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The Journal of Nephrology Social Work

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THE JOURNAL OF NEPHROLOGY SOCIAL WORK

The Council of Nephrology Social Workers (CNSW) of the National Kidney Foundation (NKF) is a professional membership organization of 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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2) Abstract
3) Text
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Not as Simple as Civic Duty: A Response to Andrew Michael Flescher's Argument to Increase Living Kidney Donations

Brandy M. Fox, PhD(c), MSHCE, Saint Louis University, St. Louis, MO

In* The Organ Shortage Crisis in America: Incentives, Civic Duty, and Closing the Gap *(2018), Andrew Michael Flescher analyzes and critiques proposed ways to solve the kidney shortage in the United States. He advocates removing disincentives to living donation and emphasizes types of nonmonetary compensation, eventually establishing "a gift exchange powered by civic engagement," (p. 16) where the relational aspect of the exchange between donor and recipient is of primary importance. Unfortunately, the project fails. A reliance and emphasis on civic duty as the primary driver of living organ donation is unrealistic and potentially harmful. Without making structural changes to the current recruitment and distribution system to account for institutional biases within the healthcare system, there is no hope for a just solution to the organ shortage crisis. Relying on "civic virtue" requires a trustworthy healthcare system that uses a fair method to distribute organs. Empirical evidence demonstrates that we do not have either of those in the U.S. Policymakers could construe arguments that frame civic virtue as the most important missing ingredient in solving the organ shortage crisis as arguments that justify the current prejudicial framework. The U.S. should remove disincentives that deter donations, but that will be only a partial solution. Alternatives that can move the U.S. closer to an ethical solution include increasing access to primary and preventive care, to reduce the need for donor kidneys in the first place, and expanding the eligible donor pool.

INTRODUCTION

In the United States, thousands of people die each year waiting for organ transplants. The number of people on the waiting list far outstrips the number of deceased donors with viable organs. The lion's share of people on the organ transplant waiting list—84%—need kidneys (Organ Procurement and Transplantation Network (OPTN), 2021). Living donation kidney transplants are an option in addition to deceased donor kidney transplants.

In response to the gap between organs needed and those available, several sources have proposed establishing a market where kidneys and livers are available for selling and purchasing (Cohen, 2014; Halpern et al., 2010; Hippen et al., 2009; Sade, 1999). There are a variety of permutations of this proposal; some advocate for the government setting a price, acquiring, and distributing the organs (Major, 2008; Schweda & Schicktanz, 2009). Others propose either an open or heavily regulated market where buyers can directly contact sellers (Larijani et al., 2004; Matas, 2007). The one thing these proposals have in common is that they are extremely controversial and have generated a storm of literature in response. One of the most recent and comprehensive responses is *The Organ Shortage Crisis in America: Incentives, Civic Duty, and Closing the Gap*, by Andrew Michael Flescher, PhD (2018). Flescher advocates for removing disincentives to living organ donation and increasing alternative types of non-monetary compensation to persuade potential donors, eventually establishing "a gift exchange powered by civic engagement" (2018, p. 16). This proposal is similar to many others discussed in bioethical and medical literature that advocate making organ donation at least a financially neutral act, but it is the emphasis on civic duty that sets Flescher's plan apart.

Unfortunately, Dr. Flescher's proposed ethical solution to the organ shortage crisis fails because he does not propose any changes to the current organ donation system. Endorsement of the existing racially and socially biased system could continue to harm certain populations. His solution requires something unavailable in the U.S.: a just healthcare system that has the trust of the public. It is impossible to have an ethically and morally acceptable solution without addressing the structure and process of the current living organ donation system. In fact, his argument, advanced in the current American social and political climate, is harmful.

The issue of trust in the healthcare system is complex and ever-evolving. The point I wish to focus on is that Dr. Flescher concedes this requirement of public trust in order for his plan to work:

> "Constraints of time and space prevent our delving too deeply into the question of how ethnicity, income, and race impacts [sic] attitudes about the formation of healthcare policy, but it is significant for purposes of the current discussion to call attention to what seems to be lacking in these vulnerable populations—namely, the feeling of trust and fellowship that optimize recruitment of donors in better-supported communities" (Flescher, 2018, p. 97).

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For the purposes of this article, I will focus on providing evidence of why this mistrust in the healthcare system could be justified, especially for particular populations, and how inspiring people with civic duty will not make these reasons go away.

After critiquing Flescher's arguments, this paper will briefly examine a solution that could lead to decreasing disparities in transplant rates and improving overall kidney health for all populations: increasing access to primary and preventive care, while expanding the pool of eligible living donors.

BACKGROUND

The scope of the kidney problem

Americans are in the middle of a kidney health crisis. Approximately 15% of the general population has chronic kidney disease (CKD), the worst and final stage of which is known as kidney failure (CDC, 2021). In 2018, over 785,000 Americans were living with kidney failure (NKF, 2021). For patients with kidney failure, the preferred treatment is a kidney transplant (Hippen et al., 2009). Until patients receive a transplant, or if they are ineligible for a transplant, the standard treatment for kidney failure is dialysis. The most common form, hemodialysis, is typically received three to four times a week, with the procedure taking around four hours each time (NKF, 2015). This is a huge time commitment and patients who choose hemodialysis must plan their lives around dialysis treatments, which can have a significant impact on their quality of life (Vandecasteele & Kurella Tamura, 2014).

In the U.S., getting a new kidney is a multistep, time- and labor-intensive ordeal. People who wish to receive a kidney must first be screened by a healthcare provider and then referred to a transplant center (NKF, 2017a). Patients can also contact transplant centers themselves to learn about their options (NKF, 2017a). Both deceased and living donations require a specialized center with the appropriate staff, equipment, and resources. There are many centers throughout the U.S., but they are not distributed evenly by geography or population. The transplant center then evaluates the person requesting the kidney, and if the patient meets that particular center's criteria for a transplant candidate, the patient will be placed on the national waiting list (NKF, 2017a). However, transplant centers do not all have the same donor criteria, and organs are sometimes allocated by geographical region, so some patients choose to get listed at more than one transplant center (NKF, 2017b). A patient can try and get on more than one institution's waiting list, but this often involves going through a separate evaluation with each of the other institutions. While kidney transplant candidates are on the transplant waiting list, the average wait time to receive a kidney is three to five years; however, it can be much less if the patient finds a living donor who is a good medical match (NKF, 2017a). So, patients who have access to specialty care and/or who have friends or family members who are able to donate a kidney have a significant advantage over those who are waiting for a deceased donor or an altruistic donation.

Recipients, medical institutions, and donors are not allowed to offer money or other incentives to arrange a transplant. The National Organ Transplant Act (NOTA) of 1984, the legislation governing organ donation, outlaws any kind of "valuable consideration" from being exchanged between recipients and donors. The phrase "valuable consideration" is generally taken to mean no money may be exchanged for the organ itself. Federal legislation allows donors to be compensated for certain nonmedical expenses, including lost wages, housing and travel expenses, and child- or elder-care expenses incurred by the donor while donating (Removing Financial Disincentives to Living Organ Donation, 2020). However, the phrase "valuable consideration" is open to interpretation as to whether the donor may receive desirable, non-monetary benefits, like health insurance. Current bioethical debate about whether lack of donor compensation is fair or not has strong supporters on both sides. Some market proponents argue that donors are the only ones not to be paid of the many parties involved in kidney transplants; surgical teams, hospitals, and recipients all get something material out of the exchange (Larijani et al., 2004; Matas, 2007). In addition, other scholars argue that it would be just to compensate donors for their time, effort, and lost wages (Giubilini, 2015; Israni et al., 2005). However, even those who agree that compensation is justified are unsettled on what form the compensation should take, and who should be responsible for covering expenses. A lump sum of cash? Reimbursement for medical and/or nonmedical expenses (Israni et al., 2005; Sickland et al., 2009)? Others, including Flescher, are against openly paying for organs, but do advocate for nonfinancial or "in-kind" compensation. Some examples include having priority on a waiting list if the donor or one of their family members needs an organ in the future, tax incentives or credits, or even a "kidney voucher" to be used at a later time that facilitates "chronological incompatibilities" between donors and recipients (Veale et al., 2017, p. 2118).

