203–232.

National Association of Social Workers (NASW). (2008). *Code of ethics of the National Association of Social Workers*. Washington DC: Author. Retrieved June 12, 2012, from **http://www.socialworkers.org/pubs/code/code.asp**

Reamer, F. (2006). *Social work values and ethics* (3rd ed.). New York: Columbia University Press.

Robert Wood Johnson Foundation (RWJF). (2004). *CPR: It's not quite like ER*. Retrieved July 7, 2008, from **http://www.rwjf.org/pr/product.jsp?id=21335**

Emerging Trends in Discharging Disruptive Dialysis Patients: A Case Study

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At the end of the 2009 calendar year, 399,000 End-Stage Renal Disease (ESRD) patients received dialysis as their treatment method, according to the U.S. Renal Data System. In addition to the consequences of their ESRD, patients on dialysis experience many challenging emotional, physical and financial burdens. Steps need to be taken to ensure safety when a patient is a threat to the rights and safety of other patients and staff. Severe cases of threat and abuse, both verbal and physical, can lead to the offending patient being involuntarily discharged from the dialysis facility. However, the ESRD Networks, as well as the state Departments of Public Health, do not have the authority to mandate that outpatient dialysis facilities accept known disruptive patients. When patients are involuntarily discharged from a dialysis facility, and cannot find another outpatient facility to admit them, they are instructed to go to the nearest emergency room for dialysis care. The Emergency Treatment and Active Labor Act requires hospitals to provide care to anyone needing emergency healthcare treatment regardless of citizenship, legal status or ability to pay. This case study attempts to explore the emerging trends of discharged, disruptive dialysis patients who are denied dialysis services from outpatient dialysis facilities.

INTRODUCTION

The prevalence of U.S. residents with End Stage Renal Disease (ESRD) receiving treatment at the end of the 2009 calendar year was more than 571,000, which is a rate of 1,738 per million population (United States Renal Data System Annual Report, 2011). The number of incident dialysis patients rose 3.9 percent in 2009, up from 1.2 percent in 2008, to 112,782. In 2009, nearly 399,000 ESRD patients received dialysis as their treatment method. Dialysis therapy allows patients the choice to dialyze at home or in an outpatient clinic. Of the 399,000 patients, 365,566 chose in-center hemodialysis, usually three times a week for a three to four hour treatment (United States Renal Data System Annual Report, 2011). Patients on dialysis experience many emotional, physical and financial challenges. These challenges can cause patients to become angry and disruptive, both in and out of their dialysis facility. With increasing numbers of patients beginning dialysis each year, we can expect increasing numbers of problems with disruptive patients. Dialysis is unique, in that in-center hemodialysis is conducted in an "open treatment setting" where one patient can observe and hear the treatment of other patients, even with the best intentions of facility staff to comply with Health Insurance Portability and Accountability Act (HIPAA) regulations. There are no "special care" dialysis units, so all conversations can be heard and staff interactions with a specific patient can be observed.

THE CENTERS FOR MEDICARE & MEDICAID SERVICES CONDITIONS FOR COVERAGE (CFCs)

On April 15 2008, the Centers for Medicare & Medicaid Services (CMS) released a final rule that revised and updated the Medicare CfCs for the nation's dialysis centers. Outpatient dialysis facilities must meet the CfCs to be certified under the Medicare program. According to the CfC V Tag 501, "the facility's interdisciplinary team (IDT) consists of, at a minimum, the patient or the patient's designee (if the patient chooses), a registered nurse, a physician treating the patient for ESRD, a social worker, and a dietitian. The IDT is responsible for providing each patient with an individualized and comprehensive assessment of his or her needs. The comprehensive assessment must be used to develop the patient's treatment plan and expectations for care" (ESRD program interpretive guidance, 2008, p. 186). The new CfCs strongly emphasize that the medical director has responsibility for the functions of the IDT. The CfC states, "The medical director is accountable to the governing body for the quality of medical care provided to patients" (ESRD program interpretive guidance, 2008, p. 276).

The definition of medical director sometimes requires the physician to take on dual roles. The role of the medical director, as part of the dialysis organization, requires the nephrologist to comply with the organization's policy and procedures. The medical director also acts as the attending nephrologist to his/her patients. Sometimes medical directors are encouraged to involuntary discharge patients by other members of the IDT. Members of the IDT work with disruptive patients on a daily basis, while some medical directors may only see these patient a few times a month. The time and energy that goes into managing disruptive behaviors may make members of the IDT feel "professional burn out". If the medical director discharges a patient from his/her dialysis clinic, he/she will most likely also discharge that patient from their nephrology practice as well.

THE NEPHROLOGIST AND THE DISRUPTIVE PATIENT

Once a nephrologist establishes a patient-physician relationship, the nephrologist has a continuing legal duty to treat that patient until the need for services is lawfully terminated (Ripley, 2009). ESRD patients will need medical services until the end of their life. According to Goldman (2008), "Medical directors and attending nephrologists must act in the best interests of the patient ('beneficence'), placing the patient's interest above their own" (p. 248). An example of unethical behavior would be to involuntarily discharge a patient for nonadherence to prescribed medical treatment because it lowers the clinic performance of the provider of service (Goldman, 2008).

While a patient may terminate the physician–patient relationship at any time, the nephrologist must take the legal concept of medical abandonment into consideration. A nephrologist can only terminate the relationship after ample warning has been given to the disruptive patient and a reasonable attempt to transfer the patient's care has been made (Goldman, 2008). "Ultimately, the courts decide what constitutes 'ample' and 'reasonable,' applying the test of what would be done by a 'reasonable person' acting under 'similar circumstances' " (Goldman, 2008, p. 248).

The Hippocratic Oath is an oath historically taken by physicians swearing to practice medicine ethically. The oath includes the statement: "I will prescribe regimen for the good of my patients according to my ability and my judgment and never do harm to anyone." Most physicians comply or strive to comply with this oath even with the complexities of medicine. According to Ripley (2009), "The obligation to treat a non-compliant, abusive dialysis patient is one area where the struggle continues'" (p. 1).

INVOLUNTARY DISCHARGE AND "CHERRY PICKING"

Severe cases of threat and abuse, both verbal and physical, can lead to the patient being involuntarily discharged from their dialysis facility. According to the CfCs, the "medical director must monitor and review each involuntary patient discharge to ensure that the facility interdisciplinary team follows the discharge and transfer policies" (ESRD program interpretive guidance, 2008, p. 280). The CfC interpretive guidance V Tag 766 states that the "medical director ensures that no patient is discharged or transferred from the facility unless –

1. The patient or payer no longer reimburses the facility for the ordered services;
2. The facility ceases to operate;
3. The transfer is necessary for the patient's welfare because the facility can no longer meet the patient's documented medical needs; or
4. The facility has reassessed the patient and determined that the patient's behavior is disruptive and abusive to the extent that the delivery of care to the patient or the ability of the facility to operate effectively is seriously impaired
5. In the case of immediate severe threats to the health and safety of others, the facility may utilize an abbreviated involuntary discharge procedure" (ESRD program interpretive guidance, 2008, p. 293 & 294).

Conditions 1-4 require a 30 day notice to the patient as well as a "good faith effort" to place the patient in another outpatient dialysis clinic. A 30-day notice also must be made to the local End Stage Renal Disease Network (ESRD program interpretive guidance, 2008).

The ESRD Network Program, under CMS contract, is a national program of 18 ESRD Networks, responsible for the 50 U.S. states, Puerto Rico, the U.S. Virgin Islands, District of Columbia and several other territories. ESRD Networks service geographic areas based on the number and concentration of ESRD beneficiaries (ESRD Network Organizations, 2012). ESRD Networks assist patients, ESRD facilities and other providers of ESRD services by assuring the effective and efficient administration of benefits, improving the quality of care for ESRD patients, collecting data to measure the quality of care, and evaluating and resolving patient grievances and complaints.

Dialysis facilities are required by the CfCs to report all involuntary discharges to Networks and State Survey Agencies. However, neither the ESRD Networks nor State Survey Agencies have the authority to mandate that outpatient dialysis facilities accept patients. ESRD Networks advocate that dialysis facilities accept patients who are being denied services. For example, patients with mental illness are often requested to obtain psychiatric services prior to admission into a dialysis facility. Mental health professionals can often determine the root cause of the abusive behavior. Often, when dialysis patients are involuntarily discharged ,and placed at another facility, they no longer display the disruptive behavior they portrayed at the previous facility. In severe cases, Networks have coordinated "sharing" of patients with difficult behaviors between dialysis facilities for a specified length of time so that one facility never "owns" the patient for an extended period of time.

Dialysis facilities have policies and procedures in place outlining their admission criteria for new patients. A dialysis facility cannot admit a patient into its clinic without a nephrologist who has agreed to treat the patient. A growing concern is the unethical "cherry picking" of patients by either nephrologists or dialysis facilities. Cherry picking is actively excluding patients with perceived negative qualities (Parker, 2011). A physician or dialysis facility that becomes focused on the characteristics of the population of patients, instead of the ethical and medical need to treat patients in a specific clinical situation, may be tempted to manipulate the patient population by excluding certain types of patients (Parker, 2011). Patients differ in age, disease burden, mental well-being and willingness to adhere to medical advice. Patients may have psychosocial burdens such as poverty and poor support systems that make them less likely to maintain good clinical outcomes. Finally, some patients are not willing to follow the advice of their physicians (Parker, 2011).

A 2008 national survey was conducted as part of the Identifying Best Practices in Dialysis (IBPiD) study, which is a multidisciplinary research effort conducted by the University of California–Los Angeles (UCLA) in collaboration with the Renal Physicians Association (RPA) and the American Nephrology Nurses Association (ANNA). The IBPiD aimed to identify best practices that may improve facility-level achievement of clinical performance measures and overall outcomes in dialysis patients. IBPiD's national survey was conducted to elicit caregiver perception regarding the extent and consequences of cherry-picking in dialysis care (Desai et al., 2009). The respondents, a random sample of 250 nurse members of ANNA, 250 nephrologist members of the American Medical Association, 50 key opinion leaders and 2000 physician members of RPA were asked about their perceptions of 1) cherry picking, including the frequency and effect of various 2) cherry-picking strategies on dialysis outcomes. Three-quarters of respondents reported that cherry picking occurred "sometimes" or "frequently." "There were no differences in perceptions by provider or facility characteristics, insurance status, or health status" (Desai et al., 2009, p. 772).

Physicians can exclude or "fire" their patients by referring them to other providers and practices or by "manipulating the patients into foregoing dialysis" (Parker, 2011). "The nephrologist might simply declare without any explicit rationale that the patient is 'not a dialysis candidate' and leave the impression for the patient, as well as the referring physician, that there is some nonvalue laden medical judgment that has been made when in reality the judgment was heavily value laden"(Parker, 2011, p. 6). If society comes to believe that nephrologists are making decisions about whether to recommend dialysis therapy for patients based on how these patients will affect clinical performance outcomes, then it will understandably develop a healthy skepticism whenever a nephrologist recommends against dialysis regardless of the potential burdens to the patient. Trust is built in a therapeutic patient–physician relationship when the physician is not focused on his or her own self-interest but in the interest of the patient (Parker, 2011). Cherry picking weakens this trust.

DECREASING DIALYSIS PATIENT-PROVIDER CONFLICT

When a patient is a threat to the rights and safety of other patients and staff, steps need to be taken to address safety issues. The Occupational Safety and Health Act of 1970 mandates that facilities ensure the safety of their staff and patients. Law enforcement should be contacted when severe threats of harm are made or physical violence occurs. Dialysis organizations have the responsibility to protect facility staff, as well as all patients, including those who are verbally disruptive and abusive, provided those patients are not a threat to the safety of themselves or others. Patients deserve dialysis care in an environment where they are safe.

When patients display abusive behaviors in the clinic, IDT members have policies and procedures in place to address these behaviors. The policies and procedures usually include plan of care meetings, behavioral agreements and mental health services referrals as effective ways to assist patients in addressing the root cause of their abusive behavior. Occasionally, changing the patient's dialysis time or facility can alter the situation, causing the stress for the patient and the abusive behavior to subside. Lastly, implementing the Decreasing Patient-Provider Conflict (DPC) Toolkit in facilities can help staff understand how to effectively manage behavioral conflict.

The Forum of ESRD Networks is a national membership organization that advocates for national policies relevant to the ESRD Networks. From 2003 to 2005, the Forum of ESRD Networks addressed the increasing national trend to involuntarily dismiss disruptive, noncompliant patients. The Forum partnered with CMS and other stakeholders to create the Decreasing Patient-Provider Conflict Committee, which developed a toolkit for defusing disruptive behavior and resolving dialysis facility-based conflict, consistent with federal regulation, medical ethics, and statute (Goldman, 2008). CMS funded the production of the DPC toolkit to implement the action plan. The Dialysis Patient Provider Conflict Committee developed three categories of disruptive behavior. "The first was disruptive behavior that places the disruptive individual at risk. The second was disruptive behavior that places the facility at risk. And the third was disruptive behavior that places others in the facility at risk" (Goldman, 2008, p. 246).

