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The Journal of Nephrology Social Work

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The Journal of
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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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JOIN THE *JNSW* EDITORIAL BOARD

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

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

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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:

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- Pediatric Issues
- End-of-Life Concerns
- Sleep Disorders
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- Aging and Gerontological Issues
- Disaster Preparedness
- Comorbid Illnesses
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- Professional Roles
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- Quality of Life
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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.

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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.

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Order of the Manuscript Sections

1) Title page
2) Abstract
3) Text
4) References
5) Appendices (optional)
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8) Figures with captions

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Expressions of Gratitude and Positive Emotion Among Hemodialysis Patients: Qualitative Findings

Rosalba Hernandez, PhD, School of Social Work, University of Illinois at Urbana-Champaign, Urbana, IL; Brett Burrows, MS, and Kenneth Wilund, PhD, Department of Kinesiology & Community Health, University of Illinois at Urbana-Champaign, Urbana, IL; Judith T. Moskowitz, PhD, Department of Medical Social Sciences, Osher Center for Integrative Medicine, Northwestern University Feinberg School of Medicine, Chicago, IL

The current qualitative inquiry solicited hemodialysis (HD) patients to identify events or incidences that have gone well in their day-to-day life and things they consider to be blessings, and to further reflect on the contributors to such events. Hemodialysis patients kept an electronic journal using investigator-purchased tablet computers. Multiple themes emerged for which HD patients expressed gratitude: 1) life itself, 2) positive or improving health, 3) family interactions and social support, 4) clinic resources, favorable treatment therapy, and staff, and 5) other small events. Clinicians are urged to explore the psychological assets that HD patients possess with a focus on how these might be further cultivated and whether their amplification leads to improved quality of life.

INTRODUCTION

Empirical evidence documents the widespread prevalence of psychological distress that hemodialysis patients routinely experience, along with the associated detrimental sequala that dramatically elevate the odds for premature death (Fischer et al., 2011; Hedayati et al., 2008). For instance, comorbid depression is associated with adverse kidney disease outcomes (Kop et al., 2011), greater risk of hospitalization, and decreased survival rates (Hedayati et al., 2010; Palmer et al., 2013). The literature to date, however, neglects to capture the positive emotions and experiences that hemodialysis (HD) patients encounter on a day-to-day basis, even in the midst of debilitating disease, and few researchers explore whether these positive states exert healthful effects. Although end-stage renal disease (ESRD) requiring hemodialysis represents a taxing condition, research on emotion contends that mixed-emotions conceivably co-occur and that positive emotions and psychological well-being are achievable states even during stressful life situations (Moskowitz, Hult, Bussolari, & Acree, 2009; Russell & Carroll, 1999). Yet, the research community has failed to document experiences of emotional well-being in this patient population, e.g., feelings of gratitude, happiness, life meaning and purpose, among others.

PURPOSE

Within the context of a single-arm pilot trial (Hernandez et al., 2018), we asked HD patients to identify events or incidences that have gone well in their day-to-day life, things they consider to be blessings, and to further reflect on the contributors to such events.

MATERIALS AND METHODS

Study Population and Data Source

We used data derived from *Joviality™*, a single-arm pre-post pilot trial testing the feasibility of an Internet-based positive psychological intervention with HD patients with elevated symptoms of depression. Details of the pilot trial have been published elsewhere (Hernandez et al., 2018). Briefly, patients were eligible for the trial if they met the following criteria: a) aged ≥ 18 years, b) on HD therapy for ≥ 3 months, c) elevated symptoms of depression defined by using the Center for Epidemiologic Studies Depression Scale (Radloff, 1977) (score ≥ 10), d) fluent in English, and e) absence of serious comorbid medical conditions, as per clinical staff, that might affect participation (e.g., blindness). The *Joviality*" trial was approved by the Institutional Review Board of the University of Illinois and written informed consent was obtained from all enrolled participants.

A total of 14 patients were enrolled in the *Joviality™* pilot trial. Patients attending regularly scheduled maintenance HD treatment completed our five-week, Internet-based positive psychological intervention using an investigator-purchased tablet computer (Apple iPad), where they learned empirically validated behavioral and cognitive skill sets known to boost positive affect and overall psychological well-being. Intervention content of our Internet-based curriculum focused on teaching the following skill sets: 1) identifying and using personal strengths, 2) noting positive events in daily life, 3) prolonged appreciation and relishing of positive events, 4) positive reappraisal of stressful events or situations, 5) gratitude, 6) regular practice of mindfulness/

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meditation, 7) setting and working toward pragmatic and achievable goals, and 8) planning and performing acts of kindness. During each HD treatment session, patients were handed an Apple iPad to visit our study website to access text, video, and audio curricula and to complete didactic exercise modules. Using a unique username and password, patients logged into the website three times per week to complete 20 30-minute sessions; that is, they accessed the site every time they were at the clinic for their regularly scheduled HD treatment.

Measurement of Positive Life Events

During Week 1 of the intervention, participants learned of the importance of noticing and acknowledging positive events that occur in day-to-day life. Positive life events are associated with increases in positive emotion (Murrell & Norris, 1984; Zautra & Reich, 1983) and scheduling of "pleasant events" is a central part of multiple types of psychotherapy for depression (Krause, 1998; Lewinsohn, Hoberman, & Clarke, 1989). Even in the midst of severe stress, most people spontaneously experience and note small positive events, and these events may help them cope with emergent stress (Folkman, 1997). After studying the curricula during Week 1, HD patients were asked to keep an electronic journal addressing the following questions: 1) Describe something good that happened in the past day, 2) What feelings or thoughts did you have while it was happening? How did your body feel? and 3) Did you do anything to amplify or savor it? Detailed journal entries were then analyzed qualitatively to extract overarching concepts identified by HD patients regarding the types of positive events experienced on a daily basis.

RESULTS

The mean age for participants was 57.4 years (SD = 12.12), 50% were female. All were born in the U.S., of which 50% were non-Hispanic White, 42.9% Black/African American, and 7.1% Hispanic/Latino. 42.9% reported an annual income below $20,000 (see **Table 1**). The average duration of HD treatment across enrollees was 3.6 years. A total of 64.3% self-reported having a diagnosis of diabetes and 92.9% reported having high blood pressure (hypertension).

Table 1.
Participant Characteristics at Baseline (*N* = 14)

Characteristics	*Mean* (SD) or *n* (%)
Age	57.43 (12.12)
Female (%)	7 (50)
Race/Ethnicity	
Non-Hispanic White	7 (50)
Black or African American	6 (42.9)
Hispanic/Latino	1 (7.1)
Avg. time on dialysis (years)	3.6 (2.98)
BMI (kg/m^2)	34.5 (18.86)
Married (%)	5 (35.7)
Currently employed	3 (21.4)
Years of education	13.29 (2.46)
U.S. born (%)	14 (100)
Annual household income (below $20,000)	6 (42.9)
Has health insurance (%)	12 (85.7)
Self-reported hypertension	13 (92.9)
Self-reported hypercholesterolemia	10 (71.4)
Self-reported diabetes	9 (64.3)
Depressive symptoms	15.48 (5.52)

Multiple themes emerged identifying events or people toward which hemodialysis patients expressed gratitude, and included the following: 1) life itself, 2) positive or improving health, 3) family interactions and social support from family and friends, 4) dialysis treatment and staff, and 5) other small events.

Life Itself

A majority of patients expressed gratitude for the gift of life itself, as depicted in the following statements: "Just waking up this morning to a day that wasn't promised."; "I woke up this morning."; "To be alive."; and "To be alive and do things that I normally do." Amid a debilitating chronic condition that can greatly affect life expectancy, our participants expressed gratitude for morning awakenings, which allowed them the opportunity to attend treatment, engaging in usual activities or hobbies (e.g., continue playing in a music band), and interacting with family, friends, and loved ones.

