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Council of Nephrology Social Workers

The Journal of
***Nephrology
Social Work***

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- Suicidality Screening by Nephrology Social Workers: A Pilot Study
- Beyond Numbers: The Liminal Experience of Kidney Transplantation Amongst Young Adults Following Transfer of Care
- Developing Quality Social Work Field Placements in Dialysis Clinics
- Perspectives of Renal Healthcare Professionals about Deceased Organ Donation



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The Journal of
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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 social workers dedicated to improving the quality of psychosocial services delivered to ESRD patients, as well as supporting the profession of nephrology social work.

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TABLE OF CONTENTS

- 5 JNSW Editorial Board Membership
5 Call for JNSW Manuscripts
6 Instructions for Authors

RESEARCH

- 9 Suicidality Screening by Nephrology Social Workers: A Pilot Study
Dodie M. Stein, Home Dialysis of Indianapolis, Indianapolis, IN; Brooke E. Chehoski, University of South Carolina, Columbia, SC

RESEARCH

- 17 Beyond Numbers: The Liminal Experience of Kidney Transplantation Amongst Young Adults Following Transfer of Care
Stephanie Bogue Kerr, MA, MSW; Marguerite Soulière, PhD, University of Ottawa, Ottawa, Canada; Lorraine E. Bell, MD, FRCPC, McGill University, Montreal, Canada

STUDY

- 27 ★ Developing Quality Social Work Field Placements in Dialysis Clinics
Dori Muench, MSW, LCSW, NSW-C, Wake Forest Baptist Medical Center, Winston Salem, NC; Melissa C. Reitmeier, PhD, LMSW, MSW, University of South Carolina College of Social Work, Columbia, SC

STUDY

- 35 Perspectives of Renal Healthcare Professionals about Deceased Organ Donation
Ann M. Andrews, MPH; Caitlin Loughery, MPH, National Kidney Foundation of Michigan, Ann Arbor, MI; Nanhua Zhang, PhD, Division of Biostatistics & Epidemiology, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH; Allyce Haney Smith, MSW; Holly Jenkins Riley, MSW; Caitlin Loughery, MPH, National Kidney Foundation of Michigan, Ann Arbor, MI; Sheri Stav, MSW, Greenfield Health Systems, Bingham Farms, MI; Ken Resnicow, PhD, Department of Health Behavior & Health Education, University of Michigan School of Public Health, Ann Arbor, MI; Remonia Chapman, BS, Minority Organ and Tissue Transplant Education Program, Gift of Life Michigan, Ann Arbor, MI; Jerry Yee, MD, Division of Nephrology and Hypertension, Henry Ford Hospital, Detroit, MI and Greenfield Health Systems, Bingham Farms, MI

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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 Teri Browne, PhD, MSW, NSW-C by email (browne@sc.edu) or phone (803.777.6258)

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

Please email manuscripts to: jnsw@kidney.org. Questions? Contact Editor Teri Browne, PhD, MSW, NSW-C by email (browne@sc.edu) or phone (803.777.6258).

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. *JNSW* is a valuable resource for practicing social work clinicians in the field, researchers, allied health professionals on interdisciplinary teams, policy makers, educators, and students.

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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/recommendations/browse/roles-and-responsibilities/author-responsibilities--conflicts-of-interest.html>].

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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 are 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.”

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.

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Manuscript Format. Manuscripts should be formatted according to the rules laid out by the *Publication Manual of the American Psychological Association, Sixth 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 | 5) Appendices (optional) |
| 2) Abstract | 6) Author note |
| 3) Text | 7) Tables |
| 4) References | 8) Figures with 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.

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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.

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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.

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

Figure 1. Exemplary formatting for all figure captions.

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- 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 300 d.p.i. minimum.

Suicidality Screening by Nephrology Social Workers: A Pilot Study

Dodie M. Stein, Home Dialysis of Indianapolis, Indianapolis, IN; Brooke E. Chemoski, University of South Carolina, Columbia, SC

Current literature demonstrates that suicidality is more prevalent among people with end-stage renal disease (ESRD) than the general population; however, is not known how often patients with ESRD are screened for suicidality. This study examined suicidality screening practices among nephrology social workers using an online survey. Data suggest that about 71% of clinicians screen for suicidality across practice settings: 66% use the Patient Health Questionnaire-9 (PHQ-9); 40% use informal questioning techniques. Though this study found suicide risk to be relatively low among patients with ESRD (<10%), good clinical practice necessitates suicidality screening when conversation with a patient indicates depression or risk of self-harm. A standardized suicidality tool is recommended. Further study on suicidality with patients with ESRD is important for improving clinical care.

INTRODUCTION

Suicide rates increased dramatically across the United States between 1999 and 2016, rising more than 30% in 25 states (Centers for Disease Control and Prevention [CDC], 2018). Suicide is the 10th leading cause of death in the United States (CDC, 2015). The percentage of adults with serious thoughts about suicide was highest among adults ages 18–25 (7.4%), followed by adults ages 26–49 (4.0%), then by adults aged 50 or older (2.7%). Suicide results in an estimated \$51 billion in combined medical and work-loss costs; nonfatal, self-inflicted injuries (including hospitalized and emergency department treated and released) results in an estimated \$10.4 billion in combined medical and work-loss costs (CDC, 2015). This suggests an enormous cost to the U.S. economy in lost work, wages, and related activities. While suicide is known to be associated with mental health concerns, more than half of the people who died by suicide did not have a known diagnosed mental health condition at time of death (CDC, 2018).

Suicidal ideation (SI), possibly with suicide attempts, increases as the severity of depression increases (Keskin & Engin, 2011). Depression in the general population has been reported at between 2% and 10% (Hedayati, Yalamanchili, & Finkelstein, 2012); however, among renal patients, depression has been documented at anywhere from about 20% to as high as 71%, sometimes depending on assessment methodology (Anees, Barki, Masood, Ibrahim, & Mumtaz, 2008; Chen et al., 2010; Chilcot, Wellsted, Da Silva-Gane, & Farrington, 2008; Goh & Griva, 2018; Kimmel, 2001; Lopes et al., 2004; Patel, Sachan, Nischal, & Surendra, 2012; Watnick, Kirwin, Mahnensmith, & Concato, 2003).

SI and chronic illness are associated (Marusic & Goodwin, 2006); those with chronic medical conditions are at increased risk of suicide (Karasouli, Latchford, & Owens, 2014;

National Institute of Mental Health [NIMH], 2017). SI also is thought to be more prevalent among adults with ESRD than in the general population (Kurella, Kimmel, Young, & Chertow, 2005; Chen et al., 2010). The risk of self-harm may be higher than expected in dialysis patients who have depression and anxiety (Pompili et al., 2013). Depression and SI increased with age as well as with lower education status in patients with chronic renal failure (Keskin & Engin, 2011), suggesting that ESRD acts to exacerbate a preexisting vulnerability or tendency toward suicidal behavior among certain high-risk groups (Kurella et al., 2005).

For adults with ESRD—the vast majority of those being on hemodialysis (US Renal Data System [USRDS], 2017)—those more likely to die by suicide were older (>75 years), male, White or Asian, with alcohol or drug dependence, and/or with a recent hospitalization for mental illness (Kurella et al., 2005). The risk of suicide was highest in the first 3 months after dialysis initiation and diminished steadily over time. No differences between dialysis patients or transplanted patients have been shown for hopelessness, SI, or depression (Andrade, Sesso, & de Madureira Pará Diniz, 2015). While it is estimated that suicide risk for dialysis patients is similar to that for transplant recipients and similar to those for patients with other chronic illnesses, the risk of and percentage with SI are not clear. Some report SI rates of hemodialysis patients as high as 28% and 37% (Patel et al., 2012; Macaron et al., 2014).

Screening for suicidality is a necessary component of clinical practice when significant depression is identified. The first step in evaluating at-risk patients is to ascertain both current suicidal behavior and history of past suicide attempts (Pompili et al., 2013). While the Centers for Medicare & Medicaid Services (CMS) requires social workers in dialysis settings to screen for depression at least annually (End-Stage

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Keywords: kidney social work dialysis suicidality suicidal ideation end-stage renal disease

Renal Disease Prospective Payment System..., 2014), there is no such mandate to follow up and screen for SI and suicidal behaviors. Thus, it is not known how often renal social workers perform screenings for suicidality in this population or what the prevalence and incidence are for these patients. The purpose of this study was to survey dialysis and transplant social workers about their clinical practice in screening for and identifying suicidality in their patient populations.

METHODS

Sample

As this study was exploratory, the authors designed a survey, *Suicidality Screening for CNSW*, to gather data on nephrology social workers screening for and identifying suicidality in dialysis and transplant patients. The authors, with feedback from colleagues who practice in nephrology social work, formed the survey questions. Suicidality in this context was used as an all-inclusive term to describe any suicidal thinking and/or behavior, and included SI, self-injurious behavior, suicide attempts, and suicide (Meyer et al., 2010). SI was limited to the thoughts, consideration, and plans about suicide prior to any attempt (Crosby, Ortega, & Melanson, 2011). While preferred terms now are SI, *suicidal behavior*, and *suicide* (Meyer et al., 2010; CDC, 2018), the term *suicidality* was used in this study to cover all circumstances (Crosby et al., 2011).

Survey responses on an electronic platform, Survey Monkey, were solicited from the listserv of the Council of Nephrology Social Workers (CNSW), a professional member group of the National Kidney Foundation (NKF). Using “word of email” and networking, additional responses were sought from dialysis and transplant social workers who were not members of CNSW. The survey link was distributed by email to about 700 social workers in October 2017. The authors are not able to estimate a response rate for either CNSW listserv participants or other nephrology social workers because that issue was not addressed in the survey. It also is important to note that not all of those responding to the survey responded to every question. Therefore, in reporting each survey item in **Tables 1** and **2**, a sample size was included for clarity.

Data Analysis

Data analysis consisted of descriptive statistics Survey Monkey gathered. The automatically retrieved analysis included means and percentages for each quantitative item. Also available were listings of individual narrative responses for each qualitative item. The authors reviewed and discussed these data and summarized themes. The data also were analyzed using SAS v9.4. To understand the overall distribution and nuances of the dataset, an analysis of descriptive statistics using the PROC MEANS and PROC FREQ functions was completed. To identify correlations among key variables, the PROC CORR function was used. With this, correlations among social workers’ suicidality screening practices and other professional factors were examined.

Results

Table 1 provides the demographic data for those responding to the online survey. One hundred sixty-seven (approximately 24% of those of listserv recipients) social workers responded to the survey. Thirty percent of them had been working 1–5 years, while 40% had worked more than 10 years. More than half (59%) worked in for-profit organizations at mostly in-center (83%), home dialysis (35%), and transplant (13%) units. There was overlap for settings; that is, some social workers worked in both in-center and home units though, the specific question (Item 10, Appendix A) of multiple modality sites worked was not asked.

Sixty percent of the responding social workers reported that their most recent training on managing suicidality had occurred within 3 years. The social workers who responded to the survey provided services to an average of 112 patients each (ranging from as few as 16, to as many as 280 patients per social worker). Most social workers (about 90%) reported serving adult patients, age 36 years to over 65 years. In contrast, only 9% reported serving patients age 16 or younger.

Table 2 summarizes social workers’ responses on screening for suicidality. About 71% of the social workers responding to the survey did screen for suicidality or SI. Screening most likely was completed when either the results of depression screening were positive for depression or when a patient, in conversation with the social worker, displayed some suicidal ideation or intent for self-harm. About 66% of social workers used the Physicians Health Questionnaire Version 9 (PHQ-9) depression screening survey that has a question about self-harm. About 40% used informal questioning for suicidality or SI screening in lieu of or in addition to the PHQ-9.

Questions from social workers to patients include: Do you have any thoughts of harming yourself? What would you do, and do you have any plans? Have you ever tried to hurt yourself? How long have you had these thoughts? Do you feel safe at home? Do you have access to lethal medications or weapons? Sixty-one percent of the social workers responded that only 1–10% of their patients were at risk for suicide; another 13% of the social workers reported a rate of 11–20%; and 13% reported no suicidality with their patients.

About 56% of the social workers responding to the survey offered comments with their answers about how they screen and, then, follow up with patients with positive SI. For those patients whose scores show a mild risk of suicidality, most responses by social workers noted that they discuss the situation with the nephrologist and/or primary care physician, monitor the patient, identify a safety plan/support system, and refer to community crisis programs and/or counseling programs. For those patients with a moderate-severe risk, referrals by social workers were immediate and included attempts to stabilize the patient, calling in support systems/family, having the patient call a phone crisis line with the social worker present, sending or taking the patient to the

Table 1. Descriptive Statistics of Sample Characteristics, Suicidality Screening Survey*n* = 167

	<i>N</i>	%	<i>Mean</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>
Years of practice experience	134					
Less than 1 year	9	6.72				
1–5 years	44	32.84				
6–10 years	27	20.15				
More than 10 years	54	40.30				
Work setting (choose all that apply)	133					
In-center hemodialysis	111	82.84				
Home hemodialysis/peritoneal dialysis	47	35.07				
Transplant	18	13.43				
Other	11	8.20				
Type of employer (choose all that apply)	132					
For-profit dialysis center	79	59.40				
Private, nonprofit hospital	24	18.05				
Government/Public	12	9.02				
Nonprofit dialysis center	12	9.02				
Private, for-profit hospital	5	3.76				
Other	5	3.76				
Most recent suicidality training	133					
Never received training	16	11.94				
Past 12 months	43	32.09				
1–3 years ago	40	29.85				
3–5 years ago	12	8.96				
More than 5 years ago	23	17.16				
Age range of clients (choose all that apply)	133					
16 or younger	12	8.96				
17–35 years old	98	73.68				
36–64 years old	122	91.04				
65 years or older	120	90.23				
Caseload	134		107.52	65.41	0	500

Table 2. Suicidality Screening Practices Among Nephrology Social Workers*n* = 167

Do you screen patients for suicidality?	119 (yes)	71.26
<i>(n</i> = 167)		
When are patients screened?		
<i>(n</i> = 93)		
When dialogue with a patient suggests risk	78	82.98
Based on the outcome of a depression screening	66	70.21
Annually	30	31.91
Upon intake	30	31.91
At every appointment	1	1.06
Other	15	16.10
Screening method		
<i>(n</i> = 93)		
No formal screener used	37	39.36
PHQ-9 (Patient Health Questionnaire-9)	52	55.32
SAFE-T (Suicide Assessment Five-step Evaluation and Triage)	7	7.45
C-SSRS (Columbia-Suicide Severity Rating Scale)	5	5.32
Other	15	16.10
Estimated percentage of patients at risk for suicide		
<i>(n</i> = 92)		
0%	12	12.90
1–10%	57	61.29
11–20%	12	12.90
21–30%	3	3.23
31–40%	0	0
41–50%	1	1.08
51–60%	0	0
61–70%	0	0
71–80%	0	0
81–90%	0	0
91–100%	1	1.08
Unsure	7	7.53

Table 3. Inter-correlations for Screening, Caseload, & SW Experiences

	1	2	3	4
1. Screen patients for SI	–			
2. Caseload	.07	–		
	$p = .40$			
3. Time since last SI training	-.08	-.15	–	
	$p = .34$	$p = .09$		
4. Years of experience	.10	.11	.12	–
	$p = .24$	$p = .21$	$p = .17$	

Note: No correlations are significant at $p < .05$.