CASE STUDY

History

Patient K is a 35-year-old female. She developed End Stage Renal Disease (ESRD) in 2009 due to untreated hypertension. Patient K has a reported history of drug and alcohol abuse, as well as aggressive/violent behavior. The patient does not have a family or social support system to assist in meeting her emotional or physical needs. The only person Patient K trusts is her longstanding therapist. Patient K was initially denied outpatient dialysis services by a nephrology group in her state. The patient's nephrologist referred Patient K to a psychiatrist, who reported that Patient K was "not a candidate for outpatient dialysis due to her behavior." The patient was seen by another nephrology group that started her on hemodialysis at an outpatient facility in August 2009. The patient received hemodialysis at the facility for two years. The nurse manager at the dialysis facility reported that Patient K was verbally abusive but generally not disruptive to facility functions, with the exception of a few incidents. The nurse manager and social worker developed behavioral contracts with the patient; however, she never adhered to them. The social worker tried to refer the patient for psychiatric therapy, which was also denied by the patient. The IDT made several efforts to have a meeting with the patient but she refused. In May 2011, Patient K was involuntarily discharged from her dialysis facility, with the facility citing "Immediate Severe Threat" according to the Centers for Medicare & Medicaid Services (CMS) Conditions for Coverage (CfCs). The patient had threatened to physically assault the nurse manager. Dialysis facilities are required by the CfCs to inform their ESRD Network as well as the State Survey Agency when a patient is involuntarily discharged from a facility. The nephrologist, and subsequently the nephrology group that was treating the patient, also discharged her from their care. The Patient Services Coordinator (PSC) for Network 1 received a call from the dialysis facility and has been involved in trying to coordinate dialysis services with the patient since the discharge. This work has involved several hours conversing with the State Survey Agency, nephrology practice groups, dialysis facilities, hospital personnel and mental health specialists. The PSC, a licensed clinical social worker, has continued to advocate for Patient K, while remaining cognizant of the safety of other patients and facility staff where the patient received or will receive her future medical care.

Presenting Problem

The patient has been denied services from every outpatient dialysis facility in her state, as well as most of the facilities in a neighboring state. Patient K has only dialyzed at one other outpatient dialysis facility, which is owned by one of the large dialysis organizations (LDOs), but has been denied services from the other LDOs, as well as independent and small dialysis organizations (SDOs). There is no nephrologist who will currently accept the patient for renal care. Since the patient's involuntary discharge, she has been arrested once for disorderly conduct and resisting arrest. The patient is currently receiving dialysis at an acute hospital that does not provide chronic outpatient dialysis. There are two acute hospitals in the patient's area, but she only dialyzes at one due to the second hospital's restraint policy. This policy allows the hospital staff to restrain the patient during dialysis if she presents in their Emergency Department. When Patient K presents at the Emergency Department, and if she meets the Emergency Medical Treatment and Active Labor Act (EMTALA) criteria for clinical emergent need, she is admitted and dialyzed. The hospital is obligated to treat this patient under the requirements of EMTALA. Patient K is not receiving her full prescription for dialysis three times a week.

LEGAL ACTION AND THE NONADHERENT DIALYSIS PATIENT

There are few legal cases documented regarding involuntary discharged dialysis patients. Two frequently-cited cases involve patients who tried to resume their dialysis services after they were discharged from their facilities for nonadherent behavior (Smetanka, 2006). In medicine, adherence (also compliance or capacitance) is defined as the degree to which a patient correctly follows medical advice (Compliance, n.d.). Prior to the 2008 revision, the CfCs did not address nonadherent behavior or involuntary discharges. In the current CfCs (2008), patients cannot be discharged for "failure to comply with facility policy unless the violation adversely affects clinic operations, shortened or missed treatments unless this behavior has a significant adverse effect on other patients' treatment schedules or failure to reach facility-set goals for clinical outcomes" (ESRD program interpretive guidance, 2008, p. 294).

In the first case, Payton v. Weaver (1982), Brenda Payton, a dialysis patient, had her services terminated by Dr. John C. Weaver, as well as her dialysis facility, after being a patient for three years. According to the physician and facility, the patient displayed persistent uncooperative and antisocial behavior, was nonadherent to the limitations of hemodialysis, dietary restrictions, and medical prescriptions, and was also an illegal drug user. Payton was denied services from two other dialysis facilities and was being treated by Dr. Weaver on an emergent basis. After receiving a second letter from Dr. Weaver stating that he would no longer treat her, Payton retained a lawyer who petitioned to have her dialysis clinic and the physician provide her with outpatient dialysis services (Smetanka, 2006). This lawsuit was resolved with an agreement that the patient, dialysis facility and nephrologist accepted. The agreement addressed that:

> The patient would keep all appointments at her scheduled time; that she refrain from use of alcohol and drugs; that she maintain prescribed dietary habits; and that she "in all respects cooperate with those providing her care and abide by her physician's prescribed medical regimen." Later, a sixth stipulation was added: that Payton would "enter into and participate in good faith in a program of regular psychotherapy and/or counseling" (Smetanka, 2006 p.72).

Payton failed to comply with the agreement, and was discharged again after 11 months. After Payton petitioned the court a second time, the court found that she knowingly and intentionally violated all the terms of her agreement. The court also found that Payton's behavior endangered other patients at the facility. The nephrologist and dialysis facility had no legal obligation to provide her with additional services (Smetanka, 2006).

The second case often cited is Brown v. Bower (1987). In this case, the patient Michael Brown was "an extraordinarily non-compliant, disruptive, violent, substance-abusing, chronic dialysis patient [who] received dialysis … and whose body had rejected two renal transplants because he apparently did not take required medications" (Smetanka, 2006, p.74). Brown either missed or was late to dialysis consistently, was rude to patients and staff and had verbally threatened to "kill, shoot or physically attack" his nephrologist, Dr. John Bower, hospital administrators and others (Smetanka, 2006). After being discharged by his dialysis facility, Brown was court ordered to be bound and gagged while receiving dialysis at the hospital. Brown was not able to find treatment at an outpatient dialysis facility because of his reputation. The court ruled that the hospital, which received federal funds, was required by law to provide dialysis treatment to Brown; however, Dr. Bower was not required by the ruling to resume the physician–patient relationship (Smetanka, 2006).

EMTALA AND "PATIENT DUMPING"

When patients are involuntarily discharged from a dialysis facility and cannot find another outpatient facility to accept them, they are instructed to go to the nearest emergency room for dialysis care. Emergency rooms are not obligated to treat chronic conditions unless that condition becomes emergent. EMTALA, passed in 1986, requires hospitals to provide care to anyone needing emergency healthcare treatment, based on medical examination, regardless of citizenship, legal status or ability to pay. Participating hospitals may only transfer or discharge patients needing emergency treatment under the patient's informed consent, after stabilization, or when their condition requires transfer to a hospital better-equipped to administer the treatment (The Public Health, 1944). Hospitals must also accept patient transfers if they have the capacity and capability to do so (Hyman, 1998). Physicians who are "on-call" to the emergency room are required to come to the hospital and provide all necessary services. This provision can force the nephrologist to treat a patient in the hospital who has been discharged from his care in the outpatient dialysis setting.

EMTALA applies to hospitals that accept payment from the Department of Health and Human Services under the Medicare program, which includes nearly all hospitals in the U.S. Medicare payment for all medical expenditures in the U.S. was $491 billion in 2009, an 8.2 percent increase from 2008 (United States Renal Data System Annual Report, 2011). These rising costs make it impractical for hospitals not to participate in EMTALA.

Involuntarily-discharged dialysis patients may not be in emergent need for treatment when they present at the emergency room. Patients may not present with clinical symptoms (e.g., chest pain, shortness of breath) and/or their laboratory values (e.g., high potassium level) may not indicate the need for emergent dialysis. The patients' regular dialysis time may be shortened or the treatment may be postponed, placing the patients at risk for increased morbidity.

The concern of placing the disruptive discharged dialysis patient is distinct from the problem of a hospital transferring indigent patients to other hospitals without stabilizing them—the original principle rationale behind EMTALA (Smetanka, 2006). The discharged dialysis patient's circumstance accelerates to a life-and-death situation when there is no other facility that will accept the patient. "At this point, the problem begins to resemble the 'patient dumping' situation that is addressed by EMTALA" (Smetanka, 2006 p. 80). Nephrologists, dialysis facilities, patients and CMS all agree that the acute hospital setting is not the ideal place to provide regular dialysis treatments for the patient with ESRD. However, it is very likely that disruptive patients will continue to be discharged or dumped by outpatient dialysis facilities (Smetanka, 2006).

CONCLUSION

With the increasing number of patients requiring dialysis treatment, it can be expected that the number of patients who present with disruptive, abusive behaviors will also increase. It is important to have resources available at the dialysis provider level to assist these patients in obtaining the help they need to assimilate to their new life with End Stage Renal Disease. ESRD Networks offer a range of instructive material and technical assistance for providers, as well as patients, that can help with these difficult situations.

When a situation arises where a patient is involuntarily discharged from the dialysis clinic it is important that the dialysis facility make a "good faith effort" as stated by the CfCs, and not "blacklist" the patient from other potential facilities.

Nephrologists are the first renal professional patients meet when they are diagnosed with ESRD. Most patients report having a trusting, therapeutic relationship with their nephrologist and rely on the nephrologist as the most important person to help them make informed medical decisions.

Utilizing the services of all members of the IDT, including the nurse manager and the social worker, helps the patient obtain the best medical care possible, as well as offer support to the nephrologist. The role of the social worker is very important in disruptive/abusive patient cases. Many times it is the social worker who is the primary person addressing the patient behavior. They can often spend days, weeks and months assisting the patient with his issues, while also trying to be supportive to the other members of the IDT. Members of the IDT will come to the social worker with complaints about patients, and the social worker will act as a facilitator between the staff and patients. Prior to a patient being involuntarily discharged, it is often the social worker who will work on behavioral contracts and outside referrals with the patient.

A growing problem is the number of patients who utilize hospitals for dialysis services when they should have access to an outpatient dialysis facility. Undocumented patients, patients without health insurance and involuntarily discharged patients with no accepting dialysis facility all become an undue "burden" on the hospital, which has no choice but to treat the patients. These patients can get lost in the system and receive fragmented care; sadly, some of them die because they do not receive the specialized services they need. As social workers we need to do our part to continue advocate for the patients in dialysis facilities who are close to being involuntarily discharged. Offering referrals for counseling, anger managements classes, and group therapy (if appropriate) are strategies to assist patients in getting services before the situation escalates.

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REFERENCES

Centers for Medicare & Medicaid Services (CMS). Center for Medicaid State Operations/Survey & Certification Group. (2008). *End-Stage Renal Disease (ESRD) Program interpretive guidance* (pp. 1–299). Retrieved from **http://www.cms.gov/Medicare/Porvider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Downloads/esrd-pgmguidance.pdf**

Center for Medicare & Medicaid Services. (2012). *ESRD network organizations*. Retrieved from: **https://www.cms.gov/Medicare/End-Stage-Renal-Disase/ESRDNetworkOrganizations/index.html?redirect=/esrdnetworkorganizations/**

Compliance. (n.d.). In *Wikipedia*. Retrieved 2012 from **http://en.wikipedia.org/wiki/Compliance_(medicine)**

Desai, A. A., Bolus, R., Nissenson, A., Chertow, G. M., Bolus, S., Solomon, M. D., et. al. (2009). Is there "cherry picking" in the ESRD program? Perceptions from a dialysis provider survey. *Clinical Journal of the American Society of Nephrology*, (4), 772–777.

Goldman, R. S. (2008). Medical director responsibilities regarding disruptive behavior in the dialysis center—Leading effective conflict resolution. *Seminars in Dialysis*, *21*(3), 245–249.

Hyman, D. (1998). Patient dumping and EMTALA: Past imperfect/future shock. *Health Matrix*, *8*(1), 29–56.

Parker, J. C. (2011). Cherry picking in ESRD: An ethical challenge in the era of pay for performance. *Seminars in Dialysis*, *24*(1), 5–8.

Ripley, E. B. D. (2009). Where does the nephrologist stand with a non-compliant abusive dialysis patient? *Internet Journal of Nephrology*, *5*(1), 1–10.

Smetanka, S. L. (2006). Who will protect the "disruptive" dialysis patient? *American Journal of Law and Medicine*, *32*(1), 53–91.

