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Psychosocial Well-being Among Individuals with Chronic Kidney Disease Undergoing Hemodialysis Treatment and Their Caregivers:

A Mixed-method Study in Sri Lanka and Poland

Doctoral dissertation

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List of Publications Forming a Cumulative PhD Thesis

1. **Bulathwatta, D. T.,** Borchet, J., Rudnik, A., & Bidzan, M. (2023). Psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis treatment and their caregivers: A protocol of a mixed method study in Sri Lanka and Poland. *Frontiers in Psychology, 14*. https://doi.org/10.3389/fpsyg.2023.1194991
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3. **Bulathwatta, D. T.,** Rudnik, A., & Bidzan, M. (2024). All good without anything good. Beyond survival: Understanding the psychosocial experiences of individuals with chronic kidney disease and their caregivers in Sri Lanka. *Health Expectations, 27*(4), e14157. https://doi.org/10.1111/hex.14157
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5. **Bulathwatta, D. T.**, Borchet, J., Rudnik, A., Ruszkowski, J., Zakrzewska, A., Dębska-Ślizień, A. M., Biedunkiewicz, B., Tylicki, L., Puchalska-Reglińska, E., & Bidzan, M. Psychosocial well-being among individuals with end-stage kidney disease undergoing hemodialysis treatment in Sri Lanka and Poland: An explorative study. *Psychology, Health & Medicine* (Manuscript under review)

List of Abbreviations Used in this PhD Thesis

AIS	Acceptance of Illness Scale
BDI	Beck Depression Inventory
CECS	Courtauld Emotional Control Scale
CKD	Chronic Kidney Disease
CKDu	Chronic Kidney Disease with Unknown Etiology
ESKD	End Stage Kidney Disease
GFR	Glomerular Filtration Rate
HRQOL	Health-Related Quality of Life
KDQOL-SF	Kidney Disease Quality of Life-Short Form
NCD	Non-Communicable Disease
QOL	Quality of life
TOSCA	Test of Self-Conscious Affect
WHO	World Health Organization

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Abstract

The aim of this research is to assess the psychosocial well-being of individuals with chronic kidney disease (CKD) undergoing hemodialysis and their caregivers. This is a cross-cultural mixed-methods project conducted in two countries (a Sri Lankan study and a Polish study) and two phases (quantitative followed by qualitative). The project resulted in five publications: a research protocol, and a scoping review on cross-cultural differences in shame and guilt among individuals with chronic diseases. The remaining three were based on the findings of the original qualitative and quantitative studies.

Publication 1. Research protocol

The project protocol included the background of the study, objectives, research questions, study design, methods, planned data analysis, and discussion. It provided a comprehensive overview of chronic kidney disease (CKD), including its nature, prevalence, different stages, and available treatments. The protocol also provided relevant literature and highlighted the significance of the psychosocial well-being of individuals living with the CKD and their caregivers in a cross-cultural context.

The study was designed as a mixed-method investigation of the psychosocial well-being of individuals with CKD undergoing hemodialysis, as well as their caregivers in both Sri Lanka and Poland.

The quantitative phase was planned to include participants undergoing haemodialysis treatment for CKD from Sri Lanka (n = 63) and Poland (n = 63). Participants were to be assessed using a set of standardized measures, including the Kidney Disease Quality of Life-Short Form (KDQOL-SF), the Beck Depression Inventory (BDI), the Test of Self-Conscious Affect

(TOSCA), the Courtauld Emotional Control Scale (CECS), the Acceptance of Illness Scale (AIS), as well as a demographic and medical information form.

The qualitative phase consisted of semi-structured interviews conducted with individuals diagnosed with CKD, randomly selected from the initial quantitative sample, along with their caregivers or close relatives. The interview guide explored key topics such as personal experiences of living with CKD, understanding and perceptions of the illness, emotional reactions to diagnosis, lifestyle changes, family relationships, sources of social and community support, coping strategies, interactions with the medical system, and the role of religion, culture, and government support in managing the disease.

Importantly, the number of participants in the qualitative phase was not predetermined. Given the exploratory nature of this phase, sample size was to be guided by data saturation.

Publication 2. Scoping literature review

This scoping review examined how individuals with chronic diseases experience and navigate emotional challenges, with a particular focus on cross-cultural differences in shame and guilt. The authors applied a three-stage search strategy across the databases PubMed, Academic Search Complete, APA PsycArticles, and APA PsycInfo, covering publications up to 14 September 2023. A total of 20 empirical studies were included, encompassing both qualitative and quantitative designs. These studies investigated shame- and guilt-proneness in the context of chronic illness and explicitly reported participants' nationality and/or ethnicity.

The review classified the included studies into five thematic categories: (1) individual experiences, (2) risk behaviours, (3) patient care, (4) social attitudes and stigma, and (5) self-perception. Findings were compared across individualistic and collectivistic cultural contexts. The results highlighted that although shame and guilt are universal self-conscious emotions,

their triggers, trajectories, and psychosocial consequences differ substantially across cultures. For example, guilt tended to be more prominent in individualistic cultures, where internal moral standards are emphasized, whereas shame appeared more salient in collectivistic societies, where external social evaluation and social sanctions play a stronger role. Recognizing these cross-cultural nuances is crucial for developing culturally sensitive psychosocial support interventions for individuals living with chronic diseases across diverse cultural settings.

Publication 3. The Qualitative Study 1 (based on the Sri Lankan Subsample)

This study explored the experiences of individuals living with end-stage kidney disease (ESKD) undergoing hemodialysis, as well as the experiences of their caregivers in Sri Lanka. It aimed to examine how participants lived with and coped with the disease and the challenges associated with long-term treatment.

The study followed an exploratory qualitative design. Semi-structured interviews were conducted with 10 individuals undergoing hemodialysis and 5 caregivers at a dialysis unit. Interviews were audio-recorded, transcribed, and analyzed using qualitative content analysis.

The findings revealed three key themes:

1. Impact on Standard of Living (Quality of Life)
2. Coping Strategies
3. Medical Experience

Traditional beliefs and practices strongly influenced participants' perspectives across all themes. The findings highlight the need for a comprehensive approach to CKD management that considers not only the physical but also the emotional, psychological, and social dimensions of living with the disease. Further research is recommended to inform the

development of culturally appropriate interventions aimed at improving the quality of life of CKD patients and their caregivers.

Publication 4. The Qualitative study 2-Cross-Cultural Comparison (based on the Sri Lankan and Polish Subsamples)

This paper further examines the results from the qualitative phase of the project, focusing on the psychosocial experiences and treatment-related processes of individuals with ESKD and their caregivers in two cultural contexts: Sri Lanka and Poland. Using an exploratory qualitative design, the research involved semi-structured interviews with 18 individuals (10 from the Sri Lankan-Sinhalese group and 8 from the Polish group) undergoing hemodialysis, as well as 8 caregivers (5 from the Sri Lankan-Sinhalese group and 3 from the Polish group).

The data were analyzed using conventional qualitative content analysis, which identified three main themes:

1. Quality of Life
2. Coping Strategies
3. Medical Experiences

The findings demonstrated significant cultural and systemic differences shaping participants' psychosocial well-being. In Sri Lanka, communal values, familial support, and traditional practices played a key role in coping with the challenges associated with limited healthcare resources. In contrast, Polish participants benefited from well-equipped healthcare systems and emphasized personal resilience and self-determination.

This research underscores the importance of cultural and systemic frameworks in shaping the lived experiences of patients with ESKD and their caregivers. By comparing Eastern and Western contexts, the study provides novel insights that can inform the development of a

conceptual model integrating collective and individual approaches to care. Overall, the findings contribute to advancing culturally sensitive strategies for supporting psychosocial well-being in chronic illness.

Publication 5. The Quantitative study: Cross-Cultural Comparison (Based on the Sri Lankan and Polish Subsamples)

This study examined the psychosocial well-being of individuals with ESKD in two culturally distinct populations: Sri Lanka and Poland. Using a cross-sectional quantitative design, the research examined cultural differences in psychosocial functioning and health related well-being and quality of life among individuals undergoing hemodialysis. The sample included 50 patients from Sri Lanka and 43 from Poland. Participants completed the Kidney Disease Quality of Life Short Form (KDQOL-SF) Questionnaire, the Beck Depression Inventory (BDI), and the Acceptance of Illness Scale (AIS). In addition, relevant medical data were extracted from participants' health records.

The findings indicated that although both groups reported similar challenges, including CKD-related symptoms, sleep difficulties, cognitive issues, and the daily burden of living with CKD, there were also notable cross-cultural differences. Participants in Sri Lanka reported higher levels of depression, poorer social quality of life, and lower perceived social support compared with participants in Poland.

These results underscore the critical role of cultural context in shaping the psychosocial experiences of individuals living with ESKD. The findings offer valuable implications for developing culturally sensitive interventions to enhance psychosocial support and improve well-being among patients undergoing haemodialysis across diverse settings.

Keywords: chronic kidney disease, hemodialysis, psychosocial well-being, caregivers, cross-cultural comparison, coping strategies.

Streszczenie

Celem podjętych badań jest ocena dobrostanu psychospołecznego osób z przewlekłą chorobą nerek (PChN) poddawanych hemodializie oraz ich opiekunów. Jest to międzykulturowy projekt o charakterze mieszanym, realizowany w dwóch krajach (badanie lankijskie i polskie) oraz dwóch fazach (ilościowej, a następnie jakościowej). Projekt zaowocował pięcioma publikacjami: protokołem badawczym, przeglądem literatury dotyczącym różnic kulturowych w doświadczaniu wstydu i poczucia winy u osób z chorobami przewlekłymi oraz trzema publikacjami opartymi na wynikach oryginalnych badań jakościowych i ilościowych.

Publikacja 1. Protokół badawczy

Protokół projektu zawierał tło badania, cele, pytania badawcze, projekt i metody badawcze, planowaną analizę danych oraz omówienie. Zawierał szczegółowy opis PChN, jej charakteru, rozpowszechnienia, etapów, dostępnych metod leczenia, przegląd literatury oraz znaczenie badania dobrostanu psychospołecznego osób z chorobą i ich opiekunów w kontekście międzykulturowym. Badanie zaplanowano jako projekt o charakterze mieszanym, obejmujący zarówno osoby z PChN poddawane hemodializie, jak i ich opiekunów w Sri Lance i w Polsce.

W fazie ilościowej planowano udział uczestników z Sri Lanki (n = 63) i Polski (n = 63), jednak ostateczna liczba badanych została zmniejszona z powodu trudności praktycznych. Uczestnicy byli oceniani przy użyciu zestawu narzędzi, takich jak: Kwestionariusz jakości życia (KDQOL-SF), Skala Depresji Becka (BDI), Test Samoświadomego Afektu (TOSCA), Skala Kontroli Emocji (CECS), Skala Akceptacji Choroby (AIS) oraz kwestionariusz danych demograficznych i medycznych.

Faza jakościowa obejmowała półustrukturyzowane wywiady z osobami chorującymi na PChN oraz ich opiekunami, wybranymi losowo z próby ilościowej. Przewodnik wywiadu obejmował

zagadnienia takie jak: osobiste doświadczenia życia z chorobą, postrzeganie choroby, reakcje emocjonalne na diagnozę, zmiany w stylu życia, relacje rodzinne, źródła wsparcia społecznego, strategie radzenia sobie, kontakty z systemem opieki zdrowotnej oraz rola religii, kultury i wsparcia państwa w radzeniu sobie z chorobą. Liczba uczestników fazy jakościowej nie była z góry określona – ustalano ją na podstawie nasycenia danych.

Publikacja 2. Przegląd literatury (Scoping Review)

Przegląd ten analizował, w jaki sposób osoby z chorobami przewlekłymi doświadczają i radzą sobie z emocjonalnymi trudnościami, ze szczególnym uwzględnieniem różnic kulturowych w przeżywaniu wstydu i poczucia winy. Autorzy zastosowali trójstopniową strategię wyszukiwania (bazy danych: PubMed, Academic Search Complete, APA PsycArticles i APA PsycInfo, stan na 14 września 2023 r.) i wyłonili 20 badań empirycznych o charakterze jakościowym i ilościowym, w których analizowano podatność na wstyd/poczucie winy u osób z chorobami przewlekłymi, przy jednoczesnym wskazaniu narodowości lub pochodzenia etnicznego uczestników.

Wyniki badań zostały pogrupowane w pięć kategorii tematycznych (doświadczenia indywidualne, zachowania ryzykowne, opieka nad pacjentem, postawy społeczne/stygmatyzacja oraz samoocena). Przegląd wykazał, że chociaż wstyd i poczucie winy są emocjami uniwersalnymi, ich źródła, przebieg i konsekwencje psychospołeczne różnią się znacząco w zależności od kontekstu kulturowego. W kulturach indywidualistycznych dominuje poczucie winy związane z wewnętrznymi standardami moralnymi, natomiast w kulturach kolektywistycznych – wstyd oparty na zewnętrznych sankcjach społecznych. Zrozumienie tych różnic jest kluczowe dla opracowania kulturowo wrażliwych interwencji psychospołecznych dla osób z chorobami przewlekłymi.

Publikacja 3. Badanie jakościowe 1 (próba lankijska)

Badanie to analizowało doświadczenia osób z końcowym stadium choroby nerek (ESKD) poddawanych hemodializie oraz ich opiekunów w Sri Lance. Miało na celu zrozumienie, w jaki sposób doświadczają oni choroby i radzą sobie z wyzwaniami związanymi z leczeniem.

Zastosowano jakościowy, eksploracyjny projekt badawczy. Przeprowadzono półustrukturyzowane wywiady z 10 pacjentami i 5 opiekunami. Dane zostały przeanalizowane metodą analizy treści.

Wyniki ujawniły trzy główne tematy:

1. Wpływ na standard życia (jakość życia)
2. Strategie radzenia sobie
3. Doświadczenia medyczne

Tradycyjne wierzenia i praktyki silnie wpływały na wszystkie tematy. Badanie podkreśla potrzebę kompleksowego podejścia do leczenia PChN, uwzględniającego nie tylko aspekty fizyczne, lecz także emocjonalne, psychologiczne i społeczne.

Publikacja 4. Badanie jakościowe 2 – porównanie międzykulturowe (próba lankijska i polska)

Artykuł ten analizował doświadczenia psychospołeczne i proces leczenia osób z ESKD oraz ich opiekunów w dwóch kontekstach kulturowych – w Sri Lance i w Polsce. Zastosowano eksploracyjny projekt jakościowy, przeprowadzając półustrukturyzowane wywiady z 18 pacjentami (10 z grupy lankijsko-syngaleskiej i 8 z grupy polskiej) oraz 8 opiekunami (5 z Sri Lanki i 3 z Polski).

Analiza treści ujawniła trzy główne tematy:

1. Jakość życia
2. Strategie radzenia sobie
3. Doświadczenia medyczne

Wyniki wykazały istotne różnice kulturowe i systemowe wpływające na dobrostan psychospołeczny uczestników. W Sri Lance kluczową rolę odgrywały wartości wspólnotowe, wsparcie rodziny i praktyki tradycyjne w kontekście ograniczonych zasobów opieki zdrowotnej, podczas gdy uczestnicy z Polski korzystali z lepiej wyposażonych systemów medycznych i podkreślali osobistą odporność oraz samodzielność.

Badanie podkreśla znaczenie ram kulturowych i systemowych w kształtowaniu doświadczeń pacjentów z ESKD i ich opiekunów oraz dostarcza podstaw do tworzenia kulturowo wrażliwych strategii opieki.

Publikacja 5. Badanie ilościowe – porównanie międzykulturowe (próba lankijska i polska)

Celem tego badania było porównanie dobrostanu psychospołecznego osób z ESKD w dwóch odmiennych kulturowo populacjach: w Sri Lance i w Polsce. W badaniu przekrojowym wzięło udział 50 pacjentów z Sri Lanki i 43 z Polski. Zastosowano kwestionariusze: Kwestionariusz jakości życia (KDQOL-SF), Skala Depresji Becka (BDI) oraz Skala Akceptacji Choroby (AIS).

Wyniki pokazały, że chociaż pewne trudności – takie jak objawy choroby, problemy ze snem, zaburzenia poznawcze i codzienne obciążenia – są wspólne, to jednak istnieją wyraźne różnice między grupami. Uczestnicy z Sri Lanki wykazywali wyższy poziom depresji, gorszą jakość życia społecznego i mniejsze wsparcie społeczne w porównaniu z uczestnikami z Polski.