FLESCHER'S ARGUMENT TO INCREASE LIVING DONATIONS OF KIDNEYS

Civic duty

Flescher believes that we can best solve the organ shortage by increasing the number of living donors. He proposes that this be done by replacing numbers and statistics about kidney transplants with faces and stories. Other authors have also concluded that stories about individuals have a significant impact on the public's sense of responsibility for different health conditions (Gollust & Lynch, 2011). Flescher hypothesizes that people who witness or form relationships with someone who needs a kidney will be compelled to donate. However, his plan has been criticized for failing to articulate why exposure to the suffering of others would increase donation rates (Sonnenberg et al., 2018). Undergirding Flescher's main argument is his notion of civic duty:

> Civic duty thus pertains to a recipient-generated inducement to care for those whose plights we know, as opposed to a moral requirement to "be a good person." When we are able to see ourselves as members of a connected society and learn more about what it means to be suffering, a sense of "ought" will begin to emanate from within that then induces us to act. It is *this* impetus to act—the action sprung from a deepening connection with the one in need—that is being proposed as a rival to the financial incentives that some believe will help living donor recruitment. (Italics in original; Flescher, 2018, pp. 103–104)

This idea is based on a communitarian vision where all citizens recognize their dependency on and interactions with each other (Bell, 2020). A particular type of society must exist in order to catalyze this civic duty, though: Flescher concedes that citizens must have a basic trust in the institutions or entities responsible for them (2018). So, in order for the panacea of a fulfilled civic duty to come into existence, there must be a state or organizational structure that the citizens trust.

A better way to attract donors

Numerous scholars have argued that while many people may be turned off by the idea of receiving money for their organs, non-monetary compensation for living organ donors is widely regarded as appropriate and fair (Giubilini 2015; Hippen et al., 2009; Schweda & Schicktanz, 2009). Flescher admits that few people become organ donors simply because it's a "nice thing to do." Donors frequently envision something in return, but that thing is not money. In addition to helping a fellow human being who is in trouble, donors expect some type of benefit, such as satisfaction at doing something good, a relationship with the person who received their kidney, and/or recognition for their good deed (Flescher, 2018; Garden & Murphree, 2007; Spital, 2004; Williams, 2018). Other studies have shown that the critical value under consideration for people who may become living organ donors is *reciprocity*:

> Many participants [recipients]...seem to have found ways to cope with this feeling of indebtedness by "repaying" something, e.g., by engaging in self-help groups or public campaigns for organ donation. It is significant that such societal engagement seems to concentrate on activities aimed towards increasing the total number of donor organs. This circumstance might be attributable to the notion that the principle of reciprocity not only posits a debt, but also determines the "currency" of redemption (Schweda & Schicktanz, 2009, p. 1133).

Several studies have also indicated that the public recognizes and appreciates the difference between money and other forms of organ donor compensation, finding the latter more palatable (Cohen, 2014; Schweda & Schicktanz, 2009; Smith, 2009).

Flescher states that his ultimate goal is to establish "a gift exchange powered by civic engagement" where more living donors come forward to provide kidneys (2018, p. 16). He believes this can be achieved by better education among the public about how people live with kidney failure and what a dramatic difference a new kidney can make in their quality of life (Flescher, 2018). Additionally, he advocates for removing disincentives to organ donation that currently exist. While insurance typically covers most of the immediate medical costs associated with donating a kidney, there are many unseen and uncovered costs of donating (Przech et al., 2018). These include lost vacation or sick days, care of self while recovering, paying for medical problems after donation, increased insurance rates, even pet care expenses (Removing Financial Disincentives to Living Organ Donation, 2020). Several other sources currently advocate for legislation to remove disincentives to organ donation (Delmonico et al., 2015; Dockser Marcus, 2018; Giubilini, 2015; Tong et al., 2014; Wiseman, 2012). This plank of Flescher's plan seems to be a realistic step in today's society.

However, his next conclusion is suspect at best. Flescher predicts that the educational component, along with the removal of disincentives to donation, will trigger citizens' sense of civic duty, leading to more living donors. He also supports varying forms of non-monetary compensation, such as free admission to Disney World® or "catered mass benefits featuring major musical and comedy acts, each with the purpose of honoring the donor who sacrificed his or her organ" (Flescher, 2018, p. 154).

Flescher asks for a mere "Two to Four Hours of Your Life"—the title of the conclusion to his book—in order to grow compassion and understanding of what a fellow human being who lives with kidney failure goes through. By witnessing a kidney failure patient's poor quality of life, Flescher believes that our natural inclinations to be "social beings who exist to act on opportunities to help one another, provided we are supplied with a little help in seeing these opportunities come to fruition" will be set into motion (2018, p. 164). It is this insistence, that a change in communal attitude is the most important factor in ethically increasing living kidney donations, that sets Flescher's plan apart from other scholars' proposals.

CRITIQUE OF FLESCHER'S ARGUMENT

Flescher's argument rests on a faulty assumption: a reliable healthcare system that holds a high degree of trust from the public that will execute these transplants. He does not propose any changes to the current organ allocation and distribution system. Flescher's recommendation, within the context of the current U.S. political and social climate, could ultimately prove damaging to individuals and society.

A trustworthy healthcare system

In order for Flescher's project to work, civic duty must be awakened, which requires a healthcare system that patients trust (Flescher, 2018). This is not the current U.S. political and social climate. The COVID-19 pandemic has exacerbated health and healthcare disparities among Americans, with people who belong to racial minorities and in lower socioeconomic classes being disproportionately affected, which has exacerbated pre-existing distrust among some communities (Baker, 2020; Okonkwo et al., 2021). Among lower income people, less than half agreed that "doctors can be trusted" (Blendon et al., 2014, p. 1571). Mistrust of the healthcare system leads to worsened clinical outcomes: patients who reported less trust in their physicians were more likely to be noncompliant with their medications (Egede & Ellis, 2008). A study conducted in 2017 indicated that Americans found honesty, reliability, and fairness lacking in the U.S. healthcare system (Prince, 2017). The lack of widespread acceptance of living donor programs may be due to the fact that people don't trust their healthcare systems to take care of them afterward.

Patient demographics have a significant impact on how much faith individuals have in their healthcare institutions. Based on results from a multidimensional trust survey about healthcare providers, institutions, and payers, Egede and Ellis found that "trust scores were significantly lower among women, African Americans, and Hispanics and those without a usual source of care" (2008, p. 811). African Americans distrust the healthcare system for a variety of historical and contemporary reasons (Baker, 2020; Sade, 1999). This lack of trust is one factor cited to explain low donation rates among minority communities (Bratton et al., 2011; Purnell et al., 2012). However, Flescher thinks that the donation rate disparity can be "loved away": "If we show vulnerable populations that we care about them for real, we will earn larger societal buy-in…" (2018, p. 98). This attitude ignores the structural inequalities within the organ allocation and healthcare systems themselves that prevent many people from donating.

Lack of trust in the current medical system and among our fellow citizens translates into less willingness to help others, especially when the benefit to ourselves is unclear (Ronnerstrand & Andersson Sundell, 2015). In an untrusted medical culture, why would healthy citizens willingly risk complications from donating an organ? As one physician put it, "when doubt becomes pervasive, it can erode the glue that binds society together, and the medicine that keeps us healthy" (Khullar, 2018, para. 22).

Justice issues with the current organ donation system

Flescher does not suggest changing the current organ distribution system, which is itself unjust. Even if more organs became available for transplantation, the discrimination present in the current system would merely be reproduced. Empirical evidence shows that people have good reason to question the fairness of the established system. In the present organ allocation structure, every other donated kidney goes to a white recipient, while African American/Black recipients get every fifth kidney, even though each race makes up one third of the waiting list (Grubbs, 2018). The donation rates among minority communities are much smaller too, for both living and deceased donations (Purnell et al., 2018; Sade, 1999). Within the medical community itself, excuses like, "African Americans[']...immune systems are just so strong" continue to be offered (Grubbs, 2018, p. 44). Despite efforts to decrease this discrepancy, racial and ethnic disparities for living donation have actually "increased in recent years, even after accounting for differences in deceased donor kidney transplantation and death" (Purnell et al, 2018, p. 60). As nephrologist Dr. Vanessa Grubbs puts it, the current organ donation system involves "a cascade of requirements vulnerable to the effects of personal bias and racism at an institutional level" (2018, p. 216). Attempting to smooth over these institutional structural barriers by an appeal to humanity's good nature, as if the kidney donation problem would go away if each American just cared enough, can ultimately be harmful to those not in the privileged classes: "There are still winners and losers, the powerful and the powerless, and the claim that everyone is in it together is an eraser of the inconvenient realities of others" (Giridharadas, 2018, para. 17).

Currently in America there are large disparities in transplant rates among race and socio-economic classes who have kidney failure (Purnell et al., 2018). An ideal transplantation system would be equitable, drawing on the principle of justice: all levels of society should share the benefits and burdens of the organ donation system (Ross & Thistlethwaite, 2021; Smith, 2009). By insisting that disparities in the current system could be overcome if only people were motivated enough, Flescher feeds the root causes of these disparities: "Neglecting these structural conditions risks legitimating them" (Smith, 2009, p. 107).