Title 42 of the United States Code. The Public Health and Welfare. (1944). *Chapter 1–The public health service*. Washington, D.C.: The U.S. Government Printing Office.

United States Renal Data System (USRDS). National Institutes of Health (NIH). National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). (2011). *USRDS 2011 annual data report: Atlas of chronic kidney disease and end-stage renal disease in the United States*. (NIH Publication No. 09-3176). Bethesda, MD: Author.

End Stage Renal Disease and Nonadherence to Hemodialysis: Evaluation of a Psychodynamic Intervention

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Background: *Skipping and shortening hemodialysis treatments are common and result in increased morbidity and mortality.* ***Objective:*** *The goal was to test whether a psychodynamic intervention reduced the number of skipped and the minutes of shortened hemodialysis sessions.* ***Methods:*** *A quasi-experiment conducted at one hemodialysis outpatient center was used to test a psychodynamic intervention. The intervention was delivered weekly for eight weeks to intervention group patients (n=13). Comparison group (n=8) patients received routine care.* ***Results:*** *Adherence improved for the intervention group from the Before Phase to the Treatment Phase and After Phase on all outcomes. The mean number of hemodialysis sessions skipped was 1.9 in the Before Phase and .9 in the Treatment Phase (p=.01) and .5 in the After Phase (p=.01). During the Treatment Phase the intervention group skipped less than one session while the comparison group skipped 3.5 hemodialysis sessions (p<.001). Adherence did not improve for comparison group patients.* ***Conclusions:*** *A psychodynamic intervention may be an acceptable and effective treatment for reducing nonadherence to hemodialysis.*

More than 383,992 people in the U.S. are on hemodialysis, and 116,946 patients began ESRD therapy in 2010 (U S Renal Data System, 2012). Hemodialysis, a treatment for removing waste substances and fluid from the blood when the kidneys are unable to do this, is the most common treatment for ESRD. Most hemodialysis patients receive three treatments per week for three-to-four hours per treatment (American Kidney Fund, 2013; Ranganathan & John, 2012). Adherence to the treatment protocol refers to the extent to which a person follows the nephrologist's prescribed orders for taking medication, following a renal diet, and attending dialysis treatments (Christensen, Smith, Turner, & Cundick, 1994). The focus of this study was on nonadherence to the treatment appointment schedule as defined by skipping and shortening prescribed hemodialysis sessions.

When patients are diagnosed with ESRD they are asked to immediately change their diet and fluid intake, take various medications, and modify their lifestyle to accommodate the hemodialysis treatment schedule (White, 2004). These major life changes are difficult to adhere to and skipping and shortening treatments are common forms of nonadherence to hemodialysis that can have serious negative consequences. Patients who skipped at least one hemodialysis treatment per month were less likely to receive a kidney transplant (Unruh, Evans, Fink, Powe, & Meyer, 2005) and had a 25 percent (Leggat et al., 1998) to 69 percent (Unruh, et al., 2005) higher risk of mortality as compared to adherent patients. On average, 5.4 percent (Gordon, Leon, & Sehgal, 2003) to 33 percent (Dobrof, Dolinko, Uribarri, & Epstein, 2001) of prescribed treatment time was shortened and 7 percent of patients shorten three or more hemodialysis sessions per month (Leggat, et al., 1998). Shortening three or more hemodialysis treatments per month has been associated with a 20 percent increased risk of mortality (Leggat, et al., 1998).

Most studies on skipping or shortening hemodialysis sessions have either examined the prevalence of nonadherence (Dobrof, et al., 2001; Gordon, et al., 2003) or the consequences of nonadherence (Chen, Wu, Wang, & Jaw, 2003; Cohen et al., 2007; Craven, Rodin, & Littlefield, 1988; Cukor, Cohen, Peterson, & Kimmel, 2007; Kimmel et al., 1995; Leggat, et al., 1998; Lopes et al., 2002; Unruh, et al., 2005; Watnick, Kirwin, Mahnensmith, & Concato, 2003). Intervention studies designed to reduce nonadherence have predominately focused on fluid-intake restrictions as the outcome, and only a few studies (Christensen & Johnson, 2002; Tsay, 2003) have demonstrated that a psychosocial intervention improved adherence to the treatment protocol. Two studies that tested a behavior modification intervention found no significant reduction in fluid-intake nonadherence (Welch & Thomas-Hawkins, 2005). An intervention that provided patients with advice and education was not effective in reducing interdialytic weight gain (Casey, Johnson, & McClelland, 2002). Studies that used education interventions found that increased knowledge was not associated with diet (Katz et al., 1998), medication (Long, Kee, Graham, Saethang, & Dames, 1998) or was inversely associated with fluid intake adherence (Molaison & Yadrick, 2003).

Only one published study has attempted to reduce skipped and shortened hemodialysis sessions. Cabness, Miller and Martina (2007) used a single-subject design, referred to as a "one-shot-case study" (p. 49), to examine the effectiveness of a psychoeducational and cognitive behavioral intervention on skipped and shortened hemodialysis sessions. Patients who skipped an average of four or more treatments per month were assigned to the social work intervention group. The mean number of missed treatments decreased between pre-intervention (mean=6.5) and three months post-intervention (mean=2.2). The mean number of shortened treatments decreased from pre-intervention

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(mean=2.5) to three months post-intervention (mean=2.2). This study makes an important and unique contribution by testing an intervention to reduce nonadherence as defined by skipped and shortened sessions. However, the possibility of regression to the mean (Campbell & Stanley, 1963) must be considered when interpreting the reduction in skipped and shortened sessions. Targeting the most treatment-resistant patients may have resulted in a sample with extremely high values on number of missed and shortened sessions. Even if the intervention was not effective, the social work group might have shown improved adherence, due to values on these variables that were more typical at the post-intervention measurement.

Best (2011) and colleagues found that a social work intervention led to fewer missed hemodialysis sessions and improved the reschedule rate. The social work intervention resulted in reducing or eliminating missed treatments in 71 percent of patients. The main reason patients reported missing hemodialysis sessions was due to problems adjusting their lifestyle to their treatment regimen.

Other interventions that improved adherence to treatment protocols shared several characteristics: helping patients accept the diagnosis of a chronic illness, giving patients the opportunity to share their experiences in coping with the treatment regimen, and providing them with the option of individual counseling that emphasized emotional adjustment to the illness (Christensen & Johnson, 2002; Moran, Fonagy, Kurtz, & Bolton, 1991; Tsay, 2003). While these studies provide encouraging results related to other types of nonadherence, the effects of a psychosocial intervention on skipped and shortened hemodialysis sessions has not been tested using an experimental design.

In the current study, a quasi-experimental nonequivalent groups design was used to test the efficacy of a psychodynamic therapy intervention on adherence to hemodialysis (Campbell & Stanley, 1963). This psychodynamic intervention was delivered by a nephrology social worker to provide direct support to ego functioning, thereby contributing to the patient becoming an active participant in his/her treatment. It was postulated that these changes would lead to psychological adjustment to the disease and the treatment protocol and result in increased adherence to hemodialysis treatment (Cukor, et al., 2007; Gilbar, Or-Han, & Plivazky, 2005).

STUDY HYPOTHESES

As compared with patients who received usual care, patients who received the psychodynamic intervention have:

1. fewer skipped hemodialysis sessions;
2. fewer minutes of shortened hemodialysis sessions;
3. smaller percentage of total time that hemodialysis sessions are both skipped and shortened.

METHODS

Procedure

A quasi-experimental design (Campbell & Stanley, 1963) was used to investigate the effects of a psychodynamic intervention on nonadherence to the hemodialysis treatment prescription. Patients were assigned to the intervention or comparison group based on the time of day that they received hemodialysis treatment. Patients who received hemodialysis during weekday hours were assigned to the intervention group because the social worker who administered the intervention was available during these hours. Patients who received nocturnal hemodialysis treatment, approximately 9:00 PM to 6:00 AM, were assigned to the comparison group.

Participants

The study population was adult hemodialysis patients at an outpatient hemodialysis center with an active caseload of almost 200 patients. The inclusion criteria were: skipped an average of at least one hemodialysis treatment or shortened an average of three hemodialysis treatments per month during the Pre-Treatment Phase; spoke English; was sufficiently cognitively intact to participate in the intervention; resided in the community rather than a long-term care facility; and did not require the assistance of a home attendant for more than eight hours per day. Patients residing in a nursing home or who had extensive attendant hours were ineligible because they were not likely to be making independent decisions about treatment adherence. Shortening treatment was defined as terminating a hemodialysis treatment session prior to the prescribed duration by at least 15 minutes. Eligible patients were identified by reviewing both the computerized medical record and the patient hemodialysis treatment flow sheets.

Eligible patients were invited to participate in the study by one of the two study social workers prior to or during their hemodialysis appointment. Patients were told that the purpose of the study was to learn whether it was helpful to patients to have the opportunity to meet with a social worker to receive extra support. If the patient expressed an interest in participating all information necessary for informed consent was provided to the patient. Signed consent was obtained at the first interview. Of the 23 patients who met the eligibility criteria, 21 were enrolled. The response rate was 91 percent. The study was approved by the Fordham University Institutional Review Board.

Ego Psychology Theory

The components of the psychodynamic intervention, which will be described directly below, were based on ego psychology theory. Ego psychology comprises a related set of theoretical concepts that focus on the ego and its capacity to cope with and adapt to changed circumstances (Wallerstein, 2002). Perhaps the most important and significant task that is required of the medically ill patient is adaptation. The ego, in theory, has certain functions that should allow it to adapt, such as intention, mastery, purpose, planning, and control of psychological and emotional behavior (Pine, 1990). If one or more of the ego functions is impaired, this could lead to maladaptation.

It is believed that in nonadherence the patient has found a strategy that gives the impression of serving him/her well by manifestly fostering a sense of control or independence (Cvengros, Christensen, & Lawton, 2004). This is, however, a maladaptive strategy because nonadherence leads to a lower level of functioning and to worse mental and physical health (Mayes, 1994). Many patients are able to adapt to the lifestyle changes because they have sufficient or flexible problem-solving mechanisms or are able to develop a new set of coping skills. Flexibility involves being open to one's inner life; accepting loss, disappointment or anger; and finding acceptable internal solutions (Bird, 1957; Mayes, 1994). For other patients, the diagnosis of a chronic medical condition and its treatment requirements produces an immediate upheaval because they are unable to respond to these painful feelings with appropriate solutions. Instead, defensive reactions, such as excessive levels of denial of the illness and treatment requirements, are mobilized (Fricchione, Howanitz, Jandorf, & Kroessler, 1992; Laplanche & Pontalis, 1974).

The purpose of denial, an ego defense mechanism, is to protect the individual from anxiety by repudiating some or all the meaning of an external event (Moore & Fine, 1994). Denial, however, becomes maladaptive when its use leads to behavior that adversely affects the physical and/or mental health of the individual, as is the case with nonadherence.

Psychodynamic Intervention

The intervention, which was created for the current study and was administered to intervention group patients, used a psychodynamic psychotherapy model based on ego psychology theory. The protocol was to administer one 30-minute therapy session to each patient once a week for twelve weeks. In fact, most patients received fewer than the twelve therapy sessions due to illness, hospitalization, and skipped hemodialysis appointments. The mean number of psychodynamic therapy sessions received was eight.

The therapy sessions were conducted by the first author, whose training was grounded in ego psychology theory and who was the facility social worker. The techniques and components of the intervention were chosen because it was believed that they would facilitate adjustment to hemodialysis. Initially, participants were encouraged to share their experience of living with and adjusting to a serious medical illness, receiving a time-consuming treatment, and the barriers they encountered in doing so. Although the timing of directly talking about the subject of nonadherence was individualized to each patient, common themes included exploring and solving specific difficulties and problems, such as how to cope with multiple medical illnesses, decreased physical functioning, anxiety, depression, fear and interpersonal struggles. During the course of the intervention, the social worker explored and confronted whichever maladaptive defense was thought to be interfering with treatment adherence. If the patient was making use of excessive denial, this was seen as an obstacle that must eventually be confronted and discussed. Timing was important, however, and discussion of the patient's need to deny the necessity of medical treatment was not introduced until a positive transference was well-established or the patient had some degree of insight into the problem of nonadherence.

Once a confrontation was made and the patient was made aware of his/her need to take an action (skip or shorten a hemodialysis session) to ward off the feelings that hemodialysis treatment engenders (Greenacre, 1950), in subsequent sessions the social worker placed emphasis on acceptance of those feelings that were warded off, such as loss, depression, disappointment or anger. The main goal of the intervention was to help patients become aware of these feelings, struggle with them, and then develop better ways to adapt to them. Once concerns are expressed through language there is less need to act out these feelings (Greenacre, 1950; Rodin, 1984).