Wyniki te podkreślają znaczenie kontekstu kulturowego w kształtowaniu doświadczeń psychospołecznych osób z ESKD i stanowią podstawę do opracowania kulturowo adekwatnych interwencji wspierających dobrostan pacjentów w różnych środowiskach kulturowych.

Słowa kluczowe: przewlekła choroba nerek, hemodializa, dobrostan psychospołeczny, opiekunowie, porównanie międzykulturowe, strategie radzenia sobie.

Introduction

Background

More than half of the general population lives with at least one chronic disease, with approximately one-third experiencing multiple chronic conditions (Keles et al., 2006; *USRDS Annual Data Report: Epidemiology of Kidney Disease in the United States*, 2020; Fuertes et al., 2025). Medical advancements have extended the lifespans of many individuals afflicted with chronic diseases. Therefore, a key aim of healthcare in chronic disease management should be to maintain a satisfactory health-related quality of life (HRQOL).

According to the World Health Organization (WHO), quality of life (QOL) is a multifaceted concept defined as individuals' perceptions of their position in life within the context of their culture and value systems, relative to their goals, expectations, and standards (Megari, 2013). HRQOL refers to a specific form of QOL related to health and diseases (Dean et al., 2017) and a multidimensional concept connected with physical, mental, emotional, and social functioning (Senanayake et al., 2020). Hence, HRQOL can be identified as a subjective phenomenon that can be influenced by individuals' experiences, expectations, and beliefs (O'Shaughnessy & Elder, 2009). Chronic diseases typically progress slowly over a prolonged period and often require long-term medical intervention. Most chronic illnesses have the potential to deteriorate patients' overall health by restricting their ability to lead fulfilling lives, limiting functional abilities and productivity, reducing HRQOL, and significantly increasing healthcare expenses (Devins, 1983). According to Megari (2013), these health conditions include cancer, stroke, diabetes, HIV, bowel diseases, renal disease, and central nervous system disorders.

Chronic Kidney Disease

Chronic kidney disease (CKD) is a progressive disease characterized by its incurable nature and high levels of morbidity and mortality. Therefore, CKD has emerged as one of the most prominent causes of death and suffering in the 21st century (Kovesdy, 2022; Zaragoza-Fernández et al., 2025). It is prevalent among the general adult populace, particularly those afflicted with diabetes and hypertension (Kalantar-Zadeh et al., 2021). The understanding and categorization of CKD have changed over the years. Currently, global standards define CKD as a reduction in kidney function, indicated by a glomerular filtration rate (GFR) below 60 mL/min per 1.73 m^2, or the presence of kidney damage markers, or both, persisting for at least three months, irrespective of the root cause (Webster et al., 2017). Because GFR is closely associated with the risk of complications, CKD is categorized into five stages based on GFR levels: Stage 1, with a GFR greater than 90 mL/min per 1.73 m^2; Stage 2, with a GFR between 60 and 89 mL/min per 1.73 m^2; Stage 3, with a GFR between 30 and 59 mL/min per 1.73 m^2; Stage 4, with a GFR between 15 and 29 mL/min per 1.73 m^2; and Stage 5, with a GFR less than 15 mL/min per 1.73 m^2 (Levey & Coresh, 2012). Once an individual enters stage 5, their condition advances to what's known as end-stage kidney disease (ESKD). This signifies a critical point where kidney function is severely impaired, rendering it incapable of adequately supporting the body's needs. At this juncture, patients typically necessitate treatments such as dialysis, renal transplant therapy, or conservative care to manage their condition (Webster et al., 2017).

Prevalence of CKD

A 2010 study on CKD prevalence and its impact revealed that, globally, 10.4% of men and 11.8% of women aged 20 and above had CKD stages 1-5. Notably, differences were observed based on geographic regions and income levels, with higher prevalence in low- and middle-

income countries. Specifically, CKD stages 3-5 affected 4.7% of men and 5.8% of women in this age group worldwide (Kovesdy, 2022). Numerous nations have implemented surveillance initiatives aimed at tracking cases of kidney failure managed through dialysis and transplantation. The incidence and prevalence rates fluctuate due to variations in the prevalence of underlying diseases and the accessibility of government-funded treatment. Webster et al; (2017) found that diabetes and hypertension are the main causes of CKD in all high-income, middle-income, and many low-income countries. Thus, they mentioned, that 30%-50% which is 285 million people are suffering from diabetes worldwide and it is expected to increase by 69% in developed countries and 20% in middle-income and low-income countries by 2030. Furthermore, more than a quarter of the adult population estimated to have hypertension in 2000 and it is was expected estimated to be increased by 60% by 2025 (Kearney et al., 2005). In several countries, the incidence has surged to approximately 200 cases per million annually. Notably, in the USA, Taiwan, and certain parts of Mexico, the incidence is approaching 400 cases per million, with the sharpest rise observed among older individuals (Levey & Coresh, 2012). Diabetes is recognized as the primary cause of CKD, and it's projected that the incidence of diabetes will surge by more than 150% in South Asia alone from 2000 to 2035 (Liyanage et al., 2022). Moreover, there's a growing occurrence of CKD cases with unknown origins in certain regions of South Asia, such as Sri Lanka and India (Ranasinghe et al., 2019; Tatapudi et al., 2018). The prevalence of CKD has been rising over the last three decades, especially among Sri Lankan farming communities, due to the identifying CKD with unknown etiology (CKDu) and the increment of non-communicable diseases (NCDs) such as hypertension and diabetes mellitus (Kafle, 2019). CKD is increasing worldwide at an annual growth rate of 8% (Senanayake et al., 2017) and is ranked among the top 20 causes of death according to the Global Burden of Diseases (Adejumo et al., 2019). Furthermore, complications of CKD include anemia, bone disease, and increased risk of cardiovascular disease and cancer (Webster et al.,

2017). Moreover, due to economically nonviable treatment methods, there is expected to be an increase of 70% in ESRD among patients in developing countries (Gunathilaka et al., 2014). However, there remains a lack of high-quality epidemiological data regarding contemporary CKD prevalence in many regions, which limits accurate projections for the future. Additionally, kidney registries in Asia have primarily focused on systematic data collection for patients who have reached kidney failure and require kidney replacement therapy, thereby limiting the availability of comprehensive information (Liu et al., 2015).

Polish data indicate that CKD is a significant contributor to cardiovascular disease risk (Zdrojewski et al., 2016). A study conducted in Poland among individuals with CKD, both on and off hemodialysis, found a higher prevalence of depression among those receiving hemodialysis treatment (Ćwiek et al., 2017). This finding emphasizes the importance of monitoring mental health in CKD patients and ensuring access to timely psychological support. Another study examined the prevalence of CKD and its association with socioeconomic status among older adults in Poland, reporting that approximately one-third of the elderly population is affected by CKD (Chudek et al., 2013). Notably, CKD was more common among urban residents, non-smokers, individuals who abstain from alcohol, and those with lower levels of physical activity. Additionally, a comparative study assessing the quality of life of hemodialysis patients with ESRD showed a significantly lower quality of life compared to a healthy control group (Dembowska et al., 2022).

Quality of Life and Psychosocial Well-being

Psychosocial well-being is a broad concept that encompasses emotional and psychological health, as well as social functioning and community well-being. According to the Encyclopedia of the UN Sustainable Development Goals (Kumar, 2020), psychosocial well-being is a multifaceted notion intertwined with various determinants of health, such as physical,

economic, social, mental, emotional, cultural, and spiritual factors. Diener & Diener (1995) emphasized that subjective well-being, closely related to perceived quality of life, includes both cognitive evaluations of life satisfaction and emotional responses. They highlighted personality traits, income levels, and social support in influencing well-being across diverse cultures. Importantly, perceptions and experiences of factors contributing to well-being may diverge between individualistic and collectivist cultures. Psychosocial well-being is predictive of QOL, both in the general population and among those with chronic illnesses (Dean et al., 2017). Because, the concept of QOL is akin to psychosocial well-being, encompassing emotional, social, and physical elements (Eirosa-Orosa, 2020).

The Rationale for the Current Study

The present research project, "Psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis treatment and their caregivers: A mixed-method study in Sri Lanka and Poland," is grounded in several key considerations drawn from existing empirical evidence.

Firstly, CKD remains a significant global health challenge that requires urgent attention. Despite advancements in CKD management, particularly in developed countries, the burden of the disease persists in low- and middle-income countries such as Sri Lanka. This underscores the importance of addressing the psychosocial well-being of CKD patients undergoing hemodialysis, as clinical concerns often overshadow this aspect. Research by McKercher et al. (2013), Wimalawansa (2015), and Liyanage (2015) highlights the multidimensional impact of CKD on patients' lives, emphasizing the need for comprehensive care approaches. Additionally, the provision of psychosocial support to both patients and their families, as advocated by Ranasinghe and Ranasingha (2015), is critical to mitigating the broader societal and individual challenges posed by CKD.

Secondly, CKD is often associated with stigma and psychosocial challenges, including feelings of shame, guilt, and social isolation. These challenges may be exacerbated by the visible effects of dialysis and changes in physical appearance, as highlighted by Pedreira Robles and Aguayo-González (2019). Addressing stigma-related processes and emotional distress is therefore vital to strengthening resilience and improving overall well-being among patients and caregivers.

Thirdly, cultural beliefs and behaviors significantly influence health perceptions and treatment-seeking behaviors. As emphasized by Kleinman et al. (1995) and Turner (1996), understanding cultural contexts is essential for delivering effective healthcare. Conducting a study in two culturally distinct settings - Sri Lanka and Poland, enables a comparative examination of how cultural beliefs and practices shape the psychosocial experiences of CKD patients and their caregivers. This cross-cultural approach not only broadens the understanding of culturally specific needs but also informs the development of tailored interventions.

Moreover, learning from the experiences of countries such as Poland, which adhere to WHO and EU standards for CKD treatment, can provide valuable insights into best practices that could be adapted to improve CKD care in Sri Lanka.

This comparative approach may help identify strategies to strengthen psychosocial support, improve healthcare delivery, and guide policy development for individuals undergoing hemodialysis.

In conclusion, this mixed-method study addresses an important research gap by examining the psychosocial well-being of individuals with CKD receiving hemodialysis treatment and their caregivers in Sri Lanka and Poland. By integrating cultural context and employing a mixed-method design, the study aimed to generate actionable insights and recommendations to improve psychosocial support and quality of care in both settings. Furthermore, drawing on

Poland's implementation of WHO/EU treatment standards may help identify adaptable practices to strengthen CKD management in Sri Lanka. This cross-cultural framework is therefore essential for informing effective, culturally responsive healthcare strategies for individuals living with CKD.

Objectives

Objectives of the Original Study (Publications 1, 3, 4, 5)

The study's primary objective is to investigate the psychosocial well-being of individuals with CKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland. The specific objectives were as follows:

- To compare the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis in Sri Lanka and Poland.
- To evaluate medical (having diabetes, having hypertension) and social factors (gender, age, marital status) that might be associated with psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis.
- To explore how individuals with chronic kidney disease undergoing hemodialysis and their caregivers experience the disease and the process of treatment in Sri Lanka and Poland.
- To provide guidelines / recommendations to improve psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis and their caregivers in Sri Lanka.

Objective of the Scoping Literature Review (Publication 2)

- To review and synthesize the existing literature on shame and guilt in the context of chronic diseases across different cultures.

Materials and Methods

This study was conducted according to the guidelines of the Declaration of Helsinki and approved by the Ethics Committee for Research Projects at the Open University of Sri Lanka (Protocol number: ER/2022/007; date of approval:15.07.2022) and the University of Gdańsk (protocol number: 03/2023; date of approval:13.03.2023). Informed consent was obtained from all participants involved in the study.

Study Design

This PhD research employed a convergent mixed-methods design to investigate the psychosocial well-being of individuals with ESKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland. The mixed-methods approach enabled the integration of quantitative assessments of psychosocial outcomes with qualitative exploration of lived experiences, thereby offering a comprehensive and culturally informed understanding of psychosocial well-being. The study was conducted in sequential phases, and findings from both components were later integrated. Detailed methodological procedures are presented in the published protocol and empirical studies included in this thesis.

Study Setting and Study Group

The study was conducted in two purposively selected hemodialysis units: the General Hospital (Teaching) in Kandy, Sri Lanka, and the University Clinical Center of the Medical University of Gdańsk, Poland. These sites were selected to represent differing healthcare contexts and sociocultural environments.

The study population consisted of adult individuals diagnosed with stage 5 CKD and receiving hemodialysis, as well as their primary caregivers. Caregivers were defined as individuals identified by the participants with CKD as their main providers of emotional and/or practical

support. Both related and non-related caregivers were included to capture diverse caregiving arrangements.

Eligibility Criteria

Individuals with CKD

Individuals were eligible for inclusion if they were aged between 18 and 70 years, had a confirmed diagnosis of stage 5 CKD, and were undergoing hemodialysis treatment at the time of recruitment. Participants were required to have been receiving hemodialysis for at least six months to ensure adequate exposure to the psychosocial demands associated with long-term treatment. To support culturally grounded comparisons, eligibility was limited to Sinhala-speaking participants in the Sri Lankan sample and Polish nationals in the Polish sample. The presence of comorbid medical conditions was not considered an exclusion criterion.

Individuals were excluded if they did not meet the inclusion criteria, declined to provide informed consent, or were unable to participate due to physical or psychological limitations that prevented meaningful engagement in the study.

Caregivers

Caregivers were eligible for inclusion if they were identified by participating individuals with CKD as significant caregivers, were aged 18 years or older, and provided informed consent. Both family members and non-related caregivers, such as close friends, were considered eligible.

Caregivers were excluded if they did not meet the inclusion criteria, refused to provide consent, or lacked the physical or mental capacity to participate in the study procedures.

Data Collection and Procedure

Data collection was carried out in two sequential phases. In the quantitative phase, individuals with CKD completed a set of standardized self-report questionnaires assessing psychosocial well-being, along with a sociodemographic survey. HRQOL was assessed using the KDQOL-SF, depressive symptoms were measured using the BDI, and acceptance of illness was evaluated using the AIS. The sociodemographic survey collected information on variables such as age, gender, marital status, education level, employment status, and self-reported clinical characteristics. Quantitative analyses included comparisons between Sri Lankan and Polish participants using parametric and non-parametric statistical tests, depending on data distribution, with effect sizes reported where appropriate (see the details of the publication 5 for full details)."

The qualitative phase involved in-depth interviews with a subsample of individuals with CKD undergoing hemodialysis who had participated in the quantitative phase, as well as their caregivers, who were recruited specifically for the qualitative phase. The number of participants for this phase ware not predetermined; instead, recruitment continued until data saturation was achieved. Qualitative data were analysed using conventional content analysis. Detailed qualitative procedures and analytic procedure are reported in the Publication 3 and 4.

Findings from the quantitative and qualitative phases were subsequently integrated using a convergent mixed-methods design. This integration provided a comprehensive understanding of psychosocial well-being among individuals undergoing hemodialysis and their caregivers and informed the subsequent studies included in this doctoral thesis.

Scientific Publications

Protocol (Publication 1)

This chapter is based on: **Bulathwatta, D. T.**, Borchet, J., Rudnik, A., & Bidzan, M. (2023). Psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis treatment and their caregivers: A protocol of a mixed method study in Sri Lanka and Poland. *Frontiers in Psychology, 14*. https://doi.org/10.3389/fpsyg.2023.1194991

Overview of the protocol

The protocol outlined the study's background, objectives, methods, data analysis, general discussion about expected outcomes. The following section summarizes this protocol, which constitutes the first publication included in this thesis.

The protocol addresses the psychosocial dimensions of chronic kidney disease (CKD) among patients undergoing hemodialysis and their caregivers in two distinct cultural contexts-Sri Lanka and Poland (Bulathwatta et al., 2023). Although CKD has been extensively examined from biomedical and epidemiological perspectives, relatively little research has explored the psychosocial burden associated with long-term hemodialysis, particularly within cross-cultural frameworks. The increasing global prevalence of CKD and its multifaceted impact on patients' physical, emotional, and social well-being, underscores the need for comparative research in this area (Kovesdy, 2022; Webster et al., 2017).

