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Council of Nephrology Social Workers

The Journal of Nephrology Social Work

Volume 38 • Issue 2

- Relaxation Therapy and Mindfulness Meditation One-Day Workshop—Part One
- Routine Use of the PedsQL™
- CROWNWeb
- Re-Framing the Gift of Life

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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.

The Council of Nephrology Social Workers of the National Kidney Foundation

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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**].

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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.
- 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.

Relaxation Therapy and Mindfulness Meditation One-Day Workshop for Nephrology Social Workers: Exploring the Impact of This Training on Professional Practice

PART ONE

Gary Petingola, MSW, RSW, Diabetes Care Service, Health Sciences North/Horizon Santé-Nord, Sudbury, Ontario, Canada

Relaxation therapy techniques and mindfulness meditation are clinical intervention tools that have demonstrated benefits associated with the reduction of negative psychological states and the enhancement of positive states of mind critical to the alleviation of physical and emotional distress (Jain et al., 2007). Many mind-body therapeutic training workshops are offered in a one-day format; however, there is a gap in the literature examining the direct impact of learning relaxation therapy and mindfulness meditation specific to nephrology social work practitioners, and how, if at all, learning these techniques might assist a practitioner in his/her work. A study was undertaken to examine the influence of a one-day relaxation therapy and mindfulness meditation educational workshop on nephrology social workers' professional practice. Eight members of the Canadian Association of Nephrology Social Workers with limited previous exposure to mind-body therapeutic approaches participated in this project. Telephone and Skype participant interviews occurred following the workshop on three separate occasions over a period of four months. The key findings from this study suggest that 1) the workshop had an impact on professional practice, 2) the workshop had an impact on self-care, and 3) amid obstacles to implementation, nephrology social workers expressed their desire to expand their current scope of practice to include relaxation therapy techniques and mindfulness meditation with their clients.

INTRODUCTION

The term "kidney disease" encompasses a variety of diseases and disorders that affect the kidneys, usually starting slowly and progressing over a number of years. Chronic kidney Disease (CKD) is defined by the Kidney Foundation of Canada as "the presence of kidney damage, or a decreased level of kidney function, for a period of three months or more" and often requires psychosocial intervention in addition to medical care (2013). The effects of kidney failure and dialysis treatment are experienced amongst patients, family members, caregivers, and nephrology staff. Dialysis treatment is unique, because patients and families spend countless hours together with staff over several times a week for many years. It is easy to understand how the frequency of treatments, dependence on staff, and the close nature of the treatment impact the entire circle of care.

End-stage renal disease (ESRD) requires ongoing dialysis treatment or kidney transplant in order to sustain life. Hemodialysis, one treatment option, typically occurs thrice-weekly in an outpatient dialysis clinic setting or hospital and is designed to remove excess fluid and filter the blood of toxins because the patients' kidneys can no longer perform these functions. Dialysis patients require this treatment for the duration of their lives, unless they are candidates for kidney transplant. All members of the circle of care struggle with the manifestations, conflicts, and suffering that this illness evokes.

Working with ESRD patients can be difficult. Nephrology social workers are frequently exposed to patients who are frightened, suffering, and dying, and are therefore vulnerable to cumulative distress. "This accumulation of work related distress facilitates a quest for healthcare workers to examine a deeper meaning of pain and suffering in their lives as well as in others, and repeated traumatization makes us vulnerable to burnout and vicarious trauma" (Schure, Christopher, & Christopher, 2008, p. 47). This unrelenting stress has negative ramifications for healthcare professionals, often illustrated with increased incidence of depression, decreased job satisfaction, disrupted personal relationships, psychological distress, and self-harm (Shapiro, Astin, Bishop, & Cordova, 2005). Stress negatively affects the healthcare professional's ability to concentrate. Stress also hampers sound decision making and deters healthy professional collegial relationships. Unmanaged stress disrupts patient/staff therapeutic relationships because healthcare professionals may become devoid of empathy, awareness, objectivity, and compassion (Shapiro et al., 2005). Segal et al. (2010) suggested that this constant influx of stress on healthcare professionals often contributes to burnout, exhibited by decreased attention, reduced concentration, compromised decision-making skills, and suboptimal relationships with patients.

This study examines how, if at all, learning mindfulness and relaxation therapy techniques in a one-day workshop format might assist the nephrology social worker both professionally and personally. This article is the first of two parts and will provide an overview of the literature in reference to mindfulness meditation, its use in social work practice, and the differences between mindfulness meditation and other mind-body interventions, such as relaxation therapies. The second article will describe the methodology used in this study and provide a detailed summary of the study results.

MOTIVATIONS FOR STUDY

Nephrology psychosocial therapeutic involvement follows the patient throughout the disease trajectory from pre-renal insufficiency (prior to the initiation of dialysis) to post-transplant and, in many cases, when the transplanted kidney fails. As a nephrology social worker for 13 years, I have provided frontline counseling and support to patients and families affected by chronic kidney disease. In my professional practice, I employ mind-body interventions that include relaxation, visualization, Autogenic Training, Progressive Muscle Relaxation, Guided Imagery, and mindfulness meditation as therapeutic interventions throughout the nephrology patient trajectory (definitions to follow). In my experience, I have found that these interventions appear to be beneficial for patients, caregivers, and nephrology health team members based on direct patient feedback, observation, and survey results (Petingola, 2010). I have come to realize that both relaxation methods and mindfulness are distinct, yet equally significant therapeutic modalities that may benefit the entire nephrology circle of care (Turk, Swanson, & Tunks, 2008).

Importantly, my own subjective experiences are reflected in the current burgeoning literature in this field. Many researchers are finding that mindfulness-based practices and relaxation exercises have benefits for a wide variety of people and problems (Jain et al., 2007). I was interested in learning more about how relaxation therapy and mindfulness meditation could help nephrology patients and become invaluable tools to assist nephrology social workers with the challenges of their everyday frontline practice.

WHY THIS RESEARCH IS IMPORTANT

This qualitative study explores the potential influence of a one-day relaxation therapy and mindfulness meditation educational workshop for nephrology social workers on their professional practices. Although mindfulness-based training workshops are frequently offered in a one-day format, there is little literature that explores the benefits of this type of training. As will be illustrated in the literature review, there is a gap in examining the direct impact of relaxation therapy and mindfulness meditation specific to nephrology social workers and how, if at all, learning mindfulness and relaxation therapy techniques might assist social workers in their practice.

The purpose of this study is to provide nephrology social workers with more information regarding the benefits of relaxation therapy and mindfulness meditation to professional practice. It is also my intention to stimulate the reader's curiosity, validate the efficacy of these mind-body therapies, and increase confidence to explore how these therapeutic modalities can be utilized within professional practice. A study of this nature may illuminate how the benefits of relaxation therapy and mindfulness meditation can assist the entire nephrology circle of care.

MIND-BODY INTERVENTIONS

Relaxation Therapy and mindfulness meditation fall under the realm of mind-body interventions. The National Center for Complementary and Alternative Medicine (NCAM) summarized that "mind-body practices focus on the interactions among the brain, mind, body, and behaviour with the objective to use the mind to influence physical functioning and promote health" (NIH, DHHS, & NCCAM, 2011). Carlson and Bultz (2008) suggested that mind-body interventions (hypnosis, imagery/relaxation, meditation, yoga and creative therapies) include all treatments that depict the interaction between the mind and the body. Cassileth and Deng (2004) highlighted that mind-body interventions strive to utilize a reciprocal connection between body and mind to assist patients in relaxing, reducing stress, and obtaining symptom relief.

Geffen (2004) described the dichotomy between Eastern and Western views of the mind-body relationship:

> Western scientific thought regards the body as a machine. Doctors are the "mechanics" and the disease is viewed as a condition that springs from a flaw in the human machinery. In Eastern medical systems, the body can be seen as a garden. Doctors are "gardeners" who seek to discover and heal the roots of disease, planted in the past by a patient's heredity, food choices, daily activities, environment and ongoing mental process. (p. 95)

In his book entitled *When the Body Says No*, Dr. Gabor Mate (2003) reinforces the notion that there is a codependent relationship between the body and the mind and that treating stress or illness necessitates a consolidated approach to care:

> People have always understood intuitively that the mind and body are not separable. Modernity has brought with it an unfortunate dissociation, a split between what we know with our whole being and what our thinking mind accepts as truth. Of these two kinds of knowledge the latter, narrower, kind most often wins out, to our loss. (Note to reader section, paragraph 1.)

Bertisch, Wee, Phillips, and McCarthy (2009) adapted the National Center for Complementary and Alternative Medicine definition of mind-body medicine, which incorporates a wide range of healing modalities, such as meditation, yoga, deep-breathing exercises, Guided Imagery, hypnotherapy, progressive relaxation, acupuncture, and tai chi, which all share a collective purpose aimed at enhancing the mind's capacity to affect bodily functions and symptoms.

Gordon (2008) suggested:

> Mind-body approaches to healing are based on the understanding that our thoughts and feelings, our beliefs and attitude, can affect and

> shape every aspect of our biologic functioning. Mind-body approaches also recognize that everything we do with our physical body—what we eat and how we stand, the ways we stretch our muscles and the tension that constricts them—can modify mental, psychological, and physical functioning. Finally, mind-body approaches are based on the understanding that the mind and body are, in fact, inseparable, and that the central and peripheral nervous system, the endocrine and immune systems, all the organs of the body, and all the emotional responses we have share a common chemical language and are constantly communicating with one another. (p. 683)

MINDFULNESS

Mindfulness may be defined as "paying attention in a particular way: on purpose, in the present moment, nonjudgmentally" (Kabat-Zinn, 1994, p. 4). The practice of mindfulness focuses on "being" as opposed to "doing," and "observing one's experience without trying to change" (Shapiro, Brown, & Biegel, 2007, p. 106). Mindfulness helps us wake up from this sleep of automaticity and unconsciousness, thereby making it possible for us to live our lives with access to the full spectrum of our conscious and unconscious possibilities (Lord, 2010). Mindfulness is simply seeing "what is" (Rock, 2006, p. 350). Riskin (2004) defined mindlessness as "lights on nobody's home" (p. 80).

Carlson and Speca (2010) explained, "mindfulness is simple; pay attention to whatever comes up in the present moment; allow it all to rise and fall of its own accord, without trying to change anything; and be with things as they are" (p. 10). This essentially requires that the individual who practices mindfulness meditation will simply acknowledge and accept the present moment even if that moment, is defined by pain, sadness, or other feelings that challenge the human condition. Kabat-Zinn (1990, p. 6) refers to this as being able to accept the whole that life gives you—the art of embracing "the full catastrophe." Mindfulness meditation reframes the experience of discomfort. Attention and awareness of discomfort or suffering is another part of human experience; rather than to be avoided, it is to be experienced and explored (Turks, Swanson, & Tunks, 2008). Caudill (2002) illustrates the concept of the mindfulness and pain paradox:

> Simply observe the pain and the feelings you may have, such as fear or anger, without running away from those feelings or sensations. And say to yourself, "oh yes, that's my pain and that's my anger." By staying focused on the pain you begin to realize how much fighting your pain or avoiding those feelings contribute to your feeling powerless. (p. 47)

Derived from Buddhist roots, mindfulness is achieved though the practice of employing meditation as a mechanism pivotal to enhanced awareness and acceptance of the present moment (Bishop, 2004). The Buddhist belief is that in order to become enlightened one must have wisdom to recognize that there is suffering; there is a cause of suffering; and there is an end to suffering. The Four Noble Truths of Buddhism suggest that the practice of mindfulness helps one to be in the moment, devoid of desires, judgment, criticism, and worry. Essentially, Buddhists believe that the practice of mindfulness facilitates a *c*atharsis that ultimately lessens one's suffering (Gyatso & Ekman, 2008).

Gyatso and Ekman (2008) suggested that:

> In the Buddhist meditation practices, one key method for cultivating this awareness is the development of mindfulness. The second one, which is thought to be more specific to the cultivation of this monitoring, is applying constant awareness to the actual processes of thought, just observing your mind and the thoughts as they arise, and being aware of what arises in the present. (p. 54)

Buddhist belief suggests that we embrace suffering rather than withdraw from it or make attempts to "fix" or get rid of it, which is typical of the Western medical model. Mindfulness is not a distraction technique but paradoxically strives to assist individuals to be fully aware of their feelings and emotions, to not label them as being right or wrong, and in doing so liberates the person to become emotionally intelligent and more reflexive than reactive. If one is experiencing pain, the individual accepts the pain and in doing so lessens its power to negatively influence the person's well-being. Sumedho (2011) summarizes that we must be willing to accept:

> The excitement and the boredom, the hope and the despair, the pleasure and the pain, the fascination and the weariness, the beginning and the ending, the birth and the death. We are willing to accept the whole of it in the mind rather than absorb into just pleasant and suppress the unpleasant. (p. 25)

Mindfulness facilitates a "fuller awareness" that promotes more "flexible, adaptive responses to events, and helps to minimize automatic, habitual, or impulsive reactions" (Bishop, 2004, p. 230). It is argued that the ability to do this helps us to be more patient and less reactive. Gyatso and Ekman (2008) term this as being more "emotionally aware." "Emotional intelligence" is a concept that refers to being in sync with our emotional existence. Emotional intelligence is derived from increased awareness and equips us with more skill to handle emotional challenges, to be more responsive to the struggles of others and to have more compassion (Gyatso & Ekman, 2008, p. 1). Baer (2006) described these phenomena as follows:

> A large part of mindfulness training is geared toward changing a stress reaction into a stress response, in which emotional arousal is effectively managed. Emotional arousal decreases present-moment awareness, and inhibits the ability to see the whole context of the situation and the options available. (p. 363)

Schmidt (2004) suggested that mindfulness fosters compassion, and this in turn connects the suffering of the patient with the healthcare provider's suffering, and that this emotional connection creates a healing synergy. Mindfulness may be viewed as being a cornerstone for increased self-awareness, greater insight, wisdom, enhanced compassion, connectivity, and equanimity (Baer, 2006).

