

Psychosocial factors affecting end-stage kidney disease patients and the impact of social worker

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Abstract

Background

End-stage kidney disease (ESKD) incidence has been increasing over time, contributing significantly to morbidity and early mortality. However, there is limited data examining the psychosocial factors affecting people with ESKD and how the social worker fits within the multidisciplinary CKD care. This integrative systematic review aims to summarise the existing evidence on psychosocial determinants of outcomes in ESKD and the role of renal social worker.

Method:

Literature search was conducted using PubMed and MEDLINE targeting articles published from database inception until May 2021. This systematic review was performed in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement. The Joanna Briggs Institute tools were employed to assess the quality of included studies.

Results

Of the 397 citations, 13 studies applicable to 1465 patients met the inclusion criteria. The studies were of cross-sectional, experimental, and exploratory qualitative design in nature. The findings of the studies were summarised into three major themes – psychosocial factors, role of the renal social worker, and impact of the renal social worker. The studies demonstrated that concerns related to adjustment, death and dying, family and social functioning, and loss were common amongst participants of the included studies indicating the need for a social worker. Three studies explored the impact of social workers in ESKD, revealing people who receive support from social workers had an improved quality of life, lower depression scores, reduced hospitalisations, and emergency room visits.

Conclusion

This review reports the multitude of physical and psychological stressors that patients with ESRD face, highlights the positive role renal social workers can play in improving the psychosocial stressors in this patient group and the need for large-scale randomised trials to understand the role of renal social workers as part of a multidisciplinary care.

Introduction

End-stage kidney disease (ESKD) imposes a tremendous economic burden on healthcare expenditure—2–3% healthcare budget of high-income countries is spent on treatment of ESKD, although this patient population represent < 0.3% of their total population. The incidence and prevalence of people with ESKD is projected to increase in most part of the world, with over 80% of all patients receiving treatment for ESKD residing in affluent countries [1]. The onset of ESKD, and subsequent commencement of dialysis or renal transplantation to sustain life, undermines and permeates each facet of an individual's everyday life, and often negatively affects physical, emotional, and psychological wellbeing [2–11]. Studies have shown that satisfactory psychosocial care enhances quality of life (QOL) and decreases the overall economic burden to the health care system [12, 13]. Moreover, untreated psychosocial problems have been shown to be associated with withdrawal from kidney replacement therapy (KRT), poor medication and dietary adherence, as well as reduced capacity to actively engage in pre-KRT education and modality choice [10].

Given the extensive illness and treatment burden as well as stringent self-management protocols, many individuals find the transition to dialysis frightening and stressful [14, 15, 10, 9]. Individuals continue to experience periods of distress throughout their time on dialysis, due to the stress of treatment, loss of sexual function, altered body image, and impaired physical and cognitive functioning leading to anxiety and depression [2, 15, 9, 10]. The emotional strain of dialysis is revealed with deteriorating levels of self-esteem and sense of personal control leading to a gross reduction in social interactions, recreational and sexual activity [2, 4, 7, 15]. Patients often experience loss of social roles, increasing dependence on others, a decline in socioeconomic status, financial stress, familial tension, and marital dissonance [5]. Identification of these increasingly complex psychosocial factors through skill assessment can reduce unexpected hospitalisations and improve clinical outcomes such as depression, care planning, and rehabilitation [16].

Due to overwhelming impact of psychosocial factors in people with ESKD, the importance of social work services within the multidisciplinary team has been highlighted [17, 18]. This integrative review of quantitative and qualitative studies aims to present comprehensive evidence on the psychosocial factors affecting adults with ESKD, their influence on ESKD outcomes, and the role the renal social worker plays in ameliorating them.

Methods

This review was performed in compliance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement [19] targeting currently available empirical and theoretical literature for studies concerning the psychosocial factors affecting adults with ESKD and the role of the social worker in ameliorating these psychosocial variables. The integrative review framework provided by Whitemore et al [20] protects against bias and improves the accuracy and rigor of conclusions.

Eligibility criteria

This integrative review aimed to identify relevant studies published in peer review English-language journals meeting the following criteria: (a) primary quantitative or qualitative study; (b) adults aged 18 or above; (c) participants with a diagnosis of ESKD; (d) described the psychosocial impact of ESKD or described the psychological and social impact of ESKD and (e) discussed the involvement of the renal social worker in the care of ESKD participants. Studies that were neither primary studies nor pertaining directly to the psychosocial impact of ESKD and the involvement of the renal social worker were excluded. Inclusion of diverse methodologies, including both experimental and non-experimental research provides a more comprehensive understanding of this relationship. Studies with sample populations, including participants not with ESKD and their caregivers were excluded.

Data sources and search strategies

A literature search for relevant articles published in English language using MEDLINE and PubMed from inception to May 2021, employing the following key words: *end-stage kidney disease, end-stage kidney failure, end-stage renal disease, end-stage renal failure, dialysis, kidney transplant, psychosocial, and social work*. These keywords were used both in free texts and medical subject heading (MeSH) terms. Manually searching the bibliographies of all potentially relevant studies to identify additional articles that may have been missed by electronic search revealed that there were missed studies reporting the renal social workers impact on psychosocial factors. Thus, electronic searching was repeated with additional terms consisting of key words: *biological, social, and psychological*.

Data extraction and quality appraisal

Studies were initially screened using titles and abstracts followed by a full-text screening based on the pre-defined inclusion criteria. An adapted data extraction form was developed to synthesise findings, including author(s) and year of publication, study objective, study design, setting (country), sample size (gender, age), treatment modality, and findings (psychosocial concerns and impact of social work intervention) [21]. Extracted data from the included research studies were then reviewed and consolidated into groups according to the similarities in meaning and/or descriptions. Data were grouped, compared, summarised, and interpreted within and across studies to appreciate psychosocial themes experienced by adults with ESKD and the impact of the renal social worker. Studies that met inclusion criteria were assessed for their quality by comparing their relevance to the primary review question by individually evaluating each for quality of data through utilisation of either the checklist for critically appraising qualitative research [22], randomised controlled trials studies [23], or analytical cross-sectional studies from the Joanna Briggs Institute [24]. According to their evaluation score, research studies were deemed of high (7–10), average (4–6), or low (1–3) quality.