One specific technique that distinguished this intervention from the other interventions mentioned in the literature review was the appreciation of the subjectively-useful component of the maladaptive aspect of the need to deny the illness, deny the need for medical treatment, and to take the action of skipping or shortening hemodialysis sessions. Appreciation was not agreement or encouragement of nonadherence, but it fostered sensitivity and allowed the health care professional to get closer to the patient's behavior, to understand it, and learn how to work with the patient in nonadversarial ways (e.g., not getting upset with the patient when s/he was nonadherent). Having the patient feel understood and helping him/her shift between denial and facing the reality of needing medical treatment, facilitated adaptation to the treatment protocol. The effectiveness of the intervention is attributed to this technique.

Usual Care Condition

Comparison group patients received the established protocol for addressing skipped and shortened sessions. This usual care protocol consisted of having a social worker who was part of the health care team at the hemodialysis center meet with each patient three times over three consecutive months to discuss nonadherence and disseminate educational material. These meetings were scheduled to occur during the patient's hemodialysis treatment. Educational material was given and discussed with patients at the end of the first month of nonadherence. At the end of the second month of nonadherence, the social worker attempted to identify the psychosocial barriers to treatment attendance. At the end of the third consecutive month of skipped or shortened sessions, patients were asked five short questions in an attempt to assess their comprehension of the importance of treatment. If a knowledge deficit was identified, patients were referred to the member of the health care team who could best provide them with additional information and education, such as the physician, dietitian, or head nurse. This protocol specified meeting with each patient three times over three consecutive months, which was comparable to the three-month Treatment Phase for the intervention group. However, because these patients were skipping hemodialysis sessions, dissemination of the material took longer than expected and ranged from three-to-five months.

The goal for this group was to learn about the consequences of skipping or shortening hemodialysis sessions, while the main goal for the intervention group was to help them become more aware and subsequently adapt to deeper, unrecognized feelings that were previously too painful to tolerate and therefore were denied.

MEASURES

Nonadherence to hemodialysis was measured in three ways. All of these measures were obtained from the medical record and patient flow sheet. Each of these measures was calculated for each of the three time periods: 1) the Pre-Treatment Phase (three months prior to the intervention); 2) the Treatment Phase (three months of intervention); and 3) the Post-Treatment Phase (three months following the intervention).

The three types of nonadherence to hemodialysis measures were:

1. *Number of skipped hemodialysis sessions:* This was calculated by adding the total number of prescribed hemodialysis sessions that were missed and were unexcused per study phase, divided by the number of months in that phase. If the patient made up the missed session within the same week, this was not considered a skipped session.
2. *Number of minutes by which hemodialysis sessions were shortened:* This was calculated by adding the total number of minutes of prescribed hemodialysis minutes that were missed due to all shortened sessions and dividing by the number of months in that study phase. Any session that was terminated early by 15 minutes or more, and if the patient did not go to the hospital to complete his/her treatment, was considered a shortened session.
3. *Percent of total minutes missed:* This was calculated by dividing the total number of skipped minutes by the total number of prescribed hemodialysis minutes, multiplying by 100 and dividing by the number of months in that study phase.

There is no gold standard for measuring adherence (Kimmel, et al., 1995). The measures used in this study are highly stable and reliable over time (Kimmel et al., 1998; Kimmel, et al., 1995; Leggat, et al., 1998). Skipped and shortened hemodialysis sessions provide a clear measure of nonadherence because health care providers routinely document a patient's absence and the amount of prescribed treatment time that is shortened (Denhaerynck et al., 2007; Kimmel, et al., 1998; Kimmel, et al., 1995; Unruh, et al., 2005).

Sociodemographic Characteristics:

The purpose of including sociodemographic measures was: 1) to describe the sample; and 2) to assess the equivalency of the intervention and comparison groups. The sociodemographic measures were collected during the Pre-Treatment Phase and were obtained from the medical evidence report that was completed in the hospital when the patient began a regular course of hemodialysis due to renal failure.

Statisical Analyses

Mixed factorial ANOVA was used to test for differences in nonadherence measures within and between the intervention and comparison groups. The goal of the analysis was to determine whether the two groups differed. Post hoc multiple comparison tests were used to determine whether the intervention and comparison groups differed on each comparison of the three treatment phases (Mertler & Vannatta, 2005). Due to the small sample size, it was not possible to conduct multivariable analyses controlling for the sociodemographic variables. Power was low for many of the analyses in this pilot study.

RESULTS

Sample Characteristics

Thirteen patients were enrolled in the intervention group and eight patients were enrolled in the comparison group. One of the comparison group patients was admitted to a nursing home during the Treatment Phase and was no longer eligible for the study.

The demographic characteristics of the patients are presented in Table 1. The mean age of patients was 44.5 years (SD=11.5), the majority were male (66.7%) and Black (61.5%), followed by Hispanic (23.8%). The most common employment status was retired (38.1%), followed by working full time (33.3%) and not working (19.1%). The mean length of time on hemodialysis was 4.7 years (SD=6.1). There were no significant differences on any of these sociodemographic characteristics or time on hemodialysis for the intervention and comparison groups.

Mean Differences Between the Two Groups

During the Pre-Treatment Phase there were no significant differences between the intervention and comparison group on number of skipped hemodialysis sessions and percent of total minutes missed. Table 2 shows that the intervention group had more early terminated minutes (107.0) as compared to the comparison group (18.1 minutes) due to two patients in the intervention group who were outliers on this variable. Two analyses were conducted to examine the optimal method for handling this. In the first analysis, the actual values were included; in the second analysis, the mean value for the intervention group was substituted for these high values. Both methods yielded the same conclusions and the original values were used in all analyses reported here.

Table 1. *Sample Characteristics*

	TOTAL		GROUP				
			INTERVENTION		COMPARISON		
CHARACTERISTICS	N	Percent or Mean (SD	n	Percent or Mean (SD)	n	Percent or Mean (SD)	P value
Age	21	44.49 years (11.52)	13	44.55 (12.3)	8	44.38 (10.9)	.97
Gender							
Male	14	66.67%	7	53.85%	7	87.50%	.17
Female	7	33.34%	6	46.15%	1	12.50%	
Ethnicity							
Black	13	61.90%	8	61.54%	5	62.50%	.42
Hispanic	5	23.81%	4	30.77%	1	12.50%	
White non-Hispanic	2	9.52%	1	7.69%	1	12.50%	
Asian	1	4.76%	0	0.0%	1	12.50%	
Employment Status							
Retired	8	38.10%	6	46.15%	2	25.0%	.79
Full time	7	33.34%	4	30.77%	3	37.50%	
Not working	4	19.05%	2	15.38%	2	25.0%	
Part time	2	9.52%	1	7.69%	1	12.50%	

During both the Treatment Phase and Post-Treatment Phase, the intervention group was significantly more adherent than the comparison group for number of skipped sessions and percentage of total minutes missed. For example, during the Treatment Phase the intervention group skipped less than one session as compared to the comparison group who skipped 3.5 hemodialysis sessions (p<.001). The intervention group missed 8.6 percent of the prescribed treatment time as compared to the comparison group who missed 28.1 percent of total minutes missed (p <.001).

Comparisons Between the Study Phases

Pre-Treatment Phase vs. Treatment Phase

For the intervention group, on all outcome measures, there was significant improvement in adherence from the Pre-Treatment Phase to the Treatment Phase (Table 3). For example, there was a significant decline in the number (p <.01) of skipped sessions, minutes of sessions shortened (p <.05), and percentage of total minutes missed (p <.001). The difference in percentage of total minutes missed was 9.6 percent (18.2% in the Pre-Treatment Phase and 8.6% in the Treatment Phase) lower. This represents a twofold improvement in adherence for the intervention group. For the comparison group, on all of the outcome measures, there was no difference in adherence from the Pre-Treatment Phase to the Treatment Phase.

Treatment Phase vs. Post-Treatment Phase

There was no significant improvement for the intervention group from the Treatment Phase to the Post-Treatment Phase on any of the adherence measures. The comparison group had significant improvement in the number of skipped sessions and percentage of total minutes missed from the Treatment Phase to the Post-Treatment Phase. For this group, adherence became worse from the Pre-Treatment Phase to the Treatment Phase, and these improvements from the Treatment Phase to the Post-Treatment Phase largely represent a return to the Pre-Treatment Phase adherence level.

Pre-Treatment Phase vs. Post-Treatment Phase

For the intervention group, on all outcome measures there was significant improvement in adherence from the Pre-Treatment Phase to the Post-Treatment Phase. For example, the difference in the number of skipped sessions was 1.4 percent less (1.9% in the Pre-Treatment and 0.5% in the Post-Treatment Phase) and the difference in percentage of total minutes missed was 12.4 percent less from the Pre-Treatment to the Post-Treatment Phase (18.2% in the Pre-Treatment Phase and 5.8% in the Post-Treatment Phase). Each of these differences represents over a threefold improvement in adherence for the intervention group.

For the comparison group, there was no difference in adherence from the Pre-Treatment Phase to the Post-Treatment Phase for all outcome measures.

Table 2. *Mean Differences on Outcome Measure Between Groups by Study Phase*

ADHERENCE MEASURE	PHASE	INTERVENTION			COMPARISON			MEAN DIFFERENCE (INT-COMP)	P value for one way ANOVA
		N	Mean	SD	N	Mean	SD		
Number of skipped sessions	Pre-Tx	13	1.92	1.26	8	2.83	0.82	-0.91	.09
	Treatment	12	0.86	0.87	8	3.47	1.47	-2.61	<.001
	Post-Tx	11	0.52	0.67	7	2.52	1.33	-2.0	.001
Minutes of shortened sessions	Pre-Tx	13	107.09	93.01	8	18.13	28.53	88.96	.02
	Treatment	12	55.00	76.09	8	54.32	63.40	0.68	.98
	Post-Tx	11	51.21	70.14	7	64.29	69.63	-13.08	.70
Percentage of total minutes missed from skipped and early terminated sessions	PreTx	13	18.15	10.94	8	22.00	7.09	-3.85	.39
	Treatment	12	8.55	7.21	8	28.11	11.32	-19.56	<.001
	Post-Tx	11	5.77	6.99	7	20.95	10.56	-15.18	.002

Table 3. *Comparisons Between Study Phases within Each Group*

ADHERENCE MEASURE	PHASE		MEAN DIFFERENCE (Column A – Column B)	
	Column A	Column B	INTERVENTION (N = 13)	COMPARISON (N = 8)
Number of skipped sessions	Pre-Tx	**Treatment**	1.06**	-0.64
	Treatment	Post-Tx	0.34	0.95*
	Pre-Tx	Post-Tx	1.4**	0.31
Minutes of shortened sessions	Pre-Tx	**Treatment**	52.09*	-36.19‡
	Treatment	Post-Tx	3.79	-9.97
	Pre-Tx	Post-Tx	55.88**	-46.16
Percentage of total minutes missed from skipped and early terminated sessions	Pre-Tx	**Treatment**	9.60***	-6.11
	Treatment	Post-Tx	2.78	7.16*
	Pre-Tx	Post-Tx	12.38**	1.05

‡<.1, *<.05, **.01, ***<.001

DISCUSSION

These results suggest that the psychodynamic intervention was effective in reducing nonadherence as defined by skipped and shortened hemodialysis sessions. For the intervention group, on all outcome measures, there was significant improvement in adherence from the Pre-Treatment Phase to the Treatment Phase and from the Pre-Treatment Phase to the Post-Treatment Phase. Nonadherence continued to decline from the Treatment Phase to the Post-Treatment Phase, but not significantly. It is extremely likely that there were no significant differences between the Treatment Phase and Post-Treatment Phase due to low statistical power to test for these differences (power =.05 for each outcome measure).

Nonadherence did not decline in the comparison group. The established protocol that provided educational materials and helped patients understand the psychosocial barriers to treatment attendance did not effectively reduce nonadherence. Consistent with prior research (Molaison & Yadrick, 2003), there was an increase in nonadherence. The increase in nonadherence in the comparison group was expected. Patients are nonadherent for a reason; if the underlying meaning behind the nonadherence is not understood this type of acting out behavior will not change. Patients who suffer from chronic disease have been educated about the importance of adherence from the onset of their condition and may not want to be lectured about this at a time when they are most likely not ready to change. Education about the reasons to receive a full hemodialysis treatment may have been heard as a demand to be adherent. When personal freedom, the freedom of nonadherence, is perceived to be taken away, that behavior (nonadherence) becomes even more desirable (Cvengros, et al., 2004). This has been referred to as the 'boomerang effect' (Cvengros, et al., 2004).