The term mindfulness can be nebulous to a person who has not practiced or experienced it. Bell (2009) used the analogy of "trying to explain the Zen of a meditation experience as being similar to trying to explain color to someone who is color blind" (p. 128). This lack of a clear definition of mindfulness and consistency across studies has been detrimental to completing scientific research that is efficacious and validated. Bishop (2004) suggested that failure to have a consistent working definition of mindfulness negates the credibility of investigations and hampers the development of measurable tools. Thus, several researchers have worked to develop an operational definition of mindfulness. For example, Bishop (2004) suggested the following operational definition of mindfulness:

> We propose a two-component model of mindfulness. The first component involves the self-regulation of attention so that it is maintained on immediate experience, thereby allowing for increased recognition of mental events in the present moment. The second component involves adopting a particular orientation toward one's experiences in the present moment, an orientation that is characterized by curiosity, openness, and acceptance. (p. 232)

Not everyone agrees that mindfulness can be operationally defined. Another school of thought is that the sheer ambiguity and complexity of mindfulness negates the possibility of actually defining or operationalizing the concept. Hick (2009) argued that since the mindful experience is so individual that it may be impossible to either capture it in words or accurately measure it, contrary to the positivist attempts to do so. Hick further argued that attempts to do so would be contradictory to a core concept in mindfulness of simply being without judgment. Gause and Coholic (2010) reinforced this notion, contending that the practice of mindfulness in a traditional context invokes a synergy that is extraordinary and immeasurable and that attempts to define it are counterproductive to the Buddhist traditional belief of non-striving. Gause and Coholic also pointed out that mindfulness is taught by people with diverse backgrounds, therefore the interpretation of what mindfulness is will be equally subjective and diverse. Rinpoche (2009) suggested that "Nonjudgmental observation is the basis of meditation, at least in terms of the Buddhist tradition. Many cultures, of course, have developed their own specific forms of meditation practice, each uniquely suited to the cultural environment from which they emerged" (p. 127).

Additionally, the profession of social work is engaging with mindfulness in a unique way that differentiates it from other behavioral sciences. Hick (2009) reinforced that the profession of social work implements mindfulness in keeping with the traditional Buddhist teachings, toward the greater good of society. This necessitates looking at person in their social environment, which means applying mindfulness system-wide as a proponent for justice and for social activism to facilitate change. Social work recognizes an interconnectedness that may be referred to as a "link," "kinship," and "wholeness." This interconnectedness encourages the social work profession to reach out rather than ignore: "And seeing suffering in others—though you do not experience suffering yourself—creates the feeling of personal unbearably. We are one family of human beings, so a person must take concern about the well-being of everyone in society" (Gyatso & Ekman, 2008, p. 196); "First, there was this perception of shared humanity. 'There is no concept of an in-group or an out-group. We are all one group.' All people have value" (p. 199).

This theme of being interconnected reinforces the instinctive desire for social workers to search for a deeper meaning of pain and suffering in their lives as well as in others. Awareness derived from mindfulness meditation can be a powerful equalizer.

MINDFULNESS INTERVENTIONS

Jon Kabat-Zinn and Saki Santorelli are two Western practitioners who sought to operationalize mindfulness as a targeted intervention that would be helpful for patients affected with chronic pain who might not be interested in subscribing to traditional Buddhist traditions or understanding the terminology, but who might benefit from many of the key concepts (Baer, 2006). In doing so, they laid the foundation for researchers and clinicians to explore a variety of interventions designed to teach mindfulness, and created the Mindfulness-Based Stress Reduction (MBSR) Program at the University of Massachusetts Center for Mindfulness. Kabat-Zinn and his colleagues successfully integrated mindfulness into conventional medicine and healthcare and it is now used to treat chronic pain as well as other ailments. The MBSR Program generally runs for eight weeks and incorporates formal practice of hatha yoga, body scan, walking meditation, and sitting meditation with informal practice (Baer, 2006). The MBSR program falls under the realm of social cognitive theory, focusing on interventions geared towards modification of behaviour. Baer summarized:

> This theory contains a number of constructs that are important for understanding human behaviour and how it can be changed. These include reciprocal determinism (in which there is a dynamic interplay between the environment and the person's cognitions and behaviours), the importance of the person's perception of the environment, behavioural capability (an index

> of the person's knowledge and skill to perform a given behaviour), anticipated outcomes of behaviour and the value a person places on the outcome, self-control, observational learning, reinforcement, self-efficacy, and emotional coping responses. (p. 363)

Mindfulness-based cognitive therapy (MBCT) is more of a prophylactic intervention that merges key concepts of mindfulness practice with cognitive behavioral therapy primarily used for depression relapse. MBCT is similar to MBSR, as it too incorporates meditation and yoga, but a key difference is that it also teaches participants preventative information and helps them to understand the links between thinking and feeling. MBCT was developed by Zindel Segal, Mark Williams, and John Teasdale (Baer, 2006; Bishop, 2004).

Dialectical behavior therapy (DBT), in brief, is a treatment intervention initially intended to treat borderline personality disorder. It blends key concepts of MBSR and MBCT, but emphasizes recognition and alteration of damaging thoughts, emotions, and behavior. DBT helps patients have a clearer understanding of reality so that they can learn to respond appropriately (Baer, 2006).

Lastly, acceptance and commitment therapy (ACT) strives to reduce potentially harmful thoughts and feelings by adopting a nonjudgmental approach to thoughts that fosters acceptance of the moment. ACT is not meditation-based like MBSR and MBCT (Baer, 2006; Hick, 2009).

Social workers are using many of these mindfulness interventions successfully in their frontline practices in healthcare. Psychosocial oncology in particular has made strides in measuring patient distress and utilizing many of the aforementioned mind-body interventions (Carlson & Bultz, 2008; Gordon, 2008; Luebbert, Dahme, & Hasenbring, 2001; Shennan, Payne, & Fenlon, 2011). Nephrology closely parallels the area of oncology in many aspects, as both populations endure invasive life-sustaining treatment, survivorship, and fear of relapse. Although nephrology social work as a specialty is just beginning to explore mind-body interventions with patients, the time is ripe for more development in this area. We are on the cusp of a major paradigm shift in treating illness and it is exciting to see this emergence. The shift has been brought on by heightened consumer demand, patient frustration, and conventional Western-influenced medicine's inability to "fix" and promote healing. We are now witnessing the emergence of complementary medicine becoming more prevalent in hospital settings, not only addressing the physicality of the body but also embracing a multidimensional approach to care that moves towards treating the whole person (Geffen, 2004).

MINDFULNESS PRACTICES

Mindfulness is typically taught using formal practice techniques aimed to heighten awareness that will extend into everyday life so that one can eat, bathe, and write mindfully. Carlson and Speca (2010) described formal and informal mindfulness practice and reinforced that both practices complement each other and are codependent:

> It helps to think of mindfulness in two ways, which we often call "big-M mindfulness" and "little-m mindfulness." The big "M" refers to mindfulness as a way of being in the world that spans all that you do every moment of your life; you can be mindful or not. It's not specific to any activity or situation. In contrast, little-m mindfulness refers to purposefully setting aside a chunk of time in your day to practice being mindful, just as you would practice the piano if you wished to learn that new skill. Mindfulness is a skill that you learn only through repeated doing. Essentially you practice little-m mindfulness to make it possible to be more mindful in the world (the big "M"). It's virtually impossible to achieve big-M mindfulness without a very strong and regular practice. (p. 35)

Mindfulness is typically taught using practice techniques that include sitting meditation, hatha yoga, walking meditation and body scan exercises. Carlson and Speca (2010) suggested that sitting meditation is often thought of as the gold standard means of achieving mindfulness. Sitting meditation can be done on a cushion or by sitting on a chair in an upright fashion with both hands resting on the thighs. This practice usually entails placing one's mind on the breath, and truly focusing on the moment. It implies acceptance of all feelings and thoughts that emerge and just "letting go."

Mindfulness walking exercises encourage people to slowly walk paying attention to the breath, heartbeat, and every associated movement that the function of walking necessitates. Carlson and Speca (2010) note that walking mindfully means walking with no agenda, no destination, and no expectations. Walking is usually done in a circular or back and forth motion.

Peel (2004) stated:

> The labyrinth is an ancient symbol that works well as a therapeutic tool to encourage mental focus through meditation or prayer, which can be instrumental in releasing mental and physical tension. Many recognize the labyrinth as a metaphor for the path we walk through life, and as an appropriate symbol that creates sacred space for enhancing psychological and spiritual growth. As a therapeutic tool, the labyrinth provides willing clients an opportunity to examine problems, questions, or issues from various perspectives, while also affording time and space for personal reflection before making a decision. (p. 287)

Curry (2000) described "walking the labyrinth" as a powerful opportunity for contemplative walking meditation and clarified that a labyrinth is distinct from a maze in that it is comprised of a safe passage in and out, and its focus is on healing rather than trickery. Curry further emphasized that the labyrinth journey is comprised of three parts: a pathway into the center, the center of the labyrinth itself, and the pathway back out. Walking a labyrinth is done in a mindful, meditative state that allows one to transcend excess worries, emerging empowered for life's challenges.

La Torre (2004) said:

> Walking a labyrinth together, client and therapist, can be a powerful activity as the movement itself around the circular path provides a connection, and can lead to a deeper relationship…. we came together again in the center and then walked out slowly, saying very little but feeling a quiet connection. (p. 121)

Eating mindfully helps to anchor one to be truly cognizant of the entire dining experience, using all senses and aware of the texture, smell, appearance, and taste of every bite. Mindfully eating truly entails the practice of using all of your senses to "be with" the food you are about to eat, while being cognizant about its origin and the stories to which it speaks. Additionally, mindfulness eating entails an examination of the body's reaction, both physically and emotionally to what one has eaten or is about to eat (Hick, 2009).

The practice of body scan is usually done by lying on one's back or sitting in a chair and sequentially moving the focus of attention through the different regions of the body, noticing sensations as they arise. Body scan invites participants to simply notice any sensations in the body with openness and curiosity (Baer, 2006).

Loving kindness is a practice that allows us to practice "metta." Salzberg (1997) stated:

> When we practice metta, we open continuously to the truth of our actual experience, changing our relationship to life. Metta—the sense of love that is not bound to desire, that does not have to pretend that things are other than the way they are—overcomes the illusion of separateness, of not being part of a whole. Thereby metta overcomes all of the states that accompany this fundamental error of separateness—fear, alienation, loneliness, and despair—all of the feelings of fragmentation. In place of these, the genuine realization of connectedness brings unification, confidence, and safety. (p. 1)

Salzberg (1997) suggests that practicing metta allows us to practice gentleness towards one's self and to see the basic goodness in all. Carlson and Speca (2010) suggest that loving kindness meditation involves a series of cultivating good wishes for a loved one, for one who causes angst, one's self, and eventually outward to all living beings. Salzberg (1997) stated:

> When we steep our hearts with loving kindness, we are able to sleep easily, to awaken easily, and to have pleasant dreams. To have self-respect in life, to walk through this life with grace and confidence, means having a commitment to non-harming and to loving care. If we do not have these things, we can neither rest nor be at peace; we are always fighting against ourselves. The feelings we create by harming are painful both to ourselves and for others. Thus harming leads to guilt, tension, and complexity. But living a clear and simple life, free from resentment, fear, and guilt, extends into our sleeping, dreaming, and waking. (p. 41)

Schmidt (2004) described loving kindness as egoless, spontaneous and unconditional, and summarized that loving kindness is an act of a balanced mind that aims for genuine happiness for others.

Baer (2006) suggests that although there are variations in the teaching methods, techniques, and duration, there are basic core instructions common to mindfulness practices. When one practices mindfulness, the person is directed to focus attention directly on an activity (breathing, walking, and eating) and to observe it. If the mind wanders, the individual is assured that this is normal and this is what minds do—that is, think. The participant is then instructed to simply label all discursive thoughts but then to come back to the target being observed, which is most frequently, the breath. If the body reacts while meditating, the participant is instructed to take notice but to not to necessarily act on the pain, itch, and desire to shift positions, et cetera. When thoughts arise, the bearer is instructed to simply label the thoughts with a word like "thinking." He is to avoid falling into the reactive pattern of judging, evaluation or self-criticism. There is no requirement to quash those thoughts and feelings that emerge but to rather substitute a curiosity and freedom of briefly noting them and allowing them to come and go (Baer, 2006). "Rather than evaluating our cognitive and emotional experiences, mindfulness teaches us to simply notice them" (Allen et al., 2006, p. 288).

PHYSICAL AND PSYCHOLOGICAL BENEFITS OF MINDFULNESS

Research to date confirms the benefits of mindfulness meditation training for the client population with regards to amelioration of illness symptomatology. There is no specific research reported to support mindfulness for CKD that I am aware of, although there is support to substantiate the effectiveness of mindfulness post-kidney transplantation. Gross et al. (2004) validated successful use of mindfulness to reduce symptoms of depression, anxiety, and sleep disturbance post-transplant. Following a MBSR eight-week program, participants demonstrated improvements in all areas. CKD is often a secondary complication of comorbidities that include hypertension, diabetes, compromised cardiac health, trauma, and advanced age. There is ever-increasing scientific evidence to support the efficacy of mindfulness meditation to treat comorbid medical conditions associated with CKD, including chronic pain (Zeidan et al., 2011), rheumatoid arthritis (Zangi et al., 2011), type 2 diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), and chronic diseases that include both multiple chemical sensitivity and cardiovascular diagnoses (Merkes, 2010). Furthermore, there is a wealth of mounting scientific evidence to support the therapeutic effect of mindfulness meditation on medical conditions, including improvement of IBS (irritable bowel syndrome), related quality-of-life and gastrointestinal-specific anxiety (Kearney, McDermott, Martinez, & Simpson, 2011), chronic low back pain (Morone, Greco, & Weiner, 2008), attention-deficit hyperactivity disorder (Smalley et al., 2009), and myalgic encephalomyelitis/chronic fatigue syndrome (Dayes, 2011).

It has also been suggested that mindfulness may be beneficial for a number of psychological stress-related conditions that often unfavorably affect patient quality of life. Garland (2007) summarized that mindfulness might assist with the prevention of stress-related illness through a number of psychological, biological, and behavioral pathways. He suggested that mindfulness facilitates heightened clarity and insight, a more comprehensive understanding of stressor demands, as well as coping strategies alternative to catastrophizing and ruminating, which are all favorable to enhanced adaptive coping. Bränström, Kvillemo, Brandberg, and Moskowitz (2010) found that mindfulness assisted in psychological well-being in a stress reduction intervention for cancer patients. Vøllestad, Sivertsen, and Nielsen (2011) concluded that MBSR is an effective treatment for anxiety disorders and related symptomatology. Segal et al. (2010) recently demonstrated that MBSR is valuable in deterring depressive episode relapse. Additionally, Bonadonna (2003) suggested that mindfulness has been proven to be an effective practice towards the amelioration of many physical and emotional challenges, including anxiety, pain, depression, mood, self-esteem, and stress.

Most recent research has begun to examine the actual effect of mindfulness meditation on the structure and understanding of the brain and this is a very exciting uncharted frontier for researchers. Hölzel et al. (2011) suggested that mindfulness is associated with changes in gray matter concentration in brain regions involved in learning and memory processes, emotion regulation, self-referential processing, and perspective taking. Hasenkamp and Barsalou (2012) examined the effect of the meditation experience on brain networks underlying cognitive actions employed during mindfulness practice. Westbrook et al. (2013) reported that mindful attention helped to reduce neural and self-reported cue-induced craving in smokers and might assist with smoking cessation and other addictive behaviors.