Table 4

Inter-correlations for Screening and Modality

	1	2	3	4
1. Screen patients for SI	–			
2. In-center hemodialysis	-.11	–		
	$p = .22$			
3. Home dialysis (HHD, PD)	.18	.13	–	
	$p = .04$	$p = .14$		
4. Transplant	.09	-.46	.03	–
	$p = .31$	$p < .0001$	$p = .72$	

Note: Correlations significant at $p < .05$ are listed in **bold**.

emergency room, and/or calling 911, often having patient sign a consent to release information for immediate care. The follow-up with patient is an integral part of the referrals.

Table 3 displays the correlations between social workers' screening practices and caseload size, time since most recent SI training, and years of experience as a CNSW participant; none were found to be significant. However, **Table 4** shows a positive correlation for suicide screening and home dialysis (home hemodialysis [HHD] and peritoneal dialysis [PD]) services; that is, social workers who work with home dialysis patients screened more often. **Table 4** also shows a strong negative correlation for suicidality screening and the transplant environment.

DISCUSSION

Nephrology social workers working primarily with ESRD patients who are on dialysis find that depression, anxiety, SI, and related emotions and behaviors are often complex and difficult to define, recognize, assess, and manage. While Medicare mandates depression screening by nephrology social workers, there is no mandate for screening for SI and/or related behaviors.

Once screening is implemented, however, social workers need to follow up routinely, either by providing relevant psychosocial support and/or crisis intervention and/or by providing referrals for appropriate evaluation and treatment by other mental health professionals. Follow-up is critical when screening is positive and/or when aberrant behaviors are reported or suspected by family and/or other nephrology professionals.

It is not clear why home dialysis patients are screened more often than in-center or transplant patients. Social workers may have more time to spend with home patients during training and/or at monthly clinic visits. On the other hand, in-center patients are seen more often (3 days/week) and staff might be able to recognize aberrant behaviors or thoughts more readily, resulting in more immediate referral for medical and/or medication follow-up. For transplant patients, the data suggest that social workers do not think there is a need to screen for suicidality, either because of the positive nature of potentially receiving a transplant or because other staff members (e.g., a staff psychologist) are handling that type of assessment.

Though the risk of suicide appears to be relatively low for dialysis patients in this small, North American study, good clinical social work practice necessitates screening for suicidal thoughts and behaviors when depression is identified or patient conversation with any member of the interdisciplinary team (IDT) suggests patient self-harm. Although a positive depression screening should lead social workers to assess for suicide risk, because suicide is not always associated with mental health conditions (CDC, 2018), it also may be important for social workers to screen for SI and behaviors regardless the outcome of depression screening.

This preliminary, exploratory study had several limitations. First, the term *suicidality* was used in this study for all related behaviors—SI, planning, attempts, and suicides. It might have been more useful to not assume social workers' knowledge of definitions for this study but to provide currently accepted terms and definitions on the survey. In addition, screening for SI and screening for behaviors may differ. Thus, defining what is being screened might have been more useful to the study as a means of parsing percentages of SI and behaviors.

Social workers in this study volunteered (self-selected) to participate in the survey. While the CNSW listserv seems large, it represents only those nephrology social workers willing to join the NKF/CNSW and pay an annual fee for services, including participation in the listserv. The 167 social workers responding to this survey represent a small minority of those practicing nephrology social work, in the United States at least. It is estimated that in 2015, the most recent year of such data collection, there were about 4,200 full-time and 3,300 part-time nephrology social workers nationally (USRDS, 2017). Finally, because the nature of this study was simply to explore the behaviors of nephrology social workers and screening for suicidality, our analysis was limited to descriptive statistics and basic correlation data. Repeating or extending this survey to include more social workers, refining the questions, defining terms for the survey, and adding additional analyses might provide a better indicator of nephrology practice for such screening.

The following conclusions seem justified: (1) Screening for SI and related behaviors is necessary when depression is identified by either the social worker or other professionals. (2) Given that an active mental health diagnosis (including depression) is not always present with SI or related behaviors, screening routinely each time one screens for depression may be most useful in identifying risk. (3) Establishment of standardized SI and related behavior tools for use by all renal social workers is recommended for tracking results as well as reporting like data. (4) Further study to better define such thinking and behaviors in both in-center and home dialysis populations would be useful for improved clinical care and patient safety. (5) Strategies to alleviate SI and related behaviors with better coping by patients need to be identified and implemented for this population.

AUTHOR NOTE

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APPENDIX A: SUICIDALITY SCREENING SURVEY

1. Do you screen patients for suicidality?
2. When do you screen patients for suicidality? (choose all that apply)
 - Upon intake
 - At every appointment
 - Annually
 - Based on the outcome of a depression screening
 - When dialogue with a patient suggests risk
 - Other (please specify)
3. Which formalized suicide screening instrument do you use, if any?
 - I do not use a formalized screening instrument
 - C-SSRS (Columbia-Suicide Severity Rating Scale)
 - SAFE-T (Suicide Assessment Five-Step Evaluation and Triage)
 - PHQ-9 (Patient Health Questionnaire-9)
 - Other (please specify)
4. If you do not use a formalized suicide screening instrument, how do you assess for suicidality? (i.e., what questions do you ask?)
5. How do you respond to patients whose score or responses indicate a mild risk of suicidality? (include follow-up and/or referral procedures)
6. How do you respond to patients whose score or responses indicate a moderate/severe risk of suicidality? (include follow-up and/or referral procedures)
7. Approximately what percent of your patients are at risk for suicide?
 - 0%
 - 1–10%
 - ...
 - 91–100%
 - Unsure
8. For how many years have you been a nephrology social worker?
 - Less than 1 year
 - 1–5 years
 - 6–10 years
 - More than 10 years
9. When is the last time that you received training on suicide screening? (e.g. academic coursework, webinar, conference session)
 - I have never received training on suicide screening.
 - Within the past 12 months
 - 1–3 years ago
 - 3–5 years ago
 - More than 5 years ago
10. How would you identify your work setting? (choose all that apply)
 - In-center hemodialysis (including 3x/week, nocturnal, extended)
 - Home hemodialysis (including short daily hemodialysis, 3x/week hemodialysis, nocturnal home dialysis) and/or Peritoneal Dialysis (CAPD, CCPD)
 - Transplant
 - Other (please specify)
11. How would you identify your employer? (choose all that apply)
 - Government/public
 - Private nonprofit hospital
 - Private for profit hospital
 - Nonprofit dialysis center
 - For-profit dialysis center
 - Other (please specify)
12. What is the total number of patients in your caseload for all of your sites?
13. Please indicate the age range of clients that you serve.
 - 16 or younger
 - 17–35 years old
 - 36–64 years old
 - 65 years or older

Beyond Numbers: The Liminal Experience of Kidney Transplantation Amongst Young Adults Following Transfer of Care

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Young adults who receive kidney transplants have unique needs. Adherence with medical therapy and with appointments can be a major challenge for this population, as is the transfer from pediatric to adult care. There is little qualitative research that tackles the experience of transplantation amongst young people, and still less from a social work standpoint. The present article reflects the findings of a qualitative, phenomenological study into the transition experience of young-adult kidney transplant recipients. The study found that for these young people, health professionals were involved in their relationship to their bodies. A major theme that emerged was the relational nature of the transfer of care. Finally, the article closes with a discussion of the micro- and macro-level factors that shape these relationships and the implications of these findings for nephrology social workers and other health professionals practicing in adult care settings.

INTRODUCTION

In a recent article (Bogue Kerr, Soulière, & Bell, 2018), we shed light on the experience of liminality, that is the “in-between life” of young-adult kidney transplant recipients. Though life and treatment trajectories were different, the experiences converged around what we called the transliminal self. This concept was proposed to render explicit to the professionals who care for this population the lived experience of transplantation. Transplant recipients are indefinitely dependent on rulings rendered by numbers to reveal at regular intervals their state of health and their place between life and death (Bogue Kerr, Soulière, & Bell, 2018). The permanent nature of the incomplete healing process characterizes their experience of daily life and is reflected in their relationship to the medical world and with health professionals.

The present article is addressed to health professionals and is intended to contribute to the improvement of practice in the domain of nephrology, particularly in regard to the transition between pediatric and adult care. This socio-anthropological analysis of the realities of young adults traversing the process of kidney transplantation and its numerous medical follow-ups is especially important to the work of professionals in health institutions, which are governed by a logic of numbers that determine objectives for quality of care on the basis of measurable efficiency. These institutional constraints delimit the intervention possibilities of professionals and mark the relationships between these professionals and those they heal. In this context, the unquantifiable needs of young people living with chronic illness can be easily overlooked, sometimes with serious consequences. We seek to

relate our findings of the experiences of young-adult kidney transplant recipients to the challenges they face within the healthcare system and the implications for social worker practice.

TRANSPLANTATION & TRANSITION LITERATURE

The problem of life transition and transfer of care

In recent years, the transition and transfer from pediatric to adult care have been the subjects of interest within the field of transplantation. A major concern for this population is adherence to treatments, appointments and blood tests, and loss of follow-up. Poor adherence may lead to serious illness-related events and personal transitions, including acute organ rejection and complications related to intensive antirejection therapy, such as opportunistic infections and increased malignancy risk, graft loss, return to dialysis, or even death (Bell et al., 2008; Foster, 2015). The World Health Organization (WHO) describes adherence¹ as a multidimensional phenomenon with five major contributing domains: (1) user related (e.g. health beliefs, self-efficacy, knowledge, motivation, psychosocial stress, and perceived barriers); (2) condition related (e.g. severity of symptoms, level of disability, comorbidities, and psychological or psychiatric factors); (3) therapy related (complexity side effects and immediacy of beneficial effects); (4) social and economic (e.g. family functioning; social supports; culture; and lay beliefs about illness and treatment, medication, and travel costs); and (5) health-system/healthcare-team related (WHO, 2003). While a number of studies have been conducted on the subject of adherence (Fletcher-Johnston,

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Marshall, & Straatman, 2011; Meade, Tornichio, & Mahan, 2009), few have sought to explore the experiences of those who live through the transfer of care (Fletcher-Johnston et al., 2011; Tong, Morton, Howard, McTaggart, & Craig, 2011).

Youth living with chronic kidney disease (CKD) may experience intense disease-related transitions during emerging adulthood (Arnett, Žukauskienė, & Sugimura, 2014), a period of major developmental processes between 18 and 29 years of age. As children mature into adolescence and young adulthood, simultaneous changes in other aspects of their lives are shaping the transplant experience. Many publications acknowledge the challenges children with chronic illness face as they mature in their teenage years and eventually transfer to an adult care hospital (Bell et al., 2008; Crowley, Wolfe, Lock, & McKee, 2011; Davis, Brown, Taylor, Epstein, & McPheeters, 2014; McDonagh, 2005; McQuillan, Toulany, Kaufman, & Schiff, 2015). The Canadian Paediatric Society (2014) recently reaffirmed a 2007 position statement calling for increased awareness of transition processes amongst health professionals and parents and advocating for a comprehensive approach towards the transition process with adapted services, follow-up, and psychoeducational support to facilitate the transfer of care. Guidelines for transition have recently been published by the Canadian Association of Paediatric Health Centres (2016) and Got Transition™ (2018). These guidelines target youth (age 15–29) with special healthcare needs (including physical, developmental, and/or mental health conditions) who require ongoing health surveillance and care to maintain optimal health into their adult years.

The psychosocial problem of pediatric kidney disease

Many researchers have observed the integrated nature of illness within a person's life story (Kleinman, 1988; Lewis, 2013; Richards, 2012). For children with kidney disease, growth and developmental processes can be significantly affected, depending on the child's age at its onset (Bawden et al., 2004; Bell, 2007). The disease can affect motor skills (Bawden et al., 2004), cognition (Bell et al., 2008; Meade, Tornichio, & Mahan, 2009), intellectual and academic performance (Meade, Tornichio, & Mahan, 2009), and psychosocial development (Bell et al., 2008). In a school setting, academic and behavioral issues, as well as problems with anxiety and depression, have been observed amongst children with kidney disease (Annunziato, Jerson, Seidel, & Glenwick, 2012). The challenges these children experience are exacerbated by stress associated with schoolwork, social exclusion, and sometimes by bullying. The interaction of these factors can make it difficult for these children to master developmental milestones that gradually prepare them to be independent and autonomous young adults (Annunziato, Jerson, Seidel, & Glenwick, 2012).