Results

Literature search results

A total of 397 citations were identified in database search and screened using titles and abstracts. Of these, 204 were screened in full-text and based on the inclusion criteria 13 studies were eligible for final inclusion. (Figure 1).

Characteristics and quality of included studies

All studies (n=1465 participants) included in the review (**Table 1**) were published in English and between 1982 and 2016. The overall quality of studies (see appendix A: appraisal of selected studies) was average [25-28,2,15,17]. Three studies were rated high quality [29,3,6]. and three studies were rated low quality [30-32]. Studies were conducted in Australia (n=1),[2] Canada (n=2) [29,6], Israel (n=1) [25], Jamaica (n=1) [30] and the United States of America (n=8) [3,15,17,26,31,32,27,28].

The majority of studies (9/13) used cross-sectional designs [30,2,17,25,26,31,32,27,28]. Two studies employed an experimental design [3,15], and two studies used an exploratory qualitative design [29,6]. Five studies utilised purposive samples [29,6,26-28] and two studies employed randomisation [3,15]. Eight studies were conducted in a single treatment facility [2,3,15,25,29,6,31,32] and five studies were conducted across multiple sites [30,17,26-28].

The total sample was predominantly male, with mean ages ranging from 31.1 to 61.3 years (analysis not possible in five studies). Sample sizes also tended to be small, with a median sample of 66 participants across the studies examined.

Outcome measures (quantitative studies)

Several outcome measures were utilised to evaluate access, adherence, coherence, depression, maladjustment, and quality of life using validated tools. The Short Form Health Survey (SF-36) was applied by three studies [25,31,32], whereas one study [15] employed the Kidney Disease Quality of Life-Short Form (KDQOL-SF). The Beck Depression Inventory (BDI) was utilised by two studies to assess depression [3,15]. Other tools used included the social amenities scale [30], the Psychosocial Adjustment to Illness Survey (PAIS) [3], Antonovsky's Orientation to Life Scale (OLS), and the Health Management Survey (HMS) [26].

Table 1. Evaluation summary and synthesis of the selected literature

Author year, country of study	Study objective/ study focus	Study design	Setting	Cohort characteristics (total number; male; female) Age in mean \pm SD unless indicated otherwise	Treatment modality	Findings
Alleyne et al 1982[30] Jamaica	To assess the influence of psychosocial factors on dialysis outcomes.	Cross-sectional design	University and public hospitals Multi-centre	n: 26 M: 15 (36.3 years; range 23-53) F: 11 (31.1 years; range 19-49)	Home haemodialysis: 3 Haemodialysis: 16 Transplant recipients: 7	<ul style="list-style-type: none"> Utilising the social amenities scale, most participants had most of their basic needs met. All participants, except home haemodialysis participants, reported disruption to social functioning. ESKD was associated with domestic strain for 38% of participants. Financial stress was a cause of concern for 73% of participants. Due to limited staffing, 25% of participants had formal contact with a social worker. Nursing and physicians offered counselling services.
Bale et al 2016[2] Australia	To review psychosocial factors affecting patients with end-stage kidney disease (ESKD) from a tertiary hospital in Australia.	Retrospective observational	Hospital Single treatment facility	n: 244 M: 148 F: 56 62.4 ± 16.9 years	Haemodialysis: 126 Peritoneal dialysis: 60 Transplant recipients: 32	<ul style="list-style-type: none"> Largely (61.6%) social work referrals were made after KRT commencement. Transport assistance was most needed by haemodialysis patients (35.6%). The most prevalent reasons for social work consultation included: maladjustment (41%), financial strain (38.5%), domestic assistance (35.2%), transport assistance (35.6%), and KRT non-adherence (21.3%). Significant independent predictors of increased risk of maladjustment included: younger age,

						<p>referral prior to KRT, and unemployment.</p> <ul style="list-style-type: none"> The most common social work interventions included: provision of information, referrals, counselling, education, paperwork, family meetings, and advocacy.
<p>Beder et al 2000[3]</p> <p>USA</p>	<p>To examine the effectiveness of social work intervention with patients new to dialysis.</p> <p>To identify the impact of recurring master's level social work.</p>	<p>Experimental design (randomised)</p>	<p>University hospital dialysis centre</p> <p>Single treatment facility</p>	<p>n: 46</p> <p>Intervention: 23 (60.7 years) M: 14 F: 9</p> <p>Control: 23 (63.3 years) M: 15 F: 8</p>	<p>Haemodialysis</p>	<ul style="list-style-type: none"> Improvements were observed over time with regards to depression and maladjustment for both the intervention and control group. The experimental group showed statistically significant changes over time with regards to depression and psychosocial maladjustment. Findings suggest social worker intervention beyond that of federal mandate to include in-depth counselling, impacts the initial dialysis experience.
<p>Beder et al 2008[15]</p> <p>USA</p>	<p>To examine the impact of social worker staffing on depression and health-related quality of life (QOL).</p>	<p>Experimental design (randomised)</p>	<p>University hospital dialysis centre</p> <p>Single treatment facility</p>	<p>n: 62</p> <p>Intervention: 31 M: 14 F: 17</p> <p>Control: 32 M: 14 F: 17</p> <p>20-35 years (n=8) 36-50 years (n=11) 51-65 years (n=19) 66-80 years (n=17) > 80 years (n=7)</p>	<p>Haemodialysis</p>	<ul style="list-style-type: none"> Results demonstrate participants with diminished access to social work intervention had significant reductions in QOL on four of five domains. Participants in the control group scored lower in domains like symptom/problem, effect of ESKD, burden of ESKD, and physical compromise. Participants scores indicative of clinical depression. Findings reinforce the significance of the renal social worker within the multidisciplinary team.
<p>Dobrof et al 2002[17]</p> <p>USA</p>	<p>To describe a demonstration project designed to explore psychosocial risk</p>	<p>Retrospective observational</p>	<p>Hospital</p> <p>Multi-centre</p>	<p>n: 100 M: 43 F: 57</p> <p>< 40 years</p>	<p>Haemodialysis</p> <p>Peritoneal dialysis</p>	<ul style="list-style-type: none"> The cohort predominantly identified family and friends (69%) and