With the current social climate in the U.S., Flescher's proposal could provide justification for continuing the current organ distribution system, which is rife with institutional bias and discrimination. In their study of public perceptions of "deservingness" in terms of healthcare, Gollust and Lynch found that public policy is significantly affected by "one's perceptions about the reasons for unequal health outcomes in society" (2011, p. 1085). In the U.S., professional advocacy is especially critical in shaping public perceptions (Blendon et al., 2014). By recommending a plan of action without confronting the many layers of discrimination in the current organ transplant system, Dr. Flescher, as an expert, can have a significant impact on future policy decisions. Merely "wishing" a new attitude into existence will not solve the organ shortage crisis and giving the impression that lack of motivation is a major reason for the crisis is irresponsible.

An alternative amelioration of the kidney health crisis

Without changing the institutional biases of our healthcare system, we cannot hope to have a just solution to the organ shortage crisis. However, there is an option that can move closer to an ethical solution: increasing access to primary and preventive care and expanding the eligible donor pool.

Increasing access to primary care can reduce the need for donor kidneys in the first place and lead to increased trust in the wider healthcare system. Basic coverage gets people involved with the healthcare system where they can form relationships with providers and learn more about what options they have in terms of health. Patients with a consistent source of care tend to have higher levels of trust in healthcare providers (Egede & Ellis, 2008).

In addition, increasing access to primary care would go a long way in helping Americans maintain healthy kidneys. Early and frequent monitoring can identify the beginning of CKD before it progresses to kidney failure. Persons who have diabetes and hypertension are predisposed to developing CKD, so having a consistent primary care provider to monitor those patients would be helpful (Rosoff, 2018; Sade, 1999). Scholars seem to agree that this preventive medicine tactic is the most just solution to the kidney health problem (Glannon, 2018; Hippen et al., 2009; Szczech & Lazar, 2004; Vandecasteele & Kurella Tamura, 2014). In addition, catching a disease early is more cost effective and leads to better patient outcomes than treating the condition once it becomes chronic.

Nationally, OPTN has issued guidelines stating that donors must be in good physical and mental health, and have a social support network (OPTN, 2018). Recent expanded criteria for donors allow some people who test positive for HIV and hepatitis C and older donors to give organs. These criteria still exclude most people with chronic illnesses, even if those persons' kidneys would otherwise be a good match (Ansari et al., 2017). One particular example is patients with amyotrophic lateral sclerosis (ALS). In their study of neurologists who specialize in treating individuals with ALS, Ansari and colleagues (2017) found that nearly half (49%) had been approached by their patients about donating their organs. If half of the general population who qualify for organ donation were interested in donating, it would be truly amazing. And even though over two-thirds (67.3%) of the neurologists have no concerns with ALS patients being donors, this group is automatically excluded by current guidelines (Ansari et al., 2017). The current donation process could be modified to address vulnerability and safety concerns for ALS patients and others with certain chronic diseases who wish to donate and who are already engaged with the medical system.

Expanding the donor pool and increasing preventive care, especially for those most at risk of kidney disease, are not the only solutions that can help, but are far more effective than Flescher's proposal. In particular, the preventive care component will do more for the health of minority communities and be more helpful in avoiding future healthcare costs. It should be part of any long-term solution to America's organ shortage crisis.

CONCLUSION

Flescher is unable to create or will into existence an equitable, safe system of living organ donation if he does not make any structural changes to the current recruitment and distribution system. While packaged to sound appealing, an emphasis on civic duty as the main driver of living organ donation is unrealistic. More likely, policymakers could construe these arguments to justify the prejudicial system that is in place now. The U.S. should continue to remove financial disincentives that deter individuals from donating, but that will be only a partial solution. There should also be increased preventive care for all individuals in order to decrease the need for kidney transplants in the first place. Expansion of donor criteria to include those who may have healthy kidneys but have been rejected by the current prohibitions on chronic illnesses also has potential for generating more donors.

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A Trauma-Informed Care Model: Addressing Adverse Childhood Experiences in Patients with End-Stage Kidney Disease

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In the healthcare field, there has been increased recognition of the long-term consequences that adverse childhood experiences (ACEs) have on the health and well-being of people. It is imperative that a trauma-informed care (TIC) approach is utilized in the treatment of patients with end-stage kidney disease (ESKD) because of high rates of non-adherence and health risk behaviors. The purpose of this article is to explore current nephrology practices and TIC approaches utilized in the healthcare field. A TIC approach, through a health-belief model lens specific to the ESKD population, can be introduced by providers to better assess and treat patients. Implications for practice include standardization of TIC in social work practice, better outcomes for patients, and ongoing research considerations.

INTRODUCTION

Adverse childhood experiences (ACEs) are a public health crisis in the United States. ACEs are defined as are exposures to physical, sexual, or emotional abuse; neglect; violence; parental incarceration; substance use/misuse; and suicide (Felitti et al., 1998). Studies have shown that people exposed to ACEs are more likely to engage in health-risk behaviors (Campbell et al., 2018; Chanlongbutra, Singh, & Mueller, 2018; Felitti et al., 1998). Due to these health-risk behaviors, there is a strong correlation between ACEs and chronic health conditions, which includes, but are not limited to, diabetes, high blood pressure, and cardiovascular disease (Chanlongbutra, Singh, & Mueller, 2018; Felitti et al., 1998). Diabetes and high blood pressure are also the two leading causes of end-stage kidney disease (ESKD), which are related to poor health management and health-risk behaviors that often continue after diagnosis (Baines & Jindal, 2000; Clark et al., 2014, Leggat et al., 1998).

Similar to the challenges associated with ACEs, chronic health conditions, and health-risk behaviors, people with an ESKD diagnosis often struggle with adherence issues to treatment recommendations, such as attending dialysis treatments, medication management, and diet and fluid restrictions (Chironda & Bhengu, 2016). While there is almost no research on ESKD as related to ACEs, there is evidence that trauma-informed care (TIC) models are effective in the care of patients with chronic health conditions (Evans & Coccoma, 2014). The implementation of a TIC model for patients with ESKD is essential, as they are at higher risk of death due to health-risk behaviors and adherence issues (Baines & Jindal, 2000; Clark et al., 2014).

The purpose of this conceptual article is to explore current social work nephrology practices and the possible adaptation of TIC approaches when treating patients with ESKD. A TIC model can be introduced through the lens of a health-belief model lens by social workers to better assess and treat patients with ESKD.

The health-belief model identifies a person's beliefs and perceptions about their health. These perceptions and beliefs predict their responses and behaviors related to their disease (Hayden, 2019; Stevenson, 2014). A person's perceptions and beliefs are influenced by their culture, heritage, education, experiences, race, or attitude (Hayden, 2019). Employing the health-belief model helps guide the structure of a TIC model for patients with ESKD, as they have unique needs and challenges that are often tied to their perceptions and beliefs related to their disease. Further, the health-belief model aims to assist social workers in understanding that trauma may be affecting a person's health choices. The health-belief model promotes the knowledge that health may be improved by identifying a person's beliefs about themselves and their health conditions, and the relationship of these beliefs with exposure to ACEs.

In this article, an argument is made for the assessment of patients with ESKD for ACEs, and for the implementation of a trauma-informed care model through the lens of a health-belief model, both being critical to their health and well-being. This development of an ESKD-specific TIC model includes initial and annual assessments for ACEs, as well as the use of TIC interventions. In understanding health-related behaviors of patients with ESKD, this model shifts focus from the person's internal characteristics and issues toward considering the effects of adverse experiences during early childhood and development. This allows social workers to better understand, treat, and care for patients with ESKD who may have histories of trauma. Additionally, this can produce better health outcomes through increased adherence behaviors for patients with ESKD than with current social

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work practices and interventions. Moreover, further research needs to be conducted, specifically in the field of social work, on TIC for patients with ESKD. The additional research may produce more evidence for the need for TIC models and inform practice and policies.

CONCEPTUAL FRAMEWORK

Health-Belief Model

The health-belief model is essential to recognizing the connection between health-risk behaviors and ACEs, and to implementing a trauma-informed care model for patients with ESKD. The health-belief model functions on the principle that a person's beliefs and perceptions about their health will determine their actions and decisions related to their health (Chou & Shih, 2018; Hayden, 2019; Rosenstock, 1974; Stevenson, 2014). There are three concepts that will be used in this framework; they are *perceived seriousness*, *perceived benefits*, and *perceived barriers* (Chou & Shih, 2018; Hayden, 2019). These concepts are influenced by a person's beliefs, values, culture, race, and experiences, including exposure to ACEs (Hayden, 2019).

The concept of *perceived seriousness* assumes that a person will address their health condition if they perceive it as serious enough to warrant attention (Chou & Shih, 2018; Hayden, 2019; Stevenson, 2014). Patients with ESKD who have experienced trauma may not fully recognize the seriousness of their condition and increased risk of death. Despite health discussions, some patients who have been exposed to trauma may struggle to recognize that nonadherence to treatment recommendations places them at serious risk (Chironda & Bhengu, 2016; Tuot et al., 2013). To best comprehend adherence barriers, it is important that providers understand a person's perception of the seriousness of their illness and that ACEs may be associated with these maladaptive behaviors (Evans & Coccoma, 2014; Waite & Ryan, 2020).