There were several limitations to this study and the results must be interpreted with these in mind. The number of patients who participated in the study was very small (n=21) and the sample was selected from a single site, which limits the generalizability of results to other hemodialysis patients. There were differences in the amount of hemodialysis prescribed for the intervention and comparison groups. Intervention group patients received, on average, four hours of hemodialysis treatment during the daytime hours and comparison group patients received nine hours of hemodialysis overnight. Aside from the difference in prescription time, the two groups were very similar. For example, there were no significant differences in sociodemographic characteristics and the two groups appeared to be very similar in age, ethnicity, employment status, and length of time on hemodialysis. There is some fluidity between the two treatment modalities and it is not uncommon for patients to alternate between standard and nocturnal hemodialysis based on their schedule, although this did not occur with any study participants. However, without random assignment we cannot rule out the possibility of differences in variables that were not measured, including level of motivation, social support, and other psychosocial factors (Campbell & Stanley, 1963).

During the Treatment Phase, the comparison group received the established protocol for addressing skipped and shortened sessions, which, according to corporation standards, required limited social work education services. It is therefore difficult to rule out the possibility that the reduction in nonadherence was due to a nonspecific or an attention effect rather than the specific techniques that were used in the psychodynamic intervention. Future research should involve a control group that receives social support, but no psychodynamic treatment intervention.

This study was the first to test a psychodynamic intervention, based on ego psychology theory, for nonadherent hemodialysis patients who are skipping and shortening hemodialysis sessions. Although a true experimental design with random assignment was not employed, the quasi-experimental nonequivalent groups design controlled for most threats to internal validity. This study design is stronger (Campbell & Stanley, 1963) than the single-subject design that was used in the one study (Cabness, et al., 2007) that attempted to improve adherence as defined by skipped and shortened sessions.

The clinical significance of the psychodynamic intervention is noteworthy. In the Pre-Treatment Phase, the mean number of skipped hemodialysis sessions was in the clinically problematic range. These patients were less likely to receive a kidney transplant (Unruh, et al., 2005), had a lower standard of living, and had a 25 percent (Leggat, et al., 1998) to 69 percent (Unruh, et al., 2005) higher risk of mortality as compared to adherent patients. In the Post-Treatment Phase, intervention group patients were no longer in the problematic range (skipping about .5 of a session per month) while the comparison group continued to display poor adherence (skipping 2.5 sessions per month).

There have been few intervention studies testing psychosocial treatments designed to decrease nonadherence and there are even fewer intervention programs that effectively reduce nonadherence. It is important to find an intervention that can reduce nonadherence. The results of the current study offer support that a psychodynamic intervention can reverse the harmful pattern of nonadherence.

REFERENCES

American Kidney Fund. (2013). *Treatment options for kidney failure*. Retrieved March 2, 2013, from **http://www.kidneyfund.org/kidney-health/treatment/**

Best, S., Canny, B., Averette, E., Cameron, D., Keaveney, D., Anderson, J., et. al., (2011). *Reducing behavior-based missed hemodialysis treatments*. Paper presented at the American Nephrology Nurses' Association 42nd National Symposium, Boston, MA.

Bird, B. (1957). A specific peculiarity of acting out. *Journal of the American Psychoanalytic Association*, *5*, 630–647.

Cabness, J., Miller, C., & Martina, K. (2007). Mastering hemodialysis to reverse patterns of missed and shortened treatments. *Journal of Nephrology Social Work*, *27*, 45–51.

Campbell, D. T., & Stanley, J. C. (1963). *Experimental and quasi-experimental designs for research*. Boston: Houghton Mifflin Company.

Casey, J., Johnson, V., & McClelland, P. (2002). Impact of stepped verbal and written reinforcement of fluid balance advice within an outpatient haemodialysis unit: A pilot study. *Journal of Human Nutrition and Dietetics*, *15*(1), 43–47.

Chen, Y. S., Wu, S. C., Wang, S. Y., & Jaw, B. S. (2003). Depression in chronic haemodialysed patients. *Nephrology*, *8*(3), 121–126.

Christensen, A., Smith, T., Turner, C., & Cundick, K. (1994). Patient adherence and adjustment in renal dialysis: A person x treatment interactive approach. *Journal of Behavioral Medicine*, *17*(6), 549–566.

Christensen, A. J., & Johnson, J. A. (2002). Patient adherence with medical treatment regimens: An interactive approach. *Current Directions in Psychological Science*, *11*(3), 94–97.

Cohen, S. D., Sharma, T., Acquaviva, K., Peterson, R. A., Patel, S. S., & Kimmel, P. L. (2007). Social support and chronic kidney disease: An update. *Advances in Chronic Kidney Disease*, *14*(4), 335–344.

Craven, J. L., Rodin, G. M., & Littlefield, C. (1988). The Beck Depression Inventory as a screening device for major depression in renal dialysis patients. *International Journal of Psychiatry in Medicine*, *18*(4), 365–374.

Cukor, D., Cohen, S. D., Peterson, R. A., & Kimmel, P. L. (2007). Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. *Journal of the American Society of Nephrology*, *18*(12), 3042–3055.

Cvengros, J. A., Christensen, A. J., & Lawton, W. J. (2004). The role of perceived control and preference for control in adherence to a chronic medical regimen. *Annals of Behavioral Medicine*, *27*(3), 155–161.

Denhaerynck, K., Manhaeve, D., Dobbels, F., Garzoni, D., Nolte, C., & De Geest, S. (2007). Prevalence and consequences of nonadherence to hemodialysis regimens. *American Journal of Critical Care*, *16*(3), 222–235.

Dobrof, J., Dolinko, A., Uribarri, J., & Epstein, I. (2001). Dialysis patient characteristics and outcomes: The complexity of social work practice with the end-stage renal disease population. *Social Work in Health Care*, *33*(3/4), 105–128.

Fricchione, G. L., Howanitz, E., Jandorf, L., & Kroessler, D. (1992). Psychological adjustment to end-stage renal disease and the implications of denial. *Psychosomatics: Journal of Consultation Liaison Psychiatry*, *33*(1), 85–91.

Gilbar, O., Or-Han, K., & Plivazky, N. (2005). Mental adjustment, coping strategies, and psychological distress among end-stage renal disease patients. *Journal of Psychosomatic Research*, *58*(6), 471–476.

Gordon, E. J., Leon, J. B., & Sehgal, A. R. (2003). Why are hemodialysis treatments shortened and skipped? Development of a taxonomy and relationship to patient subgroups. *Nephrology Nursing Journal*, *30*(2), 209–217.

Greenacre, P. (1950). General problems of acting out. *Psychoanalytic Quarterly*, *19*, 455–467.

Katz, R. C., Ashmore, J., Barboa, E., Trueblood, K., McLaughlin, V., & Mathews, L. (1998). Knowledge of disease and dietary compliance in patients with end-stage renal disease. *Psychological Reports*, *82*(1), 331–336.

Kimmel, P. L., Peterson, R. A., Weihs, K. L., Simmens, S. J., Alleyne, S., Cruz, I., & Veis, J. H. (1998). Psychosocial factors, behavioral compliance and survival in urban hemodialysis patients. *Kidney International*, *54*(1), 245–254.

Kimmel, P. L., Peterson, R. A., Weihs, K. L., Simmens, S. J., Boyle, D. H., Verme, D., et. al. (1995). Behavioral compliance with dialysis prescription in hemodialysis patients. *Journal of the American Society of Nephrology*, *5*(10), 1826–1834.

Laplanche, J., & Pontalis, J. B. (1974). *The language of psychoanalysis*. London: W.W. Norton and Company.

Leggat, Jr., J. E., Orzol, S. M., Hulbert-Shearon, T. E., Golper, T. A., Jones, C. A., Held, P. J., & Port, F. K. (1998). Noncompliance in hemodialysis: Predictors and survival analysis. *American Journal of Kidney Diseases*, *32*(1), 139–145.

Long, J. M., Kee, C. C., Graham, M. V., Saethang, T. B., & Dames, F. D. (1998). Medication compliance and the older hemodialysis patient. *ANNA Journal*, *25*(1), 43–52.

Lopes, A. A., Bragg, J., Young, E., Goodkin, D., Mapes, D., Combe, C., et. al. (2002). Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney International*, *62*(1), 199–207.

Mayes, L. C. (1994). Understanding adaptive processes in a developmental context. *Psychoanalytic Study of the Child*, *49*, 12–35.

Mertler, C. A., & Vannatta, R. A. (2005). *Advanced and multivariate statistical methods.* Los Angeles: Pyrczak.

Molaison, E. F., & Yadrick, M. K. (2003). Stages of change and fluid intake in dialysis patients. *Patient Education and Counseling*, *49*(1), 5–12.

Moore, B. E., & Fine, B. D. (1994). *Psychoanalytic terms and concepts*. New Haven, CT: Yale University Press.

Moran, G., Fonagy, P., Kurtz, A., & Bolton, A. (1991). A controlled study of the psychoanalytic treatment of brittle diabetes. *Journal of the American Academy of Child and Adolescent Psychiatry*, *30*(6), 926–935.

Pine, F. (1990). *Drive, ego, object, and self: A synthesis for clinical work.* New York: Basic Books.

Ranganathan, D., & John, G. T. (2012). Nocturnal hemodialysis. *Indian Journal of Nephrology, 22*(5), 323–332. doi: 10.4103/0971-4065.103905

Rodin, G. (1984). Expressive psychotherapy in the medically ill: Resistances and possibilities. *International Journal of Psychiatry in Medicine*, *14*(2), 99–108.

Tsay, S. L. (2003). Self-efficacy training for patients with end-stage renal disease. *Journal of Advanced Nursing*, *43*(4), 370–375.

United States Renal Data System (USRDS). National Institutes of Health (NIH). National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). (2012). *USRDS 2012 Annual data report: Atlas of chronic kidney disease and end-stage renal disease in the United States.* Bethesda, MD: Author.

Unruh, M. L., Evans, I. V., Fink, N. E., Powe, N. R., & Meyer, K. B. (2005). Skipped treatments, markers of nutritional nonadherence, and survival among incident hemodialysis patients. *American Journal of Kidney Diseases*, *46*(6), 1107–1116.

Wallerstein, R. (2002). The growth and transformation of American ego psychology. *Journal of the American Psychoanalytic Association*, *50*(1), 135–168.

Watnick, S., Kirwin, P., Mahnensmith, R., & Concato, J. (2003). The prevalence and treatment of depression among patients starting dialysis. *American Journal of Kidney Diseases*, *41*(1), 105–110.

Welch, J. L., & Thomas-Hawkins, C. (2005). Psycho-educational strategies to promote fluid adherence in adult hemodialysis patients: A review of intervention studies. *International Journal of Nursing Studies*, *42*(5), 597–608.

White, B. R. (2004). Adherence to the dialysis prescription: Partnering with patients for improved outcomes. *Nephrology Nursing Journal*, *31*(4), 432–435.

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 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 endartarectomy, 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 endartarectomy, 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, without 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 incompletion 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.

REFERENCES

Cohen, L. M., Germain, M., Poppel, D. M., Woods, A. L., Pekow, P. S., & Kjellstrand, C. M. (2009). Dying well after discontinuing the life support treatment of dialysis. (Reprinted: *Archives Internal Medicine* (2000, September 11), *160*, 2513–2518). Retrieved June 30, 2009 from **www.archinternmed.com**.

Davison, S. (2010). End-of-life care preferences and needs: Perceptions of patients with chronic kidney disease. *Journal of the American Society of Nephrology*, *15*(2), 195–204.

King, K. (2007). Withdrawal from dialysis: The literature, DOPPS, and implications for practice. *Journal of Nephrology Social Work*, *26*, 45–53.

Lelie, A. (2001–2002). Decision-making in nephrology: Shared decision-making? (Reprinted with permission from *Patient Education and Counseling*, *39*(1), 81–89.) *Journal of Nephrology Social Work*, *21*, 51–59.

McKevitt, P., Bommer, J., Bragg-Gresham, J., Pisoni, R. L., Keen, M. L., et al. (2007). DOPPS and the elderly: implications for nephrology social work practice. *Journal of Nephrology Social Work*, *26*, 55–65.

Melhado, L., & Fowler-Byers, J. (2011). Patients' and surrogates' decision-making characteristics: withdrawing, withholding and continuing life-sustaining treatment. *Journal of Hospice and Palliative Nursing*. *13*(1), 16–28.

Melnick, J., & Roos, S. (2007). The myth of closure. *Gestalt Review*, *11*(2), 90–107.

Moss, A. (2011). *Nephrology care at the end of life: New guidelines on withholding and withdrawing dialysis.* Presented at the National Kidney Foundation 2011 Spring Clinical Meetings, Las Vegas, NV.