Positive or Improving Health

Patients expressed gratitude toward subjective ratings of improved health despite having a progressively debilitating disease; typically, health and quality of life can slowly decline in HD patients without an eventual kidney transplant. Patients of the *Joviality™* trial, however, expressed gratitude, despite taxing treatment demands, because they experienced "good days" with little pain or disease-related health restrictions. Statements included the following: "That I feel good and I'm alive."; "That my health is better than a year ago…I am not in pain and I am doing more."; "…for my health…"; and "I felt pretty good when I got up today and also yesterday." Patients acknowledged and cherished the days where they felt in good spirits and when little-to-no disease-related ailments were evident.

Family Interactions and Social Support from Family and Friends

There was an overwhelming response of gratitude towards the patients' family members and friends for small gestures, including provision of transportation to and from the clinic site for dialysis treatment. Direct statements included: "My brother getting me to treatment."; "Having John bring me to dialysis."; "My wife giving me a ride to dialysis so I wouldn't have to drive. I didn't feel very good at the time and was very thankful."; and "Today, I'm thankful for the bus transportation to treatment." Patients also expressed gratitude for their social support system, as comprised of family, friends, and acquaintances, e.g., "My wife is my ROCK."; "My friend Bob took over the responsibility for getting me to surgery tomorrow."; "I'm thankful for my wife's help when I don't feel good. She doesn't even complain or ask questions."; and "Grateful for my church family for all the help." Family and friends were identified as important sources of emotional and physical support and were deemed as essential supports in meeting daily life needs—and, essential for positive emotion and psychological well-being.

Dialysis Treatment and Staff

Although HD treatment is a lifesaving procedure, it typically lasts 3–4 hours per treatment session and can cause negative side effects. Despite the inordinate amount of time in therapy, patients expressed gratitude for the clinic staff, their provision of excellent care rated as first-class, and for sessions free from complications, e.g., "For having excellent techs at dialysis and a chance to watch my granddaughter play basketball."; "I'm glad to have such good techs at my dialysis unit."; "My treatment is going well."; and "We got my treatment started without any trouble." Indeed, good-quality care at the dialysis center greatly contributed to feelings of positive emotion and gratitude.

Other Small Events

Participants of *Joviality™* also expressed gratitude for a variety of other life happenings, as depicted in the following statements: "That things are going smoothly and I use the things I've read about in this study."; "Thankful that I'm learning how to relax and not react to everything."; "I'm grateful for the spring weather."; and "That my furnace is working!"

DISCUSSION

Patients experiencing a chronic or terminal illness often experience frustration when others express condolences for their suffering and pain-centered life. But, as expressed by well-known public speaker, Claire Wineland, who had cystic fibrosis, "I'm okay. I'm just like everyone else. I'm having human experiences. I'm having pain, suffering, and joy." Similarly, hemodialysis patients have a life beyond the hemodialysis clinic where positive emotions are experienced in abundance, and positive events are happening on a daily basis. In the field of medicine, it is imperative that we move away from a strict disease-focused paradigm and instead shift to expand our view to include positive psychological assets that focus on human flourishing, resilience, and daily experiences of positive emotion. In a movement likened to a quiet revolution, the American Heart Association is embracing this shift, with a focus on the concept of cardiovascular health related to maintenance and promotion of favorable behavioral health practices and biological attributes. Likewise, the field of nephrology is urged to fully explore the psychological assets that HD patients possess, how these might be further cultivated, and whether their amplification leads to improved quality of life and survival.

Conflict of Interest and Funding

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Integrating Advance Care Planning Within the Psychosocial Care of Nephrology Patients

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Persons with end-stage kidney disease (ESKD) are at increased risk for multiple health complications, including increased hospitalizations and shortened life expectancy. These health risks elevate the urgency to complete an advance directive (AD), allowing patients to express their wishes if they are unable to because of limited capacity. Dialysis social workers are well-positioned to skillfully lead these conversations and respond to emotional distress, family conflict and pain, and symptom burden that many persons with ESKD experience. This paper outlines a framework for dialysis social workers to assess the wishes of patients in the event of worsening health and offers suggestions for interventions when patients and family members experience distress related to serious illness and advance care planning (ACP).

INTRODUCTION

People with chronic kidney disease (CKD) typically suffer a cascade of comorbid conditions with an intensity that can have a significant impact on their quality of life. After dialysis has been initiated, there is a higher incidence of heart disease, strokes, and dementia. In addition, patients on dialysis are more likely to be hospitalized and for longer; use intensive care units and experience higher treatment intensity than people with other types of end-stage diseases or organ failure (Schmidt, 2017; Wachterman et al., 2017); and have higher mortality rates (USRDS, 2017)—life expectancy is one-third of the general population (USRDS, 2017). High symptom burden, the complexity of (ESKD), and higher resource utilization contribute to a greater urgency to understand the person's wishes and goals before a crisis, through the process of advance care planning (ACP). ACP has been defined as "a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness" (Sudore et al., 2018). However, the process of ACP often becomes reduced to the completion of an advance directive (AD), a living will, or healthcare proxy, followed by a check mark for completion. At its best, ACP is a dynamic process that focuses on goals of care and shared decision-making—involving patient, family, and provider—and addresses healthcare decisions within a holistic perspective that focuses on quality of life.

The 1990 Patient Self Determination Act (GovTrack.us, 2020) requires healthcare entities to inform patients of their right to execute an AD, but dialysis facilities were not included in the requirement. In 2008, the Code of Federal Regulations (CFR) update explicitly required dialysis facilities to inform patients of their rights to execute an AD and to discontinue treatment (Federal Register, 2008). That change brought honoring the values and wishes regarding serious illness and end-of-life care for patients with ESKD to the forefront. The CFR update required dialysis facility staff to reassess unstable patients monthly, "…with extended or frequent hospitalizations; marked deterioration in health; significant change in psychosocial needs; concurrent poor nutritional status, unmanaged anemia and inadequate dialysis" (Federal Register, 2008). The CFR regulations make the requirements of dialysis facilities, but do not address how to conduct ACP.

Social workers, given their education in assessment, engagement, intervention, and evaluation of individuals, families, groups, and communities, and considering the CFR requirement for a social worker to assess and intervene regarding psychosocial care of patients with ESKD, are well positioned to not only meet this requirement, but to be a value-added team member who can contribute to the quality of life of persons with ESKD. This paper will address how nephrology social workers can contribute to ACP. We present a model for integrating ACP within psychosocial care that is provided to people with CKD/ESKD and who are on dialysis. We argue that ACP is an opportunity for psychosocial interaction that is thoughtful, personal, at times intimate and therapeutic, and consistent with best practice of nephrology social work.

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A Model for Integrating Advance Care Planning Within Nephrology Psychosocial Care

Ideally, ACP begins upstream, well before a patient starts dialysis (Sudore et al., 2018). Disease progression can bring changes in perspectives and preferences, so subsequent review of ACPs is important when there is a change in health status, hospitalization, or when a provider answers "yes" to the question, "Would you be surprised if this patient died in the next year?" (Mandel, Bernacki, & Block, 2017). A combination of both early and serial conversations allows time for providers to help patients and family members grasp the complexity of ESKD, renal replacement therapy options, and the psychosocial impact of life on dialysis. ACP can help a person explore questions such as, "Under what conditions would you want, or not want, aggressive treatment?" This is especially important given that research findings suggest as many as 61% of dialysis patients regret the decision to start dialysis (Davison, 2010). Patients have reported that they would be willing to lose as much as seven months of life expectancy in order to decrease time in the hospital, and lose as many as 15 months of life expectancy if it meant they could travel more (Morton, Tong, Howard, Snelling, & Webster, 2010). Half of patients on dialysis say they want to die at home (Phillips, MacNab, & Loewen, 2018), although hospice, a service that helps patients die at home, is vastly underutilized in the ESKD population (Murray, Arko, Chen, Gilbertson, & Moss, 2006). Medicare beneficiaries who are on dialysis can receive hospice only if they agree to forego dialysis, if a hospice agrees to pay for the treatments, or if the patient qualifies for hospice from a diagnosis other than ESKD (Grubbs, 2018; Kurella Tamura, Goldstein, & Pérez-Stable, 2010). Unfortunately, most patients state that their healthcare providers have not invited discussions about these issues (Axelsson, Klang, Lundh Hagelin, Jacobson, & Gleissman, 2015; Finkelstein et al., 2008; Phillips et al., 2018).