The concept of *perceived benefits* assumes that in order for a behavioral change to occur, a person would need to perceive the benefits of a new health behavior outweighing the cost of continuing the old behavior (Hayden, 2019). Patients with ESKD who have experienced ACEs may have difficulty seeing the benefits of changing risky behaviors to healthier ones. People who experience trauma may have an unconscious self-identity of being "damaged" and without self-value that may make it challenging for them to see the benefits of a behavioral change (Evans & Coccoma, 2014; Hornor et al., 2019; Waite & Ryan, 2020). Through a trauma-informed and health-belief-driven model of care, social workers may assist patients in recognizing the perceived benefits of a behavioral change. This may be done by helping people develop an awareness of their initial reasoning behind the maladaptive behaviors (Waite & Ryan, 2020). This may assist people with recognizing the maladaptive behaviors, engaging in healthier coping strategies, and perceiving the benefits of changing one's health-risk behaviors.

The concept of *perceived barriers* assumes that if a person perceives an obstacle to a behavior change, they are less likely to change the behavior (Hayden, 2019; Stevenson, 2014). If the problem is viewed as too much to overcome, then the person is more likely to continue the maladaptive behavior (Hayden, 2019; Stevenson, 2014). People who have been exposed to ACEs may struggle with the ability to logically evaluate situations and will construct barriers to changing the health-risk behaviors. While motivation is essential, a person's belief in their ability to change and perception of the value of the behavior change are equally important (Hayden, 2019; Stevenson, 2014).

Uncovering the perceptions of patients with ESKD about their health and how they connect to ACES may help them address health-risk barriers and reduce adherence issues. ACEs may negatively affect a person's perceptions and beliefs about their health, due to toxic stress. People who have experienced ACEs are more likely to experience avoidant behavior related to their health, due to maladaptive coping mechanisms (Evans & Coccoma, 2014; Hornor et al., 2019; Waite & Ryan, 2020). The health-belief model serves as a roadmap to recognizing the impact of trauma histories on patients with ESKD and the barriers these histories create. More importantly, the model can be used as a guide for social workers and providers to acknowledge that nonadherence to treatment recommendations is not an intentional act of defiance, but instead it may be a survival coping mechanism.

LITERATURE REVIEW

Adverse Childhood Experiences (ACEs)

In 2016, 34 million children were exposed to one or more ACEs (Bethell et al., 2017). ACEs refers to exposures to traumatic experiences in children between the ages of 0 to 17 by a caregiver or parent (Felitti et al., 1998). These traumatic exposures are separated into four groups: (a) abuse (i.e., emotional, physical, or sexual); (b) neglect (i.e., physical and emotional); (c) household challenges (i.e., domestic violence; parental/caregiver incarceration; chemical misuse/dependency, separation or divorce of caregivers, and parental/caregiver mental health challenges); and (d) community violence (Bethell et al., 2017; Centers for Disease Control & Prevention [CDC], 2019; Felitti et al., 1998; Waite & Ryan, 2020). The ACEs score is a calculation of each of the above categories that a person may have experienced (CDC, 2019). Each exposure in a specific category accumulates a higher ACE score.

A seminal study by Felitti et al. (1998) brought widespread attention to the connection between ACEs and long-term chronic health issues in adulthood. A strong correlation was found between the development of chronic health conditions, risky health behaviors, and the number of ACEs experienced by a person (Felitti et al., 1998). These studies found a "graded dose-response" between an increased number of ACEs and the leading causes of death in the U.S. (Bethell et al., 2017; Felitti et al., 1998, p. 250). A dose-response means that with an increase in the number of ACEs a person experiences, the more likely they are to develop chronic diseases and they are also at an increasing risk for mortality (CDC, 2019; Felitti et al., 1998). Therefore, as the number of ACEs increased, the health-risk behaviors also increased, which created a higher risk of developing chronic health conditions, such as ESKD, and mental health issues (Felitti et al., 1998).

ACEs, Toxic Stress, and Health

Toxic stress is defined as repeated exposures to tremendous amounts of stress hormones in the body, which may affect a person's development during childhood (Evans & Coccoma, 2014; Hornor et al., 2019; Waite & Ryan, 2020). Due to toxic stress from exposures to ACEs, people are at greater risk for chronic health conditions and premature death as a result of high-risk behaviors (Centers for Disease Control and Prevention, 2019; Chanlongbutra et al., 2018; Hornor et al., 2019; Loxton et al., 2019; Merrick, 2018; Slack et al., 2017; Sonu et al., 2019). As repeated exposures to toxic stress affect the body and mind, a person may be predisposed to physical and mental health issues (Waite & Ryan, 2020). This toxic stress exposure also disrupts a person's ability to "self-regulate" and influences their abilities to self-soothe, build stable relationships, manage compulsions, and learn (Waite & Ryan, 2020).

Toxic stress from ACEs disrupts a child's neurobiological responses and rewires the circuitry of the brain (Waite & Ryan, 2020). This creates a dysfunction of the body's regulatory response to stress and formulates maladaptive responses to stress (Waite & Ryan, 2020). These are not chosen responses, but instead are the brain's way of adapting to chronic stress. As a result, this increases health-risk behaviors and promotes mental and physical health conditions, such as anxiety, depression, high blood pressure, obesity, and diabetes (Evan & Coccoma, 2014; van Duin et al., 2018; Waite & Ryan, 2020). This is important as high blood pressure and diabetes are also strongly connected to the development ESKD (United States Renal Data System [USRDS], 2019).

End-Stage Kidney Disease

End-stage kidney disease (ESKD) is a chronic health condition that results in both kidneys failing. When a diagnosis of ESKD is acquired, the person will need a transplant or dialysis to sustain life, as their kidneys are no longer filtering toxins out of the body (Mayo Clinic Staff, 2020; MedlinePlus, 2018; National Kidney Foundation [NKF], 2021). Dialysis requires people to be connected to a machine three times a week or more to live (NKF, 2021). If a person does not start dialysis or receive a kidney transplant, death becomes imminent. While ESKD is not a new health condition, it continues to affect many people in the U.S. (USRDS, 2018).

In 2018, there were 785,883 patients in the U.S. with a diagnosis of ESKD compared to 746,557 cases in 2017 (NKF, 2021; USRDS, 2018). The leading causes of ESKD include diabetes, high blood pressure, heart disease, family history of ESKD, and obesity (CDC, 2021). Of the 746,557 people diagnosed with ESKD in 2017, 33.4% received no preventative care related to chronic kidney disease (CKD) (USRDS, 2019). Additionally, 65% of people received a diagnosis of ESKD due to diabetes and high blood pressure (USRDS, 2019). Many patients with ESKD struggle with adherence because of mental health issues which increase their risk of death (Ozen 2019; Tsur et al., 2019). However, there is little consideration of the causes of these health-risk behaviors, such as ACEs.

ESKD, Adherence, and Mental Health

On average, people with ESKD have a life expectancy of five to 10 years if they do not receive a kidney transplant (NKF, 2021; O'Hare et al., 2019). Even though some patients may live longer than 25 years, there are high rates of mortality that occur within the first year of dialysis (Brito et al., 2019). While various factors may contribute to early mortality in patients with ESKD, some may struggle with adherence and mental health challenges that contribute to premature death (Ozen 2019; Tsur et al., 2019). Studies have shown that between 50% to 80% percent of patients with ESKD engage in health-risk behaviors, such as nonadherence to treatment recommendations (Baines & Jindal, 2000; Clark et al., 2014; Leggat et al., 1998).

People who receive a diagnosis of ESKD experience many lifestyle changes. These changes include fluid and diet restrictions, completing dialysis three or more times a week depending on the modality of treatment, and medication management (Chan et al., 2014; Clark et al., 2014; Cohen & Kimmel, 2018; Ozen, 2019). If patients do not follow each of the treatment recommendations, they are at an increased risk of developing additional comorbidities, more hospitalizations, and death (Clark et al., 2014; Cohen & Kimmel, 2018; Ozen, 2019). Additionally, patients who do not adhere to treatment recommendations are viewed by providers as non-compliant or resistant to treatment.