In summary, the literature suggests that mindfulness may be a valid treatment option for many physiological and psychological health challenges because it helps people to be more insightful, less reactive, less judgmental, and more tolerant.

MINDFULNESS AND THE HEALTHCARE PRACTITIONER

Of particular interest to me, researchers have also begun to explore how mindfulness-based practices might shape practitioner behavior and health. Researchers are expressing interest in how mindfulness meditation is of assistance to the healthcare counseling professionals who provide frontline service to patients on a day-to-day basis. Hence, amongst the chaos and the work stress of healthcare counseling professionals, there is the hope that mindfulness meditation may foster resilience, clarity, and a moment-by-moment appreciation of therapeutic relationships (Schure et al., 2008).

Bell (2009) validated that the practice of mindfulness meditation enhances therapist well-being and that this indirectly benefits clients during the psychotherapy encounter. Bell maintained that psychotherapists who practiced mindfulness meditative techniques became more in touch with their essence, more reflective, less judgmental, less reactive, more creative, more compassionate, and clearer in their thinking. Further, Bell suggested that this enlightenment allows for the psychotherapist to have a more heightened "therapeutic presence" with the client (p. 140). Mindfulness meditation enhances awareness and helps the therapist to appreciate and celebrate "interconnectedness" in the therapeutic relationship with enhanced awareness of all senses (Kabat-Zinn, 1994). Hence, mindfulness awareness may also promote increased professional fulfillment.

O'Driscoll (2009) reported how numerous qualitative and quantitative research initiatives have demonstrated that healthcare professionals who are engaged in mindfulness have more enhanced therapeutic interventions with clients. O'Driscoll painted an emerging theme that increased mindfulness practice parallels with positive patient clinical outcomes due to the therapist's enhanced objectivity, comfort with silence in the therapeutic process, and comfort in a sacred space that the therapist and patient share. Both O'Driscoll (2009) and Brown and Ryan (2003) confirmed that counselling psychologists who practice mindfulness attest to more satisfaction and less rigidity in the therapeutic encounter and more positive outcomes reported by clients.

McCollum and Gehart (2010) examined the effects of mindfulness practice on beginning therapists and conclude that mindfulness meditation is a useful addition to clinical training, as it instills a calming effect, heightens therapeutic presence, and enhances compassion. Brenner (2009) confirmed that mindfulness meditation cultivates the therapist's self-awareness, fosters a nonjudgmental response, assists in helping to see clients as they truly are, and enhances therapeutic presence.

Shapiro, Brown, and Biegel (2007) examined the concept of mindfulness and its application to assisting frontline mental health professionals who are susceptible to increased physical and emotional health difficulties directly attributable to their work environment. In a mixed method study, masters-level psychology program students who were in a "Stress and Stress Management" course that included Mindfulness Based Stress Reduction (MBSR) as a component, fared better than the control group counterparts in all regards and demonstrated reduced stress, reduced negative affect, diminished vulnerability to rumination, and decreased anxiety. Participants also demonstrated increased positive affect and self-compassion.

Chan, Ng, Ho, and Chow (2006) addressed the ramifications of repeated traumatization specific to healthcare workers and promoted the embodiment of a "Body, Mind, Spirit" (BMS) Holistic Model of Care to assist both patients and healthcare workers in today's specialized, compartmentalized and heavily bureaucratic hospital settings" (p. 822). The authors acknowledged the burden that many of today's healthcare workers carry, repeatedly exposed to patients who are frightened, suffering, and dying. This accumulation of work-related distress facilitates a quest for healthcare workers to examine a deeper meaning of pain and suffering in their lives as well as in others. Their body-mind-spirit approach to care promoted the concepts of appreciation of the moment, immersion of body in movement, acceptance of pain and suffering, appreciation of life as it is intertwined with nature, and the ability to demonstrate compassion.

O'Donovan and May (2007) sought to validate that the mindful therapist (social workers, psychologists, and counselors) has the advantage of enhanced well-being, job satisfaction, diminished burnout and, as a result, correlated enhanced patient interventions and better outcomes. They further maintained that both therapist and client benefit when the practitioner has more clarity and an appreciation of the moment in a non-judgmental fashion, and confirmed that a mindful therapist is more compassionate and more present. In a quantitative study of healthcare professionals Galantino, Baime, Maguire, Szapary, and Farrar (2005) demonstrated that an eight-week program to teach healthcare workers mindfulness in an effort to combat work stress and burnout improved mood and lessened emotional exhaustion. Schmidt (2004) summarized:

> Applying the ideas derived from the Buddhist mindfulness concept it is possible to add that an emotionally charged relationship can be established if the healer/therapist encounters the patient with his or her full awareness and presence. This means that the therapist is not hiding behind a professional stance, but shows his or her full personality in a genuine human way. Moreover, a therapist or healer who is practicing mindfulness toward his own person is likely to display an unconditionally accepting and compassionate healing intention toward the patient. (p. S–10)

In closing this section, Johns (2008) suggested that:

> Mindfulness is fundamental to being a caring practitioner, because it is the root of all skillful action. Buddhadasa Bkikku describes mindfulness as "reflective awareness"; the mind's ability to recall, know and contemplate itself. It allows us to be aware of what we are about to do. It is characterised by speed and agility. (p. 37)

MINDFULNESS MEDITATION AND SOCIAL WORK

When discussing the role of mindfulness in the social work profession, Hick (2009) suggested that social workers utilize mindfulness at three distinct levels. He first conveyed that the social worker utilizes mindfulness for self. In other words, the social worker who practices mindfulness meditation benefits because it fosters an inner peace, an appreciation of the moment, enhanced self-compassion and self-acceptance, clearer insight, diminished stress and enhanced gentleness with oneself as demonstrated through self-care. This is similar to the concept of therapeutic presence. O'Driscoll (2009) referred to therapeutic presence as a heightened awareness that permeates the therapist-client relationship during the therapeutic encounter, directly attributable to the practice of mindfulness. It is suggested that therapists who practice mindfulness have enhanced therapeutic presence, allowing for them to listen deeply, experience the fullness of the client's experience, and share a sacred space. Wisniewski (2008) emphasized that mindfulness is vital to effective social work practice, because it allows the therapist the opportunity to truly be attentive to the moment. Wisniewski postulated that this heightened therapeutic presence assists the client in feeling more connected, less judged, and more akin to the therapist. Likewise, "mindfulness prevents the therapist from reacting in scripted, preconceived ways in favor of reserving judgment and reaction so that the patient, ultimately, feels more freedom to govern their own actions" (Wisniewski, 2008, p. 18).

Related to this, Hick (2009) defined what he refers to as "micro-practice influence." He cited the practice of mindfulness meditation as being instrumental in contributing to enhanced client engagement and therapeutic presence. Ultimately the social worker who practices mindfulness is more attentive to the moment, has enhanced listening skills, exercises more objectivity, and possesses enhanced compassion for the patients they serve.

Hick also suggested that a social worker who engages in mindfulness practice is more in touch with the greater community, more open minded, attentive to process, and a strong advocate who has more awareness of societal issues and feels a connectedness to others more likely to foster social change.

RELAXATION THERAPY

Relaxation Therapy (RT) includes techniques which are targeted to induce a relaxed physical and mental state in the patient, usually obtained by the implementation of deep breathing; progressive muscle relaxation with or without Guided Imagery/visualization; hypnosis; and Autogenic Training (Luebbert et al., 2001). Relaxation Therapy techniques can effectively be used as a complementary therapy with conventional medicine towards the amelioration of anxiety, sleep disturbance, fear, and pain (Barnes, Bloom, & Nahin, 2008). Relaxation Therapy and Cognitive Behavioral Therapy (CBT) attempt to alter patterns of negative thought and dysfunctional attitudes in order to cultivate more healthy and adaptive thoughts, emotions, and actions. Relaxation techniques are frequently included as a behavioral component in CBT programs (NIH, 1996). Relaxation Therapy began in 1934 when Edmund Jacobson developed a physiological means of reducing anxiety and tension through systematic tensing and releasing various muscle groups, assisting the client in achieving a state of deep relaxation (Bernstein & Borkovec, 1973). Barnes et al. (2008) defined Relaxation Therapy as a complementary therapy under the framework of mind-body intervention that, when used together with conventional medicine, can be helpful with the amelioration of anxiety, sleep disturbance, fear, and pain. Jain et al. (2007) clarified that although there are varied approaches, Relaxation Therapy instills a direct intention to invoke change. The intention of Relaxation Therapy is to use specific exercises or imagery techniques to help the participant relax. This is directly the opposite of mindfulness practice, which facilitates a nonjudgmental awareness observing one's experience without trying to change it (for instance, just noticing the tension of a muscle without attempting to alter it, or just noticing a thought as it arises as opposed to trying actively to modify it).

Allen et al. (2006) differentiated the practice of Relaxation Therapy from mindfulness meditation:

> Mindfulness is not primarily a goal-directed activity despite the fact that the practice does have its secondary effects. For example, although mindfulness may bring about relaxation, it is not primarily a "relaxation exercise" in that bringing non-judgmental awareness to the state of body and mind is the practice without any expectation of results, no matter how desirable those results might be. (p. 286)

Turk et al. (2008) highlighted that there is a broad spectrum of approaches available to assist the client, and that the exposure of many different techniques is conducive to an informed decision as to which one is best suited to individual needs. No one method is more efficacious and no one technique is effective for all people all the time. In fact, knowledge of a wide array of different methods may be the best approach in arming the patient.

Gordon (2008) suggested that, when implementing any of the mind-body interventions with patients, it is imperative that the therapist assess the needs of the individual first, highlighting the benefits and consequences of the proposed action to the patient and then respecting the patient's preference and ability to give informed consent. Gordon also emphasized that in order to truly understand and, practice any of these techniques with patients, it is prudent for therapists to have experienced and made use of these techniques themselves. Knowing and then experiencing these techniques authenticates the therapist as someone who truly understands the practice being recommended, and, I would argue, validates their expertise and instils patient trust.

Relaxation Therapy is designed to invoke the "Relaxation Response." Stephen and Smith (2003) suggested that once a patient learned how to invoke the Relaxation Response, they could effectively invoke it thereafter when required in order to achieve a state of mental and physical tranquility. When the body moves from chaos to homeostasis, cortisol and blood lactate levels decrease, the heartbeat steadies, blood pressure diminishes, and lymphocytes increase. This institutes a sense of peace and well-being for the patient.

In summary, although Relaxation Therapy techniques and mindfulness meditation are distinct and equally significant therapeutic modalities that benefit both the patient and healthcare professional, they both facilitate the Relaxation Response.

RELAXATION THERAPY TECHNIQUES

The following section will describe four relaxation therapy techniques, including deep breathing, Progressive Muscle Relaxation, Guided Imagery, and Autogenic Training. Caudill (2002) describes diaphragmatic breathing as focusing on the rise and fall of the breath as one tightens the abdomen and expands the chest with each in-breath. A diaphragmatic breath is a fuller and more complete breath than the chest breath. During this technique, one is encouraged to focus on inhaling clean, oxygen-filled air while imagining all the tension in his body and mind dissipating with the out-breath. Additionally, one might direct the breath into areas of the body where there is tension, pain, or tightness and relinquishing with the out-breath.

Progressive Muscle Relaxation focuses on sequentially tensing and relaxing individual muscles of the body, usually starting from the feet upwards or vice versa. The participant is directed to clench the area tightly, hold it, and then release it. This modality promotes body awareness and the release of tension in response to anxious thoughts or stressful events (IDEA Health and Fitness, Inc., 2005). Progressive Muscle Relaxation has been extensively studied and shown to be effective for improving sleep in persons with insomnia (Ladas, Post-White, & Hawks, 2006). Progressive Muscle Relaxation assumes that it is possible to learn the difference between tension and relaxation (one cannot be both relaxed and tense at the same time), and that relaxing the body through decreased muscle tension will, in turn, decrease mental tension (IDEA Health and Fitness, Inc., 2005).

Guided Imagery can be an effective modality in bolstering one's sense of control and helping individuals to achieve a state of calmness. Turk et al. (2008) suggested that:

> Guided Imagery involves the generation of different mental images, evoked either by oneself or with the help of the practitioner. It overlaps with different mental images, evoked either by oneself or with the help of the practitioner. It overlaps with different relaxation techniques and hypnosis. It is often used in conjunction with other treatment interventions such as relaxation and within the context of CBT. (p. 219)

Guided Imagery is often used towards achieving a life-enhancing goal with the connotation to heal, promote personal growth, heighten concentration, and alter body chemistry. Guided Imagery incorporates all the senses and focuses attention inward. Guided Imagery also focuses on a safe place or private sanctuary (IDEA Health and Fitness, Inc. 2005).

Finally, Autogenic Training consists of imagining a peaceful environment and comforting bodily sensations. Six basic focusing techniques are used: heaviness in the limbs, warmth in the limbs, cardiac regulation, centering on breathing, warmth in the upper abdomen, and coolness in the forehead (NIH, 1996).

PHYSICAL AND PSYCHOLOGICAL BENEFITS OF RELAXATION THERAPY

Helping and health professionals have been utilizing relaxation therapies since the late 1930s (Bernstein & Borkovec, 1973). Dr. Herbert Benson later popularized the Relaxation Response technique that sought to quiet the mind and diminish muscle tension (Weinberg & Gould, 2007, p. 280). The early research in this area examined the body's reaction to environmental stress in the 1960s; focused on the field of biofeedback and the body's reaction to stress in the late 1970s; substantiated the efficacy of support groups, changes in lifestyle, meditation and yoga in the 1980s; and provided impetus for the establishment of the National Center for Complementary and Alternative Medicine in 1992 (Finger & Arnold, 2002). More recently, researchers have focused their efforts on examining the effectiveness of relaxation therapy techniques for specific physical and psychological manifestations, often by using meta-analysis to facilitate evidenced-based practice acceptable to both professionals and a better-informed public.

Similar to the research on mindfulness-based practices, the literature supports Relaxation Therapy as an effective treatment for a variety of ailments that include depression, anxiety, and hostility (Luebbert et al., 2001; Uzma & Hasan, 2010); pain (Carlson & Bultz, 2008); blood pressure control (Dusek et al., 2008); and quality of life and sense of coherence (Fernros, Furhoff & Wändell, 2008). Specific to chronic kidney disease, Duarte, Miyazaki, Blay, and Sesso (2009) conducted a research study with 85 hemodialysis patients. It was demonstrated that those patients who underwent three months of weekly 90-minute sessions of CBT, including coping techniques, thinking and cognitive remodeling techniques, and relaxation activities, had a significant improvement in depressive symptoms, cognitive function, and quality of life scores. A meta-analysis that examined psychosocial interventions for anxiety and depression in adult cancer patients by Jacobsen and Jim (2008) highlighted relaxation training in randomized control trials and was found to be efficacious in preventing and relieving anxiety in patients undergoing chemotherapy. Manzoni, Pagnini, Castelnuovo, and Molinari (2008) examined 27 studies dating from 1997 to 2007 and said that results demonstrated consistent and significant efficacy of relaxation training in reducing anxiety.