Multiple issues have been identified as barriers to ACP conversations. First, a large number of nephrologists report that they have not had training on how to initiate discussions about choices (Schell, Green, Tulsky, & Arnold, 2013) and may not be comfortable having ACP conversations (Bristowe et al., 2014; Davison, 2010). **Social workers bring important skills that can help providers develop comfort with seemingly difficult conversations.** Second, many people on dialysis do not consider themselves to have a progressive disease, though Phillips et al. (2018) found that 84% of stage 5 CKD patients want to be informed of prognosis and 80% of stage 5 CKD patients would like to be informed of all of their treatment options, including withdrawal of dialysis. **Patient advocacy by social workers can improve the frequency of important conversations.** Davison and Torgunrud (2007) found that patients expect these conversations to come from their physician. Third, in a survey of dialysis facility staff, most reported being unaware of predictive algorithms or guidelines to help establish prognosis and assist in predicting disease trajectory (Culp, Lupu, Arenella, Armistead, & Moss, 2015). **Social workers can initiate in-service education about how team members can incorporate guidelines into their assessments of and interactions with patients.**

While most patients with ESKD report talking about end-of-life with family members, Phillips et al. (2018) found that 34.6% of ESKD patients would like to have this discussion with a social worker, and 36.8% would like to have it with a family doctor. Moreover, in a systematic review of social work involvement in ACP (beyond ESKD), Wang, Chan, and Chow (2018) found that up to 90% of social workers report being involved in ACP discussions with patients and that social workers are confident about their ability to have these discussions. Social work involvement in ACP has many positive outcomes including: increased patient discussions with providers about ADs (including physician order for life-sustaining treatment (POLST)), living wills and documentation, and decreased likelihood of receiving care incongruent with their values (Wang et al., 2018). In a survey of dialysis facility staff, social workers were the most knowledgeable professional group about Coalition for Supportive Care of Kidney Patients (CSCKP) resources (Culp et al., 2015).

A framework for conducting serial conversations, titled "Sample Language for Serious Illness Conversations Under Several Health Scenarios and Triggers," was developed by Mandel et al. (2017). Schmidt (2017) has identified challenges in the transitions of ESKD. We have adapted the framework and the challenges for application to social work-initiated ACP conversations. To begin, the consideration of **four questions that can guide practice** are germane to social work practice in a dialysis unit and can advise effective ACP.

- **When should ACP conversations be initiated?** 1) Before, during, or after treatment? 2) At regular intervals (e.g., quarterly, biannually?) or only after an acute event (e.g., access difficulty, hospitalization)? Consideration of patient self-determination is important; patients may a) want to either not extend the time spent at the dialysis unit by arranging a meeting outside of treatment, or have transportation challenges that make flexibility impossible, or b) be unable or unwilling to have a conversation while they are receiving treatment. Moreover, patient choice is an important principle to uphold.

- **Where should ACP conversations occur?** What is available on the unit? Is there a quiet, private space? How are the patient care areas arranged? Is privacy and confidentiality possible? ACP conversations that occur during treatment may be maximally efficient but minimally private, and there also may be distractions from treatment-related symptoms (e.g., blood pressure crises, leg cramps).

- **Who initiates ACP conversations?** ACP can be addressed by any member of the team. When social workers introduce the topic, they can discuss both the medical and psychosocial impacts of the disease and treatment. Documenting the outcomes and helping other team members understand the patient's decisions, fears and worries can direct more effective interdisciplinary care.

- **What is ACP content?** Suggestions include: patient understanding of their illness; informational preferences (How do they like to receive information and how much?); perceptions of prognosis (Social workers will not be giving out medical information, but can address the complications of multimorbidity which contribute to uncertainty.); goals (e.g., medical, personal, social, whole-life goals); fears and worries (e.g., medical, emotional, psychosocial); sources of strength and coping (What has worked in other stressful situations?); tolerance (What is acceptable or critical (or tolerable?); limitations (What tradeoffs could/would you be willing to make?); and family issues and involvement (How is your family understanding and dealing with your illness and treatment?; How involved are family members?). All of this is grounded in a psychosocial assessment, which can be enhanced by discussion of overall goals for life and for medical care (Anderson, Aldous, & Lupu, 2018; Mandel et al., 2017).

We suggest that ACP is an important and enduring element of psychosocial re-evaluation and intervention. Five distinct phases of the disease trajectory that signal the need for revisiting patients' goals of care and **five specific challenges** inform the transitions. Each phase has significant psychosocial issues. Complex healthcare decisions are complicated further by contextual issues (e.g., housing, family stressors, financial issues) that may change over time.

- **Pre-dialysis:** First, it is important to determine if social workers can meet patients before dialysis begins. Has the progression of CKD/ESKD been sudden or gradual? How has the person prepared? Have they received any dialysis education? What challenges are anticipated (e.g., work, transportation)? Patients may indicate that they have previously completed an AD, healthcare proxy (HCP), or living will, and state, "I signed the form," believing that completion is sufficient (Miller, 2015). This affords an opportunity to underscore that one conversation is not enough because perspectives may shift and need reconsideration as needs change.

- **Dialysis initiation:** Does the patient understand his/her diagnosis, i.e. the meaning of needing dialysis? Does the patient understand the rigidity of the schedule and the implications of missing treatment? What arrangements need to be made to accommodate dialysis? What life changes are causing distress?

- **Post-hospitalization or with functional decline:** What changes have occurred? (Has this influenced your way of thinking about your goals of care?) What new stressors have emerged? This event may create feelings of uncertainty about the future. Re-evaluate concrete needs for assistance. What new needs occurred throughout the hospitalization or with the decline? Is additional caregiving needed? Is placement in a care facility necessary? Was an AD, a living will, or health care proxy (HCP) invoked? Are changes to these documents needed to uphold wishes in the future?

- **After access failure/access procedure:** Has this crisis changed perspectives or perceptions?

- **Withdrawal consideration:** Is there understanding that withdrawal from dialysis will end in death? Is hospice admission a consideration? Has a POLST/MOLST/POST (physician order for life-sustaining treatment/medical order for life-sustaining treatment/physician order for scope of treatment) been completed? What are the family's needs as the end of life nears? Preparatory grieving can be addressed.

Adapted from: Mandel et al., 2017; Schmidt, 2017.

The challenges inherent in the transition from chronic to end-stage kidney disease have been documented by Schmidt (2017). We suggest that these challenges are a part of each phase of the trajectory of this disease and can be assessed as part of ACP re-evaluations. In addition, the assessment of fears and concerns, goals, sources of strength and coping, and family well-being are important to assess at each phase. We suggest that social workers consider **assessment of the following items**, which can address the challenges and natural support of the patient.

- **Status of CKD/ESKD:** Understanding of CKD/ESKD, as well as comorbid conditions, symptom burden, prognosis, and complications.

- **Psychosocial issues:** Cognitive ability, willingness, or capacity to adhere to treatment regimens, and awareness of the outcomes of nonadherence; family and social support, their influence and involvement.

- **Requirements of dialysis:** Access surgery and maintenance; logistics of scheduling, transportation; consideration of transplantation; payment issues; medication management; independence/ dependence and the need for caregiving.

- **Burdens:** Symptoms, physical, emotional, financial, existential, spiritual, logistical, and vocational, as well as family issues.

- **Fears and concerns:** Is there anything that worries you?

- **Goals of care:** What goals do you have for your health or yourself?
- **Sources of strength and coping:** What gives you strength? How do you cope?
- **Sources of meaning and purpose in life:** What gives your life meaning and purpose?

Adapted from: Mandel et al., 2017; Schmidt, 2017.