The protocol conceptualizes CKD as a chronic, life-altering illness that extends beyond physiological deterioration to encompass substantial psychological distress, social isolation, and economic strain. Patients undergoing hemodialysis often experience limitations in

mobility, dietary freedom, and employment, while caregivers shoulder considerable emotional and practical responsibilities. Together, these factors contribute to reduced health-related quality of life (HRQOL) and compromised psychosocial well-being (Gerogianni & Babatsikou, 2014; Filgueiras de Assis Mello & Angelo, 2018).

Despite these challenges, psychosocial aspects of CKD remain underrepresented in the literature, particularly in non-Western contexts such as Sri Lanka, where sociocultural factors-including stigma, shame, and guilt-may influence health behaviors and perceptions (Pedreira Robles & Aguayo-González, 2019; Ranasinghe & Ranasingha, 2015). In contrast, Poland represents a European context with more established health infrastructure and adherence to WHO/EU CKD treatment standards. Comparing these two settings enables an examination of how cultural orientations (e.g., collectivistic vs. individualistic tendencies) may influence the experiences of patients and caregivers, including coping processes and illness acceptance (Diener & Diener, 1995; Kleinman et al., 1995).

Furthermore, the protocol highlights the significance of understanding emotional regulation mechanisms such as emotional suppression, guilt, and shame proneness, which may vary across cultural and social environments. These psychosocial processes can affect treatment adherence, resilience, interpersonal functioning, and, ultimately, patients' HRQOL and caregivers' mental health (Stage, 2022; King-Wing Ma & Kam-Tao Li, 2016).

By integrating quantitative measures of HRQOL, depression, emotional suppression, shame and guilt proneness, and acceptance of illness with qualitative exploration of lived experiences, the protocol adopts a mixed-method design. This approach ensures a comprehensive understanding of CKD's psychosocial dimensions while accommodating cultural variability and contextual nuances (Bulathwatta et al., 2023).

Research Questions

This study aimed to explore the psychosocial well-being of individuals with CKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland. The research questions were as follows:

Quantitative Phase:

- Are there differences in HRQOL, depression, emotional suppression, shame- and guilt-proneness, and acceptance of illness among individuals with CKD undergoing hemodialysis in Sri Lanka and Poland?
- Do demographic and clinical factors (e.g., gender, age, marital status, diabetes, and hypertension) predict variations in HRQOL, depression, emotional suppression, shame- and guilt-proneness, and acceptance of illness among individuals with CKD undergoing hemodialysis?

Qualitative Phase:

- How do patients with CKD experience the disease and the process of hemodialysis treatment?
- How do caregivers of individuals with CKD undergoing hemodialysis experience the disease and the caregiving process?

Methods

The study adopted a mixed-methods design to explore the psychosocial well-being of individuals with ESKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland. Two hemodialysis units-District Teaching Hospital, Kandy (Sri Lanka) and the University Clinical Center of the Medical University of Gdańsk (Poland)-were purposively selected to

ensure diverse representation. Participants included adults diagnosed with stage 5 CKD and their primary caregivers who met inclusion criteria and provided informed consent.

In the quantitative phase, psychosocial well-being was assessed using standardized self-report instruments measuring health-related quality of life (KDQOL-SF), depression (BDI), emotional suppression (CECS), and illness acceptance (AIS), along with a sociodemographic survey. Data from 126 participants (63 Sri Lankans, 63 Polish) were analyzed using SPSS 25, employing regression models and group comparisons to examine cross-cultural differences and predictors of psychosocial outcomes.

The qualitative phase included semi-structured interviews with a purposively selected subsample of individuals undergoing hemodialysis and their caregivers. The exact sample size was not predetermined, as the qualitative component was exploratory; instead, recruitment continued until data saturation was achieved. Interviews focused on participants' lived experiences, coping strategies, and sources of social and emotional support. Qualitative data were analyzed using conventional content analysis to identify key themes and patterns.

Finally, findings from both phases were integrated to provide a comprehensive understanding of psychosocial well-being and to guide the subsequent studies in this PhD project.

Table 1

Summary of Study Design

Phase	Group 1 (Sri Lankan)	Group 2 (Polish)	Method	Instruments	Study design	Data analysis
1	63 patients	63 patients	Quantitative	Kidney Disease Quality of Life-Short Form (KDQOL-SF) Version 1.3 Beck Depression Inventory	Cross-sectional design	Statistical analysis: regression models, testing differences between two samples (t-test for two

				Test of Self-Conscious Affect (TOSCA-3) Courtauld Emotional Control Scale (CECS) Acceptance of Illness Scale (AIS)		independent samples or U Mann–Whitney test)
2	The sample size is not pre-determined beforehand	The sample size is not pre-determined beforehand	Qualitative	Semi-structured interviews	Cross-sectional design	Qualitative content analysis

Discussion

This study investigates the psychosocial well-being of individuals with CKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland using a mixed-methods approach. By integrating quantitative assessments and qualitative interviews, the study provides a comprehensive understanding of both measurable outcomes-such as health-related quality of life, depression, emotional suppression, shame- and guilt-proneness, and acceptance of illness-and the lived experiences of patients and caregivers (Bulathwatta et al., 2023).

The research addresses an important gap in cross-cultural studies of CKD, highlighting the ways in which cultural and systemic factors may shape psychosocial well-being. Comparing Sri Lankan and Polish samples enables exploration of potential differences in coping strategies, access to social and emotional support, and the broader impact of CKD and hemodialysis on patients and caregivers. The findings from this study are expected to inform culturally sensitive interventions and contribute to guidelines for holistic care (Bulathwatta et al., 2023).

Several potential challenges were anticipated. These include participants' understanding of the study purpose, particularly in Sri Lanka, where individuals from low-income backgrounds might expect financial or material benefits from participation. To reduce this risk, detailed participant information sheets and clear verbal explanations were used to manage expectations and ensure informed consent. In addition, the study acknowledges potential limitations related to sample size; therefore, appropriate statistical methods and cautious interpretation of findings were applied to reduce bias and enhance validity (Bulathwatta et al., 2023).

Ethical considerations were rigorously addressed. Approval was obtained from the the Ethics Committee for Research Projects at the Open University of Sri Lanka (ER/2022/007) and the University of Gdańsk (03/2023). Informed consent is obtained from all participants who were informed of their right to withdraw at any time without consequences. Confidentiality was

ensured, and all data were securely stored and will be destroyed in accordance with ethical guidelines following publication. (Bulathwatta et al., 2023).

Overall, this study is expected to make a meaningful contribution to understanding the psychosocial well-being among CKD patients and their caregivers across different cultural contexts. The findings may provide a foundation for culturally appropriate psychosocial support and informing healthcare policies and practices (Bulathwatta et al., 2023).

Author Contribution

Darshika Thejani Bulathwatta: 70% (study conceptualization, study design, and manuscript drafting).

Judyta Borchet: 15% (study design and manuscript revision).

Agata Rudnik: 10% (study design and manuscript revision).

Mariola Bidzan: 5% (study conceptualization and design, manuscript revision, supervision, and mentorship).

Scoping Literature Review (Publication 2)

This chapter is based on: **Bulathwatta, D. T.**, Borchet, J., Rudnik, A., & Bidzan, M. (2024). The cross-cultural differences in shame and guilt among individuals with chronic diseases — A scoping review. *Polskie Forum Psychologiczne (Polish Psychological Forum), 29*(2), 135–164. https://doi.org/10.34767/PFP.2024.02.02

Introduction

Publication 2 serves as a comprehensive literature review that examines the experience of shame and guilt among individuals with chronic illnesses across diverse cultural contexts. Specifically, it highlights the contrasting ways these emotions are experienced in individualistic versus collectivist cultures, particularly in relation to chronic health conditions.

Emotions are critical to understanding the lived experiences of individuals with chronic diseases, as they play a pivotal role in the recovery process. While extensive research has been conducted on psychological issues such as depression and anxiety- emotions often characterized by sadness and fear-there remains a significant gap in the literature concerning how individuals experience shame and guilt in the context of chronic illness (Bulathwatta et al., 2024a). Even less attention has been paid to the influence of culture on these emotions and their subsequent impact on recovery. Therefore, the objective of this study is to review and synthesize existing literature on shame and guilt in the context of chronic diseases across different cultures.

Method

This study employed a scoping review methodology to comprehensively explore how shame and guilt are experienced by individuals with chronic diseases across different cultural contexts (Bulathwatta et al., 2024a). The approach followed the framework proposed by Arksey and O'Malley (2005), which is designed to map existing literature, identify conceptual gaps, and accommodate both qualitative and quantitative studies. Unlike systematic reviews, this method was particularly appropriate given that many included studies treated culture as a contextual or sample-related factor rather than a primary variable (Bulathwatta et al., 2024a).

A structured three-step search strategy was conducted on 14 September 2023 across four major electronic databases: PubMed, Academic Search Complete, APA PsycArticles, and APA PsycInfo. The search combined terms related to chronic illness, culture, and shame/guilt (e.g., "chronic," "culture," "shame-proneness," "guilt-proneness"). The initial search identified 63 articles, which were screened for relevance based on titles and abstracts, resulting in 20 studies meeting inclusion criteria (Bulathwatta et al., 2024a).

Eligible studies included individuals diagnosed with chronic diseases, explored shame or guilt experiences, and specified participants' cultural backgrounds to allow classification into collectivistic (shame-based) or individualistic (guilt-based) cultures. Only observational empirical studies (qualitative or quantitative) published in English and peer-reviewed journals were included (Bulathwatta et al., 2024a).

The final set of studies was categorized into five thematic areas: individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception in the context of chronic diseases (Bulathwatta et al., 2024a).

Results

The review analyzed 20 empirical studies spanning approximately 69 years, focusing on self-conscious emotions-shame and guilt-among individuals with chronic diseases across diverse cultural contexts (Bulathwatta et al., 2024a). Findings were organized into five thematic categories reflecting key psychosocial dimensions: individual differences, risk behaviors, patient care, social attitudes/stigma, and self-perception. Within each category, studies were further classified according to cultural settings: individualistic, collectivistic, and comparative studies.

Category 1: Individual Differences

Emotional experiences of shame and guilt were influenced by cultural, demographic, and psychological factors. In individualistic cultures (e.g., Netherlands: Ten Klooster et al., 2014; Canada: Harrison et al., 2017), societal acceptance and disease awareness were associated with lower emotional distress. Conversely, collectivistic cultures (e.g., Turkey: Taşkıntuna & Özçürümez, 2011; Egypt: El-Mansoury et al., 2008) showed that cultural norms and communal expectations could heighten guilt, depression, and anxiety, highlighting the critical role of cultural context in shaping emotional responses to chronic illness.

Category 2: Risk Behaviors

Two qualitative studies examined shame, guilt, and risk behaviors. Shahram et al. (2017) found that Indigenous pregnant women in Canada who used psychoactive substances linked low self-esteem and internalized negative feedback to shame and guilt, which in turn hindered help-seeking. In Sweden, Lindqvist and Hallberg (2010) reported that guilt was associated with smoking in individuals with chronic obstructive pulmonary disease (COPD), indicating self-blame as a barrier to positive health behaviors.

Category 3: Patient Care

Three studies addressed shame and guilt in patient care within cultural contexts. Mondia et al. (2011) highlighted how family closeness, hierarchical respect, and gender roles influenced emotional expression in Asian American families. Okazaki (2000) reported that shame and stigma delayed treatment in Asian Americans with severe mental illness, despite family support. Abrams and Finesinger (1953) found that guilt-driven denial and avoidance of symptoms hindered timely cancer care. These findings underscore the need for culturally sensitive care that addresses emotional barriers to treatment.

Category 4: Social Attitudes/Stigma

Four studies examined social attitudes and stigma. Cerna et al. (2022) found guilt—but not shame—associated with chronic physical conditions. Gilbert (2000) reported interrelations among shame, social anxiety, and depression in the UK, while guilt was unrelated. In the collectivistic Dominican Republic, Cantisano et al. (2012) observed high shame and guilt among individuals with HIV/AIDS, limiting emotional disclosure. Browne et al. (2013) noted stigma, blame, and restricted opportunities for type 2 diabetes patients in Australia. Collectively, these studies illustrate the influence of cultural context on emotional responses and experiences of stigma.

Category 5: Self-Perception

Four studies examined self-perception in collectivistic cultures. Ho and Goh (2017) reported HIV patients in Singapore reconstructing identity within a shame-based society. Dam et al. (2016) compared hepatitis B virus (HBV) stigma in Vietnamese populations in Ho Chi Minh City and Chicago, revealing cultural differences in self-blame and shame. Walker et al. (2017) highlighted regret, self-blame, and systemic marginalization among Maori with CKD in New Zealand. Subandi and Good (2018) identified shame as a cultural indicator for illness, recovery,

and relapse among Javanese individuals with psychotic disorders. These findings emphasize the importance of culturally tailored approaches for effective chronic disease care.

Synthesis

Across the 20 studies, cultural context was a primary determinant of shame and guilt experiences in chronic illness. Individualistic cultures generally emphasized guilt linked to personal responsibility, whereas collectivistic cultures emphasized shame connected to communal expectations and social norms. These cultural differences intersected with demographic and psychological factors, affecting emotional responses, risk behaviors, healthcare engagement, and self-perception. Overall, the findings highlight the importance of culturally sensitive research, clinical care, and psychosocial interventions for individuals living with chronic diseases (Bulathwatta et al., 2024).

(For full results, please refer to the Results section in Publication 2).

Discussion

The scoping review provides important insights into how culture shapes the emotional experiences of individuals with chronic diseases, particularly regarding shame and guilt (Bulathwatta et al., 2024a). Findings indicate that in individualistic cultures, higher awareness of disease, access to advanced treatments, and social support networks enhance coping and reduce stigma, with guilt serving as a motivator for proactive disease management. Conversely, collectivistic cultures emphasize interconnectedness and communal values, often amplifying shame, which may hinder help-seeking and emotional disclosure (Ho & Goh, 2017; Taşkıntuna & Özçürümez, 2011; Subandi & Good, 2018).

Cultural influences on shame and guilt are persistent, even when individuals migrate to societies with different healthcare systems, highlighting the enduring impact of native cultural norms on emotional responses (Dam et al., 2016; Mondia et al., 2011; Okazaki, 2000).

Additionally, psychosocial and demographic factors—such as social support, personal beliefs, and education—interact with cultural background to shape emotional experiences to a greater extent than clinical disease characteristics alone (Ten Klooster et al., 2014; Harrison et al., 2017; El-Mansoury et al., 2008).

These findings underscore the need for culturally sensitive interventions in chronic disease care. Tailored strategies that consider cultural attitudes toward shame and guilt can improve emotional well-being, reduce stigma, and promote effective disease management across diverse populations (Bulathwatta et al., 2024a). The review also highlights the importance of incorporating cultural nuances into clinical practice and psychosocial support, ensuring holistic and inclusive care for patients from both individualistic and collectivistic backgrounds.

Author Contribution

Darshika Thejani Bulathwatta :75% (study conceptualization, research methodology, literature review, analysis, and conclusion)

Judyta Borchet: 15% (analysis, conclusion)

Agata Rudnik: 5% (conclusion)

Mariola Bidzan: 5% (study conceptualization, conclusion)

Qualitative Study 1 (Publication 3)

This chapter is based on : **Bulathwatta, D. T.**, Rudnik, A., & Bidzan, M. (2024). All good without anything good. Beyond survival: Understanding the psychosocial experiences of individuals with chronic kidney disease and their caregivers in Sri Lanka. *Health Expectations, 27*(4), e14157. https://doi.org/10.1111/hex.14157

Introduction

Chronic kidney disease (CKD) has emerged as a major health challenge within Sri Lanka, particularly in rural farming communities where both chronic kidney disease of unknown etiology (CKDu) and lifestyle-related causes such as hypertension and diabetes are prevalent (Kafle et al., 2019). Within the Sri Lankan healthcare system-historically shaped by colonial biomedical models and often limited in psychosocial resources-patients and caregivers experience substantial emotional, social, and cultural burdens throughout the illness trajectory (Mills, 2007). Traditional beliefs, limited access to supportive care, and stigma surrounding illness further shape how individuals experience treatment and cope with the disease. In this context, the present study aimed to explore the psychosocial experiences and treatment journeys of individuals undergoing hemodialysis and their caregivers in Sri Lanka, to identify culturally grounded needs and inform more holistic approaches to patient care (Bulathwatta et al., 2024b).