RELAXATION THERAPY AND THE HEALTHCARE PROFESSIONAL

Schure et al. (2008) examined the profound effect that elevated stress has both physically and emotionally on helping professionals responsible for treating persons with mental health challenges. In their study, 33 masters-level counseling students were enrolled in an elective course referred to as "Mind/Body Medicine and the Art of Self Care," where they were exposed to hatha yoga, sitting meditation, qigong (an ancient Chinese method combining gentle physical movement with meditation), and conscious relaxation techniques. Students identified profound changes to their physicality, emotional integrity, cognitive clarity, and concept of self. Students spoke of how this exposure to mind-body interventions then resonated into their practices in a positive manner, using themes of enhanced comfort with silence, reduced reactivity, more compassion, and increased empathy.

In 2008, I completed a survey with the National Kidney Foundation Council of Nephrology Social Workers (NKF-CNSW), a group of American nephrologists, and the Canadian Association of Nephrology Social Workers to determine if there was an interest in advanced relaxation therapy as a standard of practice in the overall treatment for persons affected with CKD (Petingola, 2010). Nephrology social workers reported that relaxation therapy techniques were not being utilized in their practices and clearly saw the need for their implementation. Eighty-four percent of American nephrologist respondents reported that they would like to see the implementation of relaxation therapy in the overall treatment plan. Overwhelmingly, nephrology social workers suggested the need for enhanced training to acquire more skill with using relaxation therapy techniques (Petingola, 2009). Learning relaxation therapy techniques, however, is not sufficient to guarantee successful integration of skills into professional practice with patients.

Finger and Arnold (2002) explored the use of mind-body interventions in social work practice and outlined that social workers can learn to integrate relaxation techniques into their frontline practice with additional training and a commitment to personally using the relaxation techniques. Furthermore, Finger and Arnold suggested that social workers who develop a personal practice of relaxation techniques gain a clearer and truer understanding of how these techniques can be used in stress reduction, thereby increasing their proficiency.

Adams, Camarillo, Lewis, and McNish (2010) examined the benefits of a Professional Provider Resiliency Training (PPRT) program aimed at providing military medical professionals the opportunity to significantly develop and enhance their resiliency skills. In this study, 172 medical professionals, including nurses, doctors and ancillary professionals, were taught mind-body interventions. Study participants found the deep-breathing exercise (95%), tai chi (86%), and Guided Imagery (85%) to be the three most helpful mind-body resiliency techniques. Overall, 96 percent of the participants reported that they planned to use the learned mind-body techniques in the future.

Poulin, Mackenzie, Soloway, and Karayolas (2008) examined two mindfulness-based interventions designed to reduce stress and enhance well-being amongst human services professionals in the workplace. The first study compared mindfulness to traditional relaxation therapy for nursing staff. Results demonstrated that both of these interventions significantly improved relaxation as well as life satisfaction. In the second study, relaxation intervention focused on the impact of stress on the body, and utilized abdominal breathing techniques, progressive muscle relaxation, imagery and creative visualization, and incorporated relaxation exercises into daily life.

Gallant, Holosko and Gallant (2005) argued that working conditions, client demands, and heavy workloads exacerbated high levels of stress among social workers, thereby undermining their potential for self-fulfillment and productivity. These researchers introduced a model referred to as Bio-Spiritual-Music-Focus-Energetics (BSMFE), a focusing technique for social workers and addiction counsellors, as a part of staff training and re-certification. BSMFE incorporated music, relaxing breathing techniques, body awareness, and breathing wellness. A study sample of social workers and counselors participated to heighten their awareness of inner-directed processes in their own spiritual quest toward personal fulfilment, professional growth, and transformation. The researchers argued that BSMFE was an effective tool that could be utilized to help social workers attain more personal and spiritual fulfillment.

So, while there is no doubt that researchers are finding that both mindfulness practices and relaxation therapies are beneficial for both patients and practitioners, we know little about how training in these methods is taken up by practitioners.

AUTHOR NOTE: *In this first of two articles I have provided a detailed description of relaxation techniques and mindfulness meditation definitions and practices, providing the reader with the necessary information to understand the topics covered in the workshop. In Part Two, I will discuss methodology and results of this study.*

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Routine Use of the PedsQL™ for Assessment of Quality of Life in Pediatric Dialysis Patients

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To comply with new Centers for Medicare and Medicaid Services (CMS) regulations requiring regular assessment of patient quality of life (QoL) by dialysis programs, we administered the PedsQL™ survey instrument to every eligible dialysis patient in our program beginning in October 2008. We compared findings between groups of our patients assessed from October 2008 through January 2010, and also with results of previously published multi-center studies. Compared to prior published studies using the PedsQL,the overall scores for patients and parents were lower in this routine collection of survey responses. Unexpectedly, we found that HD patients and patients living at greater distances from our center had better QoL scores than PD patients and those living closest to the medical center. These results require re-examination in larger, multi-center studies.

INTRODUCTION

The Centers for Medicare and Medicaid Services (CMS) published new Conditions for Coverage for End-Stage Renal Disease Facilities in April 2008 (CMS, 2008). These regulations, which took effect in October 2008, were the first new regulations in approximately 30 years, and brought many changes to dialysis programs. One of the new conditions requires social workers to use a validated quality of life (QoL) tool to assist in the psychosocial assessment of all chronic dialysis patients. Tools that had only previously been utilized in research settings are now incorporated into routine social work assessments across a broader patient population.

The Measures Assessment Tool (CMS, 2014) utilized by dialysis facility assessors expects that social workers will assess QoL via the KDQOL™ (Hays, Kallich, Mapes, Coons, & Carter, 1994). This instrument uses a Physical Composite Score and a Mental Composite Score for which the RAND Corporation has previously established normative responses (Hays, Prince-Embury, & Chen, 1998) and, along with the Dialysis Outcomes and Practice Patterns Study (DOPPS), has also been used to establish a correlation between QoL and morbidity and mortality (Mapes et al., 2003). Unfortunately, the KDQOL is only validated for patients aged 18 and older. Pediatric dialysis social workers are left to search for an appropriate assessment tool without specific guidance from CMS.

The PedsQL™ (Varni & Limbers, 2009; Varni, Limbers, & Burwinkle, 2007a; Varni, Limbers, & Burwinkle, 2007b) is one such QoL tool that has been developed and validated in several pediatric patient populations. The PedsQL Generic Core Scale addresses general questions about general physical health, school and social/emotional functioning, providing a QoL score that could be compared to a healthy population. In addition to the Generic Core Scale (used to measure QoL across healthy and ill populations), many disease-specific modules have been developed, including an end-stage renal disease (ESRD) module. The Generic Core Scale and the ESRD Module are designed to be completed by the patient and also by a parent (or parent proxy, as appropriate). The PedsQL tool is validated for patients aged 2 to 18 years who can speak English or Spanish (Goldstein et al, 2008). Age range adjustments can be made to accommodate developmental delays. While the PedsQL has been validated for pediatric ESRD patients in research settings (Goldstein et al., 2008; Varni et al., 2007b), no data exist on the results of its routine application.

The Dialysis Program at Seattle Children's Hospital (SCH) implemented use of the PedsQL survey in October 2008 to meet the CMS mandate to assess QoL. In this report, we examine results from our initial experience of routinely using the PedsQL in order to determine how the quality of life for SCH hemodialysis (HD) patients compares to that of SCH peritoneal dialysis (PD) patients; whether quality of life among SCH dialysis patients varies across age, gender, and ethnicity; and whether distance from the medical center in our geographic region has a significant impact on quality of life.

METHODS

The PedsQL was administered by the dialysis social worker to every eligible dialysis patient (English or Spanish-speaking only, ages 2 to 18) enrolled in our program beginning in October 2008. This gave us a baseline for each patient. Since that time, eligible patients are administered the appropriate PedsQL module during 90-day, "unstable," or annual comprehensive assessments. Patients aged 18 and over are given the KDQOL for assessment. Only results of the PedsQL are included in this report.

The PedsQL (Varni et al., 2007a; Varni et al., 2007b, Varni & Limbers, 2009) is administered to patients, who complete survey questions about their own quality of life, and

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to parents, who complete survey questions about how they perceive the quality of life of their child. The Generic Core Scale has 23 questions, while the ESRD Module has 34 questions. For each question, respondents are asked to describe how much of a problem the particular item has been over the last 4 weeks ("never a problem"; "almost never a problem"; "sometimes a problem"; "often a problem"; or "almost always a problem"). The Toddler Report (for children ages 2 to 4) is only completed by parents and has a reduced number of questions. The Young Child Report (for ages 5 to 7) has the full complement of questions, but reduced response options ("never"; "sometimes"; and "almost always"). The Young Child Report also has an optional tool with a smiling face, a straight face, and a frowning face to allow children to demonstrate their responses more visually. The Child Report (for ages 8 to 12) and the Teen Report (for ages 13 to 18) have slightly different phrasing, but each allows children and parents the full complement of questions with the full complement of responses.

The PedsQL is scored on a scale of 0 to 100, with higher numbers correlating with better quality of life. The Generic Core Scale generates a physical health subscore, a psychosocial health subscore, and a total score. The ESRD Module generates a total score and seven subcategory scores: general fatigue, disease symptoms, treatment problems, family and peer interactions, worries, perceived personal appearance, and communication.

For this analysis, we examined the first 15 months (October 2008 to January 2010) of PedsQL surveys administered in our dialysis program. All surveys completed during this time were included in this review. The Seattle Children's Hospital Institutional Review Board approved retrospective data collection for this report. SCH had previously purchased a user agreement for routine use of the PedsQL and all disease-specific modules.

Statistical Analysis

We divided the patients by the following characteristics for purposes of analysis: dialysis modality (peritoneal dialysis (PD) vs. hemodialysis (HD)), gender, age, ethnicity (Caucasian vs. Hispanic), and by geographical areas. Tables 1 and 2 show that we did collect surveys from patients and parents of racial/ethnic groups other than Caucasian and Hispanic. However, the numbers of subjects in these groups were too small to include separately in the statistical analysis, thus analysis was completed for Caucasian vs. Hispanic only. For the geographical comparison, we divided our service area into three parts: Seattle Metro (defined as King, Snohomish, and Pierce counties), other parts of Washington State, and out of state (which included patients from Alaska and Montana). For the analysis of the Generic Core Scale, the data from outside the Seattle Metro area were sparse, and therefore the geographic categorization was collapsed into two levels, Seattle Metro and outside of Seattle Metro.

Table 1. ESRD Module scores according to selected patient characteristics

	PedsQL™ **ESRD** Module:					
	Patient self-reported			**Parent-reported**		
	n	Mean (SD)	p-value†	n	Mean (SD)	p-value†
Dialysis Modality:						
Peritoneal	20	57.7 (17.0)	p = 0.28	22	58.5 (17.3)	p = 0.57
Hemodialysis	19	63.6 (16.6)		19	61.5 (14.5)	
Patient Gender:						
Female	17	59.0 (16.5)	p = 0.63	19	55.4 (15.6)	p = 0.10
Male	22	61.8 (17.5)		22	63.7 (15.6)	
Patient Age Group:						
Child ≤ 12 yrs	10	61.5 (19.1)	p = 0.83	14	61.7 (13.9)	p = 0.60
Teenager (13–18 yrs)	29	60.2 (16.4)		27	59.0 (17.1)	
Patient's Ethnicity:						
Caucasian	21	61.4 (19.3)	p = 0.10	25	64.4 (13.1)	p = 0.01
Hispanic	11	54.1 (12.2)		12	50.4 (13.4)	
Other/multiple	7	68.1 (13.3)		4	60.3 (29.1)	
Residence Location:						
Seattle Metro	21	61.1 (16.7)	p = 0.97	21	57.7 (18.0)	p = 0.70
Other WA county	13	60.7 (13.0)		15	62.4 (12.0)	
Out of state	5	58.1 (28.2)		5	61.5 (19.4)	

†*The p-values for the comparisons of means were computed using a Generalized Estimating Equation (GEE) modeling approach.*

Table 2. Generic Core Scale scores according to selected patient characteristics

	PedsQL™ **Generic** Core Scale:					
	Patient self-reported			**Parent-reported**		
	n	Mean (SD)	p-value	n	Mean (SD)	p-value
Dialysis Modality:						
Peritoneal	10	63.0 (15.9)	p = 0.98	10	53.1 (19.3)	p = 0.71
Hemodialysis	7	63.2 (14.0)		7	49.7 (20.5)	
Patient Gender:						
Female	8	58.0 (13.7)	p = 0.17	7	44.1 (14.7)	p = 0.18
Male	9	67.6 (14.8)		10	57.0 (21.0)	
Patient Age Group:						
Child ≤ 12 yrs	3	71.9 (9.2)	p = 0.08	4	49.0 (17.2)	p = 0.72
Teenager (13–18 yrs)	14	61.2 (15.2)		13	52.5 (20.4)	
Patient's Ethnicity:						
Caucasian	9	66.7 (16.7)	p = 0.31†	9	53.4 (23.0)	p = 0.45†
Hispanic	7	58.9 (12.6)		7	45.9 (11.7)	
Other/multiple	1	59.8 (n/a)		1	77.2 (n/a)	
Residence Location:						
Seattle Metro	10	57.2 (12.6)	p = 0.04	11	44.8 (15.7)	p = 0.03
Outside Seattle Metro	7	71.5 (14.0)		6	64.3 (20.1)	

† *The p-values for the comparisons of means were computed using a Generalized Estimating Equation (GEE) modeling approach.*

Scores on the ESRD Module and Generic Core Scale of the PedsQL were summarized with means and standard deviations. Patient self-reported and parent-reported data were summarized separately. Comparisons of mean scores by dialysis modality (PD vs. HD), gender, age group, ethnic group and residence location were performed using Generalized Estimating Equation (GEE) methodology. Use of GEE modeling was necessary because some subjects completed the PedsQL modules on more than one occasion and the observations contributed by the same person may be correlated. The GEE modeling approach to testing for differences between group means accounts for any within-subject correlation. For categorical factors having more than two levels (ethnicity and residence location), the p-value presented is from a joint test for the significance of the factor as a whole in the GEE model. For visits at which both patient and parent completed the PedsQL modules, differences between the paired parent and patient scores were also assessed. GEE modeling was used to obtain standard error estimates and compute 95 percent confidence intervals for the mean parent-patient difference. Scatter plots of the paired parent-patient scores were also generated and displayed along with the Pearson correlation coefficient (r).