	and resiliency factors, social work interventions, and health-related outcomes with dialysis patients.			(n=23) 40-65 years (n=48) > 65 years (n=29)		<ul style="list-style-type: none"> good familial relations (48%) as their source of resiliency. Social workers identified 28% of the cohort to have trouble coping with ESKD and KRT. In the first three months of KRT, 52% of participants were considered anxious, while 43% were depressed. Although these figures declined, 30% of participants remained anxious after ten months of social work input. The renal social worker provided 57% of the cohort formal consultation in the first three months. This figure declined as time progressed. Living with a child decreased risk of hospitalisation. Education level and reduced physical functioning was associated with increased emergency department presentations.
Frank et al 2004[25,10] Israel	<p>To determine the degree of damage to patient's quality of life at different stages of the disease and</p> <p>To identify specific variables that are related to the patients' quality of life.</p>	Comparative cross-sectional study	<p>Medical centre</p> <p>Single treatment facility.</p>	<p>n: 70 M: 71.8%</p> <p>60.3 ± 11.8 years</p>	<p>Pre-dialysis: 30</p> <p>Haemodialysis: 31</p> <p>Peritoneal dialysis: 10</p>	<ul style="list-style-type: none"> The negative psychosocial impact of ESKD is observed even in the pre-dialytic stage. Independent of objective indicators of health status, the strongest predictor of poor QOL are participant symptom reports. Social work interventions are integral to appropriate adjustment to illness and treatment prior to KRT commencement, and in advocating patients' subjective assessments. There was no significant difference in physical or mental domains

						of QOL across the treatment modalities included.
Giles et al 2004[28] Canada	To investigate the embodied life-world experiences of patients with ESKD.	Exploratory qualitative design Purposive sampling	Hospital Single treatment facility	n: 4 M:3 F: 1	Home haemodialysis	<ul style="list-style-type: none"> Findings validate that the home haemodialysis experience transforms the lifeworld of ESKD patients. The lived body was impacted by the adoption of the medical discourse. Evidence highlights the importance of adopting a holistic medical discourse practice approach and plain language. This will support bodily integrity and sovereignty. For those without homes, haemodialysis may represent decreased health care access and inequity. Expression of transformation of home into hospital were concepts identified by the cohort. Findings recommend psychosocial assessment should integrate the patient and family experience of the dialysis machine.
Giles et al 2005[6] Canada	To investigate, explore, and describe the embodied life-world experiences of people who live with a home haemodialysis machine.	Exploratory qualitative design Purposive sampling	Hospital Single treatment facility	n: 3 M: 3	Home haemodialysis	<ul style="list-style-type: none"> Data identified the paradoxical dilemma of living with a life-saving machine that participants had little control over as a central theme. Personification of the dialysis machine was common amongst the cohort. Psychosocial assessment may consider the

						<p>dialysis machine as an additional family member.</p> <ul style="list-style-type: none"> Emotional support acknowledging the dehumanising nature of the dialysis machine and its personification may improve clinical outcomes. Subversion may arise secondary to the manifestation of unmet needs.
<p>Karolich et al 2010[26]</p> <p>USA</p>	<p>To explore the association between perceived meaning of chronic illness and adherence to treatment.</p>	<p>Mixed methods study</p> <p>Purposive sampling</p>	<p>Outpatient clinics</p> <p>Multi-centre</p>	<p>n: 100 M: 48 F: 52</p> <p>67.7 ± 10.2 years</p>	<p>Haemodialysis</p>	<ul style="list-style-type: none"> Comprehension and management of chronic illness is significantly influenced by the subjective meanings attached to chronic illness by participants. Data reinforces the importance of ongoing renal social work intervention to evaluate and alleviate unique dynamic perceptions of ESKD. Ability to understand and manage KRT is impacted by changes to physical capacity, support systems, and cognitive decline.
<p>Raiz et al 2003[31]</p> <p>USA</p>	<p>To assess the prevalence of and investigate variables associated with problems in sexual functioning.</p>	<p>Mixed methods study</p>	<p>Large academic centre</p> <p>Single centre</p>	<p>n: 347 M: 214 F: 133</p> <p>46.6 ± 12.3 years</p> <p>via Kidney Transplant Outcomes Management System (KTOMS)</p>	<p>Transplant recipients</p>	<ul style="list-style-type: none"> Between 50-55% of participants reported no concerns associated with sexual difficulty. Sexual difficulty was associated with older age and lower patient perceptions of physical and mental wellbeing. Data illustrates the importance of social work psychosocial intervention.

						<ul style="list-style-type: none"> • Social workers are integral to the appropriate assessment of sexual health, and provision of education.
Raiz et al 2007[32] USA	To identify predictors of employment.	Cross-sectional study	Large academic centre Single centre	n: 411 M: 238 F: 173 42.2 ± 13.8 via KTOMS	Transplant recipients	<ul style="list-style-type: none"> • Factors like age at the time of transplant, race, gender, and perceived physical functioning predicted employment. • Those who were younger, Caucasian, and male were more likely to maintain and/or obtain employment post-transplantation.
Tijerina et al 2006[33] USA	To examine the cognitive and phenomenological dimensions of how Mexican American women receiving dialysis treatment experience their illness.	Cross-sectional study Purposive sampling	Outpatient clinics Multi-centre	n: 26 F: 26 Median age: 44.8 years (range 30-56 years)	Haemodialysis	<ul style="list-style-type: none"> • Poverty, extended treatment history, immigrant status, perceived loss of identity, family dysfunction, and near-death experiences influenced KRT non-compliance. • Concepts related to perceptions of loss, body image concerns, uncertainty, and family concerns were pervasive amongst the cohort. • Perceived loss was not independently associated with KRT non-adherence.
Tijerina et al 2009[20] USA	To understand how female Mexican American dialysis patients, experience their disease, the treatment regimen, and the consequences of that experience.	Cross-sectional study Purposive sampling	Outpatient clinics Multi-centre	n: 26 F: 26 Median age: 44.8 years (range 30-56 years)	Haemodialysis	<ul style="list-style-type: none"> • KRT non-adherence was associated with poverty, extended treatment history, and immigrant status. • Perceived loss of identity, heightened awareness of death and dying, and family dysfunction