Moss, A., Ganjoo, J., Sharma, S., Gansor, J., Senft, S., Weaner, B., Dalton, C., MacKay, K., Pellegrino, B., Anantharaman, P., & Schmidt, R. (2008). Utility of the "surprise" question to identify dialysis patients with high mortality. *Clinical Journal of the American Society of Nephrology*, *3*, 1379–1384.

Office of the Legislative Counsel, U. S. House of Representatives (2010, May). Compilation of patient protection and affordable care act. Retrieved from **http:/www.gpo.fdsys/pkg/BILLS.../PDF/BILLS-111hr3590enr.PDF**

Renal Physicians Association. (2010, October). *Shared decision-making in the appropriate initiation of and withdrawal from dialysis. Clinical practice guideline* (2nd ed.). Rockville, MD: Renal Physicians Association.

Scham, A. (2011). Palliative care. *The Leader, The Valley Hospital*, *6*.

Stuart, B., Herbst, L., Kinsbrunner, B., et al. (1995). Medical guidelines for determining prognosis in selected non-cancer diseases (2nd ed.). *Hospice Journal*, *11*, 47–63.

Weiner, Sheila. (2008). End-of-life care discussions: A survey of dialysis patients and professionals. *Journal of Nephrology Social Work*, *28*, 52–58.

Woods, A., Berzoff, J., Cohen, L., Cait, C., Pekow, P., Germain, M., & Poppel, D. (1999). The family perspective of end-of-life care in end-stage renal disease: The role of the social worker. *Journal of Nephrology Social Work*, *19*, 9–21.

Yuscak, C. (1999). The effectiveness of a structured program on the completion of advance directives among hemodialysis patients. *Journal of Nephrology Social Work*, *19*, 51–56.

Can a Social Work Intervention Reduce Kidney Donor Anxiety? A Pilot Test

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The purpose of this study is to explore the effect of social work counseling on kidney donor anxiety in Nadiad, Gujarat, India. Thirty potential kidney donors were selected to receive counseling by a nephrology social worker during the kidney donation process, and 30 potential kidney donors were selected for a control group that did not receive counseling beyond the usual course of care. Anxiety was measured using the Comprehensive Anxiety Test. The group that received counseling from a social worker had a statistically significant decrease in their comprehensive anxiety, which was measured prior to kidney donation and at six months after kidney donation, when compared to the control group. These results suggest that counseling by a nephrology social worker during the kidney donation process may lower donor anxiety. This study and future research may help more kidney disease patients receive kidney transplants from living donors in India and beyond.

When medically appropriate, a kidney transplant from a living donor is the optimal form of treatment for kidney failure (Abecassis et al., 2008; Tarantino, 2000). Compared to dialysis, kidney transplantation is less costly and results in lower morbidity, mortality, and hospitalization (Danovitch, 2008; Tonelli et al., 2011). A living donor kidney transplant (LDKT) also addresses the international phenomenon of a shortage of kidneys for transplant from deceased donors. LDKT is particularly important in countries such as India, where patients are responsible for much of their treatment costs and where there is no national kidney registry for deceased organs for transplant.

Kidney transplant donation from a living donor involves physical discomfort as well as significant surgery and recovery (Browne, 2012). Because of the potential physical and emotional consequences of donating a kidney, transplant centers around the world often require that the donor receive a thorough psychosocial evaluation prior to the donation. For example, in the United States, Medicare requires this to be done in every kidney transplant center (Medicare Program, 2007). In India, each living donor must also receive a thorough psychosocial assessment (Ministry of Law, Justice, and Company Affairs, 1994). These assessments can identify the psychosocial barriers to living donation, and transplant teams can work with potential kidney donors to ameliorate such barriers.

For example, Drotar, Ganofsky, Makker, and DeMaio (1981) found that counseling sessions helped donors and families cope with LDKT, and Kasiske et al. (1996) note that kidney donors found counseling helpful to cope with an unsuccessful LDKT. Nephrology social workers can provide individual counseling to kidney donors and prepare donors for the donation process by offering information, encouraging questions about the surgical procedure and recovery process, and discussing any of the donor's emotional concerns. The social worker stresses donor self-disclosure and openness within the individual donor's comfort level and views the donor with unconditional positive regard.

This paper presents the findings from a pilot study in India that examines the efficacy of counseling on kidney donor anxiety before and after kidney donation. This and future similar research may help ameliorate a portion of the barriers to LDKT and provide a way to encourage more living donor kidney transplantation around the world.

METHODS

Hypothesis

Based on the clinical experience of the hospital social workers where this study was conducted, it was hypothesized that providing a tailored social work counseling intervention to prospective living kidney donors will reduce self-reported anxiety compared to donors who receive social work care as usual.

Setting

This research was conducted at the Muljibhai Patel Urological Hospital in Nadiad, Gujarat, India. This hospital was the first in the country devoted entirely to nephrology and urology, and provides dialysis and kidney transplant services by an interdisciplinary team including master's-level social workers.

Participants

The participants in the study were 60 individuals who were registered as possible kidney donors at the study site. That is, these individuals had been identified as potential LDKT donors for kidney patients, but they had not yet been formally listed as such.

Editor's Note: This work was featured on an award-winning poster at the NKF 2012 Spring Clinical Meetings.

Table 1. *Frequencies for Demographic Variables*

	Control Group (*n = 30*)		Intervention Group (*n = 30*)	
	n	%	n	%
Gender				
Male	14	47	15	50
Female	16	53	15	50
Age				
18-35	3	10	12	40
36+	27	90	18	60
Marital status				
Married	24	80	23	77
Single	5	17	7	23
Widowed	1	3	0	0
Education				
No formal education	8	27	5	17
≤ 8th Grade	12	40	7	23
9th – 12th Grade	3	10	6	20
Some college	3	10	5	17
College graduate	4	13	6	20
Professional education	0	0	1	3
Occupation				
Agriculturist	2	7	3	10
Labourer	2	7	2	7
Business owner	0	0	3	10
Salaried Employee	4	13	6	20
Homemaker	15	50	13	43
Student	1	3	2	7
Unemployed	0	0	0	0
Retired	6	20	1	3
Annual income				
< 5,000 rupees[1]	12	40	10	33
5,000 – 10,000 rupees	13	43	9	30
>15,000 rupees	5	17	11	37

Note: There were no significant differences between the control and intervention groups.

[1] = As of March 11, 2013: 5,000 rupees = $91.95 U.S. dollars

There were no significant differences between the demographic composition of the control and intervention groups (see Table 1). Both the control and intervention groups had about equal numbers of females and males. The predominant relationship of the donor to the transplant recipient in the intervention group (see Table 2) were mothers (33%), brothers (13%), and wives (13%). The predominant recipient relationships in the control group were mothers (27%), sisters (20%), and brothers (20%). The control group had a greater representation of fathers (17%) than the intervention group (7%). In addition, sisters and brothers were more highly represented in the control group than in the intervention group. However, there were no statistical differences in the relationship of the donor to the patient in either group. Both groups had a large percentage of homemakers and salaried employees. The control group had a greater percentage of retired employees (20%) than the intervention group (3%), while the intervention group had a larger percentage of business owners and overall higher incomes than the control group.

Table 2. *Relationship of Donor to Patient*

	Control Group (*n = 30*)		Intervention Group (*n = 30*)	
	n	%	*n*	%
Relationship				
Father	5	17	2	7
Mother	8	27	10	33
Sister	6	20	3	10
Brother	6	20	4	13
Wife	3	10	4	13
Husband	0	0	2	7
Son	0	0	2	7
Daughter	0	0	0	0
Emotionally related	2	7	3	10

Note: There were no significant differences between the control and intervention groups.

The Muljibhai Patel Society for Research in Nephro-Urology ethics committee (Nadiad, Gujarat, India) provided institutional review board (IRB) approval and oversight of this project; this project was deemed exempt from IRB approval from the University of South Carolina (Columbia, SC, USA; the SC authors did not participate in the planning or execution of this study and were involved only with de-identified post-hoc data analysis).

Procedure and Design

Using a between-group design, the participants were randomly divided into two groups (intervention and control), with thirty individuals in each group. See Table 1 for the demographic composition of both groups of participants. Participants in both groups received the hospital's standard kidney donor psychosocial assessment and standard social work interventions that any LDKT donor would normally receive. In addition to the typical course of social work care, the individuals in the intervention group also received additional counseling conducted by a professionally trained social worker aimed at alleviating donor anxiety. Participants in both groups were assured that their participation in the study was voluntary, that it would have no impact on the usual care expected and received at the hospital, and that their responses were confidential.

Intervention

The social workers involved in this study collaborated with their interdisciplinary team experts to create the content of the unique counseling sessions provided to the intervention group. The social work intervention consisted of counseling sessions designed to provide donors with reassurance, repetitive information, and clarification of communication (Drotar, Ganofsky, Makker, & DeMaio, 1981).

In the transplant clinic involved in this study, there are three phases of the kidney donation process. The first phase is at the time of registration; the second phase is prior to kidney donation; and the third phase is six months after donation.

Phase 1 of the kidney donation process occurred at the time of registration. As is typical in this transplant center, both the intervention and control groups received social work counseling from a master's-level social worker (MSW) in phase one. The counseling session consists of a psychosocial evaluation that explores the reasons for donation; the emotional attachment between the recipient and potential donor; the current social support systems; the understanding of kidney donation; mental health or substance abuse issues; the required medical tests and procedure; donor understanding of the LDKT surgical procedure; donor willingness to engage in necessary hospitalization and post-operative recovery; and the ability of the donor to cope in the event of organ rejection. Both the control and intervention groups completed the Comprehensive Anxiety Test (CA Test) during Phase 1, after the counseling session.

Phase 2 of the kidney donation process occurred prior to the actual kidney donation. Only the intervention group was involved in two special counseling sessions from an MSW during this phase. The first counseling session for the intervention group in this phase consisted of expressed appreciation for the participant's efforts and cooperation during the medical testing stage. The participant's feelings and concerns about the approaching kidney donation were explored and validated. The second counseling session for the intervention group in this phase consisted of a discussion of pre-hospitalization issues that may require attention, such as child care, employment concerns, and financial concerns. Both the control and intervention groups completed the CA Test during Phase 2. The intervention group completed the CA Test after the counseling sessions in Phase 2.

Phase 3 of the kidney donation process occurred after the kidney donation. The first of three counseling sessions by an MSW in this phase took place soon after LDKT surgery for both the control and intervention groups. The focus of this session was to ascertain the donor's level of pain and discomfort, reassure the donor, and encourage the donor to resume daily activities when medically advised. The second counseling session in Phase 3 for the intervention group occurred one month after the LDKT. During this session, the donor and social worker discussed lifestyle changes, such as exercise resumption, sexual activity resumption, hobby pursuits, or the incorporation of meditation or prayer to improve total well-being. If the donor was female, issues concerning future child-bearing were also discussed.

The third counseling session for the intervention group in phase three occurred six months after the LDKT. The recovering donors were encouraged to discuss their perceived state of health as well as that of the kidney recipient. Potential emotional and medical impediments were discussed. In addition, the social worker advised the participants to obtain the medically advised follow-ups and seek counseling in the future if needed. The social worker offered her assistance in obtaining future counseling. Both the control and intervention groups completed the CA Test during Phase 3. The intervention group completed the CA Test after the third counseling sessions in Phase 3. The control group completed the CA Test after the standard (usual care) first counseling session in Phase 3.

Measures

Potential donors in the intervention and control groups completed the Comprehensive Anxiety Test (CA Test) during the three phases of kidney donation. The 90-item CA Test was developed by Sharma, Bharadwaj, and Bhargava (1992) and explores the biological, psychological, and sociological correlates of anxiety. Each item of the CA Test requires a yes or no response. All yes responses are totaled to ascertain the anxiety score, which ranges from 1 (very low anxiety) to 90 (very high anxiety). A high score on the CA Test corresponds to a high level of anxiety experienced by the participant. The reliability of the CA Test was ascertained to be 0.94 using the split-half method (Sharma, Bharadwaj, & Bhargava, 1992). Some examples of the test items include: "Do you always want to keep yourself busy to forget your problems?", "Do you often remain worried?", and "Do you think that life is full of disappointment?" To our knowledge, the CA test has not been used in a nephrology setting (the investigators were unable to find an Indian-specific anxiety inventory that had been used in End Stage Renal Disease); however, this test was chosen because it has been widely used in India to explore anxiety in other chronic illnesses (Khan & Sehgal, 2010).

Data Analysis

Chi-square testing was conducted to determine the differences between the demographic and relationship variables of the two groups of donors. Independent samples T-tests were performed to examine the differences in the mean anxiety scores of the two groups of donors at each phase of the project.