Providers often label people who do not adhere to treatment recommendations as non-compliant (World Health Organization [WHO], 2003). However, they often do not consider other factors that may be unconsciously influencing the health behaviors of patients. While there are many causes of non-adherence, patients with ESKD who experience significant adherence issues are more likely to struggle with their mental health (Baines & Jindal, 2000; Clark et al., 2014). Studies found that people with ESKD are three to four times more likely to experience depression (Bezerra et al., 2018; Chen et al., 2016; Treadwell, 2017). In a study by Bezerra et al. (2018), 58% of patients with ESKD and 47% of all CKD patients presented with depression. Further, other studies have found that between 27% to 45.7% of dialysis patients experienced ongoing anxiety, which affects their compliance and treatment (Cukor et al., 2007; Shafi & Shafi, 2017). The severity of depression and/or anxiety symptoms significantly increases a person's risk of mortality (Chironda & Bhengu, 2016; Khan et al., 2019; Kimmel et al., 2000). This is due to poorer health outcomes, nonadherence, and health-risk behaviors, as people often feel a perceived lack of control over their health and an inability to manage their disease sufficiently (Brito et al., 2019). This is one of the key factors as to why master's level social workers are required to be involved in the care of patients with ESKD, to address their psychosocial needs, which should include assessment for ACEs (Browne et al., 2014).

ESKD and Social Work Practice

Social workers perform a fundamental role in the interdisciplinary team's care of patients with ESKD and understand the complexity of human behavior that affects health outcomes. Social workers in nephrology partner with nephrologists, nurses, physician assistants, dietitians, other medical staff, and patients to provide comprehensive care planning for each patient (Centers for Medicare & Medicaid Services [CMS], 2020). The Centers for Medicare and Medicaid Services (2020) mandates that master's level social workers must be involved in the care of patients with ESKD to address psychosocial needs. Social workers address many components of patients' needs, such as quality of life, mental health, adherence issues, relationship concerns, end-of-life planning, grief and loss, coping and adjusting, conflict management, and financial challenges (Browne et al., 2014).

NEPHROLOGY SOCIAL WORK PRACTICE

Assessment Process

Social workers in nephrology are required to complete "peopleized" psychosocial assessments of patients' overall well-being and quality of life. Through these comprehensive assessments, social workers can identify the strengths, challenges, and barriers that a person with ESKD may be experiencing (Browne et al., 2014). A key focus of a psychosocial assessment is to evaluate patients for mental health disorders and other issues. Due to the increased risk of depression in patients with ESKD, screenings in the assessment process are required (CMS, 2020). CMS requires yearly depression screenings due to an established connection between depression, lower quality of life, adherence challenges, and mortality (Browne et al., 2014; CMS, 2020; Shirazian et al., 2017). The Patient Health Questionnaire (PHQ-9; Kroenke et al., 2001) is the most widely used measurement instrument to assess depression in people with ESKD (Browne et al., 2014). If patients present with moderate or severe depression, social workers must rescreen people and develop interventions to address the depressive symptoms (CMS, 2020). Social workers in nephrology are not required to screen for any other mental health disorders annually, which may result in gaps in care for patients.

While assessing for depression is vital due to various physical and mental health risks (Chironda & Bhengu, 2016; Kimmel et al., 2000), there is often little consideration of the potential root cause of mental health and health-risk challenges, such as ACEs. For example, ACEs may affect a person's health behaviors, which then could increase their risk of kidney disease, depression, and other chronic health conditions. Without considering the impact that ACEs and past traumas have on adherence and mental health in patients with ESKD, this group is vulnerable to other chronic health conditions and premature death (Waite & Ryan, 2020). Social workers, with their knowledge of the negative impact of trauma, should be at the forefront of standardizing trauma-informed care practices with patients diagnosed with ESKD.

Trauma-Informed Care (TIC)

Trauma-informed care (TIC) is defined as the recognition by providers and organizations that trauma is pervasive, training staff is essential to recognizing trauma signs and symptoms, and trauma-informed approaches should be incorporated into policies and practice (Evans & Coccoma, 2014). Trauma-informed care (TIC) was developed by Harris and Fallot (2009) in the belief that past traumatic experiences continually affect people psychologically, emotionally, and physically throughout their lives. TIC is a "paradigm shift" in the delivery of mental and physical health services and interventions, as it assumes that everyone has experienced trauma (Evans & Coccoma, 2014). TIC does not necessarily attempt to remedy the traumatic history but instead focuses on caring for patients in the realization that trauma significantly affects people and their health (Fallot & Harris, 2009). Under this concept, histories of trauma should be recognized by healthcare providers and shift away from a pathological perspective, *"What's wrong with you?"* to the survivor perspective, *"What happened to you?"* (Evans & Coccoma, 2014, p. 1). This is done through the *realization* of the pervasiveness of trauma, *recognizing* the signs and symptoms of trauma in patients, *resisting* re-traumatization of people, and *responding* through trauma-informed policies and procedures (Fallot & Harris, 2009; SAMHSA, 2014). From this perspective, trauma-informed care includes the organizational implementation of six principles. These principles guide the implementation of a TIC approach that recognizes the impact of trauma on people with ESKD and recognizes that non-adherence is not deliberate disregard for their health.

Trauma-Informed Care: SAMHSA Six Key Principles

The Substance Abuse and Mental Health Services Administration (2014) identified 10 key principles, six of which were selected to guide implementation of the TIC approach. These six key principles are: (a) *safety;* (b) *trustworthiness and transparency;* (c) *peer support;* (d) *collaboration and mutuality;* (e) *empowerment, voice, and choice;* and (f) *cultural, historical, and gender issues* (Substance Abuse & Mental Health Services Administration [SAMHSA], 2014). These principles are important, as they place emphases on developing a practice that moves away from pathology to one that recognizes the impact of trauma on people with ESKD. The intent of these principles is to lay the foundation for social workers to create a TIC model to better serve noncompliant patients with ESKD who have traumatic backgrounds.

Creating an environment of *safety* ensures people are physically, emotionally, and psychologically secure (Fallot & Harris, 2009; Harris & Fallot, 2001; SAMHSA, 2014). This means that organizations need to create an environment of safety for patients and staff (SAMHSA, 2014). If people do not feel safe and secure with providers, they may be less likely to engage in services necessary for their health and well-being (Evans & Coccoma, 2014). *Trustworthiness and transparency* aim to develop trust between people and their care team through openness, clarity of practice, expectations, boundaries, and clear communication (Fallot & Harris, 2009; Harris & Fallot, 2001; SAMHSA, 2014). The current medical model is often one-sided toward the provider and may create distrust, boundary challenges, and a lack of communication. In a TIC model, a provider's interactions are patient-centered and transparent, with the goal of creating a mutually trusting relationship between providers and people (SAMHSA, 2014).

Peer support allows people to experience security and hope by narrating their stories of trauma to foster healing and recovery (SAMHSA, 2014). Providers can create safety through peer support by developing collaboration and mutuality. *Collaboration and mutuality* encompass a partnership between patients with ESKD and the interdisciplinary team that gives power back to the patient (Fallot & Harris, 2009; Harris & Fallot, 2001; SAMHSA, 2014). People need to be aware of the power they hold to improve their lives and providers can help in this realization by allowing patients to have power in their choices. Through collaboration and mutuality, people can feel empowered to use their voices and identify their care options (SAMHSA, 2014). *Empowerment, voice, and choice* describe patients' abilities to choose options and control their own healthcare (Fallot & Harris, 2009; Harris & Fallot, 2001; SAMHSA, 2014). The person's strengths are recognized and enhanced instead of focusing solely on their mistakes or compliance issues. For providers to ensure that people feel empowered, they must also realize the cultural, historical, and gender issues that also arise in working with people. For example, if a female patient is from a culture where men are viewed as the decision-makers or hold rights over women, then empowering this patient without this cultural awareness may be difficult. *Cultural, historical, and gender issues* must also be recognized in a TIC model, as they can also be closely tied to trauma histories (SAMHSA, 2014). Providers should actively remove biases related to cultural components, such as age, gender, race, ethnicity, socioeconomic status, religion, disability, and sexual orientation in working with people in the healthcare settings (SAMHSA, 2014).

This SAMHSA model using each of the key principles can be used to develop a TIC perspective with patients with ESKD. It allows people with ESKD to feel psychologically and physically safe and elicits trust through collaborative communication with social workers and the care team (SAMHSA, 2014). This may increase adherence and improve patient outcomes, as the care team focuses less on labeling patients as noncompliant and more on developing mutual support and trust (SAMHSA, 2014). Understanding the impact of ACEs and trauma histories enables providers to understand that health-risk behaviors of patients with ESKD are more likely coping mechanisms due to past traumatic exposures. This will assist social workers in providing responsive services to patients with ESKD and recognizes that these actions are not a conscious disregard for their health.

DISCUSSION

Since the seminal study by Felitti et al. (1998), the association between chronic health conditions and ACEs has received significant attention in the behavioral health and healthcare fields. Providers recognizing this should implement a TIC model for patients with ESKD. This section reviews SAMHSA's six principles for the implementation of a trauma-informed model of care and identifies a trauma-informed model of care specifically for use in the treatment of patients with ESKD (TI-ESKD).