						<p>were themes that permeated the lives of the cohort.</p> <ul style="list-style-type: none"> • Advocacy of the psychosocial needs of ESKD patients and their families is a unique role of the renal social worker.
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Index: ESKD, end-stage kidney disease; KRT, kidney replacement therapy; n, number; M, Male; F, Female; SD, standard deviation

Data Synthesis

Three major themes emerged from the included studies: psychosocial factors, role of the renal social worker, and impact of the renal social worker. Eight sub-themes were identified under the psychosocial factors theme.

Major theme 1: The psychosocial impact of ESKD

The first major theme identified had eight sub-themes: adjustment to illness, death and dying, depression and anxiety, employment, family and social functioning, financial stress, perception of loss, quality of life, and sexual functioning.

Adjustment to illness

In the five studies discussing concerns related to maladjustment, severity of adjustment to illness varied between studies [30,2,3,17,26]. Rates of maladjustment varied from 28-46% at the commencement of KRT [2,3,17]. Bale et al [2] found that 61% of social work referrals were made post KRT commencement despite maladjustment concerns being most prevalent in the initial stages of the KRT discourse. Beder et al [3] found after three months of renal social work consultation, levels of maladjustment reduced to 13%. Conversely, Karolich et al [26] reported that participants were fairly positive regarding their illness, and their treatment regimen.

Dobrof et al [17] highlighted that 72% of participants focused on coping with their diagnosis and treatment in counselling sessions facilitated by the renal social worker. Bale et al [2] found that age, referral prior to KRT, financial status, and employment status independently predicted odds of maladjustment. Participants in a study carried out by Alleyne et al [30] stated that psychosocial adjustment was facilitated by informal support from friends, employers, and the church. Conversely, two studies stated adjustment to illness materialised from the realisation that not to cope meant imminent death [30,26].

Death and dying

Four studies demonstrated a heightened awareness of the precariousness of life and death for dialysis patients [2,26-28]. Evidence details participants' accounts of the uncertainty of being a dialysis patient, the possibility of complications during haemodialysis, experiencing near-death situations, and learning of fellow patients' deaths [2,26-28]. While uncertainty is pervasive in dialysis patients' lives, some patients' draw on religion and spirituality to cultivate a positive outlook [26].

Depression and anxiety

Three studies observed significant levels of anxiety and depression within the ESKD population [3,15,17]. Mild to moderate depression was prevalent amongst 62-76% of haemodialysis patients [3,15,17], while 24% registered moderate to severe levels of depression [3]. However, after three months of social worker consultation, 93% of participants registered mild levels of depression, while three percent reported to be moderately to severely depressed [3].

In the first three months of dialysis, social workers elucidated 52% of participants were anxious [17]. These figures declined with time as 39% of participants predominately used their counselling sessions to discuss feelings surrounding depression and anxiety [17]. However, anxiety continued to permeate for 30% of participants even after ten months of dialysis [17].

Employment

Three studies explored the impact of ESKD on employment retention and attainment [30,2,32]. Findings showed 10-49% of participants were employed part-time or full-time post KRT commencement [30,17,25,32], while 10% of participants expressed concerns surrounding employment [2]. Transplant source, diabetic status, gender, age at transplant, perceived physical functioning, and mental health functioning compounded ones' ability to obtain stable employment. Further, Raiz et al [32] established that perceived physical functioning was the most significant predictor of employment post-transplantation. Although some participants in a study carried out by Alleyne and colleagues [30] maintained employment, participants made special arrangements with employers to maintain appointments, or lost pay or annual leave for the day of haemodialysis appointments.

Family and social functioning

Issues related to social dynamics and family functioning emerged as a central theme for patients within six studies [30,17,26-28]. Participants illustrated concerns regarding marital strain, conflict between participants and their children, family incarceration, participants being victims of verbal or emotional abuse, and family involvement with Child Protective Services [30,2,27,28]. With regard to support through family dysfunction, participants did not identify the renal social worker as a source of support or assistance [27]. Participants held a narrow view of the renal social worker, stating the social worker managed transportation and prescriptions [27]. Alleyne et al [30] reported that only one fourth of their study population had formal contact with a renal social worker. During periods of reduced access to social work input, participants drew considerable resiliency and empowerment from family members and friends [30,17,26]. Participants highlighted emotional support, and practical support from family and friends via assistance with activities of daily living (ADLs) aided their ability to reasonably manage ESKD [30,17].

Financial stress

Three studies illustrated the negative impact of ESKD on maintaining financial stability [30,2,17]. During counselling sessions with social workers, 38% of participants focused on coping with insurance [17] while 29-40% expressed their concerns regarding financial issues [2,17]. In a study carried out by Alleyne et al [30], 73% of haemodialysis participants said they had seen their finances deteriorate secondary to utilising 48% of their monthly income on transportation to appointments. This is supported by Bale et al [2] highlighting 36% of participants required transportation assistance specifically. Renal social workers ameliorated financial strain by referring patients to obtain community resources and benefits, government or work-related benefits, insurance, transport and home care services [17]. Although participants expressed it was increasingly difficult to ascertain financial assistance when compared to emotional support, financial assistance was sought from employers, the church, and friends [30].