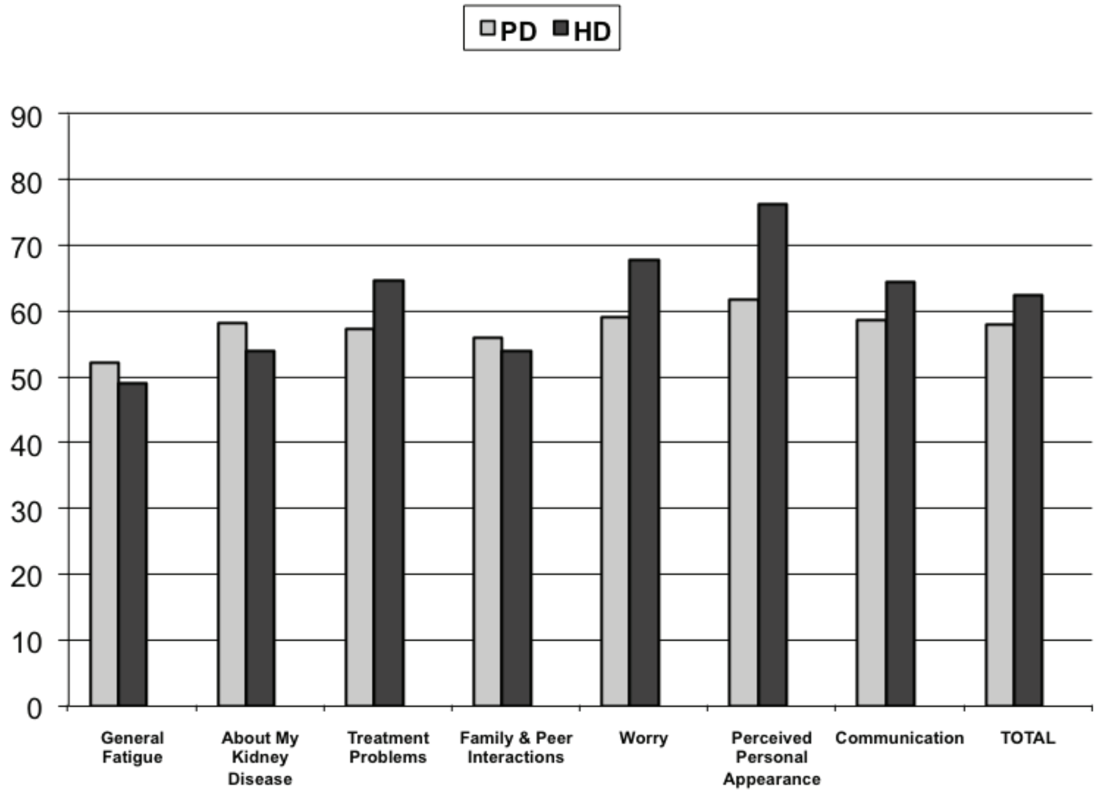
RESULTS

From October 2008 through January 2010, a total of 39 patients and 41 parents completed surveys. While most of these patients and parents represent a pair, some children did not have parents present to complete the parent reports, and some parents completed surveys while their children were not developmentally capable of doing so. As seen in Table 1, our patients represented a roughly even split between HD and PD. They were largely over the age of 12 years, more than 50 percent were Caucasian, and more than 50 percent were from within the three Washington (WA) counties closest to the medical center.

The most statistically significant differences in the parents' survey responses were seen in ethnicity (p = 0.01), with the parent-reported mean ESRD score being lowest among Hispanic children (Table 1). Similarly, the children's self-reported ESRD scores were lowest in the Hispanic group; however, those differences did not reach statistical significance (p = 0.10). Also of note in Table 1 is the trend toward lower parent-reported ESRD Module scores for female patients versus male patients, although this comparison did not reach statistical significance (p = 0.10). Geography had no significant impact on the scores in this module.

Results according to dialysis modality are highlighted in Figure 1. For many of the categories, HD patients scored higher than PD patients. In the ESRD Module, HD patients scored higher in the areas of treatment problems, worry, perceived personal appearance, and communication.

Figure 1. Mean scores across ESRD Scale categories by dialysis modality (PD vs. HD)



We did not have access to the Generic Core Scale at the beginning of this study period, and only obtained the extra scale midway through the time frame covered by this study. The results of the Generic Core responses represent 17 patients and their parents (see Table 2).

While geography did not reflect an impact on QoL in the ESRD Module scores, there was some impact reflected in the Generic Core Scale scores as seen in Table 2. Patients living closest to the hospital (residing in the three surrounding counties of King, Snohomish, and Pierce) had a significantly lower QoL (57.2 mean total patient score) than those living at greater distances (71.5 mean total patient score, p = 0.04). A similar difference in QoL scores was seen among parents, with the mean total parent score among those living greater distances from SCH being 64.3, compared to a score of 44.8 for those from surrounding counties (p = 0.03).

The overall patterns seen in the Generic Core Scale scores showed some similarities to those seen for the ESRD Module scores, with a marked, albeit not statistically significant differential between female patients and male patients. Patients and parents consistently rated girls lower on the QoL scale compared to boys (female patient total mean score 58.0, male patient total mean score 67.6; parent for girls 44.1, parent for boys 57.0). Also of note in Table 2, dialysis patients 12 years old and younger had substantially higher QoL scores than their adolescent counterparts (71.9 total mean score vs. 61.2), a difference which approached statistical significance (p = 0.08). However, parent-reported QoL scores did not show the same trend.

By observation, patients' and parents' surveys did not always have numerically equivalent scores, but often shared overall rankings of the categories addressed by the ESRD Module. For example, the patient and the parent might not agree on the numeric responses to the questions about fatigue, but both might agree that issues of fatigue are more problematic for the patient than issues of personal appearance. Table 3 shows the paired comparisons of responses supplied by the patient versus responses supplied by his/her parent. Of note, ratings by patients and their parents differed much more dramatically on the Generic Core Scale than the ESRD Module. Also of note, patients tended to rate their physical health better (mean score 64.0) than their psychosocial health (mean 61.8), while parents tended to rate the child's psychosocial health better (mean 52.8) than their physical health (mean 48.7).

Figures 2 and 3 demonstrate a distinct difference between the way patients and their parents scored on the Generic Core Scale versus the ESRD Module. For the Generic Core

Scale, Figure 2 shows that there are many pairs in which the parent-reported score was more than 10 points below their child's patient-reported score, but there are no pairs in which the parent-reported score exceeded the child's score by that much. For the ESRD Module, the scatter around the central ±10 point band is more even, with discrepancies between parent- and child-reported scores occurring in both directions (Figure 3). For both the Generic Core Scale and ESRD Module, about half of the patient-parent pairs studied scored within a ±10 point spread.

Figure 2: Generic Core Scale scores correlated between patient and their parent-proxy

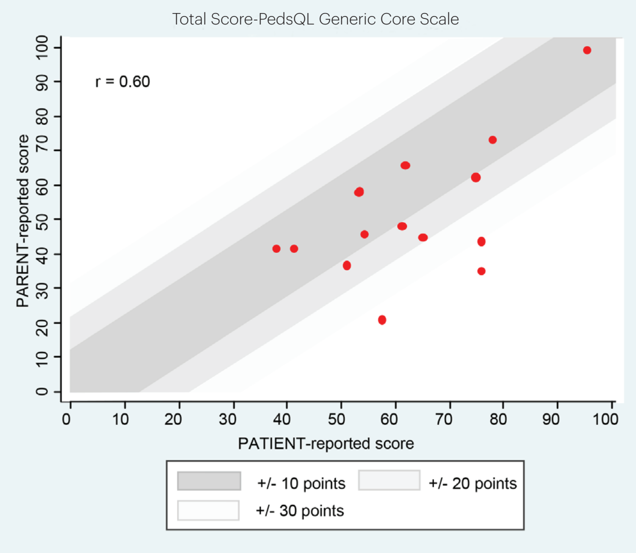
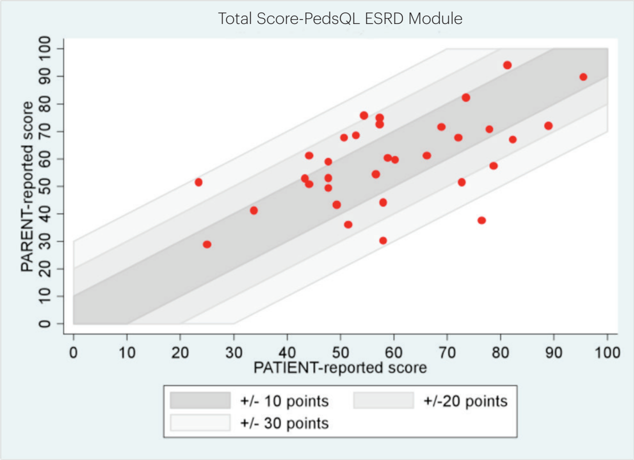


Figure 3: ESRD Module scores correlated between patient and their parent-proxy



DISCUSSION

In this report we show that routine application of the PedsQL in a pediatric ESRD population can provide important insights into QoL which may reflect the unique characteristics of the dialysis center and the patient population it serves. These insights will help social workers and the full interdisciplinary dialysis team to attend to individual care planning as well as program development.

Some results are not unexpected. For example, our data demonstrate that Hispanic patients rate their quality of life lower than other patients. It is important to note here that

Table 3. Comparison of patient-self-reported and parent-reported Generic Core Scale and ESRD Module scores

PedsQL™ ESRD Module component:	**Patient self-reported Mean (SD)**	**Parent-reported Mean (SD)**	**Difference (95% Conf. Int.) †**
General fatigue (n = 30)	53.3	46.7	+6.6 (-2.7, 15.9)
Kidney disease symptoms (n = 32)	54.7	57.2	**-2.6 (-9.0, 3.9)**
Treatment problems (n = 33)	53.8	63.1	**-9.3 (-18.4, -0.2)**
Family & peer interactions (n = 32)	57.3	50.0	**+7.3 (-2.1, 16.7)**
Worry (n = 33)	62.1	62.0	**+0.2 (-6.7, 7.0)**
Perceived physical appearance (n = 33)	67.9	64.6	**+3.3 (-6.5, 13.1)**
Communication (n = 32)	63.0	62.8	**+0.2 (-9.8, 10.2)**
TOTAL SCORE (n = 33)	59.3	59.3	**0.0 (-5.4. 5.5)**
PedsQL™ Generic Core Scale component:			
Physical (n = 15)	64.0	48.7	**+15.3 (6.6, 24.0)**
Psychosocial (n = 15)	61.8	52.8	**+9.0 (-0.4, 18.4)**
TOTAL SCORE (n = 15)	62.6	51.3	**+11.2 (2.6, 19.9)**

† *The 95% confidence interval for the difference between means were derived using a standard error estimate derived from a Generalized Estimating Equation (GEE) model. This approach accounts for any correlation that may exist among multiple observations contributed by the same patient-parent pair at different visits.*

the PedsQL is validated in the English and Spanish languages only and is not validated for use with an interpreter. The patient population captured in these responses is not as racially or ethnically diverse as the total SCH dialysis population. These results, therefore, tell us more about the Hispanic population represented, and less about other racial and ethnic patient groups. Studies in adult dialysis patients have shown Hispanic patients to have lower QoL scores than other non-Hispanic groups (Lopes et al., 2003). Hispanic patients are more likely to have residency or immigration status that disqualifies them from certain support programs and other resources. Hispanic patients are more likely to require the use of interpreters during medical appointments. Regardless of the skill and expertise of the interpreter, communication is always more challenging through translation. These issues are well known to affect QoL assessment in Hispanic populations, and may explain why there are so few published data on Hispanic patients with kidney disease (Porter, Vijil, Unruh, Lora, & Lash, 2010).

Other results are curious, but not entirely surprising. For example, when thinking about the difference between patient self-reported Generic Core Scale physical health (mean score 64.0) compared to parent-reported Generic Core Scale physical health (48.7), it is easy to speculate on these differences (Table 3). Social workers understand families as systems (Schriver, 2011). Children and parents occupy unique roles in the family system, but parents once played the child role in their own family of origin. Parents are more likely to have had a healthy childhood themselves, and are likely to have at least one other healthy child at home for comparison. Parents with healthy childhoods are likely to see how much their chronically ill child is disadvantaged in their physical health by comparing to their own childhood, or another sibling, or simply from life experience. Children who have lived with kidney disease for as long as they can remember may not view or understand their own limitations in the same way. Perhaps, patients are even aware of an improved feeling of energy since starting dialysis after a long period of decline because their chronic kidney disease progressed prior to initiating treatment. However, these are speculations only, and it is clear that further research in these areas is needed. Pediatric social workers are able to work directly with patients and their parents, allowing for exploration of these questions in routine practice.

Still, other results of this analysis challenge our assumptions about what we think is best for pediatric ESRD patients. Most notably, with the assumption that PD patients would show a somewhat higher QoL than their HD counterparts (Goldstein et al., 2009), the fact that these results show even a small difference in the opposite direction presents interesting questions worthy of further exploration. In pediatrics, we have long presumed that PD offers a better quality of life for children and their families. PD treatments are done in the home, which allow children to attend school and parents to work. Dialysis facilities are asked to consider the home treatment options for each and every patient in recognition that home modalities facilitate rehabilitation. And in fact, Goldstein et al. (2009) confirmed such beliefs in their multicenter study showing that transplant patients had higher QoL scores than PD patients, who in turn had higher QoL scores than HD patients. Our results may challenge that presumption.

In general, our patients scored lower on the PedsQL than pediatric dialysis patients in previously published studies (Goldstein et al., 2008; Goldstein et al., 2009; Varni & Limbers, 2009). This may represent the difference in a study population compared to a general patient population. The prior studies also represent multiple centers across the country, while ours is a single-center analysis.

The geography of our service region may make these findings unique to our center and not generalizable to other pediatric dialysis programs. SCH serves a geographic region that is vast and diverse, including the states of Washington, Alaska, Montana, and Idaho. Because distance from the medical center limits modality choice and creates greater financial hardships, we anticipated that distance would negatively correlate with QoL. Finding that those patients living furthest from the medical center showed better QoL than those living closest, we now wonder whether distance is not as much a factor as urban versus rural lifestyles. While we do not see a significant difference in socio-economic status between these groups, we do recognize that urban poverty is experienced differently from rural poverty (Churilla, 2008). We also wonder about the differences in service delivery expectations. Urban residents can typically shop for groceries, go to the gym, use an ATM, and visit a pharmacy 24 hours a day somewhere close to home. With that level of immediate service access, the need to drive even 30 miles from Tacoma to Seattle, passing several adult dialysis centers on the way, may seem like a real hardship. Rural residents live with the understanding and the expectation that not everything is readily available. The 10-hour drive from Kalispell, MT, to Seattle may seem quite reasonable, given there are no pediatric dialysis providers in the entire state of Montana. Some studies in adult patient populations suggest that rural communities experience less access to healthcare and lower health literacy, two issues correlated with lower health-related QoL (DiSipio, Hayes, Newman, Aitkin, & Janda, 2010; Spoont et al., 2011; Wang et al., 2013). It is possible that access at a distance, combined with the high health literacy of parents trained to perform PD, removes these barriers for our pediatric population.