Health-related transitions are an important characteristic of CKD (Hutchinson, 2005; Kierans & Maynooth, 2001) because of the progressive nature of the disease and the consequent changes in treatment options and requirements over time. For youth with CKD, transitions associated with a major disease occur alongside biopsychosocial developmental processes. In this perspective, it is important to remember that adolescence is a transitional period during which the developmental task of individuation is worked through (Liakopoulou, 1999; Loughran, 2004). The delicate balance of parental involvement in adolescent life is especially sensitive for those with chronic illness (Annunziato & Shemesh, 2010; Anthony et al., 2009; Bell et al., 2008; Gorter, Stewart, & Woodbury-Smith, 2011), for whom normal adolescent experimentation can result in serious health issues. A youthful reluctance to accept the values and advice of authority figures like teachers and health professionals, may exacerbate these challenges (Bell et al., 2008). For an adolescent effectively raised in a healthcare setting, this may symbolize a developmentally appropriate rebellion associated with the processes of separation and individuation (Liakopoulou, 1999).

During this period, adolescents become increasingly aware of their changing bodies. A negative body image may bring about a particular form of suffering, making the side effects of immunosuppressive medications (including acne, weight gain, and accelerated hair growth) particularly difficult to tolerate. These side effects are also believed to influence normal developmental processes related to sexuality and sexual relationships (Canadian Paediatric Society [CPS], 2007; Meade, Tornichio, & Mahan, 2009; Schweitzer & Hobbs, 1995). Infrequent school attendance during childhood may result in less developed social networks for these adolescents, presenting difficulties for their transition into adulthood, resulting in feelings of loneliness and issues related to self-esteem (Kaufman, Pinzon, & Canadian Paediatric Society, 2007).

Despite the developmental, psychosocial (Meade, Tornichio, & Mahan, 2009), and experiential (Fletcher-Johnston, Marshall, & Straatman, 2011) complexity of this stage, much of the literature regarding the issue of care needs of these young people focuses on correcting behaviours (such as adherence to medication) (Fletcher-Johnston, Marshall, & Straatman, 2011; Meade, Tornichio, & Mahan, 2009). This has led some experts to call for integrated supports that address the complexity of their needs (Bell, 2007; Bell et al., 2008; Crowley, Wolfe, Lock, & McKee, 2011; Kaufman, Pinzon, & Canadian Paediatric Society, 2007). Others call for the adoption of a biopsychosocial approach to transition care that would emphasize the holistic nature of the experience (Crowley, Wolfe, Lock, & McKee, 2011), while accounting for the individual's particular family situation, preferences, and personality (Gorter, Stewart, & Woodbury-Smith, 2011).

¹The WHO differentiates the use of the terms *adherence* and *compliance*. For this organization, adherence reflects the active involvement of individuals in their own care. It is thus understood that adherence requires that the individual agree to the treatment plan (WHO, 2003).

The problem of transfer of care

The cultures of care in pediatric and adult hospitals are generally different. In the pediatric setting there is usually an integrated interdisciplinary team of health professionals who treat children with chronic illnesses, encouraging a family-centered approach and promoting trusting relationships among health professionals, the children, and their families (Anthony et al., 2009). Upon arrival at the adult care hospital, young adults are typically expected to show independence in life skills, present themselves for appointments without their parents, have knowledge of their disease, be able to ask questions and participate in decision making, know how to access resources, and adhere to pharmacological treatment (Bell et al., 2008; McDonagh, 2005). Transitions related to adolescent neurodevelopment and those stemming from the organization of health services are challenging for young adults with CKD and are often further complicated by a lack of knowledge and familiarity with the adult care setting. These simultaneous transitions are further confounded by a lack of familiarity amongst adult care nephrologists not only with the developmental period of adolescence but also with pediatric kidney diseases (Bell & Sawyer, 2010).

In recent years, advances in biomedicine have allowed more children with kidney disease to survive into adulthood, leaving these young adults with the disadvantage of being among the first to transfer into the care of nephrologists accustomed to working with adult-onset diseases (Bell & Sawyer, 2010). Pediatric specialists are not only more familiar with childhood diseases, but in many cases, they have followed individual patients since the onset of a disease. Often they have spent years developing a relationship with these patients, have come to know them as people, and have firsthand knowledge of how their diseases and their selves have evolved. Research concerning the information and support needs of adolescent and young-adult kidney transplant recipients (Davis, Brown, Taylor, Epstein, & McPheeters, 2014; Tong, Morton, Howard, McTaggart, & Craig, 2011) and their experiences (Fletcher-Johnston, Marshall, & Straatman, 2011) is limited.

In light of this, we undertook this study believing that a contextualized socioanthropological interpretation of the experience of kidney transplantation amongst young adults would allow for a deeper understanding of the challenges such individuals face, the risks they might take, and how they might be better supported in their transition to adult care.

METHODOLOGY

As mentioned in the introduction, this article is based on a study conducted between 2013 and 2015, which sought to understand the lived experience of young adults who have had kidney transplants.

Phenomenology proposes a qualitative approach to research, which concerns itself with the study of lived experience. For Merleau-Ponty (1945/2012), a 20th century French philosopher, phenomenology is a search for truth, accessible only through our experiences of our bodies and of our perceptions. It emerged as an alternative to the prevailing empirical, positivist position of the natural sciences (Blaikie, 2007) and emphasized the relevance and complexity of everyday experience, thus broadening the discussion about what it means to live (Hughes, 1990). Phenomenology considers that all knowledge derives from subjective experiences of the world (Matthews, 2006) and, as such, contends that different epistemological positions complement rather than compete with one another (Creswell, 1998). Seen in this way, biomedical and subjective perspectives on transplantation are equally valuable and allow for a deeper understanding of the phenomenon.

Five in-depth interviews were conducted in a major Canadian city with young adults (two men and three women), all of whom had been followed at the same pediatric teaching hospital and subsequently cared for in the same adult teaching hospital transplant center. Participants were invited to share their health and illness experiences, the medical interventions they had undergone, as well as about their experiences of pediatric and adult care. They were also asked about the larger context of their lives as adolescents and young adults, including their family, social, academic, and career experiences. Interviews were recorded and later transcribed for analysis.

The table below summarizes the characteristics of the participants.

Gender	Age range ²	Transplanted in	Dialysis?	Complications	Donor
Female	Early-to-mid-20s	Pediatric Care	Yes	Multiple surgeries, organ rejection, second transplant, cancer	Living
Male	Late 20s to early 30s	Adult Care	No	Primarily side effects of medications	Deceased

Of the three young women, one received her transplant during childhood and two in adolescence; the young men underwent transplantation during young adulthood. The young women had more complex experiences early in their illnesses, including multiple surgical procedures, regular dialysis treatments, and longer hospital stays. All three received a kidney from a living donor in their families. At the time of the interviews, these women were all in their early-to-mid-20s; only one was working, though another reported plans to return to school.

The two young men had less complex illness trajectories; neither had undergone dialysis nor experienced multiple surgeries. Both had received deceased donor kidneys when they were in their late 20s to early 30s. At the time of the interview, the men were in their mid-to-late 30s and both were working.

The interviews were analyzed by combining elements of both narrative analysis (Labov, 2013) and analysis through writing (Paillé & Mucchielli, 2010). Narrative analysis was applied to gain insight into the context or orientation (Labov, 2013) of the participant's story (who, what, when, and where), and his or her perception of the experience, through close examination of the language used to describe the experience. This included attention to evaluative commentary ("they were *amazing*"), negative verbs ("*they wouldn't tell me*"), modal verbs ("*would they take care of me?*"), future tense verbs ("*I'm going to go to school*"), and literary devices, including similes ("*what feels like a leash*") (Bogue Kerr, Soulière, & Bell, 2018).

A process of analysis through writing, which involved writing detailed descriptive summaries of each participant's interview (Paillé & Mucchielli, 2010), was then undertaken. In reading and re-reading these summaries, similar accounts of experiences became increasingly evident, which made way for an analytical rewrite of the narratives. Through this process emerged a shared experience in regard to the nature of relationships with their bodies and with health professionals in the context of the institutions, whether pediatric or adult, where they received care.

This method of analysis is in keeping with the phenomenological framework of the study, which perceives research as an intersubjective search for meaning. The objective of this study was not to produce generalizable findings but rather to gain insight into the lived experience of the participants.

The researchers approached their work with reflexivity, or self-awareness. As is common in qualitative studies, researchers kept a self-reflective journal, the purpose of which was to keep a record of the experiences, assumptions and biases that emerged (Butler-Kisber, 2010; Morrow, 2005).

Approval for this study was obtained from the research ethics boards at both the university through which this study was conducted and the teaching hospital through which participants were recruited. All participants provided written informed consent.

Limitations

Several of the potential participants the staff of the pediatric transplant clinic had identified were unable to be reached. By broadening the criteria, the researchers were able to recruit the intended number of participants. This resulted in a wider range in age and of disease trajectories within the sample; participants had suffered from different kidney diseases, had undergone different surgeries and treatments, and had experienced different transplant-related complications. Nonetheless, participants shared common experiences of illness, and the saturation point was considered to have been reached.

RESULTS

The divergent illness trajectories of the young adults we met shaped the formation of significant relationships in their lives. The chronic illnesses with which the young men had been diagnosed in childhood required regular follow-up at the pediatric hospital, but this seemed to be minimally disruptive to their attendance at school and the development of friendships with peers. For the young women, however, the intensity of their treatments called for frequent visits and admissions to hospital. Thus, crucial moments in their lives unfolded within the institution, and relationships with health professionals were formed over the course of several years. These relationships emerged as a major theme in the lives of these young-adult kidney transplant recipients, the importance of which was illuminated by the transfer from pediatric to adult care.

Transfer of care for young adults: A relational issue

Prior to their transfer, three of these young adults viewed the transition positively and anticipated that adult care would be more or less the same as in pediatrics, with care provided by different people. For them, the transition was viewed as part of a developmental process that paralleled their drive for more independence and autonomy. Two of the young women expressed feeling "scared" about the transfer, with one (Catherine) stating she did not want to "leave behind such amazing people" and another (Melissa) wondering, "Why are you guys trying to kick me out already?" The three women who were transferred as transplant recipients reported being prepared for the transition by engaging in discussions about adult care with the pediatric team, being encouraged to advocate for themselves, and being accompanied by their pediatric nurse to visit to the adult hospital. They reported feeling prepared and supported throughout the transfer of care. They spoke little about their parents' involvement during this time, except to say that their parents seemed more concerned about the transfer than they themselves were. Both men who transferred as young adults with chronic illness shared that they received little to no education about the transfer of care, nor had they identified this as a need at the time. Transfer of care was experienced as more abrupt for these participants, whose illnesses had not required them to spend as much time at the hospital in their childhood and who, consequently, had more distant relationships with the pediatric institution and its professionals.

Each young adult we met experienced adult care differently than they had expected. Although relationships with health professionals in both pediatric and adult care were, overall, experienced positively by the transplant recipients, the way in which they contrasted their experiences of pediatric and adult care suggested different perceptions of their relationships with these professionals. Pediatric care was associated with “feeling safe,” “cared for,” “known,” “seen” and was said to communicate a sense that “you’re someone to them.” These statements contrast the vulnerability of illness with the security of being cared for. In their experience with adult care, these young adults remembered “not feel[ing] comfortable at the hospital” and health professionals who were “busy,” “didn’t care,” or “didn’t really know me.” The attentiveness of their pediatric specialists and the continuity of pediatric care were contrasted with a perception of a more disorganized, time-stressed environment in the adult clinic, and checkups that were less personal and less thorough. Many of these statements referred generally to professionals within the institution as a whole and were not necessarily specific to their transplant doctors and nurses. Despite feeling their transplant doctors and nurses had less time to dedicate to them, which they tended to comprehend, these patients missed the opportunity to develop strong relationships with their doctors and nurses. For Melissa, being referred to other specialists by her adult care team seemed to reflect a compartmentalization of her person and her care: “It’s less of a team, to be honest.... They refer me to other people if I have other problems. It’s not like they take care of everything.”

Throughout their interviews, the younger transplant recipients gave examples of ways in which they believed health professionals at the pediatric care hospital had gone above and beyond to care for them. They were all still in touch with the same nurse from their pediatric transplant unit, whom they described as someone they had known a long time, whom they could trust, and with whom they had a special relationship. Catherine spoke more extensively about the relationships she built with her pediatric dialysis nurses than she did about her treatments or her body, revealing a sense of accompaniment throughout this developmental period:

Dialysis, I’ve always said this, was the best year of my life.... [The dialysis nurses] were amazing, they were amazing. I must have been so jerky when I was a teenager, all I would talk about is boys, and they would talk to you about boys for the entire three hours, they would just constantly talk to you, because it’s what you needed.

Despite this, there were difficult circumstances in pediatrics that seemed to strain the trust that had been built. Participants provided examples of times when they were disappointed by the pediatric team’s inability to restore them to full health, illustrating to some extent a displacement of emotion in regard to their physical vulnerability—be it be frustration, sadness, anger or guilt—onto health profession-

als. Moreover, these charged moments that threatened to destabilize trusting relationships tended to occur in times of crisis or uncertainty, when the individual may have felt particularly endangered. Speaking about a serious health condition triggered by her prescription drug treatment, Emily stated that she was given medication that was supposed to make her better, but that it caused other serious health problems. Melissa expressed feelings of betrayal when she was referred to a psychiatrist for assessment, which she experienced as a rejection by her pediatric team. She felt that rather than listening to her and appreciating how difficult it was for her to be ill, she was shuffled off to a different professional:

I had an attitude as a child. Like I was just very angry at the world and angry that this was happening to me. I was always at the hospital and I basically made it my life to take it out on [the doctors and nurses], more or less. I didn’t mean to, I didn’t realize I was doing it, but I made everything so difficult. I didn’t realize I had to go through this pain in order to live, so I would just scream and cry, and not let anyone do anything to me.