Method

Procedure

This qualitative study is part of a larger mixed-method project examining the psychosocial well-being of individuals with CKD undergoing hemodialysis and their caregivers in Sri Lanka

and Poland. All participants received an informational document outlining the study objectives and provided written consent. Data were collected through semi-structured interviews conducted at the hemodialysis unit of the National Hospital, Kandy, Sri Lanka, between October 1 and October 31, 2022. The interviews were conducted by the principal investigator, a qualified female researcher with expertise in qualitative methods, who is also a university lecturer holding an MSc degree and practicing as a psychologist.

Participants

15 participants were recruited through purposive sampling, including 10 patients with Stage 5 CKD undergoing hemodialysis and 5 caregivers identified by the patients as their primary supporters. The sample comprised 8 females (53%) and 7 males (47%), with a mean age of 48 years. Inclusion criteria for patients were Stage 5 CKD, hemodialysis treatment for at least six months, age 18–70 years, and Sinhala nationality with Buddhist faith. Caregivers were required to be 18 years or older and identified by the patient as a significant supporter, irrespective of relationship type. Detailed demographic information is reported in the published article (Bulathwatta et al., 2024b).

Data Collection

Interviews ranged from 35 to 60 minutes and continued until data saturation was reached. All interviews were audio-recorded, transcribed verbatim in Sinhala, and translated into English. Back-translation was performed to ensure accuracy, and independent researchers cross-checked the translations. Participants were invited to review their transcripts to confirm accuracy before analysis.

Data Analysis

An inductive approach using conventional content analysis was employed (Bulathwatta et al., 2024b). Two researchers independently coded the data to enhance reliability and reduce bias,

following triangulation guidelines. Themes and categories were finalized after consensus discussions between the researchers, in line with Elo and Kyngäs (2008). Open-ended interview questions facilitated a rich exploration of participants' lived experiences and psychosocial challenges related to CKD.

Results

Following data analysis, three overarching themes emerged: (a) standard of living (quality of life), (b) coping strategies, and (c) medical experience. The themes were found to be mutually interconnected, with the "power of tradition" influencing all three (see Fig. 1).

Theme 1: Standard of Living (Quality of Life)

The quality of life was impacted across three categories:

- Work life: Most participants reported disruptions in employment, difficulties continuing jobs, or early retirement due to dialysis schedules.
- Family life: Disease affected family dynamics; some participants experienced isolation as relatives and friends withdrew.
- Everyday life: Daily living was challenged by dietary restrictions, financial difficulties (reported by 9 out of 10 participants), and the ongoing need to adapt to the disease and comorbidities.

Theme 2: Coping Strategies

Participants relied on multiple strategies to manage CKD:

- Attitudes: Experiences ranged from helplessness to proactive adherence to hospital timetables, dietary restrictions, and medication.
- Psychosocial support: Support from family, friends, and limited government assistance (reported 2 out of 10 participants) helped mitigate the challenges.
- Spirituality/Religion: Buddhist beliefs and cultural practices (e.g., Bodhi Puja, protective rituals) provided emotional relief and shaped perceptions of suffering, destiny, and karma.
- Perception of the disease: Many were surprised at their diagnosis and struggled with understanding CKD, leading to lowered life expectations.

Theme 3: Medical Experience

This theme encompasses participants' experiences with diagnosis, gaining knowledge, and treatment:

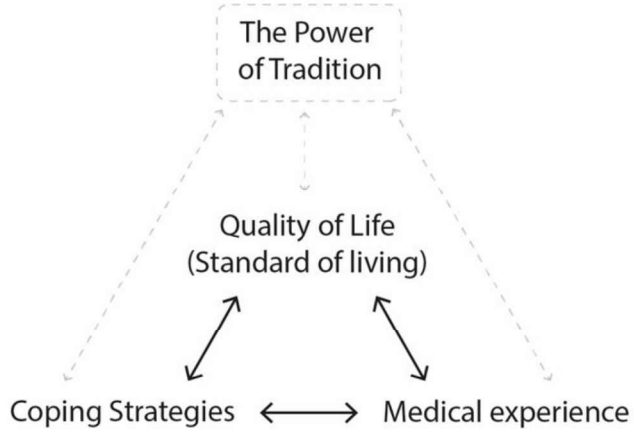
- Process of Diagnosis: Participants reported varied experiences—some developed CKD secondary to diabetes or hypertension, while others progressed to ESKD suddenly, requiring immediate dialysis. Frequent testing for dialysis and transplantation often caused insecurity and anxiety.
- Gaining Knowledge: Many participants felt they received insufficient information from doctors. Explanations were often limited to prescribing medications, leading to confusion due to inconsistent or unclear guidance from multiple sources.
- Treatment: Treatment challenges included: Treatment challenges included difficulties with travel, medication availability, transplantation, and interactions with healthcare staff.

Cross-Cutting Influence: Power of Tradition

The power of tradition was evident across all themes, influencing coping strategies, illness perceptions, and engagement with treatment. Cultural and religious beliefs provided meaning, resilience, and guidance in navigating daily challenges, emphasizing the importance of culturally informed interventions for patients and caregivers.

Figure 1

A Model Illustrating the Mutual Relationship among Three Identified Themes and the Influence of the Power of Tradition on Them.



Discussion

This study explored the psychosocial experiences of individuals with stage 5 CKD and their caregivers in Sri Lanka, revealing three key areas: standard of living, coping strategies, and medical experiences, with the "power of tradition" acting as a cross-cutting influence that shaped these dimensions.

Living with CKD significantly disrupted daily life, leading to financial hardship, social isolation, and emotional strain. Similar to findings in Europe, social support and positive psychological appraisals were found to be vital for sustaining well-being (Maguire et al., 2021; Roberti et al., 2018). However, in the Sri Lankan context, psychosocial distress was further exacerbated by structural constraints, including limited resources, long travel distances required to access dialysis, and underfunded healthcare services. These findings align with evidence suggesting that socioeconomic barriers and systemic inequalities intensify the burden of CKD, particularly in low-resource settings (Roberti et al., 2018).

Coping strategies reflected a complex interplay of religious beliefs, acceptance, and resilience. Participants often turned to Buddhism and other cultural practices—such as meditation, bodhi puja, and wearing protective charms—as means of emotional regulation. These strategies mirror the importance of spirituality and religious coping reported in prior studies (Chatrung et al., 2014; Bravin et al., 2019; Burlacu et al., 2019). The concept of karma and the acceptance of impermanence helped individuals interpret illness as part of destiny, which may serve as a psychological buffer in the context of limited healthcare access. As Joshi (2014) and Wimalasena and Marks (2019) note, such beliefs play an important, though sometimes uncritical, role in guiding coping behaviors in Sri Lankan society.

Medical experiences profoundly influenced psychosocial well-being. Participants often felt inadequately informed about treatment, experienced logistical difficulties, and struggled with limited access to medication. These challenges highlight gaps in patient-centered communication and continuity of care, reflecting broader concerns in global CKD management (Kalantar-Zadeh et al., 2021). Moreover, uncertainty about treatment outcomes and limited understanding of disease progression contributed to emotional distress. This finding contrasts with evidence from other chronic illness populations, where more positive and coherent illness

perceptions are associated with better psychological adjustment and coping (Rymon Lipińska & Nowicka-Sauer, 2022). Symptoms of depression and anxiety were frequently described, consistent with evidence that CKD patients are at heightened risk of psychological distress (Hedayati, 2010; Senanayake et al., 2018).

Overall, this study (Bulathwatta et al., 2024b) highlights the intersection between biomedical care and traditional belief systems in shaping the psychosocial realities of CKD in Sri Lanka. The results underscore the need for integrated and culturally responisive interventions that that combine health education, psychological support, and an awareness of local explanatory models of illness in order to improve the quality of life of both patients and caregivers.

Author Contribution

Darshika Thejani Bulathwatta: 80%) (study conceptualization, study design, data collection, qualitative analysis, and manuscript drafting).

Agata Rudnik: 15% (study conceptualization, study design, qualitative analysis, manuscript drafting).

Mariola Bidzan: 5% (study conceptualization and design, data collection, manuscript revision, supervision, and mentorship).

Qualitative Study 2 (Publication 4)

This chapter is based on: **Bulathwatta, D. T.,** Rudnik, A., Borchet, J., Zelechowska, S., Treppner, M., Ruszkowski, J., Zakrzewska, A., Dębska-Ślizień, A. M., Biedunkiewicz, B., Tylicki, L., & Bidzan, M. (2025). Contrasting cultures, shared struggles: A qualitative analysis of the experiences of end-stage kidney disease patients and their caregivers in Poland and Sri Lanka. *SAGE Open Nursing, 11*, Article 23779608251360594. https://doi.org/10.1177/23779608251360594

Introduction

This study explores and compares the psychosocial experiences of individuals with end-stage kidney disease (ESKD) and their caregivers in Sri Lanka and Poland, emphasizing how cultural meanings and healthcare systems shape their lived realities. In Sri Lanka, the rising burden of CKD, particularly in rural agricultural regions, intersects with economic hardship, limited medical resources, and deeply rooted cultural beliefs (Kafle et al., 2019; Bulathwatta et al., 2024b). Despite the availability of free public healthcare, the ongoing economic crisis and resource limitations have led to medication shortages, restricted access to essential services, and increased dependence on informal support networks (Kumar, 2019; Weerakoon et al., 2024). Within this context, Buddhist concepts such as karma and impermanence often influence how individuals interpret illness and suffering, offering both comfort and a sense of resignation.

In contrast, Poland's universal healthcare system ensures broad access to dialysis and transplantation (Rój, 2020; Dębska-Ślizień et al., 2021), yet patients still face psychological distress and emotional isolation (Ćwiek et al., 2017). Polish cultural traditions, shaped by Catholic values and an emphasis on individual responsibility, foster different coping strategies—often centering on endurance, autonomy, and personal strength.

By comparing these two contexts, the study aims to uncover how sociocultural values and healthcare structures interact to shape the psychosocial well-being of individuals and caregivers living with ESKD. The findings contribute to the development of culturally sensitive approaches to chronic illness care and psychosocial support.

Methods

Design

This study employed a qualitative design as part of a broader mixed-method project investigating the psychosocial well-being of patients with ESKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland. Written informed consent was obtained from all participants after providing detailed study information. Semi-structured interviews were conducted in hemodialysis units in Sri Lanka (October 2022) and Poland (October 2023–May 2024). One Polish caregiver interview was conducted online due to logistical constraints. Trained researchers in both countries conducted interviews, ensuring ethical conduct, debriefing, and psychological support when needed.

Participants

A purposive sampling approach was used to recruit participants aligned with the study objectives (Palinkas et al., 2015; Bulathwatta et al., 2023). The final sample included 18 patients (10 Sri Lanka, 8 Poland) and 9 caregivers (5 Sri Lanka, 4 Poland). Participants were selected based on nationality and religion to ensure cultural homogeneity: Sinhala Buddhist for Sri Lanka and Polish Catholic for Poland. Patients were diagnosed with Stage 5 CKD (ESKD), undergoing hemodialysis for more than six months, aged 18–84 years. Caregivers were identified by patients as significant supporters and were aged 18 or older. Participants who did not meet inclusion criteria, declined consent, or lacked capacity were excluded.

Data Collection

Semi-structured interview guides were developed for patients and caregivers, covering experiences, emotions, relationships, social support, and medical care. Interviews lasted 35–60 minutes, with field notes taken. All interviews were audio-recorded, transcribed verbatim in Sinhala or Polish, and translated into English. Translations were verified via back-translation and independent review to ensure cultural and linguistic accuracy. Member checking was conducted to confirm transcript fidelity. Triangulation of interviews, field notes, member checking, and independent analyses by multiple researchers enhanced trustworthiness.

Data Analysis

An inductive conventional content analysis approach was employed to identify patterns, categories, and overarching themes in the data (Joffe et al., 2004; Hsieh & Shannon, 2005). Researchers independently coded transcripts developed subcategories and categories, and refined themes collaboratively. Triangulation, analytic notes, and team discussions ensured credibility and reliability. Key findings were visualized using thematic maps and country-specific conceptual models (Figure 3).

Results

Participant Characteristics

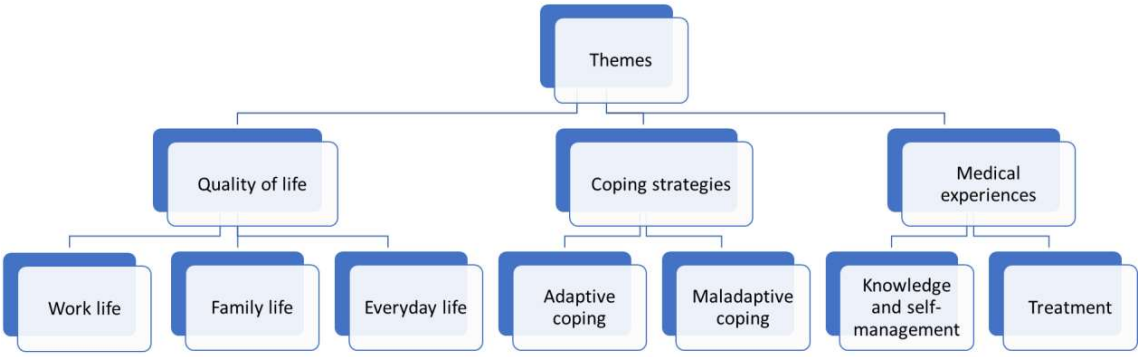
The study included 15 participants from Sri Lanka (53% female, 47% male; mean age 48 years) and 12 participants from Poland (75% female, 25% male; mean age 29 years). Participants included both patients with ESKD and their caregivers, representing the targeted cultural and religious backgrounds: Sinhala Buddhists in Sri Lanka and Polish Catholics in Poland.

Identified Themes

Three major themes emerged across both countries, illustrating the complex psychosocial experiences of patients and caregivers: quality of life, coping strategies, and medical experiences. These themes appeared to be interconnected, highlighting the complex interplay of factors affecting participants' experiences and summarized in the thematic map (Figure 2). Cultural context influenced these experiences, with the "Power of Tradition" shaping the Sri Lankan participants' experiences, while the "Power of (my)self" was predominant among Polish participants (Figure 3).

Figure 2

Thematic Map Illustrating the Main Themes, Categories, and Subcategories



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Theme 1: Quality of Life

Quality of life was shaped by four categories: financial hardship, work life, family life, and everyday life.

- Financial hardship was more pronounced among Sri Lankan participants, reflecting economic crisis, out-of-pocket healthcare costs, and travel difficulties for dialysis.

Polish participants experienced more variable financial consequences, with some reporting strain and others relative stability.

- Work life was affected in both samples, including resignations, part-time or remote work arrangements to accommodate treatment, and adjustments due to caregiving responsibilities.
- Family life was central to participants' support systems in both countries, providing practical and emotional assistance.
- Everyday life challenges included dietary restrictions, social isolation, and reduced social participation, particularly among Sri Lankan participants due to structural barriers and limited resources.

Theme 2: Coping Strategies

Participants employed adaptive and maladaptive strategies to manage disease-related challenges.

- Adaptive coping included family cohesion, social support, religious/cultural practices (Sri Lanka), positive thinking, goal setting, and knowledge-seeking (Poland).
- Maladaptive coping involved helplessness, hopelessness, withdrawal, mistrust, and social isolation, affecting participants' ability to manage illness effectively.

Theme 3: Medical Experiences

Medical experiences encompassed knowledge of the disease, self-management, and attitude towards the treatment process.

- Knowledge and self-management: Sri Lankan participants reported limited understanding of ESKD, whereas Polish participants actively sought information and engaged in self-care practices.
- Treatment : Sri Lankan participants highlighted infrastructural challenges, medication shortages, and long travel for dialysis, while Polish participants reported high satisfaction with accessible, individualized healthcare services.

Figure 3

Mutual Relationships among the Three Themes under the Influence of the "Power of Tradition" (Sri Lanka) and the "Power of (My) Self" (Poland).