While ACP and assessment of goals, fears, and strengths will likely create therapeutic healing, social workers are also skilled in treating emotional and existential distress related to serious illness and disease progression. Social workers can provide brief, short-term interventions to patients and family members who may be struggling with pain and symptoms related to ESKD, anxiety about health conditions, family conflict over decision-making, and anticipatory grief related to ESKD. Depending on what emerges in ACP, the following **interventions** may be considered:

- Mindfulness meditations
- Deep breathing exercises
- Relaxation techniques
- Problem-solving counseling
- Assertive communication training
- Family counseling
- Worry management planning
- Sleep hygiene exercises
- Anticipatory grief support

(Hunter, Goodie, Oordt, & Dobmeyer, 2009).

CONCLUSION

Social workers in dialysis facilities are well-suited to engage in ACP, given their training in engagement, assessment, evaluation of and interventions with individuals, families, groups, and communities. Despite the clear presentation of morbidity and mortality following the initiation of dialysis, a key issue to consider is that dialysis patients often do not identify as having a progressive health condition and this may create a barrier to addressing ACP (Phillips et al., 2018). This framework provides a softer approach that may provide entrée without generating resistance and yield considered thought about choice-making. Conversations about goals-of-care and the serial reconsideration of the experience of dialysis and its influence on the patient's healthcare wishes can yield meaningful and important conversations that facilitate person-centered care and dignity as death nears. ACP is an important element in the quality of psychosocial nephrology care.

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Does Autonomy Really Exist for Impoverished Kidney Vendors?

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The following paper will explore autonomy in the context of impoverished kidney vendors. I argue that people who live in impoverished countries lack the ability to provide true and informed consent to sell their organs. The focus will be on kidney vendors in Pakistan. I am writing from a social work lens and consider the oppression, exploitation, and injustices that these vendors have faced. Relational autonomy acknowledges that our relationships and environment influence our ability to be autonomous. Therefore, the impoverished vendors' autonomy in Pakistan is threatened in the context of selling their organs. Lastly, this paper will acknowledge the counterargument that selling one's kidney should be an option for anyone, regardless of socioeconomic status, and acknowledge the value that a sold organ can bring both the vendor and the recipient.

INTRODUCTION

Selling one's organs is a hotly debated topic across the world. There are legitimate arguments in favor of both sides. The following will argue that people who live in impoverished countries lack the ability to provide true and informed consent to sell their organs. The focus will be on kidney vendors (people who sell their organs) in Pakistan. Although they may appear to be autonomous adults, they lack a range of good options to make money and, therefore, they cannot provide true informed consent. Poverty in this context is coercive and it inhibits the voluntariness that is needed for consent. A social work lens would encourage one to consider the oppression, exploitation, and injustices that these vendors have faced. "Relational autonomy," a term coined by feminist ethicists, acknowledges that our relationships and environment influence our ability to be autonomous. Therefore, in the context of selling their organs, the impoverished vendors' autonomy in Pakistan is threatened. Lastly, this paper will acknowledge the counterargument that selling one's kidney should be an option for anyone, regardless of socioeconomic status and acknowledge the value that the sold organ can bring both the vendor and the recipient.

Transplant tourism is when patients from Western countries travel to the eastern hemisphere to purchase a lifesaving organ. This has become increasingly common. Commercialized body parts have been sought after by Westerners, likely due to the very long wait times for deceased donor organs in their home countries. Legislation and edicts from a range of transplant societies have failed to prevent this from happening. Several reports have shown that there is a "kidney bazaar" thriving in India and Pakistan (Sajjad, Baines, Patel, Salifu, & Jindal, 2008). In the United States, roughly 3000 people die each year waiting for a deceased donor kidney transplant (Aubert, Reese, & Audry, 2019). Despite these deaths, selling an organ in the U.S. is illegal, and one can be fined up to fifty-thousand dollars ($50,000) and or five years in prison for breaking this law (National Organ Transplantation Act (NOTA) of 1984, Prohibition of Organ Purchases). The United States has a rigorous psychosocial screening process for prospective live donors; part of these assessments is trying to ensure that people are donating voluntarily. American transplantation associations have repeatedly spoken out and taken a strong stance against paying donors, saying that it is illegal and unethical (Friedman & Friedman, 2006). Therefore, donors in Pakistan, for example, are more vulnerable to being exploited than American donors because regulations are stricter in the U.S.

The Ethical Context

The Ethics Committee of the Transplantation Society put forward a policy statement prohibiting transplant teams from being involved directly or indirectly with the buying or selling of organs (Friedman & Friedman, 2006). Within five years, the World Health Organization (WHO) issued a similar ban. They produced a document titled "Guiding Principles on Human Cell, Tissue, and Organ Transplantation" (2010). In the preamble, the document states it was provoked to create procedures, due to the shortage of organs and subsequent human trafficking of organs from unrelated donors. Guiding Principle 3 states the following: "Live donors should be informed of the probable risks, benefits, and consequences of donation in a complete and understandable fashion; they should be legally competent and capable of weighing the information; and they should be acting willingly, free of any undue influence or coercion." (p. 3). This principle does not mention the socioeconomic factors that may influence autonomy. There is an individualistic emphasis on how one achieves autonomy. The reality is, many of these vendors in Pakistan are not free of undue influence and coercion, even if it is subtle.

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This principle does not explore the complexity of attaining autonomy. The modern phase of bioethics in the 1960s and 1970s had an overly simplistic view of autonomy. The assumption was that both the physician and the patient were rational decision-makers with equal power. However, there were unspoken assumptions that both the physician and the patient were male, white, English-speaking, and able-bodied (Brody, 2009). A social work lens would encourage bioethicists to try and understand autonomy more deeply. The term "relational autonomy" is defined as the explicit recognition that autonomy is pursued in a social context and that one's social context can influence one's opportunities to develop and express autonomous skills. It is therefore imperative to understand a person's social location to see if they can adequately express autonomy. Autonomy is influenced by both social forces and oppression; hence we need to evaluate society and not just the individual when trying to determine if someone can act autonomously (McLeod & Sherwin, 2000). This understanding of autonomy is crucial when trying to determine if kidney vendors in Pakistan have the necessary skills to make autonomous decisions.

Kidney Transplantation in Pakistan

Kidney transplantation began in Pakistan in the late 1980s with no national law to regulate the process. Kidney tourism is well known in Pakistan and has remained limited to private hospitals. A study that was conducted in Pakistan interviewed 32 vendors, who sold their kidneys, and the data is startling. The term "vendor" has been carefully selected because these people did not donate their kidney. All of the vendors, except two, sold a kidney to pay off their debt. These vendors represented the most socioeconomically disadvantaged people in Pakistan. A majority were still in debt or had new debts after the surgery. None of the vendors were paid what they were originally promised. All of them used a middleman, whom they had to pay. None of the vendors, except one, would recommend selling their kidney, including those who paid off their debt (Moazam, Zaman, & Jafarey, 2009). Another study that was conducted in Pakistan concluded that 90% of the vendors were illiterate, 69% were laborers who acted like slaves to landlords, 12% were housewives, and 8.5% were unemployed. The majority vended for debt, and 88% had no financial improvement after donating. Lastly, 98% reported that their general health deteriorated after selling (Naqvi, Ali, Mazhar, Zafar, & Rizvi, 2007).

Vendors in Moazam and colleagues' study complained of various issues, including pain related to the surgical incision, even those with a nephrectomy from over three years ago. Many complained of tiredness, weakness, and all of them said they could not work as hard they could as before the nephrectomy. Some of them also complained about a sense of emptiness. Fifty percent of the vendors said that they felt anxious and felt a sense of hopelessness about their life. Even those who paid off their debt, felt a deep sadness and regret about the act. There was also a sense of being victimized and feeling cheated by the medical profession. None of the vendors knew the name of the surgeons or other doctors involved in their care, but they all knew the name of their middleman. Hospital staff were described by the vendors as being in a business of theft. The vendors studied were specific to Pakistan, but the researchers felt their circumstances, such as their economic and social inequalities, were a reality for many other vendors, regardless of the country in which they live (Moazam et al., 2009).