Relational challenges evolved after the transfer to adult care, reflecting a greater distance from health professionals. These young adults each had examples of times they perceived their questions or concerns as not being received or heard by adult care health professionals in the way they had hoped. Transplant recipients depend on the privileged knowledge and insight of their health professionals to keep them alive. They are aware they rely on highly specialized professionals, whose analysis of their delicately balanced state of health is based on quantitative measures, while their own subjective experience of their body remains confined to its boundaries. David recalled living with “unbearable dizziness for a period approaching a year,” during which time every possible cause was ruled out, until it was identified as a side effect of his medications, a connection he had hypothesized since the symptom’s onset. He understood the dilemma:

To some extent getting good care, you don’t want to be some quack who thinks they know better than the doctor when they don’t, especially if they got it from the Internet. But I’m not like an uneducated guy, and I’ve been dealing with doctors my whole life; if someone’s sort of persistent about a symptom then, I mean, they live with themselves. If they’re not proposing some new age craziness, if they’re just saying, look I think it’s this drug, it’s really worth taking seriously... they may not be aware of cause and effect but they’re certainly aware of correlation. This happened and then that happened, and that’s worth looking into.

Ralph disclosed feeling moral pressure from his treatment team, after requesting information regarding the impact of recreational marijuana use. From his perspective, he sought to access scientific knowledge that would allow him to make an informed decision but was met with expectations about how he should live his life:

Like you're expected to be super cautious and grateful afterwards, so why would you drink or smoke, or do drugs? Because it would be a waste. It's difficult... It's like I have to be better than everyone else, or more cautious than everyone else.

This was supported by other transplant recipients, who alluded to a sense of guilt about being "less careful" than they should be in regard to their health. Most of the young adults spoke about defying biomedical authority in some way, whether by smoking marijuana, having a few drinks, or leaving the house during the isolation period following transplant when the immune system is particularly suppressed.

These young people expressed a desire to assert control over their own bodies. David attempted to rein in the body's functions through exacting self-care routines. Melissa explained that having some control over the pain inflicted on her body was a way for her to cope with the experience. She recounted how she had learned to do a number of things herself while on dialysis, such as cleaning the stitches around her catheter and giving herself needles. In some cases, the lack of control over the body and ultimately its uncontrollable nature was expressed outwardly as frustration towards doctors and nurses.

The young adults in this study expressed nuanced needs that were relational in nature, thus difficult to categorize and quantify within the current paradigm of resource allocation in healthcare. Their experiences can bring about preventable illness-related transitions. In light of the importance of adherence to medication and to medical advice for transplant recipients, it seems relevant to consider how complex issues of control over the body's unpredictable nature influence individuals and their relationships with those professionals responsible for keeping them alive.

DISCUSSION

Earlier in this paper, the high risk of transplant-related complications and graft rejection amongst young adult transplant recipients was identified. Some of the literature regarding this issue addresses the transfer of care and highlights the developmental challenges associated with meeting the high expectations of autonomy in adult care settings (McDonagh, 2005). In reflecting on their transition experience, the participants of this study expressed feeling well-prepared for the transfer of care. Rather, the young adults we met identified the main difference between pediatric and adult care as relational.

These young adults also spoke about the challenges of post-transplant life: the uncertainty related to the delicate balance of the immune system; the continuous engagement with their mortality; the sense of vulnerability in relation to their reliance on the specialized knowledge of health professionals to keep them alive; and the complex feelings associated with issues of having control over their own body. All of these experiences of their bodies and of their illnesses play out in

their relationships with health professionals, which charges appointments with emotion and meaning.

The system in which these young people are treated, however, does not account for the emotional and symbolic weight of medical appointments. Instead, they are approached from a logic of productivity, efficiency, and cost cutting. Health professionals find themselves stuck between these two competing paradigms, with their working conditions shaped by the logic of New Public Management,⁵ according little importance to qualitative and experiential aspects of life. The young adult enters into this time-stressed environment for medical follow-ups, carrying with them the weight of their illness experience, their mortality, and their complex relationship to their body and, consequently, to health professionals. Without the conditions to allow these subjective experiences to be shared, heard, and worked through, medical appointments are limited to quantifiable measures of health accessible only to health professionals. In this context, it is challenging to develop relationships with health professionals, who have the exacting responsibility of overseeing, to the best of their knowledge and ability, the body of another.

The relationship between transplant recipients and health professionals is shaped by the interaction of macro- and micro-factors. Collective values and political choices shape social structures and healthcare organizations, creating the conditions that frame professional practice, and meeting with the individual's biochemical processes and subjective experiences of illness. This echoes the five dimensions of adherence⁶ identified by the WHO outlined earlier in this paper (De Geest & Sabaté, 2003). Participants of this study contrasted their experiences of person-centered pediatric care with the "chaotic, overworked, disorganized" environment at the adult care hospital. In the context of a system concerned with readily quantifiable measures of efficiency, this is unsurprising. It takes time to listen to people's narratives, to build relationships with those seeking care, and to understand how they perceive their illness. These qualitative interventions emphasize the intersubjective nature of these encounters, allow health professionals to account for the multiple and interrelated factors that influence adherence, and encourage them to adjust their approach to the individual, all of which are recommended by the WHO in addressing the issue of adherence (WHO, 2003).

⁵This approach to governance of public systems was born of neoliberal ideals that sought to put an end to the welfare state in the Western world (Merrien, 1999). This approach embraces the colonization of public services by the principles and values of the market economy, which manifest in the privatization of public services and restrained government spending (Merrien, 1999) that have come to shape public healthcare across Canada and other Western countries (Soulière, Saulnier & Desaulniers-Coulombe, 2017)⁶.

The WHO identified five dimensions of adherence: (1) user related, (2) condition related, (3) therapy related, (4) social and economic, and (5) health system/healthcare team related (De Geest & Sabaté, 2003).

As mentioned in the introduction, we recently introduced the concept of transliminal self (Bogue Kerr et al., 2018), to encompass the in-between nature of life as a young-adult kidney transplant recipient, existing between life and death, sickness and health, self and other. The transliminal self is incompletely healed and never fully emerges from sickness, thus requiring lifelong care from health professionals and within the institutions that frame these relationships.

The ambiguous state of the transliminal self, being neither sick nor healthy, can render their experiences, and thus their needs, invisible to health professionals, thereby affecting these relationships, and the care they receive within the healthcare system (Bogue Kerr, Soulière & Bell, 2018). The highly specialized care required to maintain the precarious normality of posttransplant life is dependent upon their acceptance of the involvement of professionals in their relationship to their body and their life. For the transliminal self, their body is not entirely their own.

Participants of this study were aware that a critical infection, a rejection episode, or onset of a serious disease could pose a risk to their survival. Despite this, some questioned the privileged insight of health professionals into the functioning of their bodies, and many rejected, in one way or another, the passive role of object into which their “patient” status cast them. These young adults each provided examples of ways in which they rebelled in small ways against biomedical authority. For those in a sustained liminal state, these transgressions embody a repossession of and control over one’s body (Little, Jordens, Paul, Montgomery, & Philipson., 1998), particularly in the context of a developmental stage characterized by increased independence and questioning of authority figures.

Treatment plans based solely on the principles of New Public Management may not account for important subjective factors that can influence treatment outcomes. Evidence suggests that addressing the issue of adherence amongst those with chronic illness, half of whom do not adhere with medical advice, would have a far greater impact on public health than advances in treatment and would reduce healthcare costs by preventing avoidable and costly complications (WHO, 2003). In this study, participants’ lack of control over the body and ultimately the body’s uncontrollable nature were in some cases expressed outwardly as frustration towards doctors and nurses. In light of the importance of adherence with medical advice for transplant recipients, power struggles within the relationship between the individual and their health professionals could potentially have serious consequences.

Kleinman (1988) affirms the importance of health professionals’ attentiveness to subjective experiences of illness, believing that they can provide insight not only into how a person lives with their illness, but sometimes even to the evolution of their disease. In this perspective, a shift towards narrative medicine acknowledges the emotional

and complex relationships people have with their bodies (Lewis, 2011) and by extension, with health professionals. Felitti and Anda (2010) found that a truly biopsychosocial approach to care, in which health professionals are aware of traumatic experiences in the lives of those they heal, resulted in a significant reduction in visits to the doctor (35%) and to the emergency room (11%), as well as fewer admissions to hospital (3%).

CONCLUSION

The practice of nephrology social work unfolds in the crevices between the quantification of resources stemming from New Public Management and the quantitative approach to health from a biomedical perspective. Social workers are faced with a dual focus on numbers. Biomedical analysis contextualizes the individual’s disease and treatment trajectories, while limited resources constrain the patient’s care to efficient, quantifiable short-term interventions. However an interdisciplinary approach that invests more time in understanding the perspective of the individual can provide insight into the complex relational factors that unfold with their health professionals (WHO, 2003).

Social workers have a key role to play in advocating for the needs of transplant recipients in adult care. First and foremost, they must resist the pressure to reshape their analysis and their practice in accordance with neoliberal⁷ demands aimed at streamlining human experience. In order to sensitize other health professionals to the nonquantifiable suffering of the transliminal self, they must first carve out conditions in their own practice that will allow these experiences to emerge. Social workers are often perceived, by themselves and by others, as problem solvers (Dybic, 2012), which may lead some to feel uncomfortable in situations without clear and concrete solutions. In the same way that healing in medicine involves both science and art, so too does healing in social work involve practical, critical, and therapeutic elements.

Narrative medicine draws on theories from a range of perspectives in an effort to embrace the complexity of the human experiences of sickness and healing (Lewis, 2011). For a social worker, this involves seeking deeper understanding into individuals’ perception of their illness, their goals in life, and the challenges they perceive as standing in their way (Dybic, 2012). This may well provide the social worker, and by extension other health professionals, with insights into how they may reframe their role as allies who accompany the individual on their journey, rather than mediators in the relationship to their body.

Social workers can play a role in supporting holistic healing, which extends beyond the body and involves the interaction of developmental, psychosocial, and existential

⁷Neoliberalism refers to a political-economic practice based on free market principles (Gallop, 2013).

processes that unfold alongside concerns regarding physical health. The *transliminal self* may never fully emerge from physical illness, but healing on other levels is possible nonetheless. This concept may serve as a reference point for social workers to help them deconstruct the narrative of transplant recipients who may be struggling to put words to subtle existential experiences and can sensitize other health professionals to the multilayered nature of post-transplant life. In the context of New Public Management, this is an act of resistance that challenges qualitative assessments of care. In order to acknowledge and join with the transliminal self, social workers must challenge themselves to feel comfortable in the ambiguous space between sickness and health. Here, there are no concrete problems to solve, no strategies to employ, no resources to provide. This is what makes it difficult for the healthcare system, and the professionals practicing within it, to see beyond numbers; they are challenged to remain present in the face of questions that confront us at once with our vulnerability and our reliance on others.

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Developing Quality Social Work Field Placements in Dialysis Clinics ☆

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Dialysis clinics provide rich field placement settings for social work students. In this article, field placements for advanced practice MSW students are carefully examined, as they are best suited to work with patients on a higher clinical level. This article also provides an outline of how advanced practice competencies can be applied in such settings with attention to supervision and the role of the field instructor.

INTRODUCTION

In the United States, the Council on Social Work Education (CSWE) is responsible for accrediting masters and baccalaureate social work programs through a set of criteria called the Educational Policy and Accreditation Standards (EPAS). The CSWE's Commission on Accreditation updates these standards about every seven years, and the most recent set of EPAS standards was published in 2015. As with any accredited degree program, there are required components of the Bachelor of Social Work (BSW) and Master of Social Work (MSW) degrees. The 2015 EPAS states: "Signature pedagogies are elements of instruction and of socialization that teach future practitioners the fundamental dimensions of professional work in their discipline—to think, to perform, and to act ethically and with integrity" (p.12). Field education is recognized as the signature pedagogy of social work education for emerging social work practitioners (CSWE, 2008, 2015; Shulman, 2005; Wayne, Bogo, & Raskin, 2010).

EPAS requires that students enrolled in field education courses receive supervisory oversight from a professional holding the same degree (CSWE, 2015). Additionally, EPAS requires that, before graduating, students serve a field internship in a human services organization for a minimum of 900 hours for an MSW program and 400 hours for a BSW program (CSWE, 2015). The social worker providing the supervisory oversight (called a field instructor) must have the same degree and two year's post-practice experience. The field placement setting—for BSW and foundation-level MSW students—must provide generalist practice opportunities for students to demonstrate nine core social work competencies with individuals, families, groups, organizations, and communities, and each program must illustrate how this is accomplished in field settings (CSWE, 2015).

For advanced MSW students, the field education program must be able to describe and justify how the setting provides specialized and advanced-level practice opportunities for students who demonstrate social work competencies within the specialized practice area (CSWE, 2015).

This article offers a rationale for why dialysis clinics are ideal field placement settings for MSW advanced practice, including how the role of the field instructor sets up success in such placements. Additionally, it provides an outline for how the 2015 EPAS for a CSWE-accredited MSW program aligns with the Centers for Medicare and Medicaid Services (CMS) requirements in a dialysis setting and how advanced practice competencies can be applied (Medicare and Medicaid Programs; Conditions for Coverage for end-stage Renal Disease Facilities, 2008).

Dialysis

Nephrology is a medical specialty that manages kidney health. According to the Centers for Disease Control and Prevention (CDC), in 2017 an estimated 30 million adults, 15% of the population, were thought to have kidney disease and a majority of them were not even aware they had kidney damage. (CDC, 2017). As individuals progress through the five stages of kidney disease to end stage renal disease (ESRD), individuals some will be required to choose a method of management, or modality, to replace their native kidney function. One option is dialysis. This can be done in a variety of settings, the most common being in an outpatient setting, called *in-center hemodialysis (ICHD)*. Patients are required to treat, on average, three times weekly for 4-hour sessions, as is done in one of the author's clinic. During these treatments, dialysis, in which a person's blood

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is cleansed through a dialyzer and fluid is removed, replaces a portion of the patient's kidney function. A nephrologist closely monitors patient's labs. These treatments often leave patients washed out and fatigued, making routine social interaction, community involvement, and employment very difficult. Additionally, this population is often burdened with multiple medical appointments, making mental health referrals difficult to complete. Another modality is *home hemodialysis*, where the same treatment is administered but in the privacy of the patient's home. This is a labor-intensive option, requiring the patient to have a partner present with them always. Additionally, patients are required to come to a clinic several times a month where labs will be drawn and monitored, and medications and dialysis prescriptions are managed. One other modality is called *peritoneal dialysis*, in which the kidney function is replaced through an exchange of fluids via a catheter that enters their peritoneal cavity. These patients often feel better and are more able to engage in work, school, and family life.