Perception of loss

Seven studies observed the multitudes of loss within the everyday lives of ESKD patients [30,17,29,6,26-28]. Participants' of five studies used analogies associated with employment, marriage and slavery to describe their loss of personal freedom secondary to the dominating nature of dialysis [29,6,26-28]. Studies suggest ESKD patients are denied humanity, autonomy, and power due to the paradoxical struggle between the lived body and the critical importance of the dialysis machine [6,26]. Physical changes in body image resulting from ESKD and the demanding treatment regimen emerged as an issue threatening sovereignty of the body, bodily integrity, identity, functional ability, and capacity to fulfil social roles [30,29,27,28]. Demoralised participants expressed skin discolouration, weight loss, and scarring, challenged ones' sense of identity while physical limitations challenged participants independence [27,28]. Additionally, two studies ascertained that participants perceive time as a prescription, and ultimately, time as a commodity that is lost [6,26]. Participants described a transformation of home into hospital, involving the involuntarily loss of ones' sense of home [29]. Dobrof et al [17] highlight 39% of participants utilise social work counselling to regain agency and authority to overcome issues surrounding decreased physical functioning. Social work intervention afforded participants the ability to regain control, resist compromise to day-to-day living and deinstitutionalise the dialysis discourse by compartmentalisation and tailoring the dialysis prescription to their lifestyle [29,6].

Quality of life

Two studies demonstrated that patients with ESKD experience significantly lower QOL than the general population, with the largest difference being the physical role functioning and mental health domains [15,25]. The result shows that participants in the pre-dialysis stage in particular reported poorer physical and mental QOL [25]. Among factors examined in relation to QOL, the most important were symptom reports, blood albumin levels, and the number of co-morbid conditions [25]. Personal characters of the

ESKD cohort that impinged the physical domain of QOL included gender, education, marital status, and employment [25]. Conversely, research conducted by Beder et al [15] reported low levels of compromise to participants QOL with regards to how much the participants were bothered by their illness/treatment and how much their illness/treatment made it difficult to do ADLs. However, they also found high levels of compromise to QOL secondary to illness intrusion resulting in high levels of frustration.

Sexual functioning

One study explored diminished sexual functioning following renal transplantation [31]. This study by Raiz et al [31] found that 50% of participants indicated no problem with sexual interest, sexual enjoyment, or sexual arousal. However, more than 30% of participants reported a moderate or severe problem with regards to sexual interest or sexual arousal [31]. Likewise, 25% of participants reported moderate or severe concerns regarding sexual enjoyment.

Major theme 2: Role of the renal social worker

Five studies articulate renal social workers are fundamental in facilitating the best level of functioning for the patient on KRT [2,3,15,17,25]. Beder et al [15] stated that the renal social worker uniquely views patients in their multiple social systems. In this light, social workers use astute psychosocial assessment to illuminate how patients are managing their KRT and address the multiple needs of the patient population [2,3,15,17]. Two studies revealed that interventions offered by the renal social worker encompass three domains – instrumental, informational, and emotional support [2,3]. Instrumental or social support incorporates patient advocacy and assistance with paperwork as well as referral to allied health services, community-based services, and government agencies with the aim of patient mobilisation [2,3,17]. Informational support or psychoeducation integrates the provision of helpful resources, treatment adherence, aged care services, financial management, and employment attainment [2]. Whereas the emotional component affords the renal social worker the ability to explore the patients' subjective response to KRT via counselling sessions and family meetings [2,3,17]. Two studies clarify that the social worker is central to conveying information regarding these domains to the multidisciplinary team and assuring that potential and actual problems are taken into consideration when planning, implementing and evaluating patients' treatment [3,25].

Bale et al [2] outlined that adjustment issues (41%), financial concerns (38.5%), domestic assistance (35.2%), and treatment adherence (21.3%) were the predominant reasons for social work consultation. Accordingly, social workers primarily provided information, referrals, counselling, education, paperwork assistance, family meetings and advocacy [2]. Dobrof and colleagues [17] found assistance was most frequently sought in the first four months of treatment and primarily focused on the provision of referral to governing and work-related benefits, insurance, transportation, and home care services.

Major theme 3: Impact of the renal social worker on clinical outcomes

Three studies directly attributed the role of the social worker to improved clinical outcomes [3,15,17]. In a small randomised study evaluating the effectiveness of social work intervention, a cohort of 46 participants showed a statistically significant reduction in both level of depression and degree of adjustment to illness and treatment [3]. Moreover, Beder et al [15] demonstrated significant impacts on QOL and lower levels of depression in participants who engaged with renal social work services. Participants who have one third less contact with renal social work services showed statistically significant group difference in four of five measured domains/response areas of KDQOL-SF – symptom/problem, effect of ESKD, burden of ESKD, and physical composite [15]. Moreover, depression scores measured by BDI showed participants with diminished access experienced higher levels of depressive symptomatology [15]. Research carried out by Dobrof and colleagues [17] established that social work counselling proved critical in reducing hospitalisations and emergency room visits and reduced the frequency of missed treatments.

Outcomes by treatment modalities

Most of the included studies targeted people on haemodialysis (home or in-centre), [30,2,3,15,17,25,29,6,26-28] one considered both dialysis and transplant patients, [2] while the remaining two targeted only people who received transplantation. [31,32] In terms sample size, most of the recruited in the included studies had either received renal transplantation (56.8%) [30,2,31,32] or were undergoing haemodialysis (30%) [30,2,3,15,17,25-28]. Three studies targeted participants undergoing home haemodialysis [30,29,6], three peritoneal dialysis [2,17,25] and a single study included participants in the pre-dialysis stage [25].

The only study that targeted people at pre-dialysis stage, those on haemodialysis and those on peritoneal dialysis revealed no difference among these groups in terms of the physical and mental component summaries of the SF-36.[25] However, the pre-dialytic patients tended to score lower on their present health status compared to the other two groups. Another study that compared haemodialysis, peritoneal dialysis and transplant patients reported the greater need for service-related assistances like transportation in people who were on haemodialysis (36.5%) than those on peritoneal dialysis (25%) or received transplantation (22%).[2] The role of renal social work intervention was assessed primarily targeting patients on haemodialysis patients [3,15,17] and, in one study, those on peritoneal dialysis [17].

Discussion

To our knowledge, this is the first integrative review that synthesises the body of empirical and theoretical evidence pertaining to psychosocial factors affecting adults with ESKD and the role of the renal social worker in ameliorating the psychosocial impact of ESKD. This review has yielded three key findings that can be utilised by clinicians and researchers alike to improve clinical outcomes for the ESKD population.