RESULTS

The mean scores of the CA Test for the intervention group and control group were compared at the three phases of kidney donation (see Table 3). During Phase 1 (time of registration), both groups were counseled and completed the CA Test to measure participants' anxiety levels. In Phase 1 (pre-intervention), there was no significant difference (t = 1.39, p = .08) in the anxiety level between the control group (M = 37.2, SD = 10.6) and the intervention group (M = 33.4, SD = 10.5). In Phase 2 (pre-transplant), there was a significant difference (t = 2.72, p = .004) in the anxiety level between the control group (M = 37.2, SD = 10.1) and the intervention group (M = 30.1, SD = 10.2). In Phase 3 (post-transplant), there was a significant difference (t = 2.78, p = .003) in the anxiety level between the control group (M = 37.1, SD = 9.2) and the intervention group (M = 29.8, SD = 11.1). In both Phase 2 and Phase 3, the intervention group, which received the social work counseling, had significantly lower anxiety scores than the control group, which received usual care.

Table 3. *Donor Anxiety Scores*

	M	*SD*	*t*	*p*
Phase 1 Registration				
Control group	37.2	10.6		
Intervention group	33.4	10.5	1.39	.08
Phase 2 Pre-transplant				
Control group	37.2	10.1		
Intervention group	30.1	10.2	2.72	.004
Phase 3 Post-transplant				
Control group	37.1	9.2		
Intervention group	29.8	11.1	2.78	.003

DISCUSSION

This preliminary study suggests that a social work intervention aimed at kidney donors may lessen the anxiety experienced by donors during the donation process (from registration to six months after LDKT). It appears that counseling may reduce kidney donors' fears and anxiety related to the LDKT. Kidney donors reported feelings of increased self-worth and positive regard throughout the counseling relationship. In addition, counseled donors also stated that they experienced empathetic understanding and acceptance from the counselor relationship. Social work assessments done internationally on living donors for kidney transplants may want to incorporate attention to donor anxiety as a barrier to living donation, and address such anxiety with social work counseling. This work builds on the research done previously by Drotar, Ganofsky, Makker, and DeMaio (1981) and Kasiske et al. (1996) which suggests that counseling kidney donors can promote better outcomes for the donors. Helping donors cope with the significant choice to donate an organ may help promote more LDKT, which are necessary because of a world-wide shortage of organs for deceased donor transplants.

As this was a pilot test, there are limitations to the research findings. Primarily, the generalizability of the findings may be compromised because of the small sample sizes in the control and intervention groups. Also, these findings may not be applicable to a non-Indian population, as the anxiety scale has been primarily used with an Indian population. However, the promising results of this research can prompt further research in India and beyond that explores the impact of social work interventions on decreasing the anxiety of kidney donors and other barriers to LDKT. Future research may also explore the longer-term (more than six months after transplant) impact of such interventions. Future research could also examine the effect of social work interventions on the recovery process after a donation. For example, do such interventions help reduce surgical complications, length of hospitalization, or return to pre-donation level of activities? Finally, additional research can be conducted that explores the relationship between cultural and family belief and values and how they may promote or discourage LDKT.

Kidney donors who experienced counseling during the donation process reported a greater sense of fulfillment from helping someone in need of a kidney. This sense of fulfillment, coupled with an empathetic counseling relationship, appears to have resulted in lower comprehensive anxiety. Therefore, social work counseling may be efficacious in ameliorating the fear and anxiety normally associated with kidney donation.

REFERENCES

Abecassis, M., Bartlett, S. T., Collins, A. J., Davis, C. L., Delmonico, F. L., Firedwalk, J. J., et al. (2008). Kidney transplantation as primary therapy for end-stage renal disease: A National Kidney Foundation/Kidney Disease Outcomes Quality Initiative (NKF/KDOQI™) conference. *Clinical Journal of the American Society of Nephology*, *3*(2), 471–480.

Browne, T. (2012). Nephrology social work. In S. Gehlert & T. Browne (Eds.), *Handbook of health social work* (2nd ed., pp. 468–497). Hoboken, NJ: John Wiley and Sons.

Danovitch, G. M. (2008). Options for patients with kidney failure. In G. M. Danovitch (Ed.), *Handbook of kidney transplantation* (pp. 1–22). Philadelphia: Lippincott Williams and Wilkins.

Drotar D., Ganofsky, M. Makker, S., & DeMaio, D. (1981). A family-oriented supportive approach to dialysis and renal transplantation in children. In N.B. Levy (Ed.), *Psycho nephrology 1: Psychological factors in hemodialysis and transplantation* (pp. 79–81). New York: Springer U.S.

Khan, M. A., & Sehgal, A. (2010). Clinico-epidemiological and socio-behavioral study of people living with HIV/AIDS. *Indian Journal of Psychological Medicine*, *32*(1), 22–28.

Kasiske, B. L., Ravenscraft, M., Ramos, E. L., Gaston, R. S., Bia, M. J., & Danovitch, G. M. (1996). The evaluation of living renal transplant donors: Clinical practice guidelines. *Journal of the American Society of Nephrology*, *7*(11), 2288–2313.

Medicare Program; Hospital Conditions of Participation: Requirements for Approval and Re-Approval of Transplant Centers To Perform Organ Transplants; Final Rule. 72 Fed. Reg. 61 pp. 15198–15280 (March 30, 2007) (42 CFR Parts 405, 482, 488, and 498).

Ministry of Law, Justice, and Company Affairs. (1994). *The Transplantation of Human Organs Act, 1994, No. 42 of 1994*. Retrieved from **www.archive.india.gov.in/allimpfrms/allacts/2606.pdf**

Sharma, H., Bhardwaj, R., & Bhargava, M. (1992). *Manual for Comprehensive Anxiety Test (CA Test)*. Agra, India: National Psychological Corporation.

Tarantino, A. (2000). Why should we implement living donation in renal transplantation? *Clinical Journal of Nephrology*, *53*(4), 55–63.

Tonelli, M., Wiebe, N., Knoll, G., et al. (2011). Systematic review: Kidney transplantation compared with dialysis in clinically relevant outcomes. *American Journal of Transplantation*, *11*(10), 2093–2109.

SOCIAL WORK ABSTRACTS FROM THE NATIONAL KIDNEY FOUNDATION 2014 SPRING CLINICAL MEETINGS APRIL 22–26, 2014

CKD-ESRD - Prevalence, Progression, Preparation for Dialysis

10 **Medication Self-Management and ESRD: Ascertaining a Fundamental Cause**
Tamara Estes Savage. University of South Carolina, Columbia, SC, USA

CKD-ESRD - Other

2 **Treating Depression in the Dialysis Setting: Validating Symptom Targeted Intervention**
Shaun Boyd,[1] Duane Dunn,[1] Kathryn Aebel-Groesch,[1] Deborah Evans,[1] Teresa Gonzalez,[1] Mary Burgess,[1] Tammy Howard,[1] Rich Mutell,[1] Melissa McCool[2]. [1]DaVita Healthcare Partners Inc., Denver, CO, USA; 2STI Innovations, Encinitas, CA, USA.

7 **Social Worker Driven Program to Reduce Hemodialysis Therapy Non-Adherence**
Stephanie Johnstone, Nien-Chen Li, Franklin Maddux, Eduardo Lacson, Fresenius Medical Care, North America, Waltham, MA, USA

Transplantation

1 **Dialysis Center Staff Knowledge and Attitudes Regarding Organ and Tissue Donation**
Ann Andrews[1], Holly Jenkins-Riley[2], Julia Herzog[1], Remonia Chapman[3], Allyce Haney[1], Nanhua Zhang[4], Jerry Yee[2], [5], Ken Resnicow[6]. [1]NKF of Michigan, Ann Arbor , MI, USA; [2]Greenfield Health Systems, Bingham Farms, MI, USA; [3]Gift of Life Michigan, Ann Arbor, MI, USA; [4]Cincinnati Children's Hospital and University of Cincinnati, Cincinnati, OH, USA; [5]Henry Ford Health System, Detroit, MI, USA; 6School of Public Health, University of Michigan, Ann Arbor, MI, USA

3 **Environmental Scan of Kidney Transplant Referral Practices in the South Eastern United States**
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4 **Kidney Transplant Candidacy of Long Term Care Residents- A National Survey**
Teri Browne[1], Megan Urbanski[2], Mythili Ghanta[2]. [1]University of South Carolina College of Social Work, Columbia, SC, USA; [2] Temple University Hospital, Philadelphia, PA, USA

5 **Patient Identified Barriers and Facilitators to Kidney Transplantation**
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6 **Dialysis Patient Attitudes and Knowledge About Organ and Tissue Donation**
Denise Cyzman[1], Allyce Smith[1], Sheri Stav[2],Ann Andrews[1], Holly Jenkins-Riley[2], Remonia Chapman3, Nanhua Zhang[4], Jerry Yee[2], [5], Ken Resnicow[6]. [1]NKF of Michigan, Ann Arbor , MI, USA; [2]Greenfield Health Systems, Bingham Farms, MI, USA; [3]Gift of Life Michigan, Ann Arbor, MI, USA; [4]Cincinnati Children's Hospital and University of Cincinnati, Cincinnati, OH, USA; [5]Henry Ford Health System, Detroit, MI, USA; [6]School of Public Health, University of Michigan, Ann Arbor, MI, USA

Other

8 **Root Causes of Lack of Adherence to Mineral Bone Disease (MBD) Medication in ESRD Patients**
Maureen McKinley. DaVita Healthcare Partners Inc., Irvine, California, USA

9 **Non-Adherence in Individuals on Hemodialysis: A Discussion of Three Theories to Improve Adherence**
R. Lee Phillips. The University of Georgia, Athens, GA, USA

1. DIALYSIS CENTER STAFF KNOWLEDGE AND ATTITUDES REGARDING ORGAN AND TISSUE DONATION

Ann Andrews[1], Holly Jenkins-Riley[2], Julia Herzog[1], Remonia Chapman[3], Allyce Haney[1], Nanhua Zhang[4], Jerry Yee[2, 5], Ken Resnicow[6]
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Individuals often look to their health care professionals for guidance when making health care decisions, including the decision of whether or not to be an organ donor. To date, studies have looked at the organ donation attitudes and knowledge of staff in ICUs and EDs; however, few studies have surveyed staff in dialysis centers. Dialysis center employees work directly with patients who are both waiting for a transplant and have the potential to be organ donors. Any individual, of any age or health status, may sign up on the Donor Registry.

A consortium consisting of the NKF of Michigan (NKFM), Greenfield Health Systems (GHS), Henry Ford Health System, Gift of Life Michigan, and the University of Michigan surveyed 210 GHS staff, including administrative staff, dialysis technicians, dietitians, nurses, reuse staff, and social workers, regarding their donation attitudes and knowledge. Staff at twelve GHS dialysis units in Southeast Michigan received a one-hour education session about organ donation as part of a larger study is to determine the effectiveness of a Peer Mentor intervention to increase knowledge and awareness among dialysis patients about their option to become organ donors.

At baseline, 48% of staff reported already signing up on the Donor Registry; among those not currently signed up, 38.4% indicated high intent to do so. No significant differences in mean attitude scores were found between type of staff on most items. Overall f-test shows significant difference in mean scores between type of staff on "Peer mentors can encourage patients to sign up as donors"; no difference in pairwise comparisons. Exploratory factor analysis data will be reported.

2. TREATING DEPRESSION IN THE DIALYSIS SETTING: VALIDATING SYMPTOM TARGETED INTERVENTION

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Approximately 25% of all end-stage renal disease dialysis patients are depressed, which increases risk of infections and missed dialysis sessions, leading to increased hospitalizations and mortality rates *(Boulware et al: Clin J Am Soc Nephrol 2003;1(3):496-504 and Weiner et al: Soc Work Health Care 2010;49(6):513-25).* In 2011, 46 nephrology social workers participated in a nationwide Practice Outcome Evaluation (POE) to determine if symptom targeted intervention (STI) would improve the Kidney Disease Quality of Life (KDQOL-36) and Center for Epidemiologic Studies Depression Scale (CES-D 10) scores of patients involved in the project *(Sledge et al, Nephrol News Issues 2011;25(7):24-25,28-31)*. Following STI counseling patients' KDQOL-36 and CES-D 10 scores were improved over baseline; however, mean patient-level score improvements did not reach statistical significance.

In 2013, 89 social workers in a large dialysis organization replicated the STI POE. Statistical Package for Social Sciences software was used to determine if changes in patient scores were statistically significant (pre- and post-dependent T test). Social workers received weekly training via WebEx and conference calls prior to and throughout the 6-week intervention period.

KDQOL-36 and CES-D 10 questionnaires were completed by each participating in-center hemodialysis patient (N = 91) prior to and after completion of the 6-week intervention period. Statistically significant improvement occurred in KDQOL-36 Mental Component scores ($p < 0.001$), Physical Component scores ($p = 0.042$), as well as Burden ($p < 0.001$) and Effects ($p = 0.001$) domain scores.