An alternate option for treatment is called *nocturnal hemodialysis*. This method takes place at night, and is a slower, longer treatment. Prescription times for nocturnal dialysis are usually 6–8 hours, three times a week. Some dialysis centers offer this modality at a clinic, but patients can also choose to do this at home. Some benefits for an individual are that the treatment is performed at night, improving sleep apnea (Hanly & Pierratos, 2001) and freeing up the day for work, school, or other life activities. Since treatment is slower, it is gentler on the body and patients do not have the washed-out feeling associated with ICHD. Regardless, dialysis patients face many well-documented challenges because of these treatment processes. For example, some are at increased risk of poor psychosocial outcomes (Cukor, Ver Halen, Fruchter, & Kimmel, 2015; Israel, 1986) such as depression (Finkelstein & Finklestein, 2000), anxiety (Goh & Griva, 2018), and quality of life (Al-Arabi, 2006). As a result, social workers are vital in supporting patients as they navigate these overwhelming psychosocial barriers and challenges of daily functioning.

Dialysis clinics as advanced practiced placement settings

Dialysis clinics can provide an ideal field placement setting for advanced-practice social work students. Advanced-practice MSW students function at a higher level of autonomy than foundation-level social work interns in an MSW program. They can engage in all learning activities under the supervision of a dialysis social worker. For example, an intern may assess psychosocial barriers to patient outcomes, participate in interdisciplinary team rounds, administer and review quality-of-life assessments (with the field instructor present), as well as administer depression and anxiety assessments.

Dialysis social workers may not be sure how to match themselves to a social work student for a field practicum. As a general guide, foundation-year MSW students will not have had as much course work and field experience as an

advanced-practice student, and BSW students will have had even less clinical preparation. BSW student field placements are different than MSW field placements because of the educational accrediting bodies require different levels of academic rigor as well. Thus, this article focuses on advanced-practice MSW students because they have completed the equivalent of one full-time year of social work education and have completed a year of field education courses. Dialysis clinics are not only an appropriate and robust environment for advanced-practice students, but they help them acquire the advanced-practice competencies desired for emerging MSW social workers.

First, there are many requirements to consider in designing a field placement setting for an MSW student in a dialysis clinic. According to the 2015 EPAS, any accredited social work program must clearly define how its accredited social work programs select field settings and must evaluate how effective the field setting is in developing social work competencies. Many field education programs actively seek to develop field placements in targeted areas for students based on educational levels identified within the EPAS and the competency framework associated with each level (BSW, MSW foundation, and MSW advanced/specialization). Another way field setting development occurs is when a practicing social worker or other professional reaches out to a field placement office at a school of social work to offer the opportunity to develop a field placement that meets CSWE standards. It is critically important that field placement settings provide a learning or educational experience for the student, not just a “work” experience.

Developing a quality field placement in a dialysis unit requires several steps. First, the university or college and the dialysis organization must develop an agreement for the practice of interns to cover liability and risk for such practice. Second, dialysis units must determine additional terms of agreement relevant for their organizations, such as mandatory immunizations, background checks, access to electronic medical and other records, and confidentiality topics pertinent to the establishment of the field placement and the placement for the prospective interns. Many times, field programs may need to develop this contract with a dialysis clinic's global entity, such as a large dialysis organization, which can be time consuming and lengthy if it requires coordination at a national versus local or state level. The field placement office in the school of social work can help complete the steps needed to accept an MSW student.

The 2015 EPAS emphasizes the critical importance of safety practice in field placement settings. The field placement setting must provide necessary measures to protect student safety. This may minimally include training in policies and procedures for conducting home visits, interacting with potentially difficult clients, dealing with bloodborne pathogens that might be found in a dialysis clinic, and handling emergencies, as well as appropriate screening of student assignments by the field instructor. Field placement settings

typically agree to introduce and orient the students to the organization's objectives, structure, policies, and procedures, including identifying specific policies that must be adhered to and the types of information or incidents that must be reported immediately to their field instructor or other organization representative. This commonly includes informing the prospective MSW interns of any physical dangers inherent in the field placement and providing reasonable training to prevent injuries. Dialysis clinics should also require prospective MSW interns to complete the same prerequisites as any dialysis social worker.

Dialysis social workers as MSW field instructors

Field instructors that supervise students in a dialysis clinic (acting as a field placement) must be credentialed by a CSWE-accredited MSW program and adhere to EPAS criteria. Field instructors for MSW students must have an MSW themselves from a CSWE-accredited program and two years of practical experience in social work after receiving their MSW. Many programs require prospective field instructors to complete mandatory training to equip them with the skills to become an effective field instructor.

Once a credentialed supervisor is identified, the amount of time the appointed field instructor is to spend on supervision must be determined, and this can vary from MSW program to MSW program. Typically, the field instructor is expected to provide an hour of supervision each week to an MSW student in an advanced practice clinical placement. Supervision in social work field internships is not only essential but critical to the development of a competent social work practitioner, especially a nephrology social worker. This is not a novel idea, and many have argued its centrality and importance over time in social work education since the mid-1950s by offering ways to better prepare field instructors for the task at hand (Bogo & McKnight, 2006; Cousins, 2004; Hair, 2012; Hensley 2015; Miehl, Everett, Segal, & du Bois, 2013; Raskin, 2005; Young, 1967).

Although Bogo (2006) identifies trends over time to include what "field instructors' experiences, motivations, and the factors that influence their participation and satisfaction" (p. 169), the literature does not offer dimensions of effective field instructors. In fact, other than what social work field education manuals provide under the section on the roles and responsibilities for field instructors, the literature remains scant. Although it might seem logical to lump the role of a field instructor into that of a supervisor because of similar characteristics, the roles are different in one critical and distinct way. Field instructors approach supervision from a teacher-learner framework not an employer-employee framework, which pays both the employee and the supervisor for work performed and which has organizational goals as the primary focus. To control for any possible violation of the U. S. Fair Labor Standards (29 C.F.R. chapter 8), the intern and the field instructor should develop and maintain a learning contract that centers the primary focus on the student's learning. Both are responsible for adhering

to this contract to ensure that the student's educational aims are met and that the supervisor is continually assessing the student's progress toward learning goals.

It is important to note essential characteristics that make for an effective field instructor positioned in a dialysis clinic, which may hold true for other types of settings. First, whether it be language, dress, or interaction with patients and other staff, the student looks to the field instructor for cues on what is appropriate in the field placement setting. As a mentor, it is the role of the field instructor to redirect, in a gentle way, inappropriate behavior, dress, and language as it occurs. These conversations can be difficult, but they preserve the professionalism of the field instructor, as well as the intern. Another role is that of educator. Field instructors should be aware of what the intern is working on in the classroom, so it can be applied in the field placement setting. Thus, they should familiarize themselves with all course syllabi for classes the intern is taking each semester.

Second, field instructors must act as a manager on some occasions. Assigning and holding the student accountable to learning tasks allows the intern to be responsible for his or her caseload as well as learning time management and effective documentation. Field instructors should provide structure and organization and have a realistic expectation of their interns, which may vary from student to student. For example, the learning tasks assigned to an advanced-level MSW intern would be different from those given to a foundation-level MSW or BSW student. The role of the field education office becomes central in helping determine appropriateness of field placements for level of student learning. The CSWE requires each social work program to identify how it determines this for accreditation purposes.

Third, patience by teacher and learner is an essential component of being an effective field instructor because a field instructor might expect an intern to be flexible in a fast-paced setting, such as a dialysis clinic. Field instructors must remember to be flexible as well and remember that interns progress through developmental stages of learning while in field placement. They must allow extra time for interventions to be mastered and completed, which requires providing interns with helpful feedback that is vital to a successful learning opportunity.

Fourth, field instructors should provide supervision but must be cautious not to confuse supervision with psychotherapy or counseling. There may be occasions when the intern experiences transference, countertransference, and avoidance or he or she demonstrates the need for self-awareness. It is the responsibility of the field instructor to gently explore these events and encourage the intern to grow from them. Students, however, should not be treated as coworkers, in that they will not hold the skills a field instructor has or be as experienced with the Code of Ethics of the National Association of Social Worker (NASW). It is important, however, to hold the student to the same level of professionalism as a coworker.

Fifth, sometimes students may work with other social workers on the floor, but designated field instructors are ultimately responsible for student learning and meeting the educational requirements of the partnership between the school and the dialysis clinic, which includes completing paperwork. This means that field instructors must review and sign off on all documentation related to the student and his or her performance. Additionally, field instructors must check in regularly with patients on the intern's caseload in order to maintain that relationship and to allow patients to express any concerns they have that they may not feel comfortable discussing with the intern.

It is important—and a CSWE requirement—to dedicate formal supervision time for students (CSWE, 2015); however, CSWE does not specify a specific amount of time. Some CSWE-accredited social work programs require a minimum of an hour of supervision weekly; others require a minimum of one hour of face-to-face formal supervision for each student only every two weeks. Regardless, it is important for field instructors to know what their intern's school requires and to set aside and dedicate time as a "safe place" where feedback, exploration, and clarification is used to promote the growth of the student.

Finally, field instructors should pay attention to their own motivations. Becoming a field instructor may reflect personal motivations such as a desire to "give back." Another motivation may be the desire to teach and train. A more common reason practicing social workers decide to become a field instructor is the need for assistance at the organization where they are working. Although this may complement and provide for great learning opportunities, being a field instructor is a significant time commitment. Field instructors need to remember that this may be the student's first experience in a medical setting or even in a clinical social work setting so students will need oversight and are not "free labor."

Dialysis clinic learning opportunities for advanced practice MSW students

Advanced practice MSW students interning in a dialysis setting are afforded many learning opportunities consistent with the 2015 EPAS. In general, students will have opportunities to learn not only about the medical and clinical aspects of a dialysis clinic but will experience the fast-pace of the dialysis setting. Advanced practice interns can initiate and terminate with a caseload and walk through the entire clinical practice framework by participating in client engagement, assessment, intervention, and practice evaluation. Interns may engage with patients for 2 or 3 days a week (if a concurrent model of field instruction) and develop these skill sets rapidly. These advanced practice learning opportunities provide support for students who must become licensed to work in a dialysis clinic in most states.

The 2015 EPAS identifies nine required social work competencies all students must master: (1) demonstrate ethical and professional behavior; (2) engage diversity and difference in practice; (3) advance human rights and social, economic, and environmental justice; (4) engage in practice-informed research and research-informed practice; (5) engage in policy practice; (6) engage with individuals, families, groups, organizations, and communities; (7) assess individuals, families, groups, organizations, and communities; (8) intervene with individuals, families, groups, organizations, and communities; and (9) evaluate practice with individuals, families, groups, organizations, and communities. Additionally, the 2015 EPAS identifies six dimensions associated with each social work competency—performance, knowledge, values, affective reactions, critical thinking, and professional judgment—which must be matched to the BSW/MSW curricula and their learning objectives; however, they should ideally be matched to field placement site as well. Below are examples of how each of the nine competencies link specifically to learning opportunities within a dialysis clinic with respect to these six dimensions.

Competency 1: Demonstrate ethical and professional behavior

Ethical Behavior. The dialysis setting is fraught with potential ethical dilemmas. Social workers often have to advocate for patient rights as well as have difficult conversations with patients, family members, and dialysis staff. It is imperative that the intern is familiar with the NASW's Code of Ethics, and the field instructor must have frequent conversations about this code and how it relates to the dialysis setting. Another ethical issue that comes up is mitigating the patient's best interest with the "business" aspect of the dialysis world. Reimbursement tied to dialysis outcomes has many benefits, but it is important that social workers are sure that patients understand that recommendations are in their best interest, not just the facility's "bottom line," and that there are no ulterior motives to encouraging patient adherence to medical recommendations. Especially in for-profit dialysis settings, there are times that patient and employer priorities may conflict, and this is an area that requires discussion with a social work intern about relevant ethics.

Another ethical challenge in the dialysis setting is confidentiality and privacy. It is important to orient the intern on these issues by offering to conduct assessments and conversations, in an office or more private setting, on how to talk to patients chairside while they dialyze, or when to insist on discussing something sensitive in private. Social workers also may find themselves advocating for patient's privacy with dialysis staff and needing to remind staff that they should not be sharing patient information on the dialysis floor where other patients can hear such details.

A final ethical challenge for an intern in medical settings, including dialysis, is recognizing every patient's right to self-determination. It can be easy, especially for students with

little experience, to trust that the medical team knows what is “best” for the patient. At times, the medical team may request the social worker to help the patient understand and adhere to what is “best.” The social worker must apply critical thinking when working with patients to set and clarify goals and educating them on how they can ascertain whether those goals may or may not conflict with what the team feels is best for them. Ultimately patients can refuse any part of the dialysis treatment and have the right to self-manage their kidney disease care. This may mean that patients do not take their medication as prescribed, do not show up for dialysis or end their treatments early, drink excessive fluids, or do not follow their renal diet. This can be frustrating for the dialysis team and social work interns. Dialysis social workers will need to process this ethical challenge with their students during supervision and help the student act as a liaison between and advocate for both patient and medical team to form a compromise to achieve best outcomes.

Professional Behavior. The dialysis setting can be a difficult setting in which to maintain professional behavior. The frequency with which patients are seen and the intimacy of the setting can make sustaining a professional demeanor difficult. For some interns, this may be their first experience in a medical setting ever. It is the field instructor’s responsibility to ensure and redirect the intern to behave and engage with the interdisciplinary team in a professional manner. From dress code to professional speech and documentation in the medical record, the dialysis setting is a prime environment to develop and hone these skills.