The first key finding from the reviewed studies indicated that the treated ESKD population experience lifestyle adjustment and adaptation that impinge on all aspects of living: medical, dietary, social, financial, sexual and psychological [4, 25, 31]. The majority of studies recognised that the chronicity and intrusiveness of ESKD and KRT imposed considerable loss [30, 17, 29, 6, 26–28]. Participants expressed diverse tangible and symbolic losses; loss of personal freedom [29, 6, 26–28], humanity, autonomy, power [6, 26], functional ability, and body image [30, 29, 27, 28]. While expression of loss emanated across all KRT modalities, participants expressing loss were predominantly undergoing haemodialysis. Patients also expressed psychosocial adversity in terms of social and family functioning [30, 2, 17, 26–28], employment [30, 2, 32], adjustment [30, 2, 3, 17, 26], and uncertainty associated with morbidity and mortality [2, 26–28]. Bale et al [2] found that Australian patients referred to social work typically required assistance with adjustment, treatment adherence, management of finances, and domestic assistance. Although study designs varied, findings regarding the psychosocial impact of ESKD was shared amongst different study participants. However, the review highlights a need for further studies to form a comprehensive understanding of the implications of ESKD on mental health, finances, QOL, and sexual functioning in this population.

While all treatment modalities are intensive and physically debilitating, the demands and burden of each treatment modality is considerably different [34]. Accordingly, KRT modalities impose significantly diverse psychosocial needs and psychosocial burden [34]. Although this review identified a small number of studies, the psychosocial impact of ESKD expressed by participants in this review is consistent amongst patients enduring chronic illness. Wei et al [35] reported breast cancer survivors similarly experience challenges with body image, sexual dysfunction, self-esteem, social support, sense of control, physical functioning, social role disturbances, anxiety, and depression. Largely, studies were conducted within a single treatment facility therefore findings may underrepresent the true extent and nature of psychosocial factors faced by the ESKD population. Moreover, most studies lacked statistical power to detect the extent of psychosocial impairment due to small sample size. Nevertheless, the psychosocial impact of ESKD is evident amongst patients undergoing a range of KRT modalities.

The second key finding of this review is that it highlighted the precise multidimensional role of the renal social worker within the multidisciplinary team. The fact that only a limited number of studies articulated the multi-dimensional role of renal social worker may be partially explained by the limited number of social work researchers engaging in the publication of their work or that the type of research presently undertaken fell into broader categories than those explored during this review. Predominantly, social workers across the included studies applied psychosocial assessment to identify how patients were adapting to their diagnosis and treatment [2, 3, 15, 17]. Findings from psychosocial assessment then formed the foundations of a comprehensive tailored approach to address multiple psychosocial risks and needs presented. Renal social workers also regularly engaged in counselling to support patients. Dobrof et al [17] highlighted the majority of patients utilised counselling sessions to cope with their diagnosis and treatment regimen. Similarly, Lilliehorn et al [36] demonstrated that Australian oncology social workers facilitate patients in coming to terms with cancer, and its consequences. Zilberfein and colleagues [37] found counselling, family counselling, and liver transplant support groups to be the most frequently employed psychosocial interventions with liver transplant recipients. Studies illustrate whilst the scope of the social worker extends to include assistance with legislation issues, substance misuse, social supports, financial concerns, and home care services [37], Lilliehorn et al [36] argue the essence of social work is counselling; however, patients' needs vary depending upon their illness trajectory and life as a whole [25].

The included studies also reveal that the role of the renal social worker embodies three domains – instrumental, informational, and emotional support [2, 3]. Instrumental support provided involved patient advocacy, assistance with paperwork, and referral to appropriate community services/resources [2, 3, 17]. Informational support incorporated the provision of education, promoting treatment adherence, financial management and employment attainment [2]. Lastly, emotional support involved counselling and family meetings [2, 3, 17]. Review findings are consistent with psychosocial practice undertaken, for example, by oncology social workers [38, 39]. Oncology social workers in practice engage in a number of pivotal psychosocial interventions, including cognitive/behavioural therapy, emotional support counselling, information/education, social support, and patient navigation [38, 39]. The role of a renal social worker in patients with ESKD is also likely to be as important, since patients with ESKD are confronted with lifetime of psychosocial stressors.

Finally, the included studies indicate that renal social workers are fundamental to improve clinical outcomes in people diagnosed with ESKD [3, 15, 17]. Counselling provided by renal social workers directly contributed to significant reductions in clinical levels of depression and improved adjustment to illness and treatment [3]. Social work counselling also proved critical in reducing hospitalisations, emergency room presentations, and frequency of missed treatments [17]. However, the limited evidence in this area highlights the need for further research to substantiate the effect of social work intervention within the ESKD patient population. While the included studies illustrate the success of counselling in reducing the impact of psychosocial stressors, minimal attention is afforded to the remaining diverse interventions that renal social workers employ in practice such as information provision, referral to services, education, paperwork, family meetings, and advocacy.

The three studies investigating the impact of social work intervention principally explored the psychosocial concerns of haemodialysis participants, thereby limiting transferability of study results to patients undergoing other KRT modalities. It is important to note that the psychosocial stressors and social worker interventions are likely to be different during the course of ESKD, with patients after kidney transplantation that are relatively younger and healthier requiring much less interventions as opposed to those on long-term dialysis. Additionally, limitations within the study design suggest a longitudinal study would be more appropriate to observe whether social work intervention has a protracted impact on the life course of ESKD patients. It would be particularly relevant to understand if the positive effects (e.g., reduced level of depression and psychological maladjustment) of the social work intervention observed in haemodialysis patients will transfer to other treatment modalities.