A Case Example in Pakistan

Moazam et al. (2009) brought names and faces to the stories of kidney vendors in Pakistan. They wrote about a case study, Boota and Nazeeran and their family, whom they felt resembled many of the narratives that they heard while conducting their study. This narrative is crucial in shedding light on the autonomy, or lack of autonomy, for these vendors. Boota and his wife, Nazeeran, lived in a room with their six sons and two unmarried daughters. The consent process for Boota, Nazeeran, and their son to sell their kidneys consisted of going to a small court, being asked if they were giving their kidneys happily, and then putting a thumb print on a piece of paper as a signature. They were not aware of what was written on the papers, nor could they keep the papers. Boota's son reported that Boota wakes up in the middle of the night screaming that someone is going to take him away, and Boota thinks he is better off dead. Their son said that both of his parents have insomnia and wake up crying at night. It is clear from this story, that both Boota, Nazeeran, and their son were all extremely vulnerable due to being in a dire financial situation and donated out of financial pressure.

The Counterargument

Although many agree that selling one's kidney is due to financial pressure, and the practice should be illegal and abolished, others would argue that this practice is both necessary and ethical. Vendors are, in fact, participating in a risky behavior. However, many of us do: Sky diving, volunteering for the military, working on oil rigs, smoking cigarettes, and drinking alcohol, for example, are all risky behaviors in which many Westerners partake. An argument presented is that lacking wealth should not prevent you from making a rational decision. By prohibiting the selling of organs, we still leave people just as poor and disadvantaged. Eliminating this type of transaction takes away one option for people trying to improve their financial situation. A suggestion for protecting vendors is to legalize and regulate kidney sales through an international market. This could result in better protections and guaranteed money for vendors. Money saved from the costs of dialysis could lead to more money for kidney vendors (Friedman & Friedman, 2006). A market that is ethically supportable with safeguards against exploitation could be better achieved with a singlepurchaser system. The reality is that people are dying every day while waiting for an organ. In 2010, 2.62 million people received dialysis worldwide and the need for dialysis was projected to double by 2030 (Luyckx, Tonelli, & Stanifer; World Health Organization (WHO), 2018). There are clearly compelling arguments in favor of selling one's organs.

Moazam et al. (2009) are not convinced by the counterarguments in this debate. They feel the poverty and restrictions they witnessed in Pakistan make it difficult for those people to imagine an alternative to selling one's kidney. Arguments in favor of traditional autonomy, and the notion that people should have the ability to take on risks, cannot be compared to sky diving or joining the military in the context of impoverished kidney vendors. Moazam et al. (2009) feel people are out of touch with reality if they argue that impoverished people should be able to control their own bodies. This is far too narrow and naive in their opinion. In response to a legalized market, they assert that we cannot overlook that poor and disadvantaged people will still be selling their kidneys whether the market is legal or not. They question if a legal market would really allow people to exercise a right or a freedom. They argue that even with a legalized market we fail to really see social inequalities and recognize the lived experience of society's most vulnerable.

A Clinical Social Worker Perspective

As a social worker in a large urban teaching hospital, I have the privilege of providing post-transplant care on the acute care floor. The issue of purchasing a kidney abroad from a vulnerable person leaves me very torn. I see the other side—the recipient. One case will always stand out to me. I was asked to see a young man who openly admitted to me that he purchased a kidney in Sri Lanka. He even told me exactly how much he paid, and how hard he worked to pay for it. In front of me I saw a vulnerable man, desperate, and depressed. His new kidney was infected, and he would do anything to avoid a life on dialysis. He had already experienced two years on dialysis before he purchased his kidney, and he told me, quite frankly, that it is not a life worth living, according to his own personal perspective. He even admitted that if his body rejected this new kidney, he would rather pass away from kidney disease than live on dialysis. This patient represents the other side of this controversial topic. As a social worker, I am trained to think about the larger picture. How can I only think about this vulnerable young man and not consider the vulnerable vendor? I do not have an easy answer to this worldwide crisis. I do, however, recognize and appreciate the struggle of the recipients and the sheer desperation they feel when they go abroad to purchase a kidney. As a clinician, I am left very conflicted. Although conflicted, I know for certain that it is my ethical and clinical duty to support, advocate for, and respect the patients who sit in front of me and share their stories, desperation, and hardships with kidney disease, while using a non-judgmental approach.

CONCLUSION

In sum, there is no clear or straightforward solution to the organ crisis that the entire world is currently experiencing. Even with a legalized market for organ selling, there still remains the issue of exploiting society's most vulnerable people. Poverty, especially in the context of selling an organ, can be coercive because it significantly affects one's ability to provide informed consent. The reality is that autonomy is socially situated. Therefore, kidney vendors in Pakistan, who are some of the most socioeconomically disadvantaged members of society, have provoked one to question if there was any degree of choice in "voluntarily" selling their kidneys. There are clear forces of oppression that we cannot overlook. Oppression may implicitly or explicitly limit the options that are available to an oppressed group. There is an intersection between oppression and self-trust or distrust (McLeod & Sherwin, 2000). Vendors in Pakistan may not have been capable of self-trust, and therefore not able to make a fully autonomous decision in the context of selling their kidneys.

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National Kidney Foundation
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Dawn Burroughs. Emory Dialysis Center, Atlanta, GA, United States

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Renee Bova-Collis, Lori Finch, Amber Paulus. Quality Insights, Richmond, VA, United States

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Mary Beth Callahan. Dallas Nephrology Associates, Dallas, TX, United States

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7 **Advancing Adult Leadership in Cystinosis Advocacy**
Maya Doyle[1,2], Karen Gledhill[2]. [1]Quinnipiac University, Hamden, CT, United States; [2]Cystinosis Research Network, Chicago, IL, United States

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5 **The Benefits of Exercise During Hemodialysis Treatment**
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9 **Hemodialysis Patient Characteristics and Their Effect on KDQOL-36 Scores**
R. Lee Phillips[1,3], Matthew Smith[2], Tiffany Washington[3]. [1]US Renal Care, Winder, GA, United States; [2]Texas A&M, College Station, TX, United States; [3]The University of Georgia, Athens, GA, United States

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Eric Weinhandl[1,2], Emel Hamilton[1], Lorien Dalrymple[1]. [1]Fresenius Medical Care North America, Waltham, MA, United States; [2]University of Minnesota, Minneapolis, MN, United States

1. ENHANCED CARE QUALITY AND IMPROVED EXPERIENCE FOR DIALYSIS PATIENTS:

Renee Bova-Collis, Lori Finch, Amber Paulus. Quality Insights, Richmond, Virginia, United States

The concept of patient engagement has gained increasing importance as a promising pathway toward better quality, more efficient health care, and improved population health.[1,3] Engagement establishes a culture of care requiring an authentic partnership between the care team and patient in improving health care and reducing harm. A recent study affirmed that while many healthcare teams believe they use patient engagement practices, they have limited understanding of these approaches.[2] To increase understanding of patient engagement and its application, ESRD Network 5 developed the ENGAGE program to assist dialysis providers in engaging patients through self-assessment, improved practice, and sharing of best practices.

The ENGAGE program was a requirement of 345 dialysis facilities enrolled in the Network's 2019 quality improvement activities, impacting approximately 27,832 patients. With the use of pre- and post-surveys, dialysis providers were asked to self-assess their implementation of patient engagement across three levels of engagement: patient, facility, and governance. Between surveys, dialysis facilities were required to complete an educational module.

Comparison of pre- and post-survey responses revealed statistically significant increases in patient engagement at the patient- and governance-levels. Incremental improvement occurred at the facility-level despite lack of statistical significance. The ENGAGE program promoted increased application of patient engagement approaches.

2. THE INFLUENCE OF SPIRITUALITY AMONG AFRICAN AMERICAN ESRD PATIENTS ON END-OF-LIFE TREATMENT PREFERENCES:

Dawn Burroughs. Emory Dialysis Center, Atlanta, GA, United States

Kidney disease among African Americans represent more than 30% of end-stage renal disease cases among a population that accounts for 15% overall in the United States (Harding et al., 2017). African Americans are three times as likely to require renal replacement therapy as their non-Hispanic White counterparts (Laster et al., 2018). Most patients have a five-year mortality rate (Grubbs, 2018). During the last month of life, ESRD patients age 65+ are hospitalized, admitted to intensive care units, experience medical procedures & death more than patients with cancer, CVA, & CHF (Mandel et al., 2017).