The results indicate that nephrology social workers can use STI to help in-center hemodialysis patients improve their quality of life scores and positively impact their level of depression.

3. ENVIRONMENTAL SCAN OF KIDNEY TRANSPLANT REFERRAL PRACTICES IN THE SOUTH EASTERN UNITED STATES

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The Southeastern United States has the lowest kidney transplant (KTx) rates in the country; this may be due in part to dialysis facility referral practices. Our aim was to identify the attitudes, common practices, and perceived barriers dialysis professionals in this region have to KTx. Every dialysis unit in ESRD Network 6 (n=586) was invited to participate in a survey regarding dialysis facility practices in KTx; the completion rate was 93.2%. Data were analyzed with descriptive statistics to determine trends in responses and provide foundational information for bivariate and multivariate analyses.

Completed surveys were analyzed for GA (47.5%), NC (31.9%) and SC (20.6%) dialysis facilities by nurse managers (51.0%) or social workers (26.3%). Almost all (98.4%) reported that they were comfortable discussing KTx with patients, and over 80% have a protocol in place for KTx education. Most staff reported that more than 50% of their patients were either ineligible or not interested in transplant (X^2 p-value<0.0001). Eighty-eight percent of staff believed that less than half of their patients referred for transplant completed the evaluation process and were placed on the waitlist.

More than one quarter of GA staff agreed that patient interest was a barrier to KTx, compared to NC (23.2%) and SC (23.9%) (X^2 p-value=0.023). Other patient-level barriers identified were: lack of patient education materials (34%), insufficient patient social support (61%), patient transportation (74%), and patient financial status (89%).

This is the first study in the Southeastern United States to survey dialysis professionals to determine barriers and attitudes about KTx. This study may help formulate research and program development in order to eliminate identified barriers and improve dialysis patient outcomes related to KTx.

4. KIDNEY TRANSPLANT CANDIDACY OF LONG TERM CARE RESIDENTS- A NATIONAL SURVEY

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Due to an increasingly healthier older adult population and advances in medical treatments for many chronic illnesses and serious injuries, kidney transplant centers are now receiving a greater number of referrals for patients in end-stage organ failure that live in long-term care settings (LTC). To build the literature related to kidney transplantation of long term care residents, we conducted a national online survey of kidney transplant social workers, physicians and surgeons to assess best practices in this area.

126 transplant professionals completed the survey in 2013. Almost 50% of those (47%) reported that their center has transplanted someone who resided in LTC, 27% had not, and 27% did not know if they had. The following reasons were given for not approving a LTC resident for a kidney transplant: risk of infection (43%); poor use of scarce resources (34%); likelihood of medical comorbidities (66%) and no improvement in patient quality of life (69%).

Respondents were given hypothetical patient scenarios to assess the transplant candidacy of LTC residents with poor social support, moderate mental retardation, and a stable neurological condition (such as Parkinson's disease). There was no significant majority consensus on any of the scenarios of the transplant consideration of the LTC residents as described. Exactly half of the professionals said that they would (50%) or would not (50%) transplant a LTC resident with poor social support. 53% reported that they would provide a LTC resident with moderate mental retardation (47% would not), and 54% would transplant a LTC resident with a stable neurological condition (46% would not).

The results of this national survey suggest that there is currently no best practice consensus among kidney transplant centers related to providing transplants long term care residents. Further research is needed in this area to help transplant centers provide services to LTC residents.

5. PATIENT IDENTIFIED BARRIERS AND FACILITATORS TO KIDNEY TRANSPLANTATION

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Purpose: Barriers in the access to kidney transplantation are a significant problem in the United States, and are most pronounced in the Southeastern region. To determine perceived barriers and facilitators to kidney transplantation in the Southeastern United States, we conducted patient focus groups in Georgia, North Carolina and South Carolina.

Methods: In 2012, we conducted three focus groups of kidney disease patients. Each focus group was 90 minutes in length; participants also completed a brief companion survey. An interview guide was used by the group facilitators to explore patient interest and personal experience related to kidney transplantation, perceived barriers and facilitators related to getting a kidney transplant, and ideas regarding how dialysis unit medical professionals can help patients receive a kidney transplant. A constant comparative method was used to identify themes that emerged from a line-by-line review of the focus group transcripts.

Results: Of the 40 participants, 14 (35%) were male, 25 (63%) were African American; 46% were on dialysis for more than two years. Participants described five main barriers to receiving a kidney transplant: financial, medical, informational, attitudinal, and the composition and behaviors of the dialysis team, medical providers, and others in their social networks. They identified finances, younger age, information, attitudes and beliefs, and helpful medical professionals and others as facilitators for getting a kidney transplant.

Conclusions: This study is the first of its kind to explore the barriers and facilitators of getting a kidney transplant in the Southeastern United States. The study findings provide the basis for responding to patient needs by the development of targeted interventions that can improve kidney transplant rates in a way that is patient-centered.

6. DIALYSIS PATIENT ATTITUDES AND KNOWLEDGE ABOUT ORGAN AND TISSUE DONATION

Denise Cyzman[1], Allyce Smith[1], Sheri Stav[2],Ann Andrews[1], Holly Jenkins-Riley[2], Remonia Chapman[3], Nanhua Zhang[4], Jerry Yee[2, 5], Ken Resnicow[6]
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The need for more organ donors is great, yet misconceptions about organ donation deter eligible individuals from signing up on donor registries. Inaccurate information about donation and chronic disease may lead to low consent rates among those living with end stage renal disease (ESRD). Many may believe that, due to kidney disease, they are ineligible to sign up on the Michigan Organ Donor Registry. However, anyone of any health status may sign up to donate their organs after death. ESRD patients are eligible to donate and may obtain a sense of empowerment in knowing they can give back. More information is needed both on the unique perspectives of dialysis patients on organ donation, as well as interventions to increase awareness among the dialysis community about donation.

A consortium consisting of the NKF of Michigan (NKFM), Greenfield Health Systems (GHS), Henry Ford Health System, Gift of Life Michigan, and the University of Michigan surveyed 554 dialysis patients about their attitudes and knowledge regarding donation. Patients at 12 GHS dialysis units in Southeast Michigan received education about donation as part of a larger study is to determine the effectiveness of a Peer Mentor intervention to increase knowledge and awareness among dialysis patients about their option to become donors.

Baseline data shows that 54.5% of those participating indicated high intent to sign up. We report on the psychometric properties and correlates of a measure of organ donation attitudes and practices. We created two new a priori scales – Dialysis Barriers (alpha .78) and Dialysis Benefits (alpha .70). We will report the association of these scale scores with donation intention.

7. SOCIAL WORKER DRIVEN PROGRAM TO REDUCE HEMODIALYSIS THERAPY NON-ADHERENCE:

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Missed hemodialysis (HD) treatments associate with poor outcomes. As a quality improvement project, a social worker (SW) initiated intensive intervention program was implemented to improve treatment adherence and we report preliminary findings from the initial 93 participating Fresenius Medical Care North America facilities.

One hundred fifty-one (151) patients with ≥ 1 missed treatments per 12 week period underwent the 8-session intervention between March 1 and July 31, 2013. A session was attempted every 1 to 2 weeks. The intervention included patient-empowerment education and counseling designed to address potential root causes of non-adherent behavior as well as aggravating factors from 4 surveys: KDQOL-36, CESD-10, a Sleep Quality Screen, and a Stressors Screen. Pre- and Post-intervention survey scores were compared and the rate of missed treatments from the pre-intervention baseline was compared to the rate over the 3-months immediately after the after the intervention concluded.

The patients' mean age was 52.7 years, with 48% males; 58% white/31% black; 60% had diabetes mellitus. The baseline missed treatment rate (per 12 weeks) was 1.8 vs. 1.2 post-intervention ($p<0.0001$). The survey results indicated significant improvement (all $p<0.01$) of pre- to post-intervention scores for: CESD-10 depression scores (9.1 vs. 6.7), Family/Relationship Stressors (5.0 vs. 3.8), Financial/Insurance Stressors (5.2 vs. 4.3), Difficulty Falling Asleep (4.1 vs. 3.5), Difficulty Staying Asleep (4.4 vs. 3.8), Interrupted Sleep (4.3 vs. 3.5), and Difficulty Awakening (2.4 vs. 1.9). There was also improvement in perception of Kidney Disease Effects (66.5 vs. 73.6), Burden (42.5 vs. 49.6), Symptoms (71.9 vs. 75.2), and MCS (45.7 vs. 47.6). There was no significant difference in PCS, Restless Legs, and Stressors related to Health Symptoms or Loss/Grief.

Preliminary results indicated that an intensive SW-initiated intervention program was able to reduce missed treatments in the short term (3 months). Furthermore, indicators of quality of life and well-being that potentially contributed to the non-adherent behavior also improved, which may help sustain the favorable results over the long term. This study is ongoing and updated outcomes will subsequently be reported.

8. ROOT CAUSES OF LACK OF ADHERENCE TO MINERAL BONE DISEASE (MBD) MEDICATION IN ESRD PATIENTS

Maureen McKinley
DaVita Healthcare Partners Inc., Irvine, California, USA

Adherence with MBD medications amongst ESRD patients is estimated to be only 50%. Dietitians managing MBD in hemodialysis patients are challenged to determine accurate root causes of missed doses and to perform interventions that improve adherence.

Fifty patients across 17 hemodialysis clinics were interviewed on a weekly basis over a 12-week period to determine the root causes for missed MBD medication doses. Social workers and dietitians alternated meeting with patients, using a "Patient Encounter Tool" to identify root causes for missed doses. Interventions specific to each root cause were performed and recorded on the tool.

The most frequently cited reason for missing doses was "Forgot to take" at 41%. The second most frequent reason was "Ill and not eating as many meals" at 10%. Patients reported having financial barriers to obtaining their medications only 3% of the time. Of the patients in the study, 24% reported never forgetting to take their medications, while 66% reported forgetting 5 times or less. Only 10% of patients reported forgetting 5 times or more. The phosphorus values of 58% of the patients improved during the 3 months of the study.

Adherence with MBD medications is a problem in the ESRD population. In this study, the major reason reported for non-adherence was forgetfulness. Interventions focused on helping patients remember to take their pills, like placing pills in an area where they are readily visible, setting an alarm, or carrying pills with them. Both dietitians and social workers found collaboration around medication adherence to be valuable, although 30% of social workers reported having difficulty working this additional task into their schedules.

9. NON-ADHERENCE IN INDIVIDUALS ON HEMODIALYSIS: A DISCUSSION OF THREE THEORIES TO IMPROVE ADHERENCE:

R. Lee Phillips, The University of Georgia, Athens, GA, USA

Adherence continues to prove challenging in work with Hemodialysis patients. This presentation explores three theories that can guide practice when working to improve compliance with individuals on hemodialysis. The Theory of Planned Behavior (TPB), the Common-Sense Model (CSM), and Motivational Interviewing (MI) each offer insight into behavioral change and the internal processes of individuals. Each theory seeks to empower the individual and sees client involvement as critical to patient care and improved health related outcomes. Understanding the tenants of these three theories can guide social work practice beyond education and the dissemination of health related information in order to improve compliance.

10. MEDICATION SELF-MANAGEMENT AND ESRD: ASCERTAINING A FUNDAMENTAL CAUSE

Tamara Estes Savage
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Poor medication self-management leads to increased risk for morbidity and mortality in ESRD patients. Much research also has shown that there are poor rates of medication self-management in the ESRD population. In addition, there is research that race/ethnicity is associated with unsuccessful medication self-management. Specifically African Americans have poorer rates of medication self-management when compared to Whites. However, the reasons for this racial inequity are not understood beyond the identified proximal risk factors. This is particularly troubling since ESRD patients who do not adhere suffer decreased quality of life, increased morbidity, and death. Hence medication nonadherence is an important health inequity that is worthy of further investigation.

As a first step in exploring beyond the proximal risk factors, poor medication self-management as it relates to the health inequity, a literature review was conducted to examine the broader social conditions, fundamental causes, that contribute to this lack of parity in in the ESRD population. An online search was conducted from August 2013 to December 2013 using MEDLINE, PubMed, Ovid, CINAHL, and PsychLIT databases to identify research and summarize findings from meta-analyses, systematic reviews, clinical reviews, and clinical trials published in English between January 1985 and December 2013, as they relate to fundamental causes of patient medication self-management. The results of this literature search suggest that there are indeed social conditions such as racism and structural racism which may be fundamental causes of the problem of parity as it is related to medication self-management in the ESRD population. Many barriers are explicated in the extant literature; however, little pertain to the unique circumstances of minority groups living in a society where racism is prevalent. Therefore, further research needs to be conducted to ascertain the unique factors related to unsuccessful medication self-management in minority ESRD patients.

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