Implications for further research and limitations of the review

Although the integrative review illuminates psychosocial challenges faced by patients with treated-ESKD and the role of the renal social worker in provision of care for this population, a scarcity of data exists regarding the psychosocial experience of patients who preferred not to commence KRT (those who choose conservative care), are in the pre-dialysis stage, or withdrew from KRT. Likewise, the included studies did not explore the psychosocial impact of ESKD over time, from the pre-dialysis stage to renal supportive (non-dialytic) care. Frank et al [25] found patients in the pre-dialysis stage reported considerable deterioration in physical and mental QOL over the past year compared to new or veteran haemodialysis patients. Klang et al [40] explored the effect of pre-dialysis patient education on functioning and wellbeing provided by the renal multidisciplinary team including a clinical social worker. Pre-dialysis patients receiving psychosocial intervention displayed improvements in mood, mobility, and levels of anxiety [40]. Additionally, Sesso and Yoshihiro [41] demonstrated that unsatisfactory pre-dialysis care and follow-up negatively affect haemodialysis patients' QOL. Although improvement in clinical outcomes cannot be directly attributed to the role of the social worker, findings suggest the renal social worker and the implementation of adept psychosocial intervention is integral even in the pre-dialysis stage.

In practice the renal social worker is the patients' advocate, serving as a bridge in communicating preferences for end-of-life care, maximising symptom relief, and optimising QOL [42, 2]. Scope of practice extends to aligning treatment with patient's goals through culturally sensitive collaborative decision making, advanced care planning and education, and palliative care referral [43, 44, 42]. Murtagh et al [45] highlight communication regarding renal supportive care is generally insufficient. The field of renal supportive care poses an ideal space in which renal social workers can exercise their specialty given therapeutic communication, shared decision-making, and counselling has demonstrated clinical effectiveness [46, 17, 44]. This gap in research identified by this integrative review highlights the pertinence of conducting further research regarding the psychosocial impact of ESKD for patients who did not commence KRT, are in the pre-dialysis stage or withdrew from KRT. Additional research is essential to meaningfully understand the significance of the renal social worker in the care of treated-ESKD patients, pre-dialysis patients, and those undergoing supportive or conservative renal care. Particularly, given the difference in terms of care between people on dialysis vs those who had transplant,

and because most of the evidence in this review came from studies targeting people on haemodialysis, it is important to interpret the findings of this review with caution. This highlights the need for additional research to understand the psychosocial problems and needs of people who had transplant and if these significantly varies from people receiving dialysis. The heterogenous outcomes reported along with the small number of quantitative studies have precluded the possibility of performing any meta-analysis.

Conclusion

Patients with ESKD are exposed to multiple physical and psychological stressors as a result of their illness. While KRT succeeds in stabilising the patient physiologically, overall functional ability across all domains often declines. Considerable lifestyle restriction significantly affects the quality of life, family relations, social interactions, and employment. Concerns related to adjustment, death and dying, family and social functioning, and loss were common amongst participants of the included studies. This highlights the need for comprehensive psychosocial support for patients with ESKD that may lead to improvements in QOL, morbidity, and mortality. Renal social workers have the knowledge and skills to assess the social determinants of health that impact treatment outcomes for patients experiencing multitudes of losses from ESKD. Psychosocial interventions that focus on improving patients' perceived QOL and well-being are key to maximising overall ESKD treatment outcomes. Although few rigorous study designs were found, the contextual detail and clinical setting of studies suggest a promising role for renal social work in improving health outcomes.

Declarations

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References

1. Jha V, Garcia-Garcia G, Iseki K, Li Z, Naicker S, Plattner B, Saran R, Wang AY (2013) Yang CW Chronic kidney disease: global dimension and perspectives. *Lancet* 382(9888):260–272. doi:10.1016/s0140-6736(13)60687-x
2. Bale C, Douglas A, Jegatheesan D, Pham L, Huynh S, Mulay A, Ranganathan D Psychosocial factors in end-stage kidney disease patients at a tertiary hospital in Australia. *International journal of nephrology*, 2016(2016)
3. Beder J (2000) Evaluation research on the effectiveness of social work intervention on dialysis patients: The first three months. *Soc Work Health Care* 30(1):15–30
4. Finnegan-John J, Thomas VJ The psychosocial experience of patients with end-stage renal disease and its impact on quality of life: findings from a needs assessment to shape a service. *International Scholarly Research Notices*, 2013(2013)
5. Furr LA (1998) Psycho-social aspects of serious renal disease and dialysis: A review of the literature. *Soc Work Health Care* 27(3):97–118
6. Giles S (2005) Struggles between the body and machine: the paradox of living with a home haemodialysis machine. *Soc Work Health Care* 41(2):19–35
7. Jankowska-Polańska B, Uchmanowicz I, Wysocka A, Uchmanowicz B, Lomper K (2017) Fal AM Factors affecting the quality of life of chronic dialysis patients. *Eur J Pub Health* 27(2):262–267
8. Low J, Smith G, Burns A, Jones L (2008) *The impact of end-stage kidney disease (ESKD) on close persons: a literature review.* Oxford University Press
9. Sheridan MS (1977) Renal disease and the social worker: A review. *Health Social Work* 2(2):122–157
10. Taylor F, Taylor C, Baharani J, Nicholas J, Combes G (2016) Integrating emotional and psychological support into the end-stage renal disease pathway: a protocol for mixed methods research to identify patients' lower-level support needs and how these can most effectively be addressed. *BMC Nephrol* 17(1):111
11. Van Der Borg WE, Schipper K, Abma TA (2016) Protocol of a mixed method, randomized controlled study to assess the efficacy of a psychosocial intervention to reduce fatigue in patients with End-Stage Renal Disease (ESRD). *BMC Nephrol* 17(1):73
12. Carlson LE, Bultz BD (2003) Benefits of psychosocial oncology care: Improved quality of life and medical cost offset. *Health Quality of Life Outcomes* 1(1):8