Attribution Theory (Weiner, 1974; Weiner, 1986; Gordon and Graham, 2005) suggests that a person's perception of his personal situation is what most determines how he will feel about that situation. In healthcare, the perception of problems can have an impact on the care of problems (Cella et al., 2007; Lewis & Daltroy, 1990; Pallant, Misajon, Bennet, & Manderson, 2006). Health behavior theories help us think about how personal experiences, beliefs, and opinions shape health perceptions and health behaviors (Brewer

& Rimer, 2008). PD and HD patients seem to perceive a different sense of control over some aspects of their lives, and therefore seem to have different expectations. HD patients are not able to attend school full time. This has always been seen as a significant barrier to academic achievement and social acclimation. It also means that, given these barriers, HD patients do not have the same expectations for school success, and their QoL scores seem to reflect less concern about school problems. On the other hand, PD patients are expected to attend school full time and keep up with their peers even while going home every night to dialyze for 10 to 12 hours. Perhaps PD patients feel added pressure to perform at school. We need to consider whether the PD patients work hard to "fit in" and "be normal" during a time when HD patients do not feel that same pressure; similarly, home PD may place increased burdens on parents than in-center HD, thus contributing to a perceived lower QoL.

The dialysis center can be a very supportive and caring environment for pediatric patients. HD patients attending chronic treatments 3 to 5 times per week not only have ample opportunities to meet other patients in their own situation, but understand that a number of adults (nurses, social workers, etc.) care about them as young people. HD provides consistency and routine. It is possible that the support our HD patients receive in the dialysis unit positively balances the disruption they experience at home and school. It is also possible that our PD patients feel more isolated in their treatment with less opportunity to connect with other patients in situations similar to their own. These patients may also feel that they are a burden to their family (the parents who perform and manage their treatment) in a way that HD patients do not.

When faced with known barriers, it is important that we, as social workers, continue to support families in coping with those barriers. Quality of life is impacted more by how a person handles what happens in his or her life than by the events themselves. We may not be able to remove all the barriers our patients face, but we may still be able to impact their coping and adjustment in the face of those barriers. For example, at SCH it will be important for our dialysis team to think creatively about how best to support our Hispanic patients. We may have little impact on their residency or immigration status or on the community services available to such patients, but we have much to offer them in the way they experience their dialysis care. We can team with our bilingual Spanish social worker, our pastoral care team, and our patient navigators to consider programmatic opportunities for improving support and coping strategies for these families.

Looking at individual items from the surveys, patients of all ages scored "I feel thirsty" and "I get tired" the lowest of all individual items. In the "worry" section, parents did not perceive their children to be worried that "I will get sick if I don't take my medicines." However, adolescents showed that they do indeed worry about this issue. Individual items such as these can tell us something about the adherence problems that are typically seen in a dialysis population. It also tells us something about how we might begin to address adherence as an interdisciplinary team. If we can find ways to tap into these worries at the same time we are helping kids cope with thirst and fatigue, we may be able to make some headway in the perpetual adherence battle.

The results shared here are a snapshot of the dialysis patients served by one pediatric dialysis program. It is unclear how these results translate to other settings or even to a different window of time within our own program. What is evident, however, is that these measurements give us new opportunities to challenge our assumptions. Dialysis programs have long understood the value of interdisciplinary approaches to care and the importance of patient and family involvement in care planning and decision making. These results are an important reminder of the individuality of our patients, the resiliency of children with chronic illness, and the value in ongoing psychosocial assessments of coping and adjustment. These results will give social workers new directions in clinical work, research, and psychosocial leadership within the interdisciplinary team.

LIMITATIONS

There are a number of important limitations to this study that are discussed throughout but should be highlighted again here. The sample size is relatively small. Due to the language and age restrictions of the survey, the sample is not fully representative of the patients in our program. For example, the sample does not include infants or young adults (18–21) who are part of our program. The sample does not include patients whose primary language is neither English nor Spanish. In several instances, the small sample size limited the scope of the statistical analysis: patients from both MT and AK were grouped together as "out of state"; African-American and Asian patients were excluded from the ethnicity comparison; and children from the "toddler," "young child," and "child" age groups were lumped together into a single group of children 12 and under to be compared with teens. The study is also limited by the short time frame of examination. Finally, the geographic service area of our center is incomparable to any other dialysis program in the United States. That alone may make this review incomparable to any other dialysis program in the United States.

CONCLUSION

The impetus for mandating the use of QoL surveys during routine psychosocial assessment of dialysis patients comes from social work-driven research in the adult population showing a strong correlation between low QoL scores and higher morbidity and mortality rates (Mapes et al., 2003; Tsai et al., 2010). As social workers integrate QoL surveys into routine practice, we are now tasked with using this data not just to inform individual patient care planning, but for larger program development within the dialysis unit as well. There is no normative data for the PedsQL that allows a specific score to hold interpretive meaning in the way that the KDQOL offers. Pediatric dialysis social workers are tasked now with developing such interpretive norms through collaborative review of the data now being collected in routine practice. These reviews may allow pediatric social workers to also ask whether QoL has a significant impact on morbidity and mortality in children on dialysis.

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CROWNWeb: Electronic Access to Patient-Centric Data

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In June 2012, the Centers for Medicare and Medicaid Services (CMS) implemented the national launch of its CROWNWeb data collection system as a means to transform the way end-stage renal disease (ESRD) facilities report care provided to their patients. Fulfilling requirements outlined in Section 494.180(h) of CMS' updated Conditions for Coverage for ESRD Facilities (CfC) published in 2008, CROWNWeb is currently used by more than 6,000 Medicare-certified dialysis facilities and approximately 30 kidney transplantation centers throughout the United States and U.S. territories. The system serves as a central database in which clinical and administrative information can be entered and obtained by qualified users.

Since its national release, CROWNWeb has served as a universal resource that nephrology social workers, Patient Services Directors (PSDs), other ESRD Network personnel, and CMS employees use to access near-real-time patient treatment data. These data are aiding the renal community with its ongoing commitment to work toward improving the quality of life for people with chronic kidney disease. CROWNWeb stores data for hundreds of thousands of patients, archives digital versions of completed CMS forms, compiles various reports and patient treatment data, and provides patient management capabilities that allow facilities to determine if their patients are continuing to receive treatments in the case of a disaster.

This article focuses on the CROWNWeb system's impact on the duties of social workers and the interdisciplinary teams (IDTs) that are outlined in CMS' updated CfC. This article provides real-world examples from both nephrology social workers and ESRD Networks of how CROWNWeb has assisted them with managing the patient data used to capture care efforts. In addition, this article delves into how the system has aided with reducing barriers that social workers and PSDs may face in obtaining key data regarding patients.

CROWNWEB OVERVIEW

CROWNWeb is a data management system that allows Medicare-certified dialysis facilities to securely submit patient-based data to CMS from virtually anywhere at any time (with the exception of scheduled downtime for maintenance). Enabling facilities to comply with Section 494.180(h) of CMS' updated CfC, which require all Medicare-certified dialysis facilities to submit data electronically, the system allows authorized users at facilities to submit their patient and facility data directly to CMS (Centers for Medicare & Medicaid Services, 2008).

A move away from the historic practice of submitting paper-based data to geographically assigned ESRD Networks, CROWNWeb was designed to help increase the efficiency of the processes used by both facilities and CMS to collect and evaluate data, to help improve the quality of the data that are submitted, and to provide a platform to which future enhancements and data evaluations can be added (CMS, 2008). It provides a way of expediting how patient information is reported, thus assisting with some of the requirements placed on renal social workers and IDTs by the updated CfC. Examples of these requirements include:

- Awareness of admission status
- Assurance that CMS patient and facility overview forms and reports are completed correctly
- Awareness of modality, educational level, and vocational rehabilitation status

DATA REPORTING

"The tasks performed in CROWNWeb by social workers vary from facility to facility. However, most use the system to complete CMS forms, such as the CMS-2728 Medical Evidence, CMS-2746 Death Notification, and CMS-2744 Annual Facility Survey forms; to ensure that patient activity reports are accurate; and, in some cases, to input monthly clinical data," stated Helen Rose, MSW, LCSW, the Patient Services Director for FMQAI: The Florida ESRD Network in an email interview. "At the Network, we use CROWNWeb to review patient characteristics and admission data, generate population reports, as well as to provide technical assistance to patients and facilities."

If tasked with keying data into CROWNWeb, social workers or other facility representatives have immediate access to pertinent patient treatment data, and have the ability to submit and access required data once the patient has been admitted to a facility that is within the user's scope.

The method by which data are entered into CROWNWeb and the individuals who manage data reporting vary from facility to facility, based on facility preference or organizational affiliation. CROWNWeb data reporting is handled via three channels:

1. **CROWNWeb Single User Interface (SUI)**: Data entry through this format is done directly in CROWNWeb at a facility level. It empowers the unit to have full ownership of the data reported to CMS. Primarily managed by small or medium-sized dialysis facilities, data reporting through this format includes patients' admission to the facility, the completion of CMS forms, and monthly labs.
2. **Electronic Data Interchange (EDI, also known as "Batch Data"):** Since CROWNWeb's early developmental and pilot phases, CMS has been able to work with DaVita, Fresenius Medical Care (FMC),

and Dialysis Clinics Incorporated (DCI) to develop a means of electronically uploading patient admission and monthly clinical data from their respective corporate systems into CROWNWeb. While submission via this channel assists facilities by allowing their corporate offices to complete the aforementioned tasks, facilities are still responsible for completing the forms and verifying the accuracy of all reported data.

3. **The National Renal Administrators Association's Health Information Exchange (NRAA-HIE)**: Similar to EDI, patient admission and clinical data reported by participating facilities through the NRAA-HIE are electronically uploaded into CROWNWeb. However, data are funneled through what is known as the Nationwide Heath Information Network (NwHIN) gateway.

REDUCED BARRIERS

ESRD Networks and facility social workers have identified numerous CROWNWeb features that have helped reduce the barriers that both groups may have encountered when dealing with patient data procurement. Since CROWNWeb serves as a universal system used by Medicare-certified facilities, the ESRD Networks, and CMS, the system helps eliminate the obstacles met by social workers and the IDTs by allowing them instant access to required data once the patient is affiliated with the facility in CROWNWeb. Based on the admit reason and the patient's treatment history, CROWNWeb informs the user if a CMS-2728 form must be completed, or it includes a completed copy of the CMS-2728 form if it was submitted by another facility in CROWNWeb. Additionally, the system seamlessly transfers the patient's admit/discharge history and treatment records to the current facility in order to assist the social worker and other staff with obtaining details regarding changes in the patient's modality. This historical documentation of patient treatment helps provide instant knowledge of how to best communicate with and care for the patient.

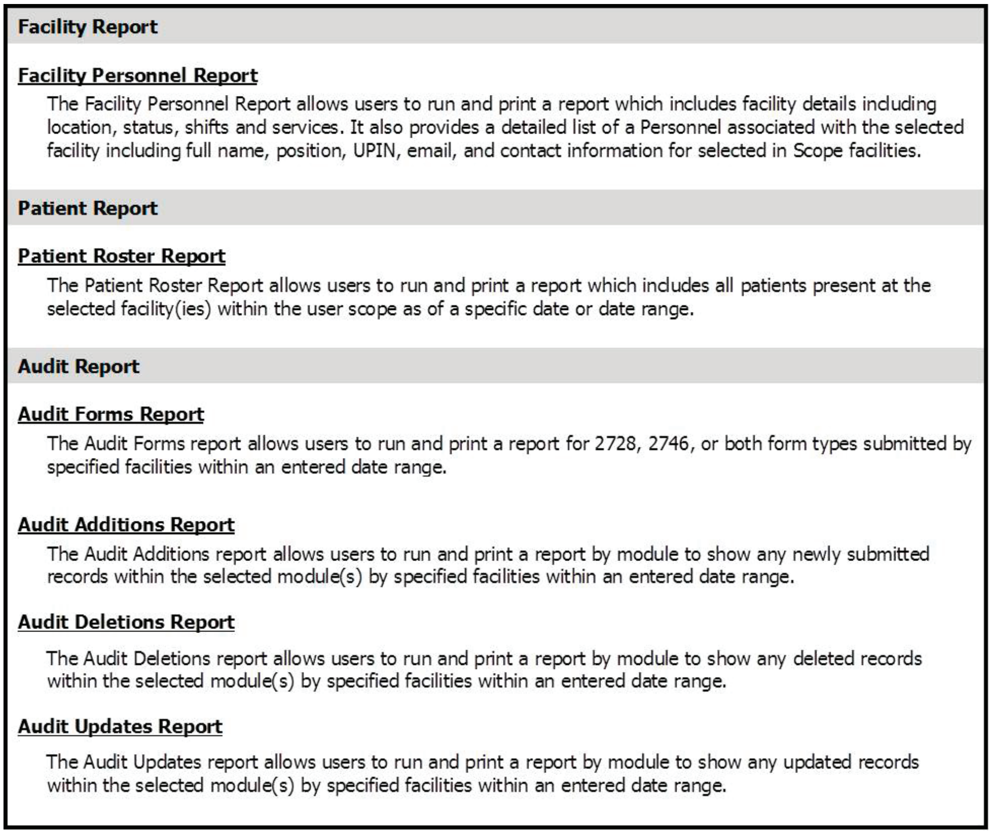
"Some social workers report using CROWNWeb to look at a patient's previous record of admissions and the treatment summary section within the system to obtain additional information in order to meet the needs of the patient," said Ms. Rose.

THE POWER OF REPORTS

Collectively, facility-level users and the ESRD Networks have access to 44 built-in reports in CROWNWeb. Renal social workers can use the "Patient Roster Report" to ensure that the proper patients are assigned to their facilities in CROWNWeb. This report includes all patients associated with the user's facility during a selected timeframe. This also provides information regarding discharge dates and discharge reasons, if applicable.

CROWNWeb also provides facilities with the ability to work with their individual ESRD Networks to run reports such as the "Gap Patients Report" to determine if a transfer patient is in a "gap" status. A "gap" patient is an individual who is not currently associated with a facility, has not been associated with any facility within the past 30 days, and is not reported to be deceased.

Figure 1: Sample CROWNWeb Reports



Facility Report

Facility Personnel Report

The Facility Personnel Report allows users to run and print a report which includes facility details including location, status, shifts and services. It also provides a detailed list of a Personnel associated with the selected facility including full name, position, UPIN, email, and contact information for selected in Scope facilities.

Patient Report

Patient Roster Report

The Patient Roster Report allows users to run and print a report which includes all patients present at the selected facility(ies) within the user scope as of a specific date or date range.