Systematic Literature Review

Keywords: spirituality, religiosity, end of life, treatment preferences, African American, cultural humility, ESRD, CKD, hospice and palliative care. The search yielded 86 peer reviewed journal articles. ProQuest, EBSCOHost, Web of Science & PubMed databases were used. Final clean sample resulted in 27 qualitative studies. Sample sizes ranged from 1 to 345 participants. Inclusion criteria >18 yrs.old, African American, ESRD pt. Studies held at academic & medical centers, faith institutions, dialysis centers, and medical record review. 26 thematic statements were initially identified and reduced to 7 recurrent themes.

Individual culture will influence how patients make sense of their illness as well as how they make end of life decisions (Smith et al., 2008). Decision making is most often a family decision that includes faith and spirituality (Moss et al. 2016).

Engagement by the medical team in treatment of the whole person, including a spirituality assessment is a significant initial step in addressing end of life concerns among African Americans. The introduction of palliative care and hospice care earlier in the disease process is warranted. A positive relationship between African Americans and faith institutions was found. Medical care providers may collaborate with faith-based community outreach organizations.

3. USING SMALL TESTS OF CHANGE TO IMPROVE ADVANCE CARE PLANNING IN CHRONIC KIDNEY DISEASE:

Mary Beth Callahan. Dallas Nephrology Associates, Dallas, TX, United States

Dallas Nephrology Associates (DNA) realized a need to improve advance care planning (ACP) across its large nephrology practice. In so doing, the opportunity to partner with the Pathways Project was accepted. This poster speaks to improving serious illness conversations with chronic kidney disease (CKD) patients while another part of DNA was working on improving ACP in dialysis.

To promote improvement in CKD, the following was implemented:

1. a needs assessment of nephrologists
2. provider education on ACP through Serious Illness Conversations and Care Project (SICP)
3. implementation of serious illness conversations
4. auditing and implementing small tests of change

At one office practice location, social worker worked with nephrologist to identify and audit CKD Stage 4/5 patients over age 65. Twenty-four patients were identified with the SICP provided. In this same setting, the physician trainer provided SICP training to 15 of 18 providers at the location. While not all trained providers provided goals of care conversations, referral to the Supportive Care Team (SCT) follow up increased.

Opportunities for continued change include ongoing follow up with identified patients with the goal being to identify a health proxy that is included in a goals of care conversation so that what matters most to the patient is supported by their loved ones and health care team. Additionally, the team has identified that use of documents from PREPARE for your Care (Sudore) are helpful in educating patients/families, identifying and documenting what matters most and documenting a health proxy.

To increase awareness, sympathy cards were developed for company wide distribution after an improvement activity identified that the office practices may not always know when a patient died. Additionally, the SCT Team gained support to have all employees review a module from the Center to Advance Palliative Care "Delivering Serious News" as a part of yearly compliance training.

Using small tests of change can spark continuous improvement in advance care planning. Finding a way to maintain gains takes continued perseverance.

4. NEPHROLOGY SOCIAL WORKERS' OPINIONS ON THE USE OF ACCEPTABLE HUMOR IN CONVERSATIONS WITH ADVANCED ILLNESS PATIENTS:

Kevin Ceckowski, Christina Yuan, Dustin Little. Walter Reed National Military Medical Center, Bethesda, MD, United States

Nephrology social workers frequently encounter patients with advanced illness, assessing them for depression, anxiety, pain and suicidality. Death is frequent and may contribute to social worker burnout. Humor—enjoying a good laugh, joking, smiling—is part of being human, and no less important for those with advanced illness. Humor has been shown to improve patient quality of life and overall well-being. In multiple studies on the use of humor in palliative care, humor appears to allow providers, patients and caregivers to better connect, provide joy and hope, enhance relaxation, and improve perspective. Acceptable humor can be a "powerful resource" for providers to manage the "negative effects of the strain of death and dying." By using acceptable humor, do nephrology social workers perceive less burden in their own lives and that of their patients? Do they believe humor can alleviate perceived pain and discomfort in advanced illness? Is acceptable humor appropriate for their practice, their gender and their particular culture? Do they believe that acceptable humor ameliorates burnout?

Cross-sectional, 33-item anonymous online survey to be administered in spring 2020. No identifiable information will be collected. All questions will be optional. The survey may be taken only once. The survey link will be emailed to the 18 End Stage Renal Disease (ESRD) Network representatives at the Centers for Medicare and Medicaid (CMS). They will be asked to send the survey link to their network social workers using their confidential network email list and tell the investigator the number of surveys they forwarded. This will determine response rate.

Opinion sample of nephrology social workers from all CMS ESRD Networks. Conversations using acceptable humor with advanced illness patients have been shown to decrease the perception of pain, create a suitable distraction from illness, and benefit patients and providers. We anticipate that our survey will add information regarding its effect in ESRD patients.

The views expressed in this article are those of the author and do not reflect the official policy of the Department of Army/Navy/Air Force, Department of Defense, or U.S. Government.

5. THE BENEFITS OF EXERCISE DURING HEMODIALYSIS TREATMENT:

Julie Costanza. Fresenius Dialysis Company, Shelby Twp., MI, United States

With dialysis patients, regular exercise is a difficult struggle. Common reasons for this are fatigue, lack of motivation, and minimal knowledge about its benefits. Exercising during hemodialysis is an effective and realistic way to improve treatment efficiency. Besides typical health benefits: studies show that doing it during treatments results in better dialysis. Patients are receiving double the benefit because it is working on both their fitness level and treatment efficiency.

Four key studies were used that were each tailored to the patients' treatment position and fitness level. Since patients either sit or lie down during hemodialysis; cycle ergometers or mini steppers allowed them to exercise while in the chair. Exercise ranged from 15 to 60 minutes total during the first 2 hours of treatment. Fitness levels and blood labs were tested before, during, and after the studies to measure changes and improvements.

The removal of urea is a standard way to measure dialysis efficiency; and is labeled as spKt/V. This substance normally comes out in urine; but dialysis patients do not produce enough to get rid of it. Exercise increases blood flow to the muscle, which leads to greater movement of urea and other toxins from the dialyzer such as creatinine and potassium. The spKt/V increased 11% after the first month and remained there throughout one study; and another showed a 38% improvement in spKt/V. One measure utilized was the 6 Minute Walk Test (6MWT). Distance increased to almost 30% for some; and all participants had some gain. Patients also showed growth in lower muscle strength and balance. This reduces their risk of falls and bone breakage.

Implementing in-clinic exercise is a safe and efficient way to promote exercise benefits. Exercise during hemodialysis can bring great improvement to patients' health quality and overall clinic outcomes.

6. PERITONEAL DIALYSIS AND PREEMPTIVE KIDNEY TRANSPLANT UPTAKE FOLLOWING MULTIDISCIPLINARY MODALITY EDUCATION:

Karen Crampton, Terrie Holewinski, Rachel Bender, Katherine Cho, Amy Barton Pai, Jonathan Segal. University of Michigan, Ann Arbor, MI, United States

Pre-dialysis education can increase the proportion of patients who select peritoneal dialysis (PD) as a modality option. One goal of the recent "Advancing American Kidney Health" executive order is to have 80% of new ESRD patients either receiving dialysis at home or a kidney transplant. We examined rates of PD and preemptive transplant following a multidisciplinary dialysis modality education session.

Patients with CKD stage IV who attended a 2-hr education session led by a nephrologist, social worker, dietician and PD patient were followed until renal replacement therapy started to determine their modality preference and actual modality used (March 2014-September 2019). We determined the proportion of PD initiation among patients whose preference was for PD as well as combined pre-emptive transplant and PD initiation.