Discussion

This study provides a cross-cultural comparison of the psychosocial experiences and treatment processes of patients with ESKD and their caregivers in Sri Lanka and Poland. The findings highlight three interrelated themes-quality of life, coping strategies, and medical experiences-shaped by cultural, economic, and healthcare contexts. Participants in both countries reported significant physical, psychological, and financial burdens due to ESKD. While Polish participants generally benefited from systemic healthcare support and financial stability, Sri

Lankan participants faced widespread economic challenges compounded by resource limitations and the ongoing economic crisis (Bulathwatta et al., 2023; Senanayake et al., 2018; Ziętalewicz & Bargiel-Matusiewicz, 2024). Despite these differences, family support emerged as a universal factor fostering resilience across contexts.

Cultural context strongly influenced coping strategies. Polish participants emphasized autonomy, goal-setting, and cognitive reframing, reflecting individualistic cultural values, whereas Sri Lankan participants relied on communal support, religious rituals, and traditional values consistent with collectivist societal norms (Bulathwatta et al., 2023; Maguire et al., 2021; Fischer & Grønning, 2021). Importantly, both samples also described maladaptive coping responses, such as hopelessness, withdrawal, and symptoms of depression, highlighting the universal need for psychosocial interventions to support both patients and caregivers.

Medical experiences revealed disparities in healthcare accessibility and quality. Polish participants reported satisfaction with individualized care within a well-structured healthcare system, whereas Sri Lankan participants encountered infrastructural challenges, long travel distances for dialysis, and medication shortages (Bulathwatta et al., 2023; Boonstra et al., 2022). These findings underscore the importance of culturally and contextually sensitive strategies that address local resource constraints while enhancing patient and caregiver support.

The study further conceptualizes two frameworks influencing psychosocial wellbeing: the "Power of (My)Self" in Poland, emphasizing resilience and self-reliance, and the "Power of Tradition" in Sri Lanka, highlighting communal and spiritual influences. These models demonstrate how cultural, spiritual, and psychological factors interact to shape coping and overall wellbeing (Bulathwatta et al., 2023; Eloia et al., 2021; Siqueira et al., 2019).

Overall, the study emphasizes the need for culturally tailored interventions that integrate local values, address healthcare disparities, and foster both individual and communal coping

strategies. Its findings provide actionable insights for patient-centered care, psychosocial support, and health policy, particularly in resource-limited settings, while contributing to a global understanding of culturally sensitive ESKD management.

Author Contributions

Darshika Thejani Bulathwatta: 40% (study conceptualization, data curation, study design, data collection, qualitative analysis, and manuscript drafting)

Agata Rudnik: 20% (study conceptualization, data curation, study design, qualitative analysis, manuscript drafting, and revision)

Judyta Borchet: 5% (data collection)

Sonia Żelechowska: 12% (data collection, qualitative analysis)

Małgorzata Treppner: 9% (qualitative analysis)

Jakub Ruszkowski: 5% (data collection, manuscript revision)

Agnieszka Zakrzewska: 1% (data collection)

Alicja M. Dębska-Ślizień:1% (data collection)

Bogdan Biedunkiewicz: 1% (data collection)

Leszek Tylicki: 1% (data collection)

Mariola Bidzan: 5% (study conceptualization and design, data collection, manuscript revision, supervision, and mentorship)

Quantitative Study (To Be Published)

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Introduction

Beyond its physiological impact, end-stage kidney disease (ESKD) imposes considerable psychosocial burdens, affecting emotional well-being, social functioning, and overall quality of life. While these effects have been explored within single-country contexts, cross-cultural differences in healthcare systems, social support structures, and cultural beliefs may shape patients' psychosocial outcomes in distinct ways.

This study investigates the psychosocial well-being of individuals with ESKD undergoing hemodialysis in Sri Lanka and Poland. Specifically, it examines the association between key social and medical factors and psychosocial well-being, as well as cross-country differences in health-related quality of life, depression, and illness acceptance. By integrating medical and social variables within a cross-cultural framework, the study aims to provide insights that inform contextually appropriate strategies to enhance the psychosocial care of individuals living with ESKD in diverse healthcare settings.

Methods

Study Design

This quantitative study is part of a broader mixed-methods project examining psychosocial well-being among individuals with ESKD undergoing hemodialysis in Sri Lanka and Poland. A cross-sectional design was employed, using standardized questionnaires and medical records to assess health-related quality of life (HRQoL), depression, and illness acceptance. This approach facilitated structured data collection, group comparisons, and assessment of social and medical factors associated with psychosocial well-being.

Study Setting

Data were collected from two purposively selected hemodialysis units: the District Teaching Hospital in Kandy, Sri Lanka, and the University Clinical Center of the Medical University of Gdańsk, Poland. Kandy was selected for its central location and access to patients from across Sri Lanka, while Gdańsk was chosen as an urban, well-connected setting within a tertiary healthcare institution.

Participants

Participants were recruited through purposive sampling to ensure comparable age and gender distributions between countries. Inclusion criteria were age over 18, diagnosed with CKD stage G5D, undergoing hemodialysis, and of Sinhalese (Sri Lanka) or Polish (Poland) nationality. A total of 93 participants were included (N = 50 in Sri Lanka; N = 43 in Poland). Participants provided informed consent and were assigned unique identifiers to ensure anonymity. Ethical approval was obtained from the Open University of Sri Lanka and the University of Gdańsk.

Data Collection

Participants completed validated instruments, including the Kidney Disease Quality of Life–Short Form (KDQOL-SF 1.3), Beck Depression Inventory (BDI), and Acceptance of Illness Scale (AIS) to measure HRQoL, depression, and illness acceptance. Sociodemographic data (age, gender, education, marital status, occupation, religion) were collected via survey. Medical information was obtained from two sources: self-reports (time since CKD diagnosis, diabetes, hypertension) and hospital records (hemoglobin levels, dialysis adequacy as Kt/V). In Sri Lanka, questionnaires were administered by the principal investigator, while in Poland, unit staff assisted due to language-related and organizational considerations.

Data Analysis

All analyses were conducted using SPSS Version 29. Group differences were assessed with independent sample t-tests, Mann–Whitney U tests, chi-square, or Fisher's exact tests, with $p<0.05$ considered statistically significant. Effect sizes were calculated using Cohen's d. Equity-relevant factors, including nationality, age, gender, education, occupation, marital status, and religion, were considered following the PROGRESS-Plus framework.

Results

Study Group Description

A total of 93 individuals with ESKD undergoing hemodialysis were recruited, including 50 participants from Sri Lanka (Sinhalese) and 43 from Poland (Polish). The Sri Lankan sample consisted mostly of men (n = 34) and women (n = 16), aged 24 to 75 years (M = 51.08, SD = 10.99). The Polish sample was more gender-balanced (male n = 22; female n = 18; 3 participants did not report gender), aged 27 to 88 years (M = 54.21, SD = 14.07). Time since CKD diagnosis ranged from 6 to 169 months in Sri Lanka (M = 37.90, SD = 37.60) and less

than a month to 30 years in Poland (M = 102.16, SD = 123.03). Further participant characteristics are presented in Table 2.

Table 2

Sample Characteristics (N= 93)

Variable		Sinhala (N = 50)	Polish (N = 43)	*P* value
Gender	Man, n (%)	34 (68)	22 (55)	0.296 (chi-sq 2 x 2)
	Woman, n (%)	16 (32)	18 (45)	
	Not reported, n	0	3	
Age	Mean (SD)	51.08 (10.99)	53.23 (14.78)	0.490 (U Mann-Whitney)
	Not reported	0	4	
Education	Primary, n (%)	6 (12.0)	3 (7.7)	**<0.001** (Fisher 4x2)
	Junior secondary, n (%)	28 (56.0)	6 (15.4)	
	Senior secondary, n (%)	15 (30.0)	17 (43.6)	
	Collegiate & tertiary, n (%)	1 (2.0)	13 (33.3)	
	Not reported	0	4	
Occupational status	Employed, n (%)	19 (38.0)	23 (76.7)	**0.022** (chi-sq 2 x 2)
	Unemployed, n (%)	31 (62.0)	7 (23.2)	
	Not reported, n	0	13	
Marital status	Married, n (%)	39 (81.3)	20 (48.8)	**<0.001** (Fisher 5x2)
	Single, n (%)	9 (18.8)	7 (17.1)	
	Informal relationship, n (%)	0	6 (14.6)	
	Widowed, n (%)	0	4 (9.8)	
	Divorced, n (%)	0	4 (9.8)	
	Not reported	2	2	
Religion	Buddhist, n (%)	50 (100.0)	0	<0.001 (Fisher 6x2)
	Christian (not specified), n (%)	0	3 (15%)	
	Catholic, n (%)	0	13 (30.2%)	
	Atheist, n (%)	0	1 (5%)	
	Muslim, n (%)	0	1 (5%)	
	Jehowah's witness, n (%)	0	2 (10%)	
	missing data	0	23	
Diabetes	Present, n (%)	32 (64.0)	14 (37.8)	0.028 (chi-sq 2 x 2)
	Not reported, n	0	6	
Hypertension	Present, n (%)	43 (86.0)	27 (75%)	

	Not reported, n	0	7	0.311 (chi-sq 2 x 2)
Cardiovascular disease	Present, n (%)	4 (8.0)	16 (45.7)	<0.001 (chi-sq 2 x 2)
	Not reported, n	0	8	
Time since CKD diagnosis	Mean (SD), months	37.90 (37.60)	102.12 (123.03)	0.504 (U Mann-Whitney)
	Not reported	0	10	
Haemoglobin level	Mean (SD), g/dL	9.1 (1.3)	10.7 (0.7)	<0.001 (U Mann-Whitney)
	Not reported	33	26	
Kt/V	Mean (SD)	1.64 (0.31)	1.61 (0.25)	0.480 (U Mann-Whitney)

Note: *Kt/V* = hemodialysis treatment adequacy

Social and Medical Factors

Social factors differed significantly between groups, with disparities observed in education, marital status, religion ($p < 0.001$), and occupational status ($p = 0.02$). Age and gender were similar between groups due to the matching sampling approach. Medical factors were largely comparable, including time since CKD diagnosis ($p = 0.50$), self-reported hypertension ($p = 0.31$), and dialysis adequacy (Kt/V; $p = 0.48$). However, Polish participants had higher prevalence of diabetes ($p < 0.05$), cardiovascular disease ($p < 0.001$), and higher hemoglobin levels ($p < 0.001$), reflecting differences in healthcare access.

Psychosocial Well-Being

Comparison of psychosocial outcomes indicated that Sri Lankan patients reported lower HRQoL in positive domains, including social support, patient satisfaction, emotional well-being, social functioning, and general health perceptions (Cohen's $d > 0.8$). They also reported higher levels of depression, role limitations, pain, and fatigue ($d > 0.8$), indicating a greater burden in negative domains. Moderate differences were observed for burden of kidney disease, quality of social interactions ($d > 0.5$), and sexual function ($d > 0.5$). No significant differences were found for symptom levels, daily life impact, sleep, physical and cognitive functioning, work status, dialysis staff encouragement, or illness acceptance ($p > 0.05$).

Overall, both groups showed similar levels of illness acceptance, but Sri Lankan patients experienced a higher burden of disease, more pain, greater role limitations, higher depression, and lower social support and functioning. This suggests lower overall psychosocial well-being among Sri Lankan patients compared to their Polish counterparts. These results are summarized in Table 3.

Table 3

Psychosocial well-being among Sri Lankan (SL) and Polish (PL) ESKD Patients

Parameters	Subsample (n)	M	SD	t/Z value	p-value	effect size (Cohen's d)
KDQOL symptom	SL (50)	69,50	14,76	-,257	,798	-,053
	PL (43)	70,44	20,57			
KDQOL effect of kidney disease on daily life	SL (50)	53,19	12,41	-,858	,393	-,180
	PL (42)	56,65	25,16			
KDQOL burden of kidney disease	SL (50)	25,00	19,19	-3,538	<,001***	*-,736*
	PL (43)	43,12	29,74			
KDQOL work status	SL (50)	18,00	33,14	-1,782	,078	-,371
	PL (43)	31,40	39,37			
KDQOL cognitive function	SL (50)	71,60	16,21	-,538	,592	-,113
	PL (41)	73,98	25,73			
KDQOL quality of social interactions	SL (50)	57,33	16,82	-2,842	,006*	*-,616*
	PL (41)	69,43	22,61			
KDQOL sexual function	SL (46)	70,38	30,32	2,742	,008*	*,626*
	PL (33)	49,24	38,14			
KDQOL sleep	SL (50)	42,53	14,59	-1,043	,300	-,220
	PL (43)	46,03	17,42			
KDQOL social support	SL (50)	55,33	22,45	-4,474	<,001***	**-,935**
	PL (42)	76,19	22,13			
KDQOL dialysis staff encouragement	SL (50)	67,25	16,34	-1,704	,093	-,368

	PL (41)	74,09	20,99			
KDQOL patient satisfaction	SL (50)	4,02	0,65	-6,342	<,001***	**-1,336**
	PL (41)	5,32	1,25			
SF36 physical functioning	SL (50)	44,20	15,82	-1,723	,088	-,358
	PL (43)	52,67	30,32			
SF36_role limitations caused by physical problems	SL (50)	1,50	10,61	-5,891	<,001***	**-1,241**
	PL (41)	38,21	42,53			
SF36 pain	SL (50)	39,21	18,40	-4,418	<,001***	**-,925**
	PL (42)	62,14	30,76			
SF36 general health perceptions	SL (50)	18,90	10,51	-5,366	<,001***	**-1,116**
	PL (43)	36,52	20,28			
SF36 emotional wellbeing	SL (50)	37,44	19,37	-7,093	<,001***	**-1,482**
	PL (43)	66,98	20,57			
SF36 role limitations caused by emotional problems	SL (50)	11,39	26,58	-8,884	<,001***	**-1,872**
	PL (41)	72,36	38,66			
SF36 social function	SL (50)	36,50	15,74	-4,848	<,001***	**-1,015**
	PL (42)	61,01	31,38			
SF36 energy or fatigue	SL (50)	31,40	16,78	-4,580	<,001***	**-,953**
	PL (43)	50,81	23,90			
BDI	SL (49)	18,04	6,26	4,079	<,001***	**,852**
	PL (43)	11,56	8,89			
AIS	SL (33)	22,85	3,73	-1,296	,199	-,301
	PL (42)	24,81	8,03			

Note: Kidney Disease Quality of Life = KDQOL-SF, Beck Depression Inventory = BDI, Acceptance of Illness Scale = AIS; t = t-test value, Z = Z test value, *p<0.05; **p=0.01; ***p<0.001

Discussion

The quantitative findings reveal both universal and culture-specific psychosocial impacts of ESKD among Sri Lankan and Polish participants. Common challenges included illness acceptance, symptom burden, physical and cognitive difficulties, sleep problems, and the effect of CKD on daily life, consistent with global data on CKD patients (Fletcher et al., 2022; Senanayake et al., 2017; Gunarathne et al., 2022).

Illness acceptance did not differ significantly between groups, suggesting a potentially universal coping response to life-threatening illness (Felton et al., 1984). However, cultural beliefs, particularly Theravāda Buddhism in Sri Lanka, may shape how acceptance is understood and expressed. For example, illness may be interpreted through a karmic framework, and suffering may be viewed as inevitable, which may support psychological adjustment without necessarily translating into improved quality of life (Silva, 2011; Obeyesekere, 1985; Ananda & Ali, 2022).

Significant differences emerged in psychosocial outcomes. Sinhalese participants reported higher depression, greater role limitations, more pain, and weaker social support, reflecting both systemic healthcare limitations and cultural factors (Karran et al., 2023; Wanigasuriya, 2019; Senanayake et al., 2018). In contrast, Polish patients experienced better emotional well-being, social functioning, and general health perceptions, which may be associated with greater access to healthcare resources, stronger institutional support, and rehabilitation services (Kubanek et al., 2024; Senanayake, 2018). Nevertheless, some domains, such as sexual function, were lower among Polish patients, possibly due to co-morbidities, treatment burden, and culturally shaped barriers to discussing sexuality in more conservative settings (Izdebski et al., 2022; Szelewa, 2021).