Trauma-Informed Care: Creating a Model for ESKD: Guidance Practices for Implementation of TIC

SAMHSA (2014) offers directions for the application of a TIC approach within organizations and is guided by six of the 10 key *principles* (SAMHSA, 2014). The guiding principles are core values of TIC.

SAMHSA (2014) also identified ten guidance *practices* for implementation of TIC within organizations or practice settings. For the TI-ESKD model, six of the 10 guidance practices are included: (a) *governance and leadership;* (b) *policies, practices, and procedures*; (c) *physical environment;* (d) *cross-sector collaboration*; (e) *screening, assessment, treatment services*; and (f) *training and workforce development*. The guidance practices for implementation are focused on how organizations effectively implement TIC. These assist in the design and execution of a trauma-informed ESKD (TI-ESKD) model of care to improve services for the ESKD population.

Table 1 depicts SAMHSA's Trauma-Informed Model of Care for ESKD: SAMHSA's six guidance practices for implementation; the SAMHSA suggestions for incorporating these TIC model guidelines; and the actual utilization of a TI-ESKD model of care.

Governance and Leadership in the TI-ESKD Model of Care

Those in authority within an organization will need to support implementing a TI-ESKD model of care (SAMHSA, 2014). This will require a "champion" to initiate and advocate for changes in policies, practices, and procedures (SAMHSA,

Table 1: A Trauma-informed Model of Care for ESKD (TI-ESKD)

SAMSHA Trauma-informed Care (TIC) Guidance Practices for Implementation	SAMSHA Trauma-Informed Care (TIC) Model	Trauma-Informed End-Stage Kidney Disease (TI-ESKD) Model of Care
a. Governance and Leadership	Leaders in the organization will need to support the implementation of a TIC approach. A champion is often responsible to lead and monitor the application of TIC within the organization.	Nephrology social workers should be champions for the implementation of a TI-ESKD model of care. If resistance or reluctance occurs from leadership and/or staff, social workers should continue to advocate for necessary changes to include TIC practices.
b. Policies, Practices, and Procedures	Current policies, practices, and procedures in organizations should be reviewed and altered to include TIC.	Centers for Medicare and Medicaid Services (CMS) policies, practices, and procedures for the care of patients with ESKD should be explored, and TIC practices should be embedded in the organizations policies, practices, and procedures. Social workers should explore and advocate for changes in organizational policies, practices, and procedures that recognize the pervasiveness of trauma, focus on safety, highlight the importance of patient involvement in organizational changes, and that are culturally sensitive.
c. Physical Environment	Providers and their staffs should create safety in their physical and social-e motional environment, including collaboration and transparency between patients and staff.	Dialysis units and nephrology office spaces should be physically and social-emotionally safe for staff and patients. Collaboration and transparency are important elements of these environments. Patients are active participants in their care and have a voice in their treatment decisions. Social workers can help the care team recognize how a collaborative environment promotes safety and trust.
d. Cross-Sector Collaboration	All staff should collaboratively understand the impact of trauma and importance of a TIC approach.	All nephrology providers' staffs should understand the impact of trauma on patients with ESKD and its connection to adherence issues. They need to work in partnership with patients and other interdisciplinary staff to address the complex needs of patients and ensure "peopleization" of plans of care.
e. Screening, Assessment, and Treatment Services	All patients receiving services from the organization should be screened, assessed, and treated for trauma.	Nephrology social workers should use the ACEs screening tool (Aces Aware, 2021) and assess patients for trauma. Further, social workers should standardize the use of ACE screenings and assessments yearly. Social workers should incorporate TIC goals and interventions in patients' plans of care to best address their needs. Social workers should share this information with interdisciplinary teams so that other members are able to incorporate TI-ESKD interventions. Partnerships with mental health providers specializing in trauma should be obtained and retained.
f. Training and Workforce Development	All providers and staff should be trained about the impact of trauma on people and the importance of TIC practices.	All interdisciplinary team members and staff should be trained in TIC practices. Nephrology social workers are often well equipped to provide education and training on TIC, the impact patient trauma may have on staff, and self-care practices for other team members and staff. If they are not, outside assistance to provide TIC training would be beneficial.

2014). Social workers should be at the forefront of advocating for implementing a trauma-informed care model. Social workers are equipped with knowledge and skills regarding the impact of trauma and the need for interdisciplinary changes in practice for the best patient outcomes. In current healthcare, the medical model has a heavy focus on disability and impairment, and the psychological aspects of a person are treated separately, often with little consideration of the impact of psychological issues on physical health (Swaine, 2011). Due to this medical model being a common approach, social workers will need to continue to advocate, often in the face of resistance or reluctance of other staff in their organization. With the buy-in from other staff in the care team, TIC policies, practices, and procedures should be discussed, changed, and implemented as a team approach.

Policies, Practices, and Procedures in the TI-ESKD Model of Care

Current policies, practices, and procedures should be reviewed and revised to include TIC which are integral to the successful deployment of the TI-ESKD model (SAMHSA, 2014). While each organization has different policies, practices, and procedures for patients with ESKD, the Centers for Medicare and Medicaid Services (CMS) requirements are consistent (CMS, 2020). CMS requires many practices to be put into place when working with patients with ESKD to optimize health outcomes (CMS, 2020). While these range according to the responsibilities of each discipline, they also include interdisciplinary approaches and interventions. Social workers should lead in reexamining current CMS policies, practices, and procedures, and research how a TI-ESKD model of care may be adapted to these requirements.

TI-ESKD Model of Care and the Physical Environment

To develop a sense of safety, organizations must be mindful of the physical environment (SAMHSA, 2014). From staff to patients, everyone should perceive the physical space as open, collaborative, and be free from psychological and physical hazards (SAMHSA, 2014). In the care of patients with ESKD, it is imperative that patients feel safe and be free from harm. The physical environment for patients with ESKD should be examined and altered to provide safety and comfort. For example, a unit's temperature, harsh lighting, music choices, etc., should be altered to be more comfortable and welcoming for patients, as these may be potential sources of trauma triggers. Additionally, the physical environment should encourage collaboration and transparency (SAMHSA, 2014). Under a TI-ESKD model, patients are provided with the opportunity to discuss their needs and the barriers to their care. This approach removes the perception of defiance and blame and requires the medical team to view patients as active, collaborative partners in developing a care plan instead of the team making decisions for them. Social workers can advocate for the importance of patients being participants in their care and help the care team recognize how a collaborative environment promotes emotional safety and trust (Levenson, 2017).

TI-ESKD Model of Care Cross-Sector Collaboration

Cross-sector collaboration requires that all involved in patient care have a universal understanding of the impact of trauma, and that the components of TIC are understood (SAMHSA, 2014). Utilizing a TI-ESKD care approach, providers learn how trauma may hinder a person's adherence to recommendations and their health choices. By implementing a TI-ESKD care approach, providers collaborate with patients to meet their "peopleized" and complex needs. This includes enlisting the trauma-informed expertise of other interdisciplinary team members to reach the best health outcomes for patients. Providers also have opportunities to realize the impact of trauma and assist patients in connecting to mental health services that provide trauma-specific interventions. In order for this to be successful, patients will need to be screened and assessed for ACEs so appropriate treatments and referrals are implemented.

ACEs Screening, Assessments, and Treatment Services

SAMHSA (2014) advocates for the screening, assessment, and treatment of trauma in a healthcare organization setting. People with histories of trauma or ACEs may not initially disclose the trauma due to shame, distrust, or anxiety about divulging the experiences (McGregor et al., 2010). However, it is vital that the screening, assessment, and treatment be implemented at some point in their care. Therefore, under a TI-ESKD care model, nephrology social workers should screen and assess people with ESKD annually, similar to the requirements for administering the PHQ-9 annually (Kroenke et al., 2001). If assessment and screening for ACEs are standardized in the care of patients with ESKD, social workers will have the ability to identify people who may require trauma-specific interventions. Additionally, social workers are best suited to incorporate "peopleized" TIC goals and interventions into their care plans for optimal treatment outcomes. Social workers should also share these findings with the interdisciplinary team to ensure that TI-ESKD interventions are addressed in each area of the patient's plan of care, which will require all providers and staff to be adequately trained in TIC practices.

Training and Workforce Development in TI-ESKD Model of Care

For a TIC model to be implemented, all providers must be trained in the utilization of TIC practices (SAMHSA, 2014). Social workers are best equipped to provide TIC education and training to staff. In the event staff are not trained, nephrology social workers should engage in TIC training and pass on the information and education to other providers. Social workers should also advocate for mandatory TIC training for new staff and annual competency education. Further, social workers have the ability to educate patients with ESKD on TIC, self-care, and secondary trauma care (SAMHSA, 2014).