In some field settings, social workers and social work interns are offered the opportunity to follow a business-casual dress code with a white lab coat or they can wear scrubs. Regardless which is chosen, the intern needs to be aware of the implications each may have. One who wears scrubs may need to be more prepared and diligent in identifying themselves as a social worker or social work intern rather than a nurse or patient care technician. Those who choose business-casual with lab coat will need to be prepared to identify themselves as a social worker rather than a doctor or advanced practitioner. It is the field instructor’s role to ensure the intern is dressed appropriately. Definitions of business-casual may change, requiring the field instructor to provide feedback when an intern is dressed inappropriately. In medical settings such as a dialysis unit, there are likely policies or procedures in place about employee dress codes. For example, because of the possibility of blood or other spills, staff and interns cannot wear open-toe shoes or must observe other restrictions. Students also must learn about how they should behave while on the dialysis floor i.e. not to approach patients or staff during shift changes when patients are being taken off of the machine, what to do in case of a medical emergency, etc.

Inappropriate dress and behavior can have a negative impact the team’s perception of the intern but also of the field instructor. Interns will not be able to thrive in the professional environment if they are not given appropriate guidance. It is vital for the field instructor to model professional behavior. This entails use of language, proper use of cell phones, and conduct in a medical environment, including what to do in case of a patient emergency or even death.

Competency 2:

Engage diversity and difference in practice

Kidney disease affects people of all ethnicities, races, socioeconomic classes, and genders. It does not discriminate on the basis of sexual orientation, gender identification, comorbid status, the state of an individual’s mental health, or extent of substance use. The dialysis setting is a rich learning environment and exposes a student to much client diversity. It provides the opportunity to use a variety of screening tools and therapeutic interventions. It requires that the student be aware of multiple cultural nuances. In author Muench’s clinic there is a significant Hispanic population, who may not understand or speak English. The clinic uses language lines and interpreters, and students can explore the effectiveness of each. Some African American patients may also express distrust of the medical community because of historical medical mistreatment. These concepts are important to be aware of in order to assist patients most effectively. Health literacy is also a significant issue for many dialysis patients, and it is important for students to understand interventions that can be used to improve disparities, assessment and interventions.

Self-awareness is a skill that can be enhanced through supervision. Assisting a student in identifying instances of over-identification, countertransference, and boundary crossing provides great learning opportunities. The diverse nature of the dialysis setting increases the likelihood a student will experience this. Muench gives students a caseload that consists of a bay or shift of patients, which allows them the opportunity to develop a therapeutic relationship with the patients. Student comments like “They remind me so much of my cousin” can be cues to the field instructor that there may be some countertransference issues, which the instructor can bring to the student’s attention.

The concept of “difference” is as important to address as that of “sameness.” Regardless of the student’s background—age, gender, race, ethnicity, religion, sexual orientation—there will likely be a patient in a given facility who is the “same” as the student. Muench has had the experience where the student feels that this sameness allows them into the patient’s group and the student overidentifies with the patient. It is important to keep an eye open for such developments and prevent the student from inappropriate interactions with patients, or even staff, related to these issues.

**Competency 3:
Advance human rights and social, economic and environmental justice**

Like many other medical settings, there are many opportunities for an intern to address policies that relate to social justice. Throughout the United States, there are many disparities with access not only to healthcare but to housing, transportation, insurance, and financial resources. Many patients begin dialysis with no insurance or primary care provider. This, coupled with the widespread lack of community resources, offers an intern many opportunities to be exposed to issues related to social and economic justice. Ongoing research into community and commercial assistance exposes a student to the limited resources some patients have available to them. Interns have the unique opportunity to witness the clinical effects that low income, unstable housing, and chronic health problems can have on an individual.

One of the tenants of social work is to work with the person in their environment. When working with this population, it is vital to be aware of the theories of human behavior, including those posited by Erik Erikson, Abraham Maslow, and others. So often, our patients are forced to experience end-of-life events and conversations in timeframes significantly earlier than they might have expected. It can be a significant clinical intervention to begin conversations surrounding the patient's psychosocial development and help them to explore the significance of their health status.

According to McLeod (2007), being aware of Maslow's hierarchy of needs is important in goal setting with patients. Holley (2012) notes that, while CMS's Conditions of Coverage for ESRD focuses on MSWs addressing the emotional concerns of patients, Maslow reminds us that this is not possible when our patients are concerned about maintaining adequate housing, appropriate food, and access to the healthcare resources required to manage their kidney disease. Additionally, cultural competence is vital in establishing therapeutic relationships with our patients.

When it comes to advancing human rights, another area where the dialysis social worker can have an impact is with regard to transplantation. There are many kidney transplant disparities including race, ethnicity, citizenship status, age, gender, and insurance. The dialysis social worker can be an invaluable tool in providing education and overcoming real and perceived barriers to this process.

Insurance and immigration status are areas of dialysis settings that afford students learning opportunities related to human rights and justice. If patients do not have adequate insurance or are not legal residents of the United States, they likely will encounter challenges getting routine outpatient dialysis (Hogan, Fox, Roppolo, & Suter, 2017; Madden & Qeadan, 2017). Scholarship about such problems is emerging, which provides additional learning opportunities that can be applied to this EPAS competency in dialysis clinics.

**Competency 4:
Engage in practice-informed research and research-informed practice**

Nephrology research is constantly evolving. To help interns more fully understand this practice setting and evidence-based practice of nephrology social work, it is important to share with them current medical and social work research relevant to nephrology. Dialysis social workers can share the most recent issues of the *Journal of Nephrology Social Work* (JNSW), Internet and local professional-education resources, and online/print articles relevant to the most recent research on kidney disease and social work. Dialysis social workers should encourage their students to accompany them (when possible) to local Council of Nephrology Social Work, ESRD Network, NASW, and other educational events. Social workers supervising students should be sure to provide historical information to students about nephrology social work that can help them understand research-informed practice in dialysis settings. This information can come from issues of JNSW (now available online), websites such as the National Kidney Foundation (NKF) and the ESRD Conditions for Coverage. It may be difficult for those not experienced in working in a dialysis clinic to understand how a dialysis unit operates; therefore, it would be normal for an advanced practice social work student to know very little about kidney disease and dialysis. As the intern's field instructor, it may be helpful to design an introductory curriculum for assigned interns to teach them about these things and update it to reflect the latest research in kidney disease.

**Competency 5:
Engage in policy practice**

Dialysis settings offer rich experiences for social work interns to engage in policy practice. Numerous and constantly changing policies can have an impact on dialysis patients and social workers. Social workers can help interns understand the policy implications of practice in dialysis settings. For example, on a federal level, Medicare and Medicaid policies are critically important to our patient population, as are federal and state budget policies related to disability, housing, education, and food assistance. At a state and local level, transportation or social work ratio policies can affect patient care. The NKF, the American Society of Nephrology, and other renal organizations often have advocacy information about current legislation affecting kidney disease populations. The state chapter of the NASW has information about proposed policies that have an impact on local issues as well. Interns can learn more about all these and create a plan for policy practice that is relevant for the dialysis setting. For example, healthcare reform and policies related to a new American healthcare plan are critically important for people with kidney disease. Interns can study and learn how these policy changes may affect the unit's dialysis population, and they participate in advocacy activities. Another far-reaching policy relates to the coverage of immunosuppressant medications after a transplant. There have been

yearly efforts, including proposed legislation, to extend this coverage. Interns can learn more about this, study the policies proposed, and engage in policy practice by advocating for changes. Author Muench's involvement with the ESRD network, IPRO, and the NKF provides interns a unique look into how changes are proposed and the impact an individual can have on policy recommendations.

In the dialysis clinic setting, Medicare requires that an MSW be available to each patient in order to assess an individual's cognitive status and ability to understand treatment recommendation, their ability to meet basic needs, whether there are any substance abuse and/or mental health concerns, and the history of treatment. In addition, the MSW is expected to evaluate and advocate for education, housing, financial, rehabilitation, and legal (e.g., advanced directive, guardianship) needs. Medicare also requires that an MSW assess not only the patient's ability to cope with and adjust to living on dialysis but also the patient's quality of life (Medicare and Medicaid Programs; Conditions for Coverage for End-Stage Renal Disease Facilities, 2008). Dialysis social workers also now must assess all patients for depression, quality of life, and rehabilitation needs. It is vital for these patients to have an MSW who can not only provide short-term clinical interventions but also understand how policy drives practice and the policies behind these interventions. Advanced practice MSW interns may not perform this work independently but do benefit from shadowing and assisting in these processes.

Competencies 6–9:

Engage with individuals, families, groups, organizations, and communities

The advanced practice MSW intern is required to engage each patient and client system and work along the social work practice framework of engagement, assessment, intervention, and evaluation. Muench's interns are provided a group of patients to engage, for which they become fully responsible in terms of assessment, intervention, and ongoing evaluation. After establishing rapport, the assessment interview provides the intern a first opportunity to determine psycho-social-spiritual factors, including past stressors that shape the here and now for the patient. This information is important as it can foretell how an individual may cope with the emotional stress of dialysis. The social worker is often the first professional in the dialysis experience who will acknowledge and listen to the emotional components of a chronic illness. It is the goal of the social worker to empower patients so as to improve their coping skills and address their needs, including reaching out to appropriate support networks, connecting with community resources, and advocating and verbalizing their needs to their other healthcare professionals. It is important to do this without disclosing the social worker's own ethical, moral, political, or religious views. This can be increasingly difficult as politics and governmental policies are beginning to have more influence in the decisions medical professionals make.

CONCLUSIONS AND IMPLICATIONS

As the renal patient population continues to grow, the psychosocial needs of this population will be ever emerging. According to the United States Renal Data System (USRDS) 2017 annual data report, there has been an average growth in incident cases of 4.1% per year since 2000. As this population continues to grow on both sides of the age spectrum, patients may be less likely to seek emotional support outside of the dialysis center (Bowman et al., 2018). The exposure to and training of MSW interns in recognizing and treating depression and other mental health issues will be vital to the improved outcomes in the future renal population and in better preparing and training future nephrology social workers.

In addition, as we see an increase in health issues in the general population and a larger social work presence in the medical field, the dialysis center becomes an ideal place for interns to be exposed to the complex needs of patients with multiple comorbidities and varied financial, social, and insurance access. An informed and invested instructor can truly set the field for interest and success not only in the dialysis setting but the medical field.

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Perspectives of Renal Healthcare Professionals about Deceased Organ Donation

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Little is known about the attitudes of renal healthcare professionals (HCPs) toward deceased donation. We surveyed 222 renal HCPs from 12 dialysis units in southeast Michigan about their attitudes toward organ donation as part of a cluster-randomized, intervention study. Factor analysis identified three subscales: general benefits (alpha .88), general barriers (alpha .80), and staff dialysis barriers (alpha .79). We compared subscale values with two variables: enrollment status in the state donor registry (DR) and intentions for future DR enrollment. Higher scores on all three scales were positively associated with DR enrollment. Mean scores varied by HCP role within the dialysis unit. Tailoring donation education to a role and focusing on the benefits may have an effective impact on HCP attitudes. Results from this study can inform future interventions to improve promotion of organ donation amongst professionals working in dialysis units.

BACKGROUND

An aging U.S. population combined with increasing rates of chronic disease and increases in life expectancy have created a demand that exceeds the supply of organs available for transplantation. The U.S. population age 65 and over was 15% in 2014 and is expected to grow to 17% in 2020 and 21% by 2030 (Colby & Ortman, 2017). Since 2008, the prevalence of chronic disease among U.S. adults over age 18 has remained constant at 42%. However, these rates increase with age: among U.S. adults 45–64 years old, 47% of the women and 54% of the men have multiple chronic conditions, and among adults 65 and over, 81% of the women and 82% of the men have multiple chronic conditions (Buttorff, Ruder, & Bauman, 2017). Nationally, life expectancy increased from 72.6 years in 1975 to 78.8 years in 2015 (National Center for Health Statistics, 2017). The number of people on the U.S. organ transplant waiting list exceeded 115,000, based on Organ Procurement and Transplantation Network data as of 12/28/17. The growth of the transplant waiting list has prompted revision of policies for organ allocation and exploration of new sources of donations (Hirth, Pan, Schaubel, & Merion, 2010).

A review of donor data in Michigan from 2004 to 2008 supported the use of brain-dead donors with end-stage renal disease (ESRD) as a source of liver donation; 35% of liver-alone donors had ESRD (Stoll et al., 2010). Utilization of extended-criteria liver donors can reduce wait-time without negatively affecting survival after transplant (Tector et al., 2006). In addition to being liver donors, individuals with

ESRD can serve as tissue donors. However, these individuals, and the renal healthcare professionals (HCPs) providing their care, may believe they are unable to donate their organs and tissue after death. Many older adults have the perception that they are unable to donate organs after death as the result of having a medical condition (Downing & Jones, 2008; Health Resources and Services Administration [HRSA], 2013; Quick, Reynolds-Tylus, Fico, & Feeley, 2016).

Research suggests that the attitudes of HCPs toward organ donation and end-of-life issues as well as patient-HCP communication regarding end-of-life issues and advance directives (ADs) have an impact on patient attitudes and actions (Black, 2007; Nam, Chesla, Stotts, Kroon, & Janson, 2011). The 2012 National Survey of Organ Donation Attitudes and Behaviors found that 31.5% of adults cited a medical professional, clinic, or doctor's office as an "important source of information" about organ donation (HRSA, 2013). Thornton, Curtis, and Allen (2006) found that having signed a living will and talking with a physician about donation were both associated with willingness to become a donor and thus recommended that primary care physicians integrate organ donation into end-of-life discussions. Patients with kidney disease prefer to receive end-of-life information from their nephrology staff (Davison, 2010). Perry and colleagues reported that individuals with ESRD were more likely to complete ADs when they felt dialysis staff members were comfortable discussing the decision (Perry, Buck, et al., 1995; Perry, Swartz, Smith-Wheelock, Westbrook, &

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Buck, 1996). Comfort level differed among professional disciplines, and support from supervisory staff encouraged discussion within a dialysis unit (Perry, Schwartz, et al., 1996). The attitudes of HCPs toward kidney transplant also affected patients waiting to get on the transplant waiting list; a positive attitude toward transplant among dialysis center staff improved the center's performance on the measure of kidney transplant wait-listing (Gander et al., 2015).