The study highlights the role of social determinants and systemic inequities in shaping psychosocial outcomes. Rural residence, limited health literacy, financial constraints, and cultural misconceptions contributed to the higher psychosocial burden among Sri Lankan patients (Liyanage, 2022; Bulathwatta et al., 2024b; O'Neill et al., 2014; De Maio, 2015). These findings underline the need for culturally sensitive interventions, integration of psychological support, and educational initiatives to address stigma, enhance coping, and improve overall psychosocial well-being in CKD care.

Strengths of this study include its cross-cultural design, providing comparative insights into how cultural, social, and healthcare factors influence psychosocial well-being. Limitations include the small sample size, cross-sectional design, and reliance on self-reported data, which may introduce cultural bias and limit generalizability.

In conclusion, while some aspects of psychosocial burden are universal, Sinhalese patients experience higher depression and weaker social support than Polish patients, highlighting the need for systemic and culturally tailored interventions to reduce inequities and improve psychosocial care for ESKD patients (Barsoum, 2006; Izdebski et al., 2022; Szelewa, 2021; Bulathwatta et al., 2024a).

Author Contributions

Darshika Thejani Bulathwatta: 60% (study conceptualization, study design, data collection, analysis, and manuscript drafting)

Judyta Borchet: 15% (study design, statistical analysis, and manuscript revision)

Agata Rudnik: 10% (manuscript revision)

Jakub Ruszkowski: 5% (data collection, manuscript revision)

Agnieszka Zakrzewska: 1% (data collection)

Alicja M. Dębska-Ślizień: 1% (data collection)

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Mariola Bidzan: 5% (study conceptualization and design, data collection, manuscript revision, supervision, and mentorship)

Discussion and Summary of own Research

General Discussion

This doctoral project examined the psychosocial well-being of individuals with CKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland through a mixed-methods design integrating a scoping review, qualitative investigations, and a quantitative comparison. Together, these studies offered a multidimensional understanding of how culture, healthcare systems, and social structures shape the lived experience and emotional adaptation of patients and their caregivers.

The project revealed both universal and culture-specific dimensions of psychosocial well-being. Across contexts, patients experienced fatigue, pain, sleep difficulties, depressive symptoms, and functional limitations, reflecting a global pattern of emotional and physical burden among individuals with ESKD (Fletcher et al., 2022; Senanayake et al., 2017; Gunarathne et al., 2022). However, clear cultural contrasts emerged. Sri Lankan-Sinhalese participants, embedded in a collectivist society guided by Buddhist and traditional values, relied heavily on religious and communal coping but reported higher depression, weaker social support, and lower quality of life than Polish participants (Karran et al., 2023; Wanigasuriya, 2019; Senanayake et al., 2018). In contrast, Polish participants demonstrated stronger autonomy-based coping and emotional well-being, benefitting from a structured healthcare system and psychosocial rehabilitation (Kubanek et al., 2024; Senanayake, 2018).

The findings also confirm that illness acceptance may represent a universal coping response, although its meaning appears to differ across cultural contexts. For Sinhalese participants, acceptance reflected spiritual resignation linked to karma and impermanence (Silva, 2011; Obeyesekere, 1985; Ananda & Ali, 2022) whereas for Polish patients it was often associated with realistic adjustment and active management of illness. Synthesizing evidence across the

included studies supports the conceptual distinction between two overarching frameworks: the "Power of (My)Self" (autonomy-driven resilience in Poland) and the "Power of Tradition" (community and spirituality in Sri Lanka. These frameworks help explain how sociocultural values shape emotion regulation, coping strategies, and patterns of help-seeking across settings.

Table 4

Collective Characteristics of Publications Included in the Doctoral Cycle

Publication number	Study type	Study group/Sample	Aim	Design and tools used	Key findings	Main conclusion
1	Protocol	Not applicable	To design and outline the mixed-method project on psychosocial well-being of individuals with CKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland	Conceptual paper describing research rationale, ethics, and mixed-method design.	Established methodological and ethical framework for subsequent empirical studies.	Provided structured foundation and ensured methodological coherence across qualitative and quantitative phases.
2	Scoping literature review	Literature on chronic diseases (global)	To explore cross-cultural differences in shame and guilt among individuals with chronic diseases.	Scoping review guided by Arksey and O'Malley (2005) framework	Identified cultural differences in emotional responses to chronic disease—shame in collectivist, guilt in individualist cultures	Highlighted the need for culturally sensitive psychosocial approaches in chronic disease management.
3	Qualitative Study 1	Sri Lankan CKD patients and caregivers	to delve into the psychosocial experiences and treatment journeys of individuals diagnosed with CKD and their caregivers.	An exploratory Qualitative design was employed, utilizing semi structured interviews	Three interrelated main themes emerged: (1) Impact on Standard of Living (Quality of Life), (2) Coping Strategies, and (3) Medical Experience, with a strong influence of traditional beliefs and practices	Conclusion: Highlights the need for holistic CKD care integrating physical, emotional, and social aspects while addressing traditional influences.
4	Qualitative Study 2	Sri Lankan and Polish CKD	To explore the psychosocial	An exploratory qualitative	Three themes—quality of life, coping, and medical	The study underscores the importance of culturally informed

		patients and caregivers	experiences and treatment processes of individuals with ESKD and their caregivers in Sri Lanka and Poland, focusing on cultural, systemic, and personal influences on wellbeing.	design was employed, utilizing semi structured interviews	experiences—emerged. Polish participants relied on individual resilience ("Power of Self"), while Sri Lankans depended on cultural and communal coping ("Power of Tradition"); resource gaps and emotional struggles varied between contexts	care, suggesting that interventions should acknowledge and integrate both autonomy-based and tradition-based coping styles to meet diverse psychosocial needs in ESKD management.
5	Quantitative Study	Sri Lankan and Polish CKD patients undergoing hemodialysis	To examine the psychosocial well-being of individuals with ESKD in Sri Lanka and Poland, exploring how cultural differences may influence their psychological experiences and quality of life.	Cross-sectional survey; validated psychometric instruments; KDQOL, BDI and AIS	CKD symptoms, sleep problems, cognitive difficulties, and overall burden were common to both groups. However, Sri Lankan participants reported higher depression, lower social quality of life, and weaker social support than Polish participants.	Cultural context strongly shapes psychosocial experiences in ESKD, underscoring the need for culturally sensitive interventions to enhance psychosocial support and quality of life.

Integration of Study Components

The scoping review provided an empirical foundation by mapping cultural variations in shame and guilt across chronic illnesses. It showed that guilt in individualistic societies can promote self-regulated behavior and health-seeking, whereas shame in collectivist cultures often leads to withdrawal and concealment (Bulathwatta et al., 2024a). These insights framed the later empirical investigations by identifying emotional constructs relevant to understanding psychosocial adaptation in CKD (Bulathwatta et al., 2024b; Bulathwatta et al., 2025).

The qualitative studies expanded on these concepts within the lived realities of patients and caregivers. Study 1 (Sri Lanka) exposed the dominance of traditional and religious coping, economic strain, and inadequate health literacy, thereby situating illness experience within broader structural and cultural constraints (Bulathwatta et al., 2024b). Study 2 (Sri Lanka and Poland) illustrated how contrasting healthcare infrastructures and cultural worldviews produce divergent psychosocial pathways- self-reliance versus communal reliance-while also reflecting universal emotional struggles shared across both contexts (Bulathwatta et al., 2025).

Finally, the quantitative study statistically supported several qualitative observations, demonstrating significant cross-cultural differences in depression, pain, role limitations, and social support while confirming comparable illness acceptance levels across groups. Together, these findings establish a coherent mixed-method narrative linking structural inequities, cultural meaning systems, and individual adaptation.

Strengths and Limitations

This project's principal strength lies in its cross-cultural, mixed-method triangulation, allowing a comprehensive understanding of psychosocial well-being in ESKD across two culturally distinct populations. The use of both qualitative narratives and quantitative measures enabled

deep contextual insight and cross-validation of findings across methodological approaches. This integration strengthened the overall interpretation by capturing both culturally specific and universally shared psychosocial experiences.

However, several limitations should be acknowledged. First, modest sample sizes in both countries may limit statistical power and the generalizability of the findings. Second, since self-report measures formed a core component of the study, cultural response bias may have influenced participants' answers, particularly given different norms regarding emotional expression across settings. Third, the Sri Lankan sample consisted exclusively of Sinhala Buddhist participants. Major ethnic and religious groups-such as Tamil, Muslim, and Burgher communities-were not included. This limits the cultural representativeness of the Sri Lankan findings and constrains the extent to which the conclusions can be generalized to the broader Sri Lankan population.

Despite these limitations, the integration of qualitative and quantitative findings across culturally distinct contexts enhances the credibility, depth, and applicability of the conclusions. The triangulated design provides a robust foundation for understanding psychosocial well-being in ESKD and offers valuable insights for the development of culturally sensitive interventions.

Theoretical Implications

The project contributes to psychosocial and cultural health psychology by demonstrating that cultural frameworks shape both emotional regulation and illness representation in chronic disease. The dual concepts of the Power of (My) Self and the Power of Tradition extend existing models of coping by integrating spirituality, collectivism, and self-agency into the understanding of chronic illness management.

These findings also enrich the PROGRESS-Plus framework, emphasizing how socioeconomic status, residence, and culture intersect with psychological processes to determine health outcomes (Karran et al., 2023; Wijewickrama & Herath, 2022). Overall, the results highlight the importance of embedding cultural meaning systems within biopsychosocial models of chronic illness, moving beyond universalist assumptions toward more context-sensitive psychological theory.

Practical Implications

The results point to the need for culturally sensitive psychosocial interventions in kidney care. In collectivist societies such as Sri Lanka, programs should integrate community-based mental health services, religious leaders, and family networks to address stigma and improve engagement. Psychological interventions could draw on Buddhist practices like mindfulness and compassion while promoting accurate illness education to counter misconceptions about karma and destiny.

In contrast, for contexts such as Poland, strengthening self-efficacy, autonomy, and goal setting within rehabilitation programs may enhance emotional adaptation. Across both contexts, embedding psychological screening and counseling within dialysis units, expanding social support systems, and ensuring equitable healthcare access are key strategies for improving patients' quality of life.

Implications for Future Research

Future investigations should pursue longitudinal, mixed-method, and intervention-based designs to examine how psychosocial adaptation evolves over time and across treatment modalities. Comparative work including other ethnic groups in Sri Lanka could clarify the role of religion and social class in coping and illness perception. Further, cross-cultural studies

could test the proposed Power of (my) Self, Power of Tradition model empirically across broader regions to evaluate its generalizability.

Research integrating caregiver perspectives and exploring the dynamic between patient and family adaptation would also be valuable, as caregiving stress and reciprocal coping emerged as salient themes. Finally, intervention studies assessing the effectiveness of culturally tailored psychoeducational and counseling programs are essential to translate these findings into practice.

Summary of own Research

In summary, this doctoral project demonstrates that while CKD patients worldwide face common physical and emotional burdens, cultural context fundamentally shapes their interpretation, coping, and psychosocial outcomes. The Sri Lankan-Sinhalese sample embodied collective resilience grounded in tradition yet burdened by structural inequities and stigma, whereas Polish participants exhibited autonomy-oriented coping supported by systemic healthcare and psychosocial services.

The synthesis across studies reveals that psychosocial well-being in chronic illness is neither purely medical nor purely cultural but arises from the interplay of biological, psychological, social, and cultural dimensions. By articulating this interplay, the thesis advances a culturally responsive framework for understanding chronic illness and provides actionable directions for both theory and practice in health psychology.

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Psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis treatment and their caregivers: a protocol of a mixed method study in Sri Lanka and Poland

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Chronic Kidney Disease (CKD) can be identified as one of the non-communicable diseases (NCDs) which affect millions of people worldwide, including in Sri Lanka and Poland. The prevalence of CKD has been rising over the last three decades due to the identification of CKD with unknown etiology and the increment of NCDs such as hypertension and diabetes mellitus among the Sri Lankan population, Poland can be identified as a European country that has 4 million patients with CKD, which is the second most common chronic disease in the country. CKD is associated with the physical, economic, psychological, and social burden on patients and their caregivers. The current study is aimed to investigate the psychosocial well-being of CKD patients and their caregivers in Sri Lanka and Poland. The current study is a mixed-method study aimed to investigate the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis and their caregivers in Sri Lanka and Poland. Participants in the quantitative part of the project will be individuals with chronic kidney disease undergoing hemodialysis from Sri Lanka ($n = 63$) and Poland ($n = 63$) who are currently undergoing hemodialysis treatment. Kidney Disease Quality of Life-Sort Form, Beck Depression Scale, Test of Self-Conscious Affect, The Courtauld Emotional Control Scale, Acceptance of Illness Scale, and a demographic and medical information sheet will be used in both Sri Lankan and Polish samples. Apart from that, the qualitative phase of the study will involve semi-structured interviews with individuals diagnosed with CKD, selected randomly from the initial part of the research, and their close relatives. Notably, the participant count will remain undetermined, as this approach addresses the inherent challenges of exploratory research.

KEYWORDS

chronic kidney disease, psychosocial well-being, shame and guilt-proneness, emotional suppression, acceptance of illness, caregivers, mixed-method study

1 Introduction and the background to the study

Chronic Kidney Disease (CKD) can be identified as one of the non-communicable diseases (NCDs) which affect millions of people worldwide, including in Sri Lanka and Poland, every year (Lameire et al., 2021; Adoli et al., 2022). The prevalence of CKD has been rising over the last three decades, especially among Sri Lankan farming communities, due to the identifying CKD with unknown etiology (CKDu) and the increment of NCDs such as hypertension and diabetes mellitus (Rajapakse et al., 2016; Kumaresan and Senawirathne, 2017; Katle et al., 2019). Although the definition and the classification have evolved over time, according to international guidelines, CKD is a condition that can decrease kidney function as measured by glomerular filtration rate (GFR) of less than 60Ml/min per 1.73m^2, or markers of kidney damage, or both and this condition needs to last for at least 3 months regardless of the underlying cause (Webster et al., 2017). Furthermore, hypertension and diabetes are the leading causes of CKD and their incidence is increasing at an alarming rate (Hernandez and Nasri, 2013; Kovesdy, 2021).

CKD is a progressive disease that does not have any warning signs. Sometimes people lose up to 90% of their kidney function before getting any symptoms, and they progress to a state that can be called end-stage kidney disease (ESKD)/end-stage renal disease (ESRD), or end-stage kidney failure (Vithange et al., 2021). According to the proposed criteria of the National Kidney Foundation (2002), CKD is divided into five stages based on the function of the individual's kidneys, and conservative treatment is recommended until the disease reaches its fourth stage (Andrade and Sesso, 2012). However, as a consequence of the disease reaching the fifth stage (ESRD), people need artificial filtering or a kidney transplant. There are two types of artificial filtering which are called peritoneal dialysis (PD) and hemodialysis (HD). However, HD can be identified as the most frequent treatment modality in the world (Gerogianni and Babatsikou, 2014a, b; Odette Dorcas et al., 2018). HD is a treatment method in which the patient is connected to a machine that takes over the function of the damaged kidneys. This treatment method is inconvenient as the procedure is time-consuming and needs to be performed frequently - often lasts several hours and must be performed at least three times a week. Moreover, patients need to restrict their fluid intake (Lindsay et al., 2014). Hemodialysis patients' lives are challenging not only due to the long-term nature of their diseases but also because of the nature of the treatment they are undergoing. According to a study on hemodialysis patients, the quality of life of hemodialysis patients was poor and even though hemodialysis increases patients' lifespan, it has serious physical, psychological, and social implications that impact their quality of life and their families (de Assis et al., 2018). Hence, ESRD can be identified as a multi-dynamic health hazard as it affects significantly their family, education, financial and professional status, physical and social functioning, and mental health (Gerogianni and Babatsikou, 2014a, b).