Of 210 participants, the mean age was 65.6 years, 80.2% were white, 53.7% women, and 47.5% had diabetes. Mean follow up from date of class to renal replacement therapy or end of study was 15.7 months. Modality preferences were: 39.9% PD, 40.9% HD, 3.4% palliative care, 2.5% planned pre-emptive transplant and 12.8% no/unknown preference. Of the 100 patients who started renal replacement therapy, 51% initiated HD, 35% PD, and 14% were preemptively transplanted before dialysis. Among the 40 patients who preferred PD and started dialysis, 85% actually initiated PD as their first modality.

Multidisciplinary modality education was associated with a 49% uptake of PD and preemptive kidney transplant. Most patients were able to start with their preferred modality, but additional interventions will be needed to achieve higher rates of PD and preemptive transplantation.

7. ADVANCING ADULT LEADERSHIP IN CYSTINOSIS ADVOCACY:

Maya Doyle[1,2], Karen Gledhill[2]. [1]Quinnipiac University, Hamden, CT, United States; [2]Cystinosis Research Network, Chicago, IL, United States

Cystinosis is a rare metabolic disease with particular impact on kidneys, eyes, and muscles. Improved treatment has extended the lifespan with cystinosis from adolescence into adulthood,[1,2] but challenges remain. Patients with cystinosis are taking an active role in advocacy, done by caregivers in the past.

Following 10 years of research and advocacy related to the transition to adulthood, the Cystinosis Research Network (CRN) convened its Adult Leadership Advisory Board (A L A B) as a formal way of empowering patients. A L A B's intention is to nurture patients who have cystinosis, and provide advice, support, and companionship along the disease process.

The goal of all A L A B projects is to use newer communication technologies to reach crucial young adult and adult constituents with cystinosis. For 2019-2020, A L A B projects include video conferencing, podcasts on issues such as mental health, relationships, and regimen adherence; and teen-oriented photo updates highlighting community members' challenges and successes. Survey instruments will be created and disseminated by email to assess satisfaction and impact of these projects. New projects will be developed over time as A L A B leadership rotates and new concerns arise.

Recipients of A L A B content will strengthen their knowledge of cystinosis (i.e., treatment options, adherence); education, employment, and relationships; navigating the healthcare system; and overall problem-solving. Those creating A L A B project content will gain teaching and leadership skills, and motivation for their own disease management and coping. A L A B members want healthcare providers and researchers to recognize that cystinosis patients are well-versed in their own disease and can clearly speak about how it impacts their lives.

8. PROVIDER PERCEPTIONS OF THE MY WAY INTERVENTION: IMPLEMENTING ADVANCED CARE PLANNING IN CKD CLINICS:

Alice Lee[1], Annette Aldous[1], Liz Anderson[2], Dale Lupu[1]. [1]George Washington University, Washington, DC, United States; [2]Western Carolina University, Cullowhee, NC, United States

Patients with chronic kidney disease (CKD) benefit from integration of advance care planning (ACP) into their care, and many patients report wishing they had engaged in ACP before the dialysis decision. The MY WAY trial randomized participants from four CKD clinics in the eastern United States to receive printed ACP materials or printed materials plus an ACP coaching session that used motivational interviewing. We interviewed providers at each site to gain insights into the impact of the intervention on clinic workflows and patient outcomes as well as challenges and facilitators to implementation.

Telephone interviews were conducted with clinical providers and research staff at each intervention site. We invited principal investigators, ACP coaches, and research staff. The semi-structured interview used open-ended questions to elicit personal impressions as well as perceptions of clinic-wide responses, changes in workflow, and intentions for future use of the intervention. Interviews were audio recorded, transcribed, and analyzed using Dedoose software. Grounded theory was used to identify patterns and discover core concepts and categories.

12 participants were interviewed between September 2019 and November 2019. Participants from all four clinical sites included three nephrologists, one palliative care doctor, three ACP coaches (two social workers, one nurse practitioner), and five research staff. The intervention was well-received; providers were overwhelmingly in favor of integrating ACP into CKD care. The interviews revealed themes as to what inhibited or encouraged integration. Some major obstacles were lack of time, provider discomfort/lack of training, and a need for dedicated staff for ACP. Despite varied perceptions of issues with recruitment, providers reported positive patient reception of the MY WAY intervention.

Interviews with clinical providers revealed positive reactions to an ACP coaching intervention at diverse sites. Qualitative analysis provided insight into the possible future implementation of aspects of the MY WAY intervention as part of ACP integration into CKD care. The themes revealed in this analysis can guide conversations within CKD providers about how to resolve obstacles to integrating ACP into care.

9. HEMODIALYSIS PATIENT CHARACTERISTICS AND THEIR EFFECT ON KDQOL-36 SCORES:

R. Lee Phillips[1,3], Matthew Smith[2], Tiffany Washington[3]. [1]US Renal Care, Winder, GA, United States; [2]Texas A&M, College Station, TX, United States; [3]The University of Georgia, Athens, GA, United States

The quality of life for those on dialysis is challenged daily by the disease and treatment regimens. Quality of life has been linked to health outcomes and the Center for Medicare and Medicaid Services (CMS) has identified the Kidney Disease Quality of Life 36 (KDQOL-36) as the preferred health-related quality of life survey for use with dialysis patients.

The purpose of this study was to identify possible relationships between patient attributes and KDQOL-36 scores. Data consisted of patient attributes and KDQOL-36 scores for 116 hemodialysis patients and was analyzed using Chi-square and One-way ANOVA. Relationships between KDQOL-36 subscales was analyzed using Pearson correlation for continuous scores and Chi Square for categorical scores (below average, average, above average).

Key findings include relationships between physical activity level and BMI with the Physical Component Summary, between the Mental Component Summary and each of the disease specific subscales, and between each of the disease specific subscales.

Encouraging physical activity, managing symptoms, and maintaining mental well-being appears critical in quality of life among dialysis patients and for positive health outcomes.

10. STAFF PERCEPTION OF NEEDS FOR IN-CENTER DIALYSIS CLIENTS: A PARTICIPATORY ACTION RESEARCH PROJECT:

Shannah Pinkston. Emory Dialysis, Decatur, GA, United States

Chronic kidney disease impacts the quality of life of dialysis clients. Poor quality of life can have a negative impact on mental health and clients with a poor quality of life may have problems adjusting to kidney disease. This project explored dialysis staff's perceptions of client needs and potential services that could address those needs and improve client quality of life.

Participatory action research was used to identify in-center hemodialysis client needs and services. Fourteen interviews were conducted with dialysis staff about the needs of dialysis clients. Six dialysis staff participated in a focus group to discuss services that could address the needs identified and improve client quality of life. The responses were audio recorded and transcribed verbatim and then qualitatively analyzed using a thematic analysis.

Dialysis staff observed clients having various mental health concerns, such as depression. It was recommended that staff receive training on how to interact with clients that have mental health issues. It was suggested that therapeutic services be provided to clients to address these concerns. Needs, such as transportation and financial barriers to services, were also observed by multiple dialysis staff.

This project was instrumental in identifying needs of dialysis clients that can impact their quality of life. Dialysis staff identified mental health concerns as a primary issue and want more information on how to best address the identified needs. Dialysis staff were provided mental health training to learn how to provide better care for clients.

11. COPING WITH AN ESRD DIAGNOSIS: DIFFERENCES AMONG PATIENTS ACCORDING TO PRESENCE OF PRE-ESRD NEPHROLOGY CARE:

Megan Urbanski[1], Levent Dumenci[1], Crystal Gadegbeku[2], Laura Siminoff[1], Amy Waterman[3], Heather Gardiner[1]. [1]Temple University, Philadelphia, PA, United States; [2]Lewis Katz School of Medicine, Temple University, Philadelphia, PA, United States; [3]David Geffen School of Medicine, UCLA, Los Angeles, CA, United States

More than one third of patients with end-stage renal disease (ESRD) had not been under the care of a nephrologist when they received the diagnosis. The aim of this study was to explore the coping styles and strategies used at the time of ESRD diagnosis among patients with varying amounts of pre-ESRD nephrology care.