Trust issues regarding the healthcare system are multifaceted and often measured broadly (Robinson, Perryman, Thompson, Lamonte Powell, & Jacob Arriola, 2015). Racial differences in trust often reflect the cultural experiences of a racial group, personal experiences with the healthcare system, and expectations of treatment based on race (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Hammond, 2010). A study among African Americans with ESRD found evidence of a relationship between attitudes toward living donor transplantation and trust (McDonald, Powell, Perryman, Thompson, & Jacob Arriola, 2013). The authors measured trust in several dimensions: trust in the healthcare system in general, trust in doctors, trust in the donation/allocation system, and trust in the racial equity of treatment. They found a strong positive association between trust in physicians and positive organ donation attitudes, while they found no association between trust in the healthcare system and donation attitudes.

Studies suggest that healthcare professionals can inform the attitudes of their patients and the community at large in regard to organ donation (Jawoniyi, Gormley, McGleenan, & Noble, 2018; Radunz, Juntermanns, et al., 2012; Symvoulakis et al., 2012). Studies regarding attitudes of a variety of categories of HCPs toward deceased organ donation conducted worldwide reveal knowledge gaps among HCPs about donation despite overall support for donation (Burker et al., 2015; Matten et al., 1991; Radunz, Juntermanns, et al., 2012; Zambudio, Martinez-Alarcon, Parrilla, & Ramirez, 2009). Several studies found that an understanding of brain death affects attitudes toward organ donation (DuBois & Anderson, 2006; Jelinek, Marck, Weiland, Neate, & Hickey, 2012). A study in 11 countries showed that the attitudes and donation-related skills of critical-care staff correlated positively with national donation rates (Roels, Spaight, Smits, & Cohen, 2010). A 2014 review of studies conducted among HCPs showed that most organ donation interventions among HCPs were not based on theoretical frameworks and did not measure the intervention's impact on HCP behavior (Douville, Godin, & Vézina-Im, 2014).

Research conducted on renal HCP attitudes has focused on living donation, the processes for evaluating and listing individuals for deceased donor transplant, and such end-of-life issues as discontinuation of dialysis, decisions about care, AD, and organ allocation and procurement (Ayanian et al., 2004; Davison, Kromm, & Currie, 2010; Waterman et al., 2013). However, little research has focused on the attitudes of renal HCPs regarding deceased donation or the

concept of dialysis patients donating organs and tissue after death. A Turkish study of nurses and physicians working in dialysis and transplant units found sufficient knowledge and positive attitudes about organ donation among the group and recommended group members act as role models to improve attitudes among the general public toward organ donation (Demir, Selimen, Yildirim, & Kucuk, 2011). Therefore, an examination of attitudes among renal HCPs is warranted.

Our group developed a three-factor organ-donation scale for HCPs that addressed common beliefs with respect to deceased donation and beliefs about whether individuals on dialysis could donate organs. In this study, we expanded on previous work by adapting an existing organ-donation attitude scale to assess the attitudes of renal HCPs toward deceased donation. The new survey instrument was administered to nonphysician renal staffs at 12 dialysis units in metropolitan Detroit. The goal of this study was to examine the attitudes of renal healthcare professionals about deceased organ donation and validate a new organ-donation attitude scale for renal HCPs.

STUDY DESIGN

The data reported herein came from the baseline assessment of a group-randomized intervention trial that tested the effectiveness of using lay health advisors (termed peer mentors) with individuals on dialysis in order to increase enrollment in the Michigan Organ Donor Registry. Baseline data were collected after randomization but prior to the initiation of any intervention activities. Data collection was done by 222 staff members from 12 dialysis units in southeast Michigan between June 2011 and September 2013.

SETTING AND PARTICIPANTS

The National Kidney Foundation of Michigan (NKFM) received funding from the Health Resources and Services Administration (HRSA), Healthcare Systems Bureau, Division of Transplantation, to implement an organ donation intervention in 12 dialysis units in southeast Michigan. Of the 12 units, 11 were hemodialysis units, the majority of which also had a peritoneal dialysis component. One unit was a home only program. The NKFM partnered with the University of Michigan, Gift of Life Michigan/Minority Organ and Tissue Transplant Education Program, Henry Ford Hospital, and Greenfield Health Systems to design the intervention. The social work manager for the units prioritized the order in which paired units would implement the study, taking into account staffing levels and other ongoing projects. The baseline survey instrument was completed by 222 renal HCPs in southeast Michigan between June 2011 and September 2013. The study was approved by the Henry Ford Health System Institutional Review Board and the University of Michigan Health Sciences Institutional Review Board.

METHODOLOGY

The attitude scale used in this study was adapted from a similar instrument used by our group in three prior organ donation studies among clients of African American hair stylists, members of African American churches, and members of historically African American Greek Letter Organizations (Andrews, Zhang, Beuchley, et al., 2016; Andrews, Zhang, Magee, et al., 2012; Loughery et al., 2017; Resnicow, Andrews, Beach, et al., 2010; Resnicow, Andrews, Zhang, et al., 2012). The scale was adapted for use among renal HCPs, including nurses, social workers, dietitians, technicians, and administrative staff. One item was added to further probe about brain death, and five items were added to address the ability of hemodialysis or peritoneal dialysis patients to donate organs after death and the appropriateness or “cruelty” of discussing this topic. The questions were tested with renal HCPs and individuals on dialysis and revised iteratively.

The baseline survey comprised 32 items and assessed renal HCP barriers and benefits to organ donation. All items were scaled 1 (strongly disagree) to 7 (strongly agree). Higher scores indicated more positive attitudes about donation. Items that assessed barriers to donation were reverse coded so that higher scores were considered more positive, pro-donation attitudes. Barriers included family disapproval, cost, religious and spiritual beliefs, misconceptions about the donation process, and what was called ick and jinx factors (respectively, a negative emotional reaction to the idea of the organ donation and superstitions about harm or premature death occurring as a result of signing up on a donor registry). Ick factors capture the feeling of disgust some experience regarding the organ donation and transplant process and cutting or “mutilating” the body. Jinx factors capture feelings of anxiety, fear, or superstition about what will happen if one actually registers on a donor registry (Morgan, Stephenson, Harrison, Afifi, & Long, 2008). Benefits to organ donation included altruism, providing comfort to family members after death, and religious beliefs.

Enrollment status on the Michigan Organ Donor Registry was assessed by the question, “Have you ever signed up to donate your organs?” A response of yes indicated positive “donor registry enrollment status.” Follow-up questions asked people which method was used to register them and whether they had a red heart sticker on their driver’s license, an indicator of having signed up on the registry in Michigan. For those who had indicated they had not enrolled in the donor registry enrollment, we assessed their intent to do so with the question, “How likely are you to sign up as an organ donor?” Response options were scaled 1 (not at all likely) to 10 (very likely). We designed three categories “high” (8–10), “medium” (4–7), and “low” (1–3) to delineate gradations of “intended donor registry enrollment status.” Positive donor registry enrollment status and intended donor registry enrollment status were used to assess the validity of the

attitude scale, with the assumption that more positive attitudes would be associated with higher likelihood of donor registration and higher intention among those not enrolled.

Respondents were asked, “Have you talked to your family members about whether or not you want to donate your organs?” Personal connection to organ donation was assessed through three yes/no questions, which asked the respondent if they knew anyone who needed an organ transplant, had received an organ transplant, or had donated an organ. Additional questions asked, “Have you ever heard of the Michigan Organ Donor Registry?” and “How likely are you to donate a kidney to a family member who needed one?” Again, we used a scale from 1 (not at all likely) to 10 (very likely).

Demographic data included age, sex, race/ethnicity, education, and income. Age was obtained by asking for the participant’s date of birth. Educational status was determined by asking, “What is the highest grade or degree you have completed?” Response categories were “Some high school or less,” “High school graduate or GED,” “Some college or 2-year degree,” “4-year college graduate,” “Master’s degree” and “Doctoral or professional degree.” To measure household income, we queried “What is your current total yearly household income before taxes? (Please include income from all sources in your home.)” Response categories were “Under \$10,000”; “\$10,000–\$19,999”; “\$20,000–\$39,999”; “\$40,000–\$59,999”; “\$60,000–\$79,999”; “\$80,000–\$99,999”; “\$100,000–\$149,999”; “\$150,000–\$199,999”; and “>\$200,000.” Response options were collapsed for data analysis. Staff roles in dialysis units were determined by the question, “What is your role in the dialysis unit?” Response categories were “social worker,” “nephrologist,” “dialysis technician,” “reuse staff,” “registered dietitian,” “registered nurse,” “administrative staff,” and “other.”

Prior to implementation in a given dialysis unit, study staff met with the clinic manager, social worker, and local leadership personnel to provide a study overview/timeline, gain buy-in, discuss preferences for patient recruitment, and schedule staff training. Study staff led the 30-minute staff training, which included a study overview, the staff’s role in the study, and basic facts about organ donation. The training was held on two consecutive days to reach all staff.

We administered the baseline survey at start of training to assess staff attitudes and beliefs about organ donation. Participation was voluntary. A positive introduction of the study by the nurse manager facilitated staff completion of the survey. All data collection for these analyses occurred before any intervention activity was initiated in the unit. Each questionnaire contained a unique participant code that indicated the unit in which the staff member worked. The participant’s name and address were associated with the unique participant code on the cover sheet and in a separate database of cover sheet information. The survey responses were stored separately from the staff contact information to protect confidentiality.

ANALYTICAL APPROACH

Factor analysis, with varimax rotation, was used to identify potential subscales. After identifying a three-factor solution based on eigenvalues >1 , factor loadings >0.35 , and face validity of subscales, we computed internal consistency of each scale (Cronbach's alpha), and examined the relationship between scale scores and demographics, self-reported enrollment status, and intended enrollment status. Multivariate analyses included age, gender, income, and education as covariates. Because we collected the data in dialysis units, we used a mixed-effects model to account for the potential nonindependence of response by individuals in the same unit. We adjusted p values for intraclass correlation coefficients (ICCs) because of the design effect of sampling individuals within units. The ICCs of the three scales identified ranged from 0.008 to 0.024. The data analysis for this paper was generated using Proc Mixed in SAS software, Version 9.1.3. (SAS Institute Inc., Cary, NC, USA).

RESULTS

A total of 222 renal staff members completed the baseline survey. This represented 65.5% of all nonphysician staff at the 12 dialysis units. Three subscales were identified as shown in **Table 1**: general benefits (alpha .88), general barriers (alpha .80), and staff dialysis barriers (alpha .79). The general benefits scale contains 9 items, the general barriers scale contains 11, and the staff dialysis barriers contains 4. In general, there were no items whose removal would have increased the internal consistency on any scale.

Staff demographics.

As shown in **Table 2**, the average number of staff members completing a survey per dialysis unit was 19, with a range of 5 to 34. Most were under the age of 45 (63%), with 32% between 45 and 60, and 5% over the age of 60. Most (80%) were female. Race/ethnicity broke down as follows: 40% White, 32% Black, 21% Asian/Pacific Islander, 4% other, and 3% Latino/Hispanic. More than half (59%) had received a 4-year college education or above. By income, slightly more than half (54%) reported income of \$20,000–\$59,999, while 4% reported income of less than \$20,000 and 42% reported income of \$60,000 or more. The most prominent staff roles were nursing staff (33%), dialysis technician (33%), and social worker (10%). Other roles included reuse staff/equipment technician, registered dietitian, administrative, and other. Nephrologists were invited but did not attend the training and complete the survey. Consequently, they are not included in the sample. The intervention group differed from the control group in having a larger percentage who identified as Black, while the control group had more staff who identified as White.

Association of scale scores and demographics.

As shown in **Table 3**, scores did not differ by age, education, or income for any of the three scales. For scale 1 (general benefits), females had significantly higher scores than did males; scores on scale 2 (general barriers) and scale 3 (staff dialysis barriers) did not differ by gender. All three scales showed significant differences by race. On scale 1, White respondents had significantly greater attitudes favoring donation than Hispanic/Latino and Asian/Pacific Islander respondents. On scale 2, Whites had significantly higher mean scores than staff of all other racial groups; Black respondents also had significantly higher mean scores on scale 2 than Asian/Pacific Islander respondents. On scale 3, Whites again reported significantly higher pro-donation attitudes than staff who were Hispanic/Latino and Asian/Pacific Islander; likewise, Blacks again reported significantly higher mean scores than Asian/Pacific Islander respondents.

Association of scale scores and donor registry enrollment status.

On all three scales, as shown on **Table 3**, staff members who reported they had enrolled on the donor registry had higher mean scores than those who reported they had not enrolled. Intended enrollment was measured for those who indicated they were not already enrolled. In partial and fully adjusted analyses, higher mean scale scores were associated with greater intent to enroll. On scale 1, all pairwise comparisons were significant in univariate and multivariate analyses across levels of intention. On scale 2, the pairwise comparison between high intention and medium intention was significant. On scale 3, the pairwise comparison between high intention and low intention was significant, as was the pairwise comparison between medium intention and low intention. As shown on **Table 4**, all three scales were positively associated with current enrollment on the donor registry. For each 1 point of increase in the mean score on the scale, the odds of indicating enrollment increased by 2.81 times on scale 1, by 2.52 times on scale 2, and by 0.34 times on scale 3.

Association of scales scores and staff role

On scale 1, there were no significant differences in mean attitude score between staff categories as shown on **Table 3**. On scale 2, the pairwise comparisons between social worker and dialysis technician, between social worker and reuse staff, and between social worker and other staff were all significant; in all cases social workers had higher scores indicating more favorable attitudes toward donation. On scale 3, the pairwise comparisons between social worker and dialysis technician were significant as were pairwise comparisons between registered dietitian and dialysis technician, with social workers and registered dietitians each having higher scale scores than dialysis technicians.