Audit Report

Audit Forms Report

The Audit Forms report allows users to run and print a report for 2728, 2746, or both form types submitted by specified facilities within an entered date range.

Audit Additions Report

The Audit Additions report allows users to run and print a report by module to show any newly submitted records within the selected module(s) by specified facilities within an entered date range.

Audit Deletions Report

The Audit Deletions report allows users to run and print a report by module to show any deleted records within the selected module(s) by specified facilities within an entered date range.

Audit Updates Report

The Audit Updates report allows users to run and print a report by module to show any updated records within the selected module(s) by specified facilities within an entered date range.

Each built-in CROWNWeb report provides specific information that can be used by facilities and ESRD Networks in various ways. Understanding the importance of these reports, CMS reviews the accuracy and validity of the data presented as part of these reports on an ongoing basis. Further, the agency works towards implementing enhancements and updates to each report if any technical issue arises. All reports are housed on the "Reports" screen in CROWNWeb. See Figure 1 for a sample of the reports used by facilities in CROWNWeb. Visit **http://www.projectcrownweb.org/assets/crownweb_info/CROWNWeb_Facility_Reports.pdf** and **http://www.projectcrownweb.org/assets/crownweb_info/CROWNWeb_Network_Reports.pdf** for a complete list of facility-level and Network-level reports in CROWNWeb.

MANAGING ADMISSION/DISCHARGE STATUS

CROWNWeb can help simplify the patient discharge documentation process by allowing facility staff (including social workers) to log in to the system and process a patient discharge, entering a reason of "Discontinue," "Acute," "Lost to Follow Up," "Transplant in the U.S.," or "Death" in a matter of seconds.

Furthermore, the system allows users to indicate if the discharge was "Involuntary," and to provide a justification for the discharge. Section 494.70(b)(2) of the updated CfC notes that a patient has the right to receive written notice 30 days in advance of a facility terminating his/her care involuntarily, and requires that the procedure described in Section 494.180(f) be followed. Only in the case of an immediate threat to the health and safety of others may an abbreviated discharge procedure be followed (CMS, 2008). Social workers may enter any involuntary discharge into CROWNWeb once the requirements outlined by the updated CfC have been met.

DISASTERS AND TRANSIENT PATIENT TRACKING

CROWNWeb can assist social workers with ongoing patient care efforts by providing a better method of tracking patients after disasters that result in the displacement and relocation of dialysis patients. The system includes a "Transient Status" feature that has allowed facilities to locate displaced patients and ensure that they are continuing to receive treatments during a disaster.

In 2005, Hurricane Katrina forced the evacuation and relocation of more than one million residents of New Orleans and the Gulf Coast of the United States. There were almost 6,000 patients with ESRD on life-sustaining dialysis treatment in the region affected by the storm (Anderson et al., 2009). In an interview with the *Wall Street Journal*, then-acting CMS Chief Medical Officer Barry Straube said an "accurate guesstimate" was that "hundreds" of patients were still missing (Jeffrey, 2005). According to the ESRD Networks in that region, the majority of the missing patients were located through the efforts of dialysis providers and ESRD Networks; however, it took months to document the patients' statuses.

Learning from this tragedy, CMS designed CROWNWeb to provide facilities and ESRD Networks with a common means of tracking all patients who are in a "Transient Status," i.e., receiving treatments at a temporary facility for 13 or fewer treatments, or 30 days or less.

In late 2012, CROWNWeb assisted dialysis facilities, the ESRD Networks, and CMS with monitoring treatment efforts in the Northeastern part of the United States when Superstorm Sandy devastated that region. According to IPRO ESRD Network of New York, as many as 300 facilities in the Network's geographic area used CROWNWeb during Superstorm Sandy to help ensure that displaced patients continued receiving the appropriate care. "CROWNWeb actually helped our Network office find some patients whose local facility could not locate them to make sure they were safe," reported Bernadette Cobb, Assistant Director of Information Management for IPRO.

ADDITIONAL INFORMATION

For more information regarding tasks completed by users, the system's data reporting capabilities, or the steps that must be followed to obtain a CROWNWeb account, visit **www.projectcrownweb.com** or visit the CMS CROWNWeb website at **www.qualitynet.org** and click on the "ESRD" tab.

DISCLAIMER

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Re-Framing the Gift of Life: An Examination of Altruism, Social Distance, and Material Incentives as Factors in Non-Directed Kidney Donor Motivation Among Nurses

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The purpose of this research is to examine motivations for undergoing a living kidney donation among professional helping service workers—specifically, nurses—using a research design reproduced from an earlier investigation evaluating the persuasiveness of the National Kidney Foundation's (NKF) altruistic "gift of life" frame. Because the earlier study revealed limits to altruism and suggested, as a means to enhance the rate of living donations, strategic "re-framings" that address material incentives and donor-recipient relationships, we assessed in this study the motivations of key representatives of the caring professions. An international sample of 60 nursing professionals participated in a survey assessing the relationship between material incentives, social distance, and donor motivation. The results show a significant negative relationship between altruism and donor motivation and strong support for material incentives as a complement to living kidney donation. We consider the values and demands of the nursing profession, including the elevated risk of compassion fatigue, as a potential mitigating factor bearing on the willingness of individuals to give the "gift of life." It is necessary to supplement this study with additional research by nephrology social workers and allied care professionals to both recognize and address the different factors influencing motivation for living kidney donation.

INTRODUCTION

According to the Organ Procurement and Transplantation Network [OPTN] (2013), more than 98,000 individuals are currently listed for a kidney transplant in the United States. Due to an ongoing kidney shortage, however, thousands of these individuals are expected to die prior to receiving a life-saving transplant. The active waiting list has grown to three times the available supply of donor kidneys and live organ donations—the preferred source for transplant surgeons—have continued to decline to just 1.2 transplants per 100 patient years on dialysis in 2011 (DHHS, 2011; USRDS, 2013).

The need to increase the rate of live kidney donations presents an ongoing challenge not only for patients and their families, but also for transplant teams, nephrologists, nurses, and social workers. Given the Institute of Medicine's mandate for inter-professional social work-nursing collaborative practice within the healthcare system, those on the front lines of the organ shortage are uniquely positioned to work together across disciplines to collect relevant data and develop meaningful solutions that better address supply-side issues and dynamics (La Motte, 2012).

In one of the few studies of its kind, Humphries, Conrad, Berry, Reed, and Jennings (2009) provide empirical evidence of altruistic and other motivations among individuals related and unrelated to kidney recipients, arguing that how the National Kidney Foundation (NKF) and related organizations "frame" the organ shortage may help to increase the living donor pool. For several decades, the NKF has framed living donation as a "gift of life" (Fox & Swazey, 1978; 1992, p. 33). In this research, we build upon and extend the work of Humphries et al. (2009) in examining the persuasiveness of this "gift of life" frame by focusing on the factors that influence non-directed kidney donation among an international sample of nurses. The critical role that nurses play as healthcare and helping professionals, we argue, is instrumental in shaping how individuals understand and respond to health challenges, including live organ donation.

Following Humphries et al. (2009), we first explore the social factors that motivate nurses to become living kidney donors. Second, we examine the willingness of nursing professionals to give to various recipients, using an established measure of social distance. We are particularly interested, with regard to social distance, in the unique demands of the nursing profession and the potential effect of compassion fatigue on the willingness to donate to unrelated recipients (Figley, 1995). Third, we explore the appeal among nurses of the use of material incentives relative to "gift of life" altruism in the framing of living kidney donations.

FRAMING THE GIFT OF LIFE: ALTRUISM AND INCENTIVES

As transplant rejection has taken a backseat to the issue of organ availability and integrity within the transplant community, meeting the challenge of an ongoing organ shortage has moved a growing number of scholars and commentators to reconsider how the NKF and other interested parties might "re-frame" live organ donation (Matas, 2007, p. 2). The literature on social movements defines collective action

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"frames" as slogans or catchphrases strategically designed by movement entrepreneurs to persuade target audiences (for a review, see Benford & Snow, 2000). Movement scholars contend that such messages have the potential to recruit members to an organization, or followers to a cause, often by tapping culturally "resonant" beliefs in ways that facilitate mobilization (Snow & Benford, 1988). The concept of "frame resonance" thus provides a necessary counterpoint to the more deliberate activity of framing in that it encompasses broader cultural notions that are commonly taken for granted (Snow, Rochford, Worden, & Benford, 1986; Williams, 2004).

In their examination of organ transplantation, Fox and Swazey (1992) contend that the "gift of life" frame has rhetorical power because it embodies the culturally "resonant" or commonly held ethics of volunteerism and freedom of choice (p. 33). It also recasts living donors as folk heroes, members of a special class of persons ready and willing to sacrifice a part of themselves for purely altruistic reasons (p. 33).

In their empirical examination of donor motivation, however, Humphries et al. (2009) find that altruism is significantly related to the willingness of individuals to donate a kidney only for immediate family and close friends and that strategic re-framings of the "gift of life" that include limited material incentives should be explored as a means to improve the rate of living kidney donations. Although Humphries et al. (2009) find little support for direct monetary compensation as a persuasive material incentive, they address the controversial claim among some commentators, including some notable medical professionals, that altruism alone is insufficient to motivate individuals to donate a kidney, particularly to an unrelated recipient, and that material incentives are necessary (McKenzie, 2007; Satel, 2011).

Debates over the desirability of material incentives offered as a supplement to live organ donation rest largely on ethical considerations related to the exploitation of the poor in a global market that "trafficks" in illegally acquired organs (Castillo, 2013; Satel, 2011). Reports of illegal organ sales are now widespread in many major news outlets, with the World Health Organization estimating that approximately 10,000 black market transplant operations are performed every year (Bilefsky, 2012; Campbell & Davison, 2012; Smith, 2011). Alongside the growing incidence of anecdotal reports is the release of a 2013 HBO documentary entitled "Tales from the Organ Trade," which provides an inside look at the once-thriving black market in organs, led principally by the harvesting of kidneys, in the Philippines (Lynch, 2013).

Payment for organs is illegal in the majority of countries in the world (Campbell & Davison, 2012). Some commentators allege that any payment, even for transplant expenses or future medical care, carries the potential to turn the poor, particularly those in the developing world, into "spare parts" for the rich (Fox & Swazey, 1992). Others call for legalizing organ sales to stem the more abhorrent practices, including unsafe procedures, lack of informed consent, and unfulfilled promises of payment, associated with what is increasingly acknowledged as an irreversible and growing global industry (Satel, 2011).

We incorporate these ethical concerns into our analysis by utilizing a value-added ethical-motivation scale developed by Humphries et al. (2009) that allows us to assess supportiveness among nurses for living kidney donation simultaneous with support for material incentives of increasingly greater value. As Humphries et al. (2009) argue, "identifying an ethically-based tipping point beyond which individuals may be less supportive of linking material rewards to living kidney donations is critical to determining whether or not and what kind of material incentives should be incorporated into the 'gift of life' frame" (p. 22). In the present study, we use frame theory to determine if material rewards have "resonance" for those working within a caring profession.

NURSES, ALTRUISM, AND THE GIFT OF LIFE

At the core of nursing, a profession that developed as a response to care for the sick, is the desire to have concern for others (Baer, 2009). This desire to care for others leads to compassion satisfaction as a characteristic of the profession through "the ability to receive gratification from caregiving" (Simon, Price, Roff, & Klemmack, 2006, p. 6). Nurses are experts with the knowledge to eradicate diseases, improve patient conditions, maintain health, or return patients to a previous state of health (Milton, 2012). Due to their education and fundamental foundation in a caring, trusting profession, it would seem that nurses would be more motivated to consider living kidney donation based on either altruistic principles or material incentives or both. However, it must be considered that nurses are also more knowledgeable of the potential risks of surgery and lifelong recovery with the potential need for lifestyle changes. Nurses may also have negative opinions about life choices that increase the need for kidney donations, with questions as to whether the patient will make adjustments that would increase the success of the transplant. As with the general public, more research is needed on nurses' opinions about motivation, judgment, risk appreciation, liability risk, and ethics relative to non-directed kidney donation (see e.g., Jendrisak et al., 2006).

Altruism in particular is considered core to the nursing profession. The American Association of Colleges of Nursing (AACN) includes altruism as one of five professional values that guide nurses to ethical patient care and "epitomize the caring, professional nurse" in both the Bachelor of Science in Nursing (BSN) and Master of Science in Nursing (MSN) Essentials (AACN, 2011, p. 27). Altruism is explained by the AACN (2008) as concern for the well-being of others, including nurses' concern for clients, other nurses, and other healthcare providers. The other professional values include autonomy, human dignity, integrity, and social justice. In order for baccalaureate and master's nursing education programs to be accredited in the United States, they must demonstrate that altruism is a component of the curriculum. Activities that demonstrate altruism, according to the AACN (2008), include: understanding the cultures, beliefs, and perspectives of others; advocating for clients, especially the most vulnerable; addressing the risk behaviors of clients; and mentoring professionals.

We contend that the "gift of life" frame should resonate with nurses because it is an altruistic appeal consonant with the values of the nursing profession. However, because nurses assume the caregiver role for patients, they may suffer from compassion fatigue as a component of their work, in contrast to compassion satisfaction. Compassion fatigue is defined as a combination of "work-related, physical, and emotional symptoms associated with caring for patients in physical distress" (Lombardo & Eyre, 2011). The risk of compassion fatigue is high in that nurses are often expected to take on more responsibilities and work in poorly-staffed units with high patient-to-staff ratios, which may lead to high nursing turnover and work dissatisfaction, poor patient outcomes, and decreases in the quality of care provided (Bodin, 2008; Moody & Pesut, 2006). Due to these working conditions, compassion fatigue may emerge gradually throughout a nurse's career, leading to symptoms of chronic stress and negative attitudes reflecting a sense of "burnout" that involves "a state of physical, emotional and mental exhaustion caused by long-term involvement in emotionally demanding situations" (Figley, 1995, p. 11). Hence, compassion fatigue may serve as a barrier to altruistic motives for non-directed kidney donations by nurses (Watson, 1988, p. 8).

We explore donor motivation among nurses using the Bogardus Social Distance Scale (Bogardus, 1925; 1933) as a measure of willingness to donate. We expect that the less the social distance between the donor nurse and recipient, or the closer their social relationship, the more favorable the respondent will be toward live kidney donation. We are particularly interested, given their role as care providers, in support among nurses for non-directed donation for purely altruistic reasons. Traditionally, living kidney donors have been immediate family members who are pressured toward altruism (Fox & Swazey, 1992, p. 33; Matas, 2007, p. 8). Like nephrology social workers, nurses are often expected to show empathy to patients as a component of altruism by identifying emotionally with the experiences of others (McCamant, 2006). Nurses and social workers are also often held to high standards, relevant to their respective working conditions, and possess knowledge of transplantation risks that are lacking in other populations. These factors may suggest the need for "re-framings" of non-directed kidney donation for this population that tap cultural meanings other than altruism. In so doing, this research helps nephrology social workers understand the importance of collaboration with their nursing counterparts to provide a comprehensive understanding of live kidney donations.