IMPLICATIONS

Recommendations and Implications for Social Work Practice

Social workers need to advocate for implementation of TIC practices for patients with ESKD and in many other areas of the medical field that address chronic health conditions. The utilization and standardization of a TI-ESKD model of care will improve outcomes for patients with ESKD, as it addresses why adherence issues may be occurring. This will help patients and providers develop partnerships to address these challenges. This could decrease negative health outcomes and premature death in patients with traumatic histories. If the TI-ESKD model of care is implemented, it will create a safer environment for patients that moves away from pathologizing their choices and toward trauma-specific interventions.

Need for Future Research

Ongoing research is needed on the impact of trauma on patients with ESKD and other chronic illnesses. To this author's knowledge, there are no current studies that examine the correlation between ACEs and ESKD. This is crucial to understanding the influence of trauma on adherence and the provision of trauma-informed interventions within care plans. This knowledge will inform training, policies, practices, and procedures in the care of patients with ESKD. Further research is needed to explore nephrology providers' and staff perceptions and awareness of ACEs and implementation of TIC. The author is in the process of completing research exploring nephrology providers' current knowledge of TIC, its utilization, and where improvements may be made. Lastly, ongoing research is needed to evaluate and improve the TI-ESKD model. This may be done through assessing, tracking, and monitoring the outcomes of the current model and evaluating efforts to improve it. This will ensure that the TI-ESKD model of care is being utilized effectively and as intended.

CONCLUSION

Both ESKD and ACEs have a significant impact on the lives of people, which puts them at considerable risk of premature death. Due to ACEs, patients with ESKD may be at a higher risk of mental health issues, adherence issues, and lower quality of life due to health-risk behaviors. Nephrology social workers are required to address the mental health challenges of patients with ESKD, with specific attention paid to depression. While addressing depression and other mental health issues is essential, it is equally critical to assess ACEs and implement interventions to best serve patients with ESKD. Therefore, a TIC model should be developed for patients with ESKD in each unit, as they are often labeled non-compliant. If a TI-ESKD model approach is implemented for patients with ESKD, it may enhance adherence, quality of life and reduce their risk for mortality. Additionally, providers may better understand that adherence issues may be connected to a person's trauma histories and not blatant disregard for their health.

A TI-ESKD model of care can only be implemented effectively if all healthcare team members, not just social workers, receive education and training related to ACEs and TIC. This is a paradigm shift for many nephrology providers, as they are not often provided with education or training on TIC or ACEs during academic studies or continuing education. Menschner and Maul (2016) advocated for a standardization of TIC education in their academic studies of clinical staff and, at the very least, continuing education hours related to TIC practices. This would strengthen the providers' competency in and practice of TIC and would positively affect patients' lives (Menschner & Maul, 2016). If TIC practices are utilized, they may reduce long-term effects of trauma on patients with ESKD, improve health outcomes, and reduce costs associated with health-risk behaviors that may be perpetuated by a person's traumatic history.

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National Kidney Foundation
2022 Spring Clinical Meetings Abstracts
April 6–10, 2022

CKD/ESRD—Other

1 **Acuity Score Directed Psychosocial Assessments in Hemodialysis**
Kathleen Belmonte, John Larkin, Felicia Speed, Anna Rutherford, Sheetal Chaudhuri, Joanna Willetts, Jeffrey Hymes, Len Usvyat. Fresenius Medical Care North America, Waltham, MA, United States

4 **Effect of Music Therapy on Dialysis Patients: A Quality Improvement Project**
Janavi Kolpekwar[3], Sonali Birewar[1,2], Matthew Shanks[1], Shannon Garcia[1], Stephen Weber[1]. [1]Fresenius Medical Center, Cedar Park, TX, United States; [2]Austin Diagnostic Clinic, Austin, TX, United States; [3]Round Rock High School, Round Rock, TX, United States

3 **Factors Associated with Functional Health Limitations in Chronic Kidney Disease**
Veronica Morawek. Catholic University of America, Washington, DC, United States

CKD/ESRD—Prevalence, Progression, and Preparation for Dialysis

2 **Healthcare Providers' Perceptions of Urgent-Start Peritoneal Dialysis: A Qualitative Descriptive Study**
Dawn Burton. Grand Canyon University, Phoenix, AZ, United States

1. ACUITY SCORE DIRECTED PSYCHOSOCIAL ASSESSMENTS IN HEMODIALYSIS:

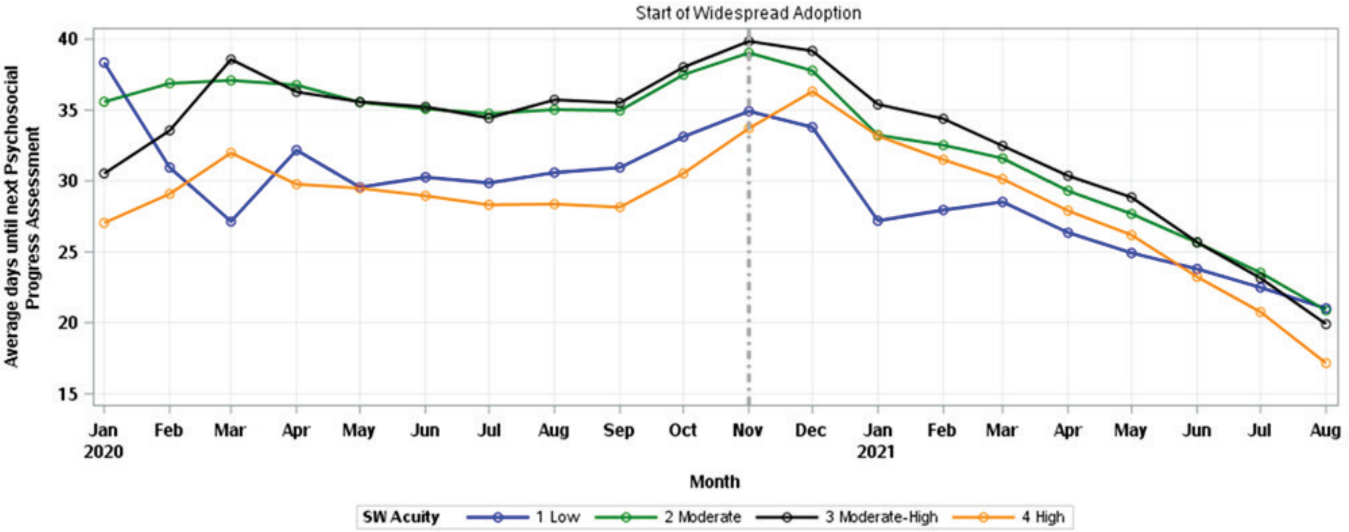
Kathleen Belmonte[1], John Larkin[1], Felicia Speed[1], Anna Rutherford[1], Sheetal Chaudhuri[1], Joanna Willetts[1], Jeffrey Hymes[1], Len Usvyat[1]. [1]Fresenius Medical Care North America.

We developed an acuity score to identify hemodialysis patients' level of need for psychosocial support and help social workers' (MSW) optimize visits and deliver personalized care. For preliminary evaluation, we assessed the profiles of MSW psychosocial progress assessments (PPAs) conducted before and after widespread adoption of the acuity score at a national hemodialysis network.

Using patient data from Jan-2020 throughout August-2021, a weekly acuity score was computed using an array of routinely captured variables (n=95) considered critical (i.e., psychosocial, cognitive, clinical, treatment, hospitalization data). Unique variables were assigned points based on a priori assignment, and then totaled and categorized based on population distribution for each week. Acuity was assigned as Low, Moderate, Moderate-High, or High based upon percentile distribution. Average days from the highest weekly acuity score in each month to completion of the next subsequent PPA was computed.

Acuity scores assigned weekly to an average of 214,296 patients/month across 20 months, with 95% having a follow-up assessment. After widespread adoption by MSW, the average days from the highest weekly acuity score in a month until the next PPA decreased steadily with patients in all acuity categories, with marked changes in patients with higher acuity categories (Figure). Patients with high acuity evidenced more frequent MSW interactions than those with lower acuity.

Findings suggest use of acuity score is associated with the occurrence and frequency of subsequent PPAs. It appears the acuity score may have the ability to identify dialysis patients in greater need of psychosocial support and assist social workers with prioritization of care to those with the greatest needs and optimize assessments overall. Future analyses are needed to confirm results.