CKD is increasing worldwide at an annual growth rate of 8% (Senanayake et al., 2017; Senanayake, 2018) and is ranked among the top 20 causes of death according to the Global Burden of Diseases (Adejumo et al., 2019). Furthermore, complications of CKD include anemia, bone disease, and increased risk of cardiovascular disease and cancer (Webster et al., 2017). Moreover, due to economically non-viable treatment methods, there is expected to be an increase of 70% in ESRD among patients in developing countries (Gunathilaka et al., 2014). Abraham et al. (2015) stated the effect of ethnicity on CKD development. According to them, the prevalence of CKD is lower in whites than in Asians. Furthermore, they have identified South Asia as a "hotspot" for developing ESRD due to a lack of managing patient registries, poor access to health care, and limited opportunities for early detection and management of the disease. Another study also highlights the high incidence of ESRD among Indo-Asian residents in the United Kingdom. This high incidence of ESRD is in part due to the prevalence of diabetic mellitus, small kidneys, unremarkable urinary sediment, and unknown etiology (Ball, 2001). Similarly, Chandie Shaw et al. (2002) found that Indo-Asian people who are residents in the Netherlands had a 40-fold risk of having ESRD due to type II diabetics compared to the native Dutch population. Moreover, according to the results of a cohort study between British and South Asian infants, South Asian infants have smaller kidneys than British white infants, even after considering potential confounding factors such as birth weight (Roderick et al., 2015).

Psychosocial well-being can be identified as a superordinate construct as it includes emotional or psychological well-being, as well as collective well-being (Eirosa-Orosa, 2020). According to Encyclopedia of the UN Sustainable Development Goals (Kumar, 2020), psychosocial well-being is a multidimensional construct incorporated with the physical, economic, social, mental, emotional, cultural, and spiritual determinants of health. Diener and Diener (1995) pointed out that, subjective well-being, which is comparable to one's quality of life, pertains to both the cognitive evaluation of life satisfaction and the emotional responses experienced by the individual. He has emphasized that personality traits, income levels, and social support play key roles in shaping the well-being of individuals across cultures. Notably, the way people perceive and experience the factors contributing to their well-being can vary between individualistic and collectivist cultures.

The term "quality of life" (QOL) is similar to psychosocial well-being as it involves emotional, social, and physical components (Eirosa-Orosa, 2020). Further, this term is used in healthcare research to measure how an individual's well-being is affected by medical conditions over time. Especially, chronic diseases can reduce the life expectancy or the life quality of individuals (Christensen et al., 2004). QOL is not just an abstract or subjective concept but holds tangible relevance in the context of ESRD patients. It implies that how patients perceive their own well-being and daily functioning has a direct impact on their health outcomes, including the risk of developing complications or even death (Kimmel et al., 1998; Kimmel, 2006). ESRD can affect a patient's health-related quality of life (HRQOL) in many ways. The symptoms, side effects of the medicines, various food and fluid restrictions, limitations related to social life, as well as associated stigma and taboo can negatively affect the well-being of patients with CKD (Senanayake et al., 2020). According to the reports of some patients with advanced CKD, their health-related quality of life was equivalent to those with terminal malignancy (Webster et al., 2017). Ultimately, HRQOL will affect the overall well-being of individuals with chronic kidney disease undergoing hemodialysis.

Therefore, the Kidney Disease Outcomes Quality Initiative (K/DOQI), a leading organization developing standards and guidelines

related to CKD, and the Center for Medicare Services in the United States have identified the importance of health-related quality of life of all patients undergoing dialysis treatment (Senanayake et al., 2020).

Furthermore, the prevalence of mental health conditions are much higher among ESRD patients than among patients with other chronic conditions (Chilcot et al., 2010). Depression has been recognized as the most common psychological problem that causes resistance to treatment and there is a significant association between depression and mortality of dialysis patients (Andrade et al., 2010; Ma and Li, 2016). Moreover, Andrade and Sesso (2012) found that the percentage of depressive symptoms among patients undergoing dialysis is slightly higher compared to patients under conservative treatment of CKD. According to the authors, the disease's physical discomforts and the demands of dialysis treatment can worsen individuals' functional capacity, potentially resulting in unemployment and a lack of monthly income, ultimately leading to depression. However, individuals undergoing conservative treatments face fewer challenges in comparison to those on hemodialysis.

Moreover, caregivers of patients with advanced CKD who are undergoing dialysis play a pivotal role in the coordination of care, such as medication administration, preparation of a special diet, transportation to the hospital for clinical attendance, dialysis, and personal care (Adejumo et al., 2019). Deterioration of family relationships, stress, and social isolation are frequently encountered by CKD caregivers (Brunier and McKeever, 1993). Low et al. (2008) emphasized the importance of promoting the psychological health of close persons of individuals with ESRD to continue to care effectively. Furthermore, they highlighted the lack of studies regarding how health services support close persons of individuals with ESRD and the necessity of further research to explore the relationship between health services and close persons to empower the interventions of individuals with ESRD.

According to Polish statistics, CKD is a major risk factor for cardiovascular disease (Zdrojewski et al., 2016). A study on a Polish sample of CKD hemodialyzed and non-dialyzed patients revealed that there is a higher rate of depression among hemodialyzed patients (Cwiek et al., 2017). Furthermore, this study highlighted the importance of monitoring the mental state of CKD patients and providing timely psychological care. Another study investigated the prevalence of CKD and its relation to the socioeconomic status among the Polish elderly population. The results indicated that CKD is a frequent disease and affects one-third of the Polish elderly population (Chudek et al., 2013). Additionally, CKD is frequently present among urban residents, non-smokers, alcohol abstainers, less physically active people, and less educated women. A comparative study on the quality of life in patients with ESRD and undergoing hemodialysis revealed that their quality of life is low compared to the control group (Dembowska et al., 2022).

Based on the information provided, CKD can be recognized as a worldwide public health threat that has not yet been adequately tackled (McKercher et al., 2013; Wimalawansa, 2015). In developing countries like Sri Lanka, the need to provide not only accessible healthcare for the patients but also mental health support is urgent. According to the report of the International Expert Consultation on Chronic Kidney Disease of unknown etiology in Sri Lanka (World Health Organization, 2016), developing effective interventions for promoting the well-being of CKD patients was highly recommended. Hence, activities aimed at prevention, early detection, treatment, care, surveillance, and social interventions also were recommended. Even though the Sri Lankan government has implemented the recommended activities to a certain extent for 30 years, CKD is still a tragedy for those who are affected. CKD outcomes already overburden the country's health sector, and yet there are indications of cutting back on services such as dialysis and kidney transplant (Liyanage, 2015). According to Ranasinghe and Ranasingha (2015) providing psychosocial support to both individuals with CKD and their family members, increasing the allowances, and effectively using all personnel, ministries, and media support are important to eliminate this health hazard from Sri Lankan society. An ethnographic study by Liyanage (2022), it is crucial to conceptual shift to an ethno-medical model to address CKD in Sri Lanka. The author suggested improving the cultural competency and communication skills of healthcare providers to apply the "bio-psychosocial perspective in the healthcare delivery system to bridge the gap between the community and the hospital. Moreover, although the international human rights regime could successfully address the humanitarian needs of chronic diseases like CKD, the domestic jurisdiction is yet not to be prepared to address this fatal disease (Wijayath, 2019).

In our paper, we emphasized that psychosocial well-being is a multifaceted concept often referred to as quality of life. One of the dimensions of quality of life is health-related quality of life (HRQOL), which specifically pertains to the experiences of individuals dealing with chronic illnesses. Nevertheless, quality of life goes beyond just health-related aspects and encompasses various aspects of daily life, including emotional well-being, marital status, income, housing, cultural background, personal values, spirituality, and overall life satisfaction. Kimmel (2006) pointed out that there is still a lack of clear and adequate methods for evaluating the QOL in individuals with CKD and it is essential to establish a standardized framework that specifically addresses QOL assessment, including aspects like depressive affect, the perception of the burden of illness, and social support. Therefore, this study aims to evaluate the quality of life of individuals with ESRD by comprehensively addressing all the mentioned aspects.

Chronic Kidney Disease (CKD) carries stigma due to factors like the need for dialysis, changes in appearance, functional issues causing pain, feelings of constraint, and sexual challenges (Pedreira Robles and Aguayo-González, 2019). These stigmas can lead to feelings of shame and guilt in individuals with CKD. Although there is research on guilt and shame related to chronic illnesses, no studies have explored shame and guilt connected to chronic conditions across both individualistic and collectivist cultures. Therefore, this study addresses the gap in the research literature. Moreover, cultural beliefs and behaviors influence an individual's perception of disease etiology, illness, treatment, and disease labels (Kleinman et al., 1995; Turner, 1996). Hence, the cultural approach of the patient becomes a significant factor, as it determines the patient's care-seeking behavior, treatment options, choices, and compliance. Therefore, this study will provide an opportunity to understand how cross-cultural beliefs determine the understanding of the disease and expectations toward individuals with CKD and their caregivers.

Learning from the experience of other countries that are undergoing the process of implementing the WHO/UE CKD treatment standards, such as Poland, can inform the practitioners working with CKD patients in Sri Lanka. However, according to the research literature, the importance of providing comprehensive psychosocial support to patients with advanced CKD and with hemodialysis was highlighted regardless of the socioeconomic status of the country. Thus, assessing ESRD patients' psychosocial well-being in these two countries and comparing their healthcare systems might enable them to form recommendations for the Sri Lankan health service.

1.1 Objectives

The study's primary objective is to investigate the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis and their relatives in Sri Lanka and Poland. Its specific objectives are as follows:

1. To compare the psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis in Sri Lanka and Poland.
2. To evaluate medical (having diabetes, having hypertension) and social factors (gender, age, marital status) that might be associated with psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis.
3. To explore how individuals with chronic kidney disease undergoing hemodialysis and their caregivers experience the disease and the process of treatment in Sri Lanka and Poland.
4. To provide guidelines to improve psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis and their caregivers in Sri Lanka.

1.2 Research questions

1. Are there differences In HRQOL, depression, emotional suppression, shame and guilt proneness, and acceptance of illness among individuals with chronic kidney disease undergoing hemodialysis In Sri Lanka and Poland?

2a. Does gender predict variations in HRQOL, depression, emotional suppression, shame and guilt proneness, and acceptance of illness among individuals with chronic kidney disease undergoing hemodialysis?

2b. Does age predict variations in HRQOL, depression, emotional suppression, shame and guilt proneness, and acceptance of illness among individuals with chronic kidney disease undergoing hemodialysis?

2c. Does marital status predict variations in HRQOL, depression, emotional suppression, shame and guilt proneness, and acceptance of illness among individuals with chronic kidney disease undergoing hemodialysis?

2d. Does having diabetes predict variations in HRQOL, depression, emotional suppression, shame and guilt proneness, acceptance of illness among individuals with chronic kidney disease undergoing hemodialysis?

2e. Does having hypertension predict variations in HRQOL, depression, emotional suppression, shame and guilt proneness and acceptance of illness among individuals with chronic kidney disease undergoing hemodialysis?

3a. How do patients with CKD experience the disease and process of treatment?

3b. How do the caregivers of individuals with chronic kidney disease undergoing hemodialysis experience the disease and process of treatment?

We hypothesized that there are differences in psychosocial well-being (operationalized as health-related quality of life, depression, shame and guilt-proneness, emotional suppression, and acceptance of the illness) among individuals with chronic kidney disease undergoing hemodialysis in Sri Lanka and Poland. As CKD affects populations in different regions of the world unequally and as a result of their demographic characteristics, comorbidities, and access to healthcare resources (Kovesdy, 2021), we presume that there will be group differences in psychosocial well-being. Limited research has delved into the notion of acceptance of illness within the context of Chronic Kidney Disease (CKD), despite the considerable focus on other chronic illnesses (Chan, 2013). Notably, the degree of acceptance appears to be more pronounced in recipients of kidney transplants in comparison to individuals undergoing dialysis. Moreover, this acceptance level is linked to factors like age, ethnicity, and even instances of transplant failure (Keogh and Feehally, 1999). Stage (2022) investigated the intricate impact of shame on individuals with chronic conditions, particularly through storytelling. The study revealed that shame is connected to feeling tired and sluggish and shaped by cultural and political factors, which challenges the notion of solely concentrating on personal health enhancement. Moreover, Sharing stories of shame among peers on social media can help alleviate this pressure. Stage concluded that the experience of shame related to chronic conditions is not well-studied, and the study provides a starting point for understanding this topic.

In addition, we assumed that gender, age, marital status, diabetes, and hypertension predict the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis. According to previous studies, the prevalence of CKD is higher among females than males (Kafle et al., 2019; Kovesdy, 2021). Some studies pointed out the gender disparities in the quality of life of CKD patients. Mujais et al. (2009) found that the female gender was a significant predictor of low HRQOL in CKD patients. Similarly, Paraskevi (2011) reported female patients who have ESRD are more depressed than male patients. However, another study confirmed that both male and female patients presented with high levels of depression compared to the control group (Fountoulakis et al., 2001). However, Senanayake et al. (2020) found that gender was not a significant predictor of HRQOL. Kovesdy (2021), mentioned that the prevalence of CKD increased with advancing age. Paraskevi (2011), reported that younger CKD patients have better QOL in physical, psychological, and social well-being and that the older patients are falling behind in social activities and interests, being more socially restricted and depressed.

Concerning marital status, previous studies note it as a protective factor for CKD patients' QOL. Marital status is positively associated with the good quality of life of patients with ESRD (Gerogianni and Babatsikou, 2014a, b). Furthermore, Paraskevi (2011) found that compared to divorced CKD patients, married patients enjoy a better quality of life and are satisfied in their lives. However, according to John and Thomas (2012), intimate relationships and sexual activities among couples are badly affected by ESRD.

Mujais et al. (2009) found that the HRQOL of CKD patients is not only influenced by the stage of the CKD, age, and gender, but also by having diabetes. According to Megari (2013) and Anees et al. (2011) having diabetes and experiencing its complications is directly associated with decreased quality of life. Comparably, Senanayake et al. (2020) reported that the advanced stage of CKD and being diagnosed with depression were significantly associated with low HRQOL. Andrade and Sesso (2012) found that depression was associated with some clinical and sociodemographic variables. However, Andrade et al. (2010) reported that there was no significant difference between the stages of the disease. Last but not least, Soni et al. (2010) highlighted the importance of controlling hypertension for better HRQOL. Thus, we presume that having diabetes and hypertension will predict CKD patients' psychosocial well-being and depression.

2 Methods

2.1 Study design

The project consists of two phases and assumes a mixed-method study design to deeply investigate the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis and their caregivers. Hence, quantitative and qualitative methods will be combined. The quantitative research will evaluate the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis by measuring their HRQOL and levels of depression as psychosocial well-being is a multifaceted concept. The qualitative study will focus experiences of individuals with chronic kidney disease undergoing hemodialysis and their caregivers to address the areas that cannot be assessed with quantitative study (e.g., thick description of perceptions, knowledge, beliefs, emotions, social, and medical support of individuals with chronic kidney disease undergoing hemodialysis and their caregivers which addresses the psychosocial wellbeing). There are several ways of mixing quantitative and qualitative methods. In this study, qualitative and quantitative data will be collected and analyzed simultaneously. Then the results of both studies will be integrated and discussed in view of the main objective of the study (Adoli et al., 2022). The methodologies of the quantitative and qualitative studies and the strategies for integration of the results will be discussed in the next sections.

The quantitative data (phase 1 of this project) will be collected in a cross-sectional study and analyzed with SPSS 25 software. Regression models and dependent group differences will be tested. The qualitative data (phase 2 of the project) will be collected using semi-structured interviews and analyzed with qualitative content analysis (Table 1).

The project's initial phase aims to enroll a total of a minimum 126 individuals with chronic kidney disease undergoing hemodialysis undergoing dialysis treatment, with at least 63 participants from each country (see for reference Kohn and Senyak, 2021). The selection of this sample size takes into account practical considerations related to the clinical population. Additionally, a matching sampling technique will be employed specifically for the Polish group, which will enhance the study's validity. Although larger sample sizes might be preferred, the chosen number is the most feasible and suitable given the study's objectives and limitations. Sample size bias will be taken into account while processing the data and making conclusions while at the same time, we are mindful of resource limitations and the unique characteristics of our study population.

Randomly selected individuals with chronic kidney disease undergoing hemodialysis who participated in the first phase of the study and their caregivers will participate in the second phase (qualitative part) of the study from each country. However, the specific number of participants for this phase will not be predetermined, as determining the sample size in advance is inherently challenging due to the exploratory nature of this study. The data saturation will determine the sample size.

To achieve the target sample size, participants will be recruited at the hemodialysis units of the hospitals. Once the research proposal receives approval from relevant ethical committees in both countries, the field arrangements will be finalized. Data collection will commence only after obtaining all the necessary permissions and consent of the participants and relevant personnel.