Table 1. Survey questions, subscale grouping, and factor loading

		Rotated factor loading
Scale 1 General benefits <i>alpha 0.88</i>	Organ donation is an act of charity.	.47
	Organ donation allows something positive to come out of a person's death.	.63
	Signing up to donate my organs is a way I can do something good for others.	.73
	Signing up to donate my organs will allow my family to carry out my wishes.	.83
	Signing up now to donate my organs can help my family by removing the stress of making that decision.	.76
	Donating my organs allows me to help others to live.	.78
	Donating my organs may provide my family with some comfort.	.76
	Donating my organs can help my family cope with their grief.	.73
	Donating my organs is consistent with my religious tradition.	.57
Scale 2 General barriers <i>alpha 0.80</i>	If I signed up to donate my organs, my family members would not approve.*	.39
	If a person has donated his or her organs, it is impossible for that person to have a regular funeral service.*	.47
	It costs a donor family money to donate organs.*	.66
	Organ donation is against the rules of my religion.*	.47
	It is possible for a brain dead person to recover from their injuries.*	.40
	A person needs to have all of their parts in order to go to heaven.*	.69
	It would be weird to have my organs inside someone else.*	.50
	Even thinking about death could bring about bad things.*	.71
	I can't decide whether I want to donate my organs until I know more about brain death.*	.56
	If a person has signed the organ donor registry, doctors won't try as hard to save that person's life. *	.52
	Organs can be bought and sold in the United States.*	.39
Scale 3 Staff dialysis barriers <i>alpha 0.79</i>	Dialysis patients cannot donate any organs at all.*	.66
	Dialysis patients are too sick to donate their organs.*	.80
	It is inappropriate to talk with dialysis patients about donating their organs.*	.76
	It is cruel to talk with dialysis patients about donating their organs.*	.75

*Items were reverse coded so that higher scores indicate more positive feelings toward donation

Table 2. Staff demographics and baseline[^] information

	Intervention (n=125)	Control (n=97)	Total (n=222)
Age group			
45 or younger	60.40	58.76	63.06
45-60	27.20	38.14	31.98
>60	6.40	3.09	4.95
Gender (Female %)	78.23	83.33	80.45%
Race/ethnicity			
Black	40.80	21.65	32.43%
Latino/Hispanic	3.20	2.06	2.70%
White	29.60	52.58	39.64%
Asian/Pacific Islander	22.40	19.59	21.17%
Other	4.00	4.12	4.05%
Education			
Some high school or less	0	0	0
High school or GED	5.60	5.15	5.41
Some college or 2-year degree	33.60	39.18	36.04
4-year college or above	60.8	55.67	58.56
Income			
\$20,000 or less	3.53	4.41	3.92%
\$20,000–\$60,000	56.47	50.00	53.59%
\$60,000 or more	40.00	45.59	42.48%
Mean scale 1: General benefits (sd)	5.54 (1.13)	5.63 (1.21)	5.58 (1.17)
Mean scale 2: General barriers* (sd)	5.72 (1.02)	5.88 (0.97)	5.79 (1.00)
Mean scale 3: Staff dialysis barriers* (sd)	5.48 (1.53)	5.69 (1.39)	5.57 (1.47)
Rate of positive donor registry enrollment status	49.59	48.42	49.07%
Positive intended donor registry enrollment status**			
Low (1–3)	13.85	23.53	18.10%
Medium (4–7)	61.54	50.98	56.90%
High (8–10)	24.62	25.49	25.00%
Number of staff members per unit (mean, range)	21.00 (8-34)	16.17 (5-29)	18.50 (5-34)
Staff role			
Social worker	9.60	11.36	10.33%
Dialysis technician	32.80	34.09	33.33%
Reuse staff/Equipment Technician	4.80	2.27	3.76%
Registered dietitian	6.40	5.68	6.10%
Registered nurse	29.60	38.64	33.33%
Administrative staff	0.80	2.27	1.41%
Other	16.00	5.68	11.74%

[^] Hybrid of baseline. After randomization but before any intervention activity as is common in group randomized trials due to logistics.

*:Reverse coded so that higher scores reflected more positive attitudes toward donation.

**Positive intended donor registry enrollment status among subjects who are not signed up on the registry.

Table 3. Predictors/correlates of attitudes toward donation—Staff (n=222)

	Mean attitude (1: General Benefits)	Mean Attitude (2: General Barriers) *	Mean Attitude (3: Staff Dialysis Barriers) *
Age group			
45 or younger	5.53	5.74	5.52
45-60	5.72	5.85	5.72
>60	5.36	6.00	5.28
Gender			
Male	5.10¹	5.66	5.38
Female	5.70¹	5.82	5.61
Race/ethnicity			
Black	5.56	5.72¹	5.65¹
Latino/Hispanic	4.79¹	5.24²	4.63²
White	5.89^{1,2}	6.19^{1,2,3}	5.95^{2,3}
Asian/Pacific Islander	5.16²	5.24¹	4.90^{1,3}
Other	5.35	5.48³	5.36
Education			
High school or GED	5.42	5.84	5.50
Some college or 2-year degree	5.70	5.93	5.77
4-year college or above	5.52	5.71	5.46
Income			
\$20,000 or less	5.92	5.69	5.51
\$20,000–\$59,999	5.47	5.84	5.61
\$60,000 or more	5.53	5.68	5.49
Positive donor registry enrollment status			
Yes	6.09¹	6.17¹	5.86¹
No	5.11¹	5.43¹	5.28¹
Intended donor registry enrollment among non-enrolled			
Low (1–3)	3.99¹	5.21	4.31^{1,2}
Medium (4–7)	5.09¹	5.31¹	5.40¹
High (8–10)	5.98¹	5.82¹	5.79²
Staff role			
Social worker	5.50	6.45^{1,2,3}	6.30¹
Dialysis technician	5.59	5.74¹	5.24^{1,2}
Reuse staff/Equipment Technician	5.63	5.31²	5.31
Registered dietitian	6.05	6.01	6.19²
Registered nurse	5.52	5.70	5.62
Administrative staff	6.41	6.14	5.42
Other	5.32	5.63³	5.41

*Items were reverse coded so that higher scores indicate more positive feelings toward donation.

Common superscript indicates groups significantly different in pairwise comparison with p value < .05 based on mixed effect modeling on the mean scales accounting for correlation of subjects in the same center.

Table 4. Association of Staff Attitudes and Donor Status:

	Odds Ratio	95% CI	P-Value
General benefits (scale 1)	2.81	(1.95, 4.04)	< .0001
General barriers (scale 2)*	2.52	(1.74, 3.64)	< .0001
Staff dialysis barriers (scale 3)*	1.34	(1.10, 1.64)	.0046

*Items were reverse coded so that higher scores indicate more positive feelings toward donation

LIMITATIONS

The study has several limitations. Data were self-reported and enrollment status on the donor registry was not validated. In addition, the sample was not randomly drawn, so selection bias may be present. Staff members were aware of their randomization condition at the time they completed the baseline survey, which may have influenced their responses. However, scores in the attitude scales are not very different, nor is the rate of positive enrollment; it doesn't appear that knowledge of treatment group impacted their attitudes. The sample had 42% who had an annual income of \$60,000 or more, 59% of the sample had a college degree or above, and 80% was female. The survey was voluntary for staff. By virtue of their willingness to participate, staff members who responded may be more supportive of organ donation than those who did not agree to participate. Thus, our results may not be generalizable to the larger renal staff population. Furthermore, the presence of a vocal staff member who was either supportive or against organ donation may have affected results. The clinic manager introduced the study staff and the introduction varied based on that manager's support for the study and organ donation in general.

The study was conducted in 12 units of a regional dialysis provider located in the metropolitan Detroit area, so results may not be generalizable to rural areas or larger, national dialysis providers. We did not ask how long the renal staff member was employed (a) in the given unit or (b) worked in renal care. In this study, we did not directly ascertain contact time between staff members and patients. All renal staff, including the nephrologists, were invited to attend the lunch training sessions; however, physicians did not and so did not complete the survey. We administered the survey on two separate days, so second-day participants may have discussed the content with participants from the first day. The study was cross-sectional, and therefore we cannot assume a causal relationship between attitudes and positive enrollment status. Longitudinal studies examining the association of attitudes and donation behaviors are needed to verify the findings observed here.

CONCLUSIONS

We examined the attitudes of renal HCPs toward deceased donation and tested the psychometric properties of a new scale measuring those attitudes. We found that more positive attitudes were associated with those already enrolled in a donor program and that mean scale scores differed by race and staff role. The first factor (general benefits scale) contained the same questions and had a similar alpha as our work in the sorority-fraternity population and supports the validity of the scale (Andrews, Zhang, Buechley, et al., 2016). The second factor (general barriers scale) contained similar questions to surveys used in our previous work in other settings but the factors loaded differently. The third factor (dialysis barriers scale) contributes new knowledge to the field by providing insight into the current beliefs and attitudes about the practice of asking individuals who are on

dialysis about donating organs after death. This finding can have an impact on epidemiological studies to help understand the relationship between patient behavior and staff attitudes. Additionally, the measures can be used to identify intervention targets and measure intervention effectiveness in a pretest and posttest design.

We also examined the association of scale score with the status of donor registry enrollment and intended donor registry enrollment among renal HCPs. Self-reported enrollment status and high-intention to sign up to donate organs were both associated with more positive attitudes toward organ donation on each subscale. These findings suggest validity of the instrument as the attitudes were associated in the expected direction with positive enrollment status.

Mean scores differed by race on all three scales. The instrument has been previously administered in studies that comprised more than 90% African American participants, so we cannot compare to past studies. The current study of renal HCPs was a more racially/ethnically diverse group: 40% White, 32% Black, 21% Asian/Pacific Islander, 4% other, and 3% Latino/Hispanic. However, the fact that the general benefits scale included the same questions with a similar alpha (.88 in current study vs .87 in sorority-fraternity) implies that the benefits of organ donation are viewed the same across races. Thus, the measures are generalizable across ethnic populations.

Mean scale scores also differed by staff role. While social workers had the highest mean scores on the two barriers scales, the associated, respective mean scores for the general benefits scale were lower. Furthermore, the differences between the various staff roles in the scores for the general benefits scale were not significant, suggesting that perhaps renal HCPs do not see the benefits of organ donation. They are often witnesses to individuals returning to dialysis after a failed transplant but may not see transplant success stories as frequently. Waterman, Goalby, Hyland, McCabe, and Dinkel (2012) surveyed dialysis clinic managers in a Midwest ESRD network and determined that knowledge of kidney transplant was inadequate. Over 70% of respondents did not know that a living kidney transplant can last 15–20 years, and that most kidney transplants are functioning one year after transplantation. Waterman, Dew et al. (2013) also found that positive attitudes toward transplant and facility policies supportive of transplant education at the highest levels of administration contributes to dialysis staff educating patients about transplant. Education that focuses on the benefits of organ donation would be a useful intervention for all levels of renal HCPs.

The role and amount of interaction that a staff member has with the individual on dialysis may have an impact on patient attitudes. Staff role could also be a proxy for education, although there were no differences in scale scores by education. Education of HCPs regarding organ donation is one component that can increase the number of organs avail-

able for transplant (Jawoniyi et al., 2018). Using a single educational approach for all staff, such as the typical lecture, may not be as effective as tailoring education for HCPs based on factors such as staff role or barriers. A review article showed that interventions tailored on barriers can change professional practice, although the effect is variable and tends to be small to moderate (Baker, 2015). Current evidence is inconclusive on the best methods for tailoring.

Strategies targeted at renal HCPs may be more effectively designed using behavioral theories and behavior change strategies similar to how interventions for “patients” are created and generate customized interventions. However, “there is a lack of sound theoretical interventions aimed at improving professional practices regarding the donation process or at increasing donation rates” (Douville, Goudin, & Vézina-Im, 2014). A study investigating the impact of a training program for nurses on organ donation rates mentioned the use of the change theory but did not explain how the theory was used (Taylor, Young, & Kneteman, 1997).

Looking outside the realm of organ donation, one study confirmed that the theory of planned behavior (TPB) variables were associated intention to use clinical practice guidelines for patient care among HCPs (Kortteisto, Kaila, Komulainen, Mäntyranta, & Rissanen, 2010). The TPB suggests that an individual's behavior is determined by his or her behavioral intention, which is shaped by attitude toward behavior, subjective norms, and perceived behavioral control. The authors suggested that different strategies should be used to target physicians, nurses, or other HCPs.

A theory-led, systematic review of interventions targeting HCP behavior change found that interventions that modify peer group norms through action (such as reminders or audit and feedback) and educational outreach tend to be more successful than those based on persuasion (Johnson & May, 2015). Multiple interventions packaged together were more effective than single interventions. The authors suggested that interventions in professional healthcare settings should focus on a collective rather than individual action, which can lead to normative and relational restructuring.

Furthermore, targeting healthcare professionals for educational campaigns on transplantation and organ donation is recommended because they can act as role models who have a positive impact on attitudes of the general public (Demir, Selimen, Yildirim, & Kucuk, 2011). Medical school is also a viable setting for educating future physicians to become disseminators of organ donation information (Radunz, Benkő et al., 2015; Radunz, Juntermanns et al., 2012). Radunz, Benkő, et al. (2015) found that a 45-minute lecture for fourth-year medical students improved their attitude toward donation

Our findings suggest that it may be beneficial to address the benefits of organ donation and transplant among renal HCP educators as they often do not witness the successful outcome of a transplant. Intervention messages that empha-

size a prosocial, transcendent benefit may be effective in this population. Studies to identify effective messaging and development of tailored interventions for HCPs are warranted. Previous studies have not looked at race-specific benefits and racial salience in relation to organ donation and this represents a direction for future study. Finally, researchers and practitioners are encouraged to use the measure presented herein, and adapt it as needed.

Author Note

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