2. HEALTHCARE PROVIDERS' PERCEPTIONS OF URGENT-START PERITONEAL DIALYSIS: A QUALITATIVE DESCRIPTIVE STUDY:

Dawn Burton. Grand Canyon University

Despite reports that patient use of urgent-start peritoneal dialysis is safe, viable, effective, and financially sustainable, healthcare providers involved with initiating patients on dialysis in the United States initiate patients lacking kidney failure preparedness on in-center hemodialysis with central venous catheters. It was not known how healthcare providers from North Carolina locations with in-center hemodialysis expertise perceive adopting urgent-start peritoneal dialysis for patients lacking kidney failure preparedness. Using Diffusion of Innovation Theory and Sustainability Leadership Theory as an interpretive lens, the purpose of this qualitative descriptive study was to describe how healthcare providers from North Carolina locations with in-center hemodialysis expertise perceive adopting urgent-start peritoneal dialysis for patients lacking kidney failure preparedness.

By purposive sampling, data from 10 of 14 healthcare provider study participants involved with initiating patients on dialysis recruited from North Carolina locations with in-center hemodialysis expertise were collected for thematic analysis.

Six themes emerged from analysis of data collected from seven individual interview and three group interview participants.

North Carolina healthcare providers are receptive to urgent-start peritoneal dialysis but made suggestions as they expect barriers to adoption in their workplace locations.

Study participants attribute suitability, knowledge deficits, and readiness barriers of the area as factors that slow adoption of peritoneal dialysis for patients lacking kidney failure preparedness.

3. FACTORS ASSOCIATED WITH FUNCTIONAL HEALTH LIMITATIONS IN CHRONIC KIDNEY DISEASE:

Veronica Morawek. Catholic University of America

CKD affects both the physical and emotional health of the adult experiencing it. For many, access to and affordability of appropriate nephrology care may not be available. The burden of care prevents or reduces a person with CKD the ability to develop a purposeful treatment plan to reduce the development of comorbid diseases and manage the progression of his or her CKD. As a result of these challenges, one may experience functional health limitations. Functional health refers to the ability for one to complete a task or activity, either physical or behavioral, in a controlled environment without difficulty (Physical Activity Guidelines Advisory Committee, 2008). The purpose of this study is to explore the factors that are associated with functional health limitations in adults with CKD.

The study used the National Health Interview Survey, 2016 Adult Sample examining only adults who reported having CKD. The study addresses the research question of "What are the factors that predict the presence or absence of functional limitations in chronic kidney disease patients?" The study applied an adapted version of Andersen's Behavioral Health Model to test the hypothesis that factors influence functional health limitations in adults with CKD. A logistic regression analysis was used to determine the likelihood that predisposing, enabling, personal health practices, and use of health services variables predict the presence or absence of functional health limitations.

The results of the study indicated that adults with CKD were more likely to: be older in age; not working; reduce caloric intake after speaking with a doctor; delay filling prescriptions due to cost; and visit a medical specialist when reporting the presence of functional health limitations.

The study provides support to the social work and nephrology communities as a baseline in developing future studies and programs to address the disparities regarding CKD disease management and functional health limitations.

4. EFFECT OF MUSIC THERAPY ON DIALYSIS PATIENTS: A QUALITY IMPROVEMENT PROJECT:

Janavi Kolpekwar[3], Sonali Birewar[1,2], Matthew Shanks[1], Shannon Garcia[1], Stephen Weber[1]. Fresenius Medical Center[1]; Austin Diagnostic Clinic[2]; Round Rock High School[3]

Dialysis patients face a multitude of physiological, psychological, and social challenges on a daily basis. Music therapy, along with traditional approaches, have shown positive implications in different clinical setting. The objective of this project was to assess the effects of brief music therapy on depression and anxiety markers with Incenter dialysis patients and also gather qualitative data on the desirability and practicability of music therapy.

Color coated Flash drives (40 minutes each) of six different genres of music being offered at the beginning of treatment after obtaining consents. Pretest and Post-test PHQ-9 depression scale and a GAD-7 anxiety scale results were obtained after 5 weeks.

The results from this small clinic quality project were encouraging not only in the reduction of reported anxiety and depression symptoms. The feedback was overwhelmingly positive as patients reported the soothing and relaxing nature of the music, as well as the pleasant memories it kindled of past experiences and loved ones. The constructive feedback was mostly centered around having a wider and more easily accessible variety of music.

Overwhelmingly the response to this clinic quality project was positive. By offering user friendly music options in the clinic, patients may experience a better quality of life and improvement in anxiety and depression symptoms and increased levels of enjoyment and comfort associated with music therapy. It may have positive effects on other medical and social parameters, including BP and HR, compliance with dialysis treatment, and more involvement in dialysis treatment. Reliable randomized control trial is necessary with a greater number of participants and consideration of confounding variables.

Patient Health Questionnaire (PHQ) Score			**Generalized Anxiety Disorder (GAD) Score**		
Patient	Before Music	After Music	Patient	Before Music	After Music
1	8	3	1	7	5
2	6	2	2	5	1
3	1	3	3	1	3
4	7	9	4	6	8
5	1	1	5	2	1
6	6	1	6	6	2
Avg PHQ-9	4.8	3.2	Avg GAD	4.5	3.3
P-value (t test)	0.282		P-value (t test)	0.341	
Non-significant decrease, remained in category with minimal depressive symptoms			**Non-significant decrease, remained in category with mild to no anxiety**		

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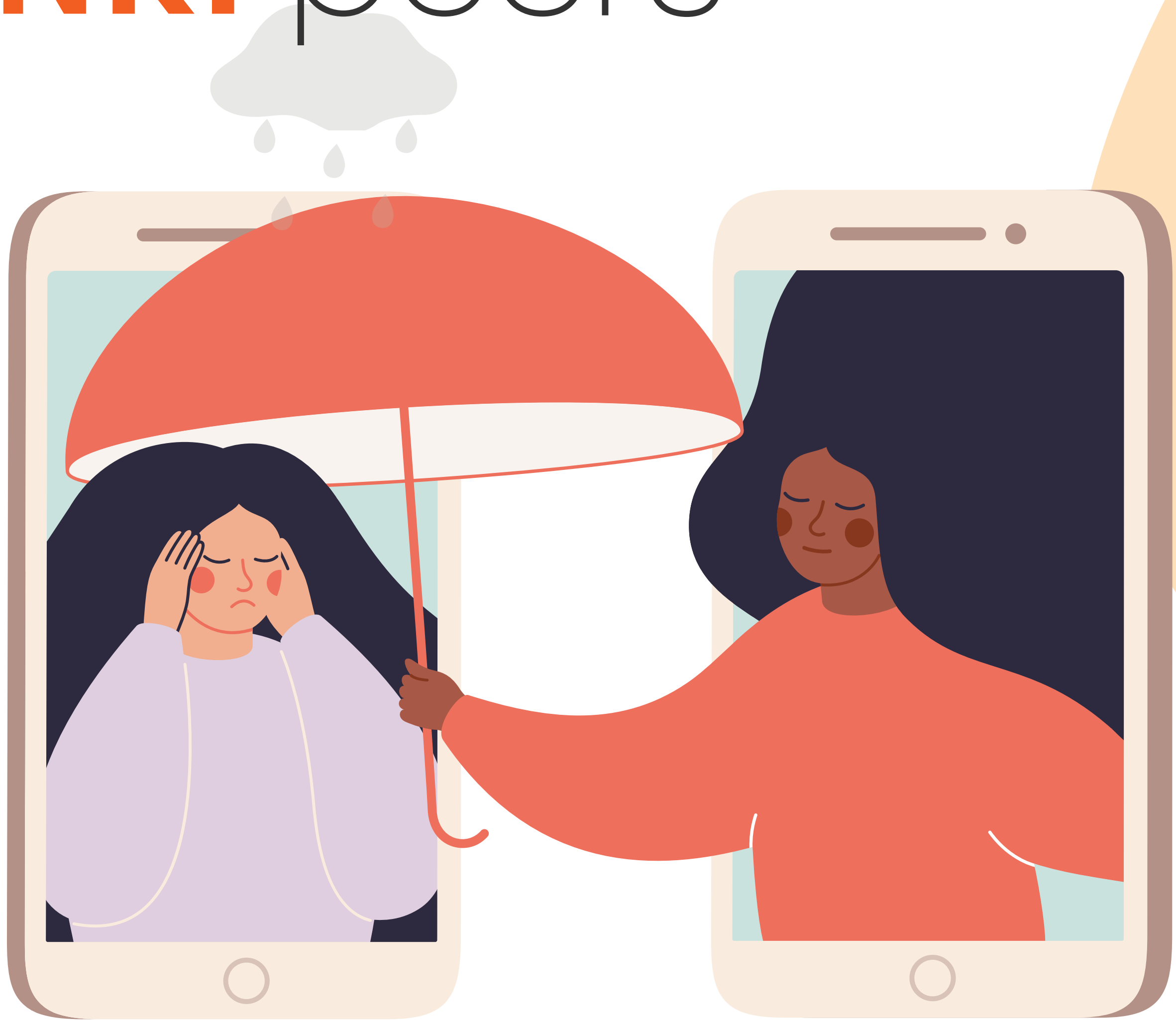

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