13. Reiss M, Sandborn WJ (2015) The role of psychosocial care in adapting to health care reform. *Clin Gastroenterol Hepatol* 13(13):2219–2224
14. Abdel-Kader K, Unruh ML, Weisbord SD (2009) Symptom burden, depression, and quality of life in chronic and end-stage kidney disease. *Clin J Am Soc Nephrol* 4(6):1057–1064
15. Beder J (2008) Evaluation research on social work interventions: a study on the impact of social worker staffing. *Soc Work Health Care* 47(1):1–13
16. Callahan MB Begin with the end in mind: The value of outcome-driven nephrology social work. *Advances in chronic kidney disease*, 14 (4) (2007),409–414
17. Dobrof J, Dolinko A, Lichtiger E, Uribarri J (2002) Epstein I Dialysis patient characteristics and outcomes: the complexity of social work practice with the end stage renal disease population. *Soc Work Health Care* 33(3–4):105–128
18. Callahan MB (2011) The role of the nephrology social worker in optimizing treatment outcomes for end-stage renal disease patients. *Dialysis Transplantation* 40(10):444–450
19. Moher D, Liberati A, Tetzlaff J, Altman DG (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 151(4):264–269
20. Whitemore R, Knaf K (2005) The integrative review: updated methodology. *Journal of advanced nursing* 52(5):546–553
21. Fineout-Overholt E, Melnyk BM, Stillwell SB, Williamson KM (2010) Evidence-based practice, step by step: Critical appraisal of the evidence Part III. *AJN The American Journal of Nursing* 110(11):43–51
22. Lockwood C, Munn Z, Porritt K (2015) Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc* 13(3):179–187
23. Tufanaru C, Munn Z, Aromataris E, Campbell J, Hopp LC (2017) Systematic reviews of effectiveness, 3. Joanna Briggs Institute Reviewer's Manual The Joanna Briggs Institute
24. Moola S, Munn Z, Tufanaru C, Aromataris E, Sears K, Sfetcu R, Currie M, Qureshi R, Mattis P, Lisy K (2017) Chap. 7: Systematic reviews of etiology and risk. *Joanna Briggs Institute Reviewer's Manual The Joanna Briggs Institute*, 2019 – 2005
25. Frank A, Auslander GK, Weissgarten J (2004) Quality of life of patients with end-stage renal disease at various stages of the illness. *Soc Work Health Care* 38(2):1–27
26. Karolich RL, Ford JP (2010) Meaning, comprehension, and manageability of end-stage renal disease in older adults living with long-term hemodialysis. *Soc Work Health Care* 49(1):19–37
27. Tijerina MS (2006) Psychosocial factors influencing Mexican-American women's adherence with hemodialysis treatment. *Soc Work Health Care* 43(1):57–74
28. Tijerina MS (2009) Mexican American women's adherence to hemodialysis treatment: a social constructivist perspective. *Social work* 54(3):232–242
29. Giles S (2004) Transformations: a phenomenological investigation into the life-world of home haemodialysis. *Soc Work Health Care* 38(2):29–50
30. Alleyne SI, Vassall-Hurd SA, Morgan AG, End-Stage (1982) Renal Disease in Jamaica: How Patients Cope in a Developing Society. *Health Soc Work* 7(2):130–133
31. Raiz L, Davies EA, Ferguson RM (2003) Sexual functioning following renal transplantation. *Health Soc Work* 28(4):264–272
32. Raiz L, Monroe J (2007) Employment post-transplant: a biopsychosocial analysis. *Soc Work Health Care* 45(3):19–37
33. Reid WJ, Hanrahan P (1982) Recent evaluations of social work: Grounds for optimism. *Soc Work* 27(4):328–340
34. Winterbottom A, Bekker HL, Conner M (2014) Mooney A Choosing dialysis modality: decision making in a chronic illness context. *Health Expect* 17(5):710–723
35. Di Wei X-YL, Chen Y-Y, Zhou X, Hu H-P (2016) Effectiveness of physical, psychological, social, and spiritual intervention in breast cancer survivors: An integrative review. *Asia-Pacific journal of oncology nursing* 3(3):226
36. Lilliehorn S, Isaksson J, Salander P (2019) What does an oncology social worker deal with in patient consultations?-An empirical study. *Soc Work Health Care* 58(5):494–508
37. Zilberfein F, Hutson C, Snyder S (2002) Epstein I Social work practice with pre-and post-liver transplant patients: A retrospective self study. *Soc Work Health Care* 33(3–4):91–104

38. Pockett R, Dzidowska M, Hobbs K (2015) Social work intervention research with adult cancer patients: a literature review and reflection on knowledge-building for practice. *Soc Work Health Care* 54(7):582–614
39. Pockett R, Peate M, Hobbs K, Dzidowska M, L Bell M, Baylock B (2016) Epstein I The characteristics of oncology social work in Australia: Implications for workforce planning in integrated cancer care. *Asia-Pacific Journal of Clinical Oncology* 12(4):444–452
40. Klang B, Björvell H, Berglund J, Sundstedt C, Clyne N (1998) Predialysis patient education: effects on functioning and well-being in uraemic patients. *Journal of advanced nursing* 28(1):36–44
41. Sesso R, Yoshihiro M Time of diagnosis of chronic renal failure and assessment of quality of life in haemodialysis patients. *Nephrology, dialysis, transplantation: official publication of the European Dialysis and Transplant Association-European Renal Association*, 12 (10) (1997),2111–2116
42. Germain MJ, Cohen L (2001) Supportive care for patients with renal disease: Time for action. *Am J Kidney Dis* 38(4):884–886
43. Davison SN, Jassal SV (2016) Supportive care: Integration of patient-centered kidney care to manage symptoms and geriatric syndromes. *Clinical journal of the American Society of Nephrology* 11(10):1882–1891
44. O'Halloran P, Noble H, Norwood K, Maxwell P, Shields J, Fogarty D, Murtagh F, Morton R (2018) Brazil K Advance care planning with patients who have end-stage kidney disease: a systematic realist review. *J Pain Symptom Manag* 56(5):795–807. e718
45. Murtagh FE, Burns A, Moranne O, Morton RL, Naicker S (2016) Supportive care: comprehensive conservative care in end-stage kidney disease. *Clin J Am Soc Nephrol* 11(10):1909–1914
46. Cukor D, Cohen SD, Peterson RA, Kimmel PL (2007) Psychosocial aspects of chronic disease: ESRD as a paradigmatic illness. *J Am Soc Nephrol* 18(12):3042–3055

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Figure 1

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