A mixed-methods design was used, and semi-structured interviews were conducted with patients with varying amounts of pre-ESRD nephrology care, exploring their coping styles and strategies as it related to their ESRD diagnosis and renal replacement therapy (RRT) initiation. Participants were grouped according to amount of pre-ESRD nephrology care. Interviews conducted to date were analyzed using applied thematic analysis and codes were created deductively and inductively. Two members of the research team independently coded each interview transcript. Relevant sociodemographic data were also collected, and three coping-related validated measures were administered. Data collection is ongoing.

Thus far, 40 patients with varying amounts of pre-ESRD nephrology care participated. Interim analyses reveal that coping styles and strategies vary according to amount of pre-ESRD nephrology care and the following qualitative themes have emerged: (1) psychological distress; (2) adjustment to illness issues; (3) influences on primary appraisal of the stressor; and (4) secondary appraisal of the stressor. Mean scores on the Denial, Acceptance, and Active Planning subscales of the Brief COPE measure and on the Coping Strategies Index-Short Form Emotion-Focused Disengagement subscale vary between groups, with higher mean scores seen among patients with no history of pre-ESRD nephrology care.

The qualitative and quantitative differences in coping with the ESRD diagnosis and RRT initiation according to amount of pre-ESRD care suggest further exploratory and targeted intervention research is necessary to help all patients optimally adjust to this life-altering illness.

12. "I WAS JUST BLINDSIDED" — THE DIAGNOSIS AND RENAL REPLACEMENT INITIATION EXPERIENCES OF PATIENTS NEWLY DIAGNOSED WITH ESRD WITH VARYING AMOUNTS OF PRE-ESRD NEPHROLOGY CARE:

Megan Urbanski[1], Levent Dumenci[1], Crystal Gadegbeku[2], Laura Siminoff[1], Amy Waterman[3], Heather Gardiner[1]. [1]Temple University, Philadelphia, PA, United States; [2]Lewis Katz School of Medicine, Temple University, Philadelphia, PA, United States; [3]UCLA, Los Angeles, United States

According to recent data, more than a third of new cases of end-stage renal disease (ESRD) in the U.S. had no or minimal pre-ESRD nephrology care. Little is known about the ESRD diagnosis experiences of this patient group, how they initiate renal replacement therapy (RRT), or how their experiences compare to patients with a history of pre-ESRD nephrology care.

Using a mixed-methods design, semi-structured interviews were conducted with patients with varying amounts of pre-ESRD nephrology care, exploring their ESRD diagnosis experiences and RRT initiations. Participants were grouped by amount of pre-ESRD nephrology care. Applied thematic analysis was used and codes were created deductively and inductively. Two members of the research team independently coded each interview. Sociodemographic data were also collected, and 7 validated measures were administered. Data collection is ongoing.

To date, 40 patients have participated. Preliminary analyses reveal that the diagnosis experience is similar across participant groups and the following themes have emerged: (1) diagnosis occurs on a spectrum of emergency; (2) diagnosis communication environment; (3) emotional reaction to the news; (4) characteristics of the first dialysis treatment; and (5) perception that the disease could have been avoided. A majority of participants (n=37; 92.5%) had an inpatient RRT initiation and initiated to hemodialysis (n=39; 97.5%). Most participants without pre-ESRD nephrology care blamed themselves for their disease development, and this was reflected in corresponding quantitative measure scores.

ESRD diagnosis does not occur as a dichotomous phenomenon in the U.S. but occurs on a continuum of suboptimal and often occurs as an emergency, irrespective of amount of pre-ESRD nephrology care. Further research is needed to improve the patient experience and reduce the burden on the healthcare system at the time of ESRD diagnosis.

13. LOWER PREVALENCE OF KIDNEY TRANSPLANT WAITLISTING IN MICROPOLITAN AREAS, SMALL TOWNS, AND RURAL AREAS:

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The Percentage of Prevalent Patients Waitlisted (PPPW) measures the percentage of patients at a dialysis facility who were on the kidney or kidney-pancreas transplant waitlist. This measure joined the End Stage Renal Disease Quality Incentive Program in performance year 2020, with a weight of 4%. PPPW is adjusted for age, but not for other factors. Physical distance between residence and transplant center may influence PPPW. As an indirect test of this hypothesis, we assessed whether PPPW was associated with rural-urban commuting area (RUCA) levels.

We analyzed data in Dialysis Facility Compare (DFC), as of October 30, 2019. DFC included PPPW values that quantified wait-listing prevalence during 2018. According to ZIP code, we classified the location of each dialysis facility as metropolitan (RUCA values, 1-3), micropolitan (4-6), small town (7-9), or rural (10). We estimated weighted mean PPPW values in each location class, with the weight of each facility equal to the number of patients contributing to PPPW. We fit a linear regression model to test differences in PPPW values between the location classes.

PPPW values were reported in 7086 (94%) of 7566 dialysis facilities, and RUCA values were identified in 6999 (99%) of 7086 facilities. The weighted mean PPPW value among all facilities was 17.5%. There were 5363 (77%) facilities in metropolitan areas, 954 (14%) in micropolitan areas, 550 (8%) in small towns, and 132 (2%) in rural areas. By location class, weighted mean PPPW values were 18.5% in metropolitan areas, 12.8% in micropolitan areas, 12.1% in small towns, and 10.8% in rural areas. Relative to the mean PPPW value in metropolitan areas, mean PPPW values were 5.8, 6.5, and 7.7 percentage points lower in micropolitan areas, small towns, and rural areas, respectively ($P < 0.01$ for each).

The PPPW measure takes significantly lower values in dialysis facilities located in micropolitan areas, small towns, and rural areas, relative to metropolitan areas. The physical distance between residence and transplant center may preclude many patients in non-metropolitan areas from completing the process of kidney transplant evaluation. New processes are needed to improve access to transplantation in outlying areas.

14. NATIONAL ESTIMATES OF MENTAL HEALTH NEEDS AMONG PATIENTS WITH CHRONIC KIDNEY DISEASE:

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The Advancing American Kidney Health initiative encourages greater use c transplant and home dialysis among patients with new-onset end-stage kidney diseas (ESKD). Poorly controlled mental health (MH) disorders are a contraindication t these preferred treatments, yet national estimates of the MH needs of patients wit chronic kidney disease (CKD) are not available.

We used 2015-17 data from the National Survey of Drug Use and Health to identif three nationally representative populations of adults (age ≥22) with: (1) no identifie chronic conditions ("healthy"), (2) hypertension or diabetes but not CKI ("HTN/DM"), or (3) CKD. Outcome measures assessed self-reported MH and use c MH services in the prior year, and were compared across the three populations i unadjusted descriptive analyses and regression analyses, adjusted for other responden characteristics (age, sex, race/ethnicity, insurance, education, family income).

We identified n=70,530 individuals with no chronic conditions, n=19,417 wit diabetes or hypertension but not CKD, and n=1,508 with CKD in our data. CKI patients were more likely than HTN/DM or healthy patients to report having an mental illness in the past year (30.9% vs. 23.4% or 18.6%, respectively, p<0.01), an psychological distress in the past year (17.3% vs. 13.4% or 12.0%, respectively, p<0.01 and any suicidal thoughts in the past year (7.2% vs. 5.1% or 4.1%, respectively, p<0.01 CKD patients were also more likely than HTN/DM or healthy patients to have receive MH services in the past year (any outpatient: 12.1% vs. 9.6% or 6.3%, respectively p<0.01; any prescription medication: 21.1% vs. 18.2% or 10.1%, respectively, p<0.01 and yet were still more likely to report having unmet MH needs (7.8% vs. 6.4% or 5.6% respectively, p<0.01). These differences persisted in regression models.

In the U.S., patients with CKD have greater levels of unmet MH need than health or HTN/DM patients despite greater use of MH services. More effective managemen of CKD patients' MH care needs will be needed to advance goals of treating greate numbers of patients with ESKD with transplant and home dialysis.

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