RESEARCH DESIGN AND METHODS

Conceptualization and Measurement

This exploratory study uses the Bogardus Social Distance Scale (Bogardus, 1925; 1933) to assess the willingness of nurses to undergo a living kidney donation, based on their social proximity to the recipient. This scale is generally used to measure respondents' level of comfort associating with people who are different in some fundamental way, on the assumption that this difference is a marker of social distance (Babbie, 2004; Neuman, 2000). Humphries et al. (2009) were the first to use it as an indicator of the willingness of individuals to donate a kidney to close or distant others. Following that study, we use the Bogardus Social Distance Scale as follows:

1. I would donate one of my kidneys to a member of my immediate family.
2. I would donate one of my kidneys to members of my extended family (e.g., aunt, uncle).
3. I would donate one of my kidneys to a close friend.
4. I would donate one of my kidneys to an acquaintance or a friend of a friend.
5. I would donate one of my kidneys to a stranger.

As explained by Humphries et al. (2009):

> The Bogardus Social Distance Scale assumes that individuals who would donate their kidney to a stranger would also donate a kidney to an acquaintance, a close friend, members of their extended family and their immediate family. Based on their responses to this one to five scale, respondents were grouped into distance levels, which we used as an indicator of altruism (e.g., individuals who answered "yes" to item five were categorized as more altruistic than individuals who answered "yes" to item four but "no" to item five). This allowed us to measure the intensity of respondents' altruism with regard to the "gift of life." (p. 23)

To measure the appeal of material incentives, we use a cumulative summated-rating scale that links various material rewards to living kidney donation (Humphries et al., 2009). This Ethical-Motivation scale consists of nine dimensions of increasingly valuable material incentives. On a scale of 1 to 5, with 5 being the most favorable, nurse respondents were asked to indicate the extent of their agreement with each of nine statements used as an indicator of donor motivation. These nine items are as follows:

1. Living kidney donors should not be compensated. The donation should be considered a free-will donation and purely altruistic.
2. Living kidney donors should be entitled to compensation for medical expenses related to the procedure.

3. Living kidney donors should be entitled to compensation for medical expenses and lost wages relating to the procedure.
4. Living kidney donors should be compensated for medical expenses, lost wages related to the procedure, and should receive a "reward" package that may include a weekend getaway.
5. Living kidney donors should be compensated in the form of a Federal deduction tax incentive.
6. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that may include cash or tax credit incentives.
7. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that includes life-long medical coverage.
8. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that includes life-long medical coverage, plus an amount of instant compensation up to $60,000–$70,000.
9. Living kidney donors should be able to freely negotiate the price, compensation, and reward they receive for their donation with no limitation on the amount or criteria.

Data Collection

Data for this research is based on a self-administered, self-reported survey using a non-representative sample of convenience from an international nursing conference in August 2013 in Prague, Czech Republic. The study was approved by the Pittsburg State University Committee Involving the Use of Human Subjects. Although the sample represents 18 different nationalities, the U.S. is over-represented. A total of 57 nurses out of 60 completed the survey, with 3 surveys missing data (RR = 100%). Sample demographics are presented in Table 1.

Data Analysis

SPSS 20 was utilized for the statistical analysis of survey data. We rely primarily on descriptive statistics, including frequency counts and cross-tabulations and the calculation of means and standard deviations. A Cronbach's alpha was used to test the Ethical-Motivation scale for internal consistency and reliability and produced a result of $\alpha = 0.81$ (Voght, 2005, p. 71). The relationship between the Ethical-Motivation scale and the Bogardus Social Distance Scale was examined using a Spearman correlation technique.

RESULTS

The first objective in this study is to assess the willingness of care professionals—specifically, nurses—to donate a kidney to related and unrelated recipients. Like Humphries et al. (2009), we hypothesize that those who have the least social distance from the respondent will be the most likely choice for a donation and use the Bogardus Social Distance Scale (Bogardus, 1925; 1933) as our test. The data in Table 2 support the hypothesis that increased social distance decreases altruistic motivation. Specifically, although there is a strong willingness to donate to a member of one's immediate or extended family, only 22.8 percent of respondents indicated that they were willing to donate a kidney to an acquaintance and 15.8 percent to donate to a complete stranger. Hence, 77.5 percent fewer nurse respondents were willing to donate a kidney to a stranger than to an immediate family member. This result is statistically significant at the $p > .05$.

A second purpose of this study is to understand the motivations of potential donors who work in a caring profession that values altruism as a professional goal. A nine-statement Ethical-Motivation scale, first developed by Humphries et al. (2009), was used to examine the amount of support among nurses for increasing material incentives. As illustrated in Table 3, respondents agreed that living donors should be able to freely negotiate compensation without limitation (3.96). They also agreed that living donors should receive compensation for medical expenses, lost wages, and an instant cash payout of up to $60,000 to $70,000 (3.77). In declining order of importance, less support was expressed for 1) a reward package consisting of compensation for medical expenses, lost wages, and a weekend getaway (3.20);

Table 1: Demographic Characteristics of the Sample

					Totals
Gender	*Males*	*Females*	*No Answer*		
	1.6% (n = 1)	76.6% (n = 46)	21.8% (n=13)		100% (N = 60)
Age	*21-30*	*31-40*	*41-50*	*51-70 +*	
	3.38% (n = 2)	16.9% (n = 10)	16.9% (n = 10)	62.7% (n = 37)	100% (N = 59)
Education	*Bachelor*	*Masters*	*Doctorate*	*Other*	
	1.6% (n = 1)	18.3% (n = 11)	75.0 % (n = 45)	3.3% (n = 2)	100% (N = 60)

Years in Practice Mean = 24.86 Mode = 30 Median = 27

Table 2: Social Distance and Kidney Donation (N = 60)

	Yes	**No**
I would donate one of my kidneys to an immediate family member	93.3% (n = 56)	6.6% (n = 4)
I would donate one of my kidneys to a member of my extended family	65.0% (n = 39)	35.0% (n = 21)
I would donate one of my kidneys to a close friend.*	66.5% (n = 27)	53.4% (n = 31)
I would donate one of my kidneys to an acquaintance.*	22.8% (n = 13)	77.2% (n = 44)
I would donate one of my kidneys to a stranger.*	15.8% (n = 9)	84.2% (n = 48)

**Missing Data*

2) compensation for medical expenses, lost wages, and a tax credit (3.18); and 3) life-long medical coverage (3.15). Respondents expressed little support for compensation packages involving 1) a Federal tax deduction (2.69); 2) lost wages (1.74); or 3) medical expenses (1.72). Free will, altruistic donations also received little support (2.34).

As illustrated in Table 4, a statistical examination of the relationships between the statements comprising the Social Distance Scale and the Ethical-Motivation Scale revealed positive correlations between willingness to donate a kidney to a member of one's immediate or extended family and a variety of material incentives, including: 1) compensation for medical expenses; 2) a Federal tax deduction; and 3) a reward package involving a weekend getaway. Also positive was the relationship between willingness to donate to an immediate family member and reward packages involving 1) medical expenses, lost wages and lifelong medical coverage; 2) medical expenses, lost wages, lifelong medical coverage and a cash payout; and 3) freely negotiated unlimited compensation. Willingness to donate to an unrelated other, namely an acquaintance, was also positively correlated with a reward package involving compensation for medical expenses and lost wages.

Except for the relationship between a reward package involving medical expenses, lost wages and a weekend getaway and willingness to donate to an immediate family member, none of these positive relationships were statistically significant. Willingness to donate a kidney to a distant or close other was negatively correlated with support for all other material incentives. Perhaps most striking of these negative correla-

Table 3: Supportiveness for Linking Material Incentives to Living Donation (N = 60)

	Mean	*SD*
1. Living kidney donors should not be compensated. The donation should be considered a free-will donation and purely altruistic.	*2.34*	*1.32*
2. Living kidney donors should be entitled to compensation for medical expenses related to the procedure.	*1.72*	*1.57*
3. Living kidney donors should be entitled to compensation for medical expenses and lost wages related to the procedure.	*1.74*	*1.10*
4. Living kidney donors should be compensated for medical expenses, lost wages relating to the procedure and should also receive a "reward" package that may include a weekend getaway.	*3.20*	*1.50*
5. Living kidney donors should be compensated in the form of a Federal tax deduction.	*2.69*	*1.50*
6. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that my include cash or a tax credit.	*3.18*	*1.44*
7. Living kidney donors should be compensated for medical expenses and lost wages relating the procedure and should also receive a "reward" package that includes life-long medical coverage.	*3.15*	*1.39*
8. Living kidney donors should be compensated for medical expenses and lost wages relating to the procedure and should also receive a "reward" package that includes life-long medical insurance coverage plus an amount of instant compensation of up to $60,000–$70,000.	*3.77*	*1.30*
9. Living kidney donors should be able to freely negotiate the price, compensation, and reward they receive for their donation with no limitation to the amount or criteria.	*3.96*	*1.29*

Table 4: Correlations Between Social Distance and Support for Material Incentives

	Immediate Family	Extended Family	Close Friend	Acquaintance	Stranger
Altruism	-.235*	-.073	-.176	-.254*	-.234*
Medical expenses only	.051	.125	-.026	-.017	-.028
Medical expenses and lost wages	-.003	-.173	-.191	-.083	.000
Medical expenses, lost wages, and weekend getaway	.231*	.026	-.029	-.085	-.029
Federal tax deduction	.167	.057	.045	.036	-.090
Medical expenses, lost wages and cash or a tax credit	-.003	-.173	-.191	-.083	.000
Medical expenses, lost wages, and lifelong medical coverage	.153	-.064	-.011	.069	-.051
Medical expenses, lost wages, lifelong medical coverage, and a lump-sum cash payout	.171	-.110	-.009	-.026	-.194
No limits to compensation	.148	-.153	-.027	-.047	-.204

** *p < .01, 1-tail test*
 * *p < .05, 1-tail test*

tions are those between willingness to donate to an immediate family member, acquaintance or stranger, and altruism, with these negative correlations being statistically significant at the p < .05 level.

DISCUSSION

Using the research design of Humphries et al. (2009), this research assesses the effectiveness of the NKF's altruistic "gift of life" frame on kidney donor motivation among nurses. Like Humphries et al. (2009), we provide empirical evidence, using the Bogardus Social Distance Scale (Bogardus, 1925; 1933), that individuals are willing to donate a kidney to close others (e.g., a member of their immediate family) but less willing to donate to an acquaintance or stranger. However, we found a lower overall willingness to donate a kidney among nurses versus a comparable sample of college-going adults (Humphries et al., 2009). Future research should look at other healthcare and helping professions (like social work) utilizing this research design and consider qualitative initiatives to explore how to increase altruistic motivation. In this study, the nurses had an average of 25 years of practice. This population could potentially have high levels of compassion fatigue and further research should investigate this as a factor in their decisions. A compassion fatigue questionnaire could be utilized along with this study to determine significance, since nurses had a lower motivation rating than college-going adults (Humphries et al., 2009).

More importantly, we found through an assessment of support among nurses for material incentives, that altruism alone does not resonate with those in a profession characterized by caring. Our respondents were supportive of a variety of material rewards linked to living kidney donation, with the strongest support expressed for reward packages involving lump-sum cash payouts or in which the relevant parties were able to freely negotiate compensation without restriction. These findings contrast with those of Humphries et al. (2009), which show that direct cash rewards are not especially compelling as a motivating factor for living kidney donation. There is limited research or theory development to explain why nurses are motivated to care, yet this is a critical element of nursing (Moody & Pesut, 2006).

Given the important role nurses play as frontline professionals in shaping how individuals understand and respond to health challenges, it is necessary to understand their perspectives and experiences. With regard to social distance, it is important to consider the demanding nature of the nursing profession and the extent to which it may increase the risk of emotional exhaustion, depersonalization, and a sense of reduced personal accomplishment, which may drive a wedge between the relationship of nurses to their patients. The experience of compassion fatigue, along with a heightened knowledge of the ethical dilemmas and risks associated with transplantation and live organ donation, may lead to a more practical orientation among nurses in which material incentives are valued over pure altruism.

Although the offering of material rewards as an incentive to live organ donation continues to be a controversial issue, evidence is accumulating, aided in part by the present study, that suggests that altruistic appeals alone are insufficient to motivate individuals to donate a kidney, particularly to

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recipients who are not known to the donor. Humphries et al. (2009) contend that strategic re-framings that tap cultural understandings other than altruism are necessary to address the challenge of an ongoing organ shortage. Because these authors find evidence of an ethical tipping point beyond which material incentives seem distasteful, they argue in favor of limited material incentives framed in a language of "rights."

The present study makes an even stronger case for re-framing the "gift of life" by uniting two distinct ideologies—one rooted in ethics and the other in the language of the market—under a single rhetorical banner, an alignment technique social movement scholars refer to as "frame bridging" (Snow et al., 1986). We argue that nurses, in particular, are credible claims-makers, whose professional experiences and values may lead them to regard material compensation as *a just reward* for the otherwise disadvantaged, particularly those living donors for whom financial security might be necessary to preserve their "right" to autonomy, dignity, and integrity. Hence, the values of the nursing profession, as articulated by the American Association of Colleges of Nursing (2011), can perhaps be used to combine market messages of personal worth and wealth with altruistic notions of generosity and self-sacrifice to create a persuasive message campaign. Like social workers, nurses are familiar with both patient rights and themes of social justice and may assist in interdisciplinary efforts that shed light on the contributions of these professional values to efforts to reframe the "gift of life."

Most importantly, the present study points to the value of theoretically-informed analyses that measure the "resonance" of various health-related messages for a target audience as a means to solve our most pressing healthcare challenges, including the problem of a persistent organ shortage. Because the "gift of life" message lacks the resonance necessary to persuade nurses to undergo a living kidney donation, healthcare and helping professionals should seek ways to move beyond framing living organ donation in altruistic terms.

LIMITATIONS OF THE STUDY

Because the present study uses a similar exploratory research design to that used by Humphries et al. (2009), it shares many of the same limitations. These include a small, non-representative sample and the use of measures of attitudes (i.e., willingness to donate a kidney and support for linking various material rewards to living kidney donations) as "indicators" of motives, despite the imperfect correspondence between attitudes and motivations (Meyers, 1999). These limitations are outweighed, we think, by the differences between the results of the present study and those of Humphries et al. (2009). Given the critical need to find effective strategies to increase the organ supply, future analyses should further investigate the links between donor motivation, health-related frames and their relationship to healthcare and helping service professionals, like nephrology social workers.

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