2.2 Study setting

The project will be held in two countries (Poland and Sri Lanka) in two hemodialysis units of the following hospitals based on a purposive sampling design: the Hemodialysis Unit of the District Teaching Hospital, Kandy, Sri Lanka, and the Hemodialysis Unit of The University Clinical Center of the Medical University of Gdańsk, Gdańsk, Poland. Kandy Hospital is planned to choose as the Sri Lankan study location as it lies in the central part of Sri Lanka and patients from different parts of the country can easily access this hospital. Therefore, it is easily accessible for the patients. The University Clinical Center of the Medical University of Gdańsk is planned to participate in the study as this is the only Polish Nephrology Clinic for adults that is part of the European Reference Network for Rare Kidney Diseases.

TABLE 1 Summary of study design.

Phase	Group 1 (Sri Lankan)	Group 2 (Polish)	Method	Instruments	Study design	Data analysis
1	63 patients	63 patients	Quantitative	Kidney Disease Quality of Life-Short Form (KDQOL-SF) Version 1.3 Beck Depression Inventory Test of Self-Conscious Affect (TOSCA-3) Courtauld Emotional Control Scale (CECS) Acceptance of Illness Scale (AIS)	Cross-sectional design	Statistical analysis: regression models, testing differences between two samples (t-test for two independent samples or U Mann–Whitney test)
2	The sample size is not pre-determined beforehand	The sample size is not pre-determined beforehand	Qualitative	Semi-structured interviews	Cross-sectional design	Qualitative content analysis

2.3 Eligibility criteria

The study participants with CKD will be recruited according to the following eligibility criteria:

(1) being a person who is diagnosed with stage V of CKD, as patients whose CKD advancement is from stages I to IV are not undergoing dialysis treatment;
(2) being a person who is undergoing hemodialysis treatment;
(3) being within the age range from 18 to 70 years;
(4) being a person whose CKD treatment has been lasting for more than 6 months as this time duration might bring a significant burden for patients.
(5) the study has also nationality inclusion criteria, which are Sinhala for the Sri Lankan sample and Polish for the Polish sample.
(6) comorbidities will not be considered for inclusions.

The exclusion criteria for patients include:

(1) Persons who do not meet the defined inclusion criteria,
(2) Persons who decline to provide consent.
(3) Persons who lack the physical or mental capability to participate in the study.

The inclusion criteria for caregivers include:

(1) Caregivers (who can be related or non-related, e.g., friend, spouse, child, sibling, or parent) of CKD patients will be eligible if they are identified by the participating CKD individuals as their significant supporters.
(2) Caregivers who are over 18 years old.

The exclusion criteria for caregivers include:

(1) Caregivers who do not meet the defined inclusion criteria.
(2) Caregivers who refuse to give consent.
(3) Caregivers who lack the physical or mental capacity to participate in the study.

2.4 Recruitment

Individuals with chronic kidney disease undergoing hemodialysis who will meet the eligibility criteria will be enrolled at the hemodialysis unit at the District Teaching Hospital in Kandy (Sri Lanka) and the hemodialysis unit at the University Clinical Center of the Medical University of Gdansk in Gdansk (Poland) by a researcher through medical records. The researcher will be responsible for the first contact with potential participants in order to provide them with oral and written information about the project, alongside an informed consent form to sign. Participation in the project will be voluntary. Each participant will have the right to refuse to participate in the study without any negative impact on the care received in the hospital.

Moreover, the participants will be assured of the confidentiality of their interviews and the subsequent data arising from the same. The anonymity of the participants will be protected by all means, for which they will be given pseudonyms/numbers and any information that could reveal their identity will be wiped out from the transcripts. They will be asked to reach out to the researchers if they felt any discomfort during and after the interviews.

2.5 Variables and measurement tools

There are five dependent variables in this study - health-related quality of life, depression, shame and guilt proneness, emotional suppression, and acceptance of illness.

2.5.1 Health-related quality of life

Kidney Disease Quality of Life (KDQOL-SF) Version 1.3 will be used to assess the health-related quality of life of individuals with chronic kidney disease undergoing hemodialysis. KDQOL-SF questionnaire is a self-report measure developed by Hays et al. (1997) for individuals with kidney disease and on dialysis. This instrument has good construct validity and test–retest reliability (Senanayake et al., 2020). KDQOL has two components; Kidney Disease Specific Component and SF-36. Altogether, the instrument has 81 questions in 19 domains. 11 domains assess kidney disease-specific components through 43 questions and 8 domains assess the general health-related components through 36 questions. The 11 domains of Kidney Disease Specific Components are symptom/problem list (12 items), the effect of kidney disease on daily life (8 items), the burden of kidney disease (4 items), cognitive function (3 items), quality of social interaction (3 items), sexual function (2 items), sleep (4 items), social support (2 items), work status (2 items), patient satisfaction (1 item) and dialysis staff encouragement (2 items) (Senanayake et al., 2017).

SF-36 components are physical function (10 items), role limitations caused by physical problems (4 items), role limitations caused by emotional problems (3 items), pain (2 items), general health perceptions (5 items), social function (2 items), emotional well-being (5 items), and energy/fatigue (4 items). The final item assesses the overall health on a scale from 0 to 10. Different questions have different answer options, which range from two to seven.

When scoring, each question is scored on a scale ranging from 0 (worst health) to 100 (best health). Three summary scores Kidney Disease summary component (KDSC), Physical Component Summary (PCS), and Mental Component Summary (MCS) will be derived from 19 domain scores of KDQOL-SF, by averaging the domain scores in respective three summary scores. Summary scores range from 0 to 100 and a higher score will represent better Health-Related Quality of Life (Senanayake et al., 2020). The KDQOL-SF was culturally validated and adapted for Sri Lankan (Senanayake et al., 2017) and Polish (Sapilak et al., 2006) cultural settings.

2.5.2 Depression

Beck Depression Inventory (BDI) will be used to assess the depression of individuals with chronic kidney disease undergoing hemodialysis. It is a 21-item, self-administered questionnaire that covers the full spectrum of depressive symptomatology (Bautovich et al., 2018). Those items cover areas such as 1. Mood, 2. Pessimism, 3. Sense of Failure, 4. Lack of satisfaction, 5. Guilt Feeling, 6. Sense of Punishment, 7. Self-dislike 8. Self-accusation, 9. Suicidal Wishes, 10. Crying, 11. Irritability, 12. Social Withdrawal, 13. Indecisiveness, 14. Distortion of Body Image, 15. Work Inhibition, 16. Sleep Disturbance, 17. Fatigability, 18. Loss of Appetite, 19. Weight Loss, 20. Somatic Preoccupation, and 21. Loss of Libido (Beck et al., 1988).

The items are rated on a 4 -point Likert scale (0–3) and ranked for severity within the time frame of the past 2 weeks and the total score will be obtained by adding the values of the selected sentences. The range of the score that can be obtained is 0–63 points. Cut-off score guidelines for the BDI-II are given with the recommendation that thresholds be adjusted based on the characteristics of the sample, and the purpose for use of the BDI-II. A total score of 0–13 is considered a minimal range, 14–19 is mild, 20–28 is moderate, and 29–63 is severe (Jackson-Koku, 2016).

The BDI has a reliability measure (Cronbach's alpha) of 0.87 (González-Flores et al., 2021) Some items can be shifted as per the population sample, and those items are called affective or emotional items (Arnarson et al., 2008). Furthermore, the BDI has been frequently used to assess depression in patients with end-stage renal disease (Richter et al., 1998; Andrade and Sesso, 2012). In the Polish cultural setting, the Polish adaptation of BDI-II will be used (Zawadzki et al., 2009). In the Sri Lankan cultural setting, the BDI - II adaptation prepared by Rodrigo et al. (2015) will be used.

2.5.3 Shame and guilt proneness

The Test of Self-Conscious Affect (TOSCA-3) questionnaire will be used to assess shame and guilt proneness of individuals with chronic kidney disease undergoing hemodialysis. This questionnaire was developed by Tangney et al. (1989) (Broerman, 2020). This is a tool that employs brief scenarios to evaluate individuals' tendencies to experience shame and guilt. These scenarios reflect everyday situations, like someone breaking something at work and hiding it. Respondents choose from different options that represent either shame or guilt. For instance, one option might be thinking about leaving the job (related to shame), while another could be feeling bothered and wanting to fix the issue (related to guilt). Respondents rate how likely they had choose each response on a 5-point scale. This helps them show if they would feel both shame and guilt in each situation.

The questionnaire includes 11 negative and five positive scenarios. Respondents rate their responses from 1 to 5. These ratings determine scores on six scales: guilt-proneness, shame proneness, externalization (blaming others), indifference to responsibility, pride in oneself (alpha pride), and pride in behavior (beta pride). For each scenario, respondents show how likely each reaction is, usually ranging from 4 to 5. A score of 1 means unlikely, while 5 means very likely. In our study, we will utilize the Polish adaptation of the test (Adamczyk and Sobolewski, 2022). It demonstrates good consistency in its results over time. The reliability for shame measurement was 0.85 over 3 months, and for guilt measurement, it was 0.74 over 5 months (Adamczyk and Sobolewski, 2022).

2.5.4 Emotional suppression

The Courtauld Emotional Control Scale (CECS) will be utilized to evaluate the emotional control of individuals with chronic kidney disease undergoing hemodialysis. This primary assessment tool is widely employed to measure the subjective management of negative emotions such as anger, anxiety, and depression in challenging situations. Designed to encompass both healthy and unwell adults, CECS was originally developed by Watson and Greer in 1983 (Lewicka et al., 2012). The CECS comprises 21 items, organized into three subcategories focusing on suppressing or expressing anger, anxiety, and depressed mood. Respondents rate their agreement with item statements on a 4-point scale that ranges from "Almost never" to "Almost always." The items are scored in such a way that higher scores indicate greater control over emotional responses. The different parts of the scale showed good internal consistency, with reliability scores ranging from 0.86 for the anger section to 0.88 for the sections measuring depressed mood and anxiety. The connections between these sections and the total scores suggest that the questionnaire effectively gauges how people generally handle their emotions. When tested again after three to 4 weeks (with a group of 40 participants), the scale's reliability remained strong: 0.86 for anger, 0.84 for anxiety, 0.89 for depressed mood, and an impressive 0.95 for the overall CECS score (Durá et al., 2010).

2.5.5 Acceptance of illness

As quality of life is interrelated with factors like pain and the degree of acceptance of an individual's illness, we decided to assess for acceptance of illness in individuals with chronic kidney disease undergoing hemodialysis. It will be measured through the utilization of the Acceptance of Illness Scale (AIS), introduced in 1984 by B. J. Felton, T. A. Revenson, and G. A. Hinrichsen (Polish adaptation by Czerw et al., 2021). The AIS questionnaire comprises eight statements that outline adverse outcomes of compromised health, encompassing evaluations of limitations imposed by the illness, reduced self-sufficiency, a sense of dependence on others, and diminished self-esteem. The overall assessment of illness acceptance is calculated as the cumulative score of all the statement points. A lower score signifies a lack of adaptation to the illness and a strong sense of psychological discomfort, while a higher score indicates acceptance of one's medical condition and is accompanied by a dearth of negative emotions tied to the illness. Each statement presents a five-point scale, with patients indicating their current health status by selecting the appropriate number: 1 – Strongly agree, 2 – Agree, 3 – Uncertain, 4 – Disagree, 5 – Strongly disagree. Choosing answer number 1 denotes poor adaptation to the disease, while answer number 5 indicates complete acceptance of the disease. The sum of all points falls within a range of 8 to 40, serving as a measure of illness acceptance. The AIS scale exhibits the reliability of Cronbach's α at 0.83 (Felton et al., 1984).

Apart from the instruments mentioned above, a sociodemographic survey will be distributed to all study participants (both individuals with chronic kidney disease undergoing hemodialysis and their caregivers). The survey will measure independent variables. The following information will be collected:

- *Nationality*: Participants' nationality will be the grouping variable. Information on the participant's nationality will be gathered with an open question in the demographic information sheet. The question will be: "Please, state your nationality." The participants will write down their answers.
- *Gender*: Information on the participant's gender will be collected using a single-choice question. As gender will be considered bivariate, the participants will mark if they are a woman or a man.
- *Age*: The participant's age will be measured as a continuous variable. Thus, the participants will be asked an open question "How old are you?," the participants will write down their answers.
- *Ethnicity*: Information on the participant's ethnicity will be collected using a single-choice question. The participants will be asked an open question "What is your ethnicity?," the participants will write down their answers.
- *Religion*: Information on the participant's religion will be collected using a single-choice question. The participants will be asked an open question "What is your religion?," the participants will write down their answers.
- *Marital status*: Information on the participant's marital status will be collected using a multiple-choice question. The participants will be able to choose among options such as: married, widowed, separated, divorced, single, or in an informal relationship. The participants will mark their answers.
- *Educational level*: Information on the participant's education level will be collected using a single-choice question. The participants will be asked to answer the question about the last level of education they earned. They will be presented with options such as: primary, junior secondary, senior secondary, collegiate, and tertiary. The participants will mark their answers.
- *Occupation*: Information on the participant's profession will be collected using an open question ("What is your profession?"). The participants will write down their answers. (This question will be asked from the individuals with chronic kidney disease undergoing hemodialysis only)
- *The stage of CKD*: (self-reported; considered as a number from 1 to 5) will be asked using an open-ended question (What is your stage of CKD?/What is your friend's/relative's stage of CKD?). The participants will write down their answers.
- *Diabetes* (self-reported): the information about this will be collected by asking an open-ended question ("Do you have diabetes?") and the participant will write down the answer (This question will be asked from the individuals with chronic kidney disease undergoing hemodialysis only).
- *Hypertension* (self-reported):the information about this will be collected by asking an open-ended question(Are you suffering from Hypertension?) and the participant will write down the answer (This question will be asked from the individuals with chronic kidney disease undergoing hemodialysis only).
- *Cardiovascular disease* (self-reported): the information about this will be collected by asking an open-ended question(Are you suffering from Cardiovascular disease?) and the participant will write down the answer (This question will be asked from the individuals with chronic kidney disease undergoing hemodialysis only).
- *The number of family members diagnosed with CKD*: Information on the number of family members diagnosed with CKD will be gathered with an open question in the demographic information sheet ("How many members of the family are diagnosed with CKD?"). The study participants will note the number.
- *The history of the disease/the duration* - the information about this will be collected by asking an open-ended question (How long have you had this disease?) and the participant will write down the answer.
- *The information about the relationship to the patient* will be asked from caregivers.

The objective of the second phase of the study is to explore the experiences of the disease of individuals with chronic kidney disease undergoing hemodialysis and their caregivers in Sri Lanka and Poland with the aim of a deeper understanding of the psychosocial well-being of the target group. The qualitative part of our research does not have a predetermined sample size, as we recognize the challenges associated with setting one in exploratory studies (Emmel, 2013; Sim et al., 2018). Our main focus in this phase is to explore the experiences of individuals with chronic kidney disease undergoing hemodialysis and their caregivers to gain a comprehensive understanding of the complex concept of psychosocial well-being within this target group. Our approach is to conduct a broad study of the participants' experiences, allowing us to embrace and uncover key themes that may emerge during the research process, rather than imposing predetermined notions. Although we anticipate conducting a smaller number of interviews, our goal is to attain robust qualitative insights into the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis and their caregivers (Adler and Adler, 2012). This thoughtful methodology will enable us to deeply understand the psychosocial well-being of this specific population.

The interviews will be based on semi-structured interview guides. There will be two semi-structured interview schedules – one for individuals with chronic kidney disease undergoing hemodialysis and one for their caregivers. Each interview guide consists of 27 questions. The first 12 questions will be based on general information about both patients and caregivers. The rest of the questions will be open-ended and allow participants to express their answers in detail. The open-ended questions will focus on patients' and caregivers' experiences, emotions, perceptions, relationships, social support, and medical support they receive. The questions in Sinhala and Polish languages are presented in Attachment 1 and Attachment 2, respectively.

While the study intends to include both patients and their caregivers (caregivers), the interviews will be conducted separately for each participant. Nonetheless, the subsamples are interconnected, allowing for future dyadic analysis. The sample size for each of the subsamples will be determined by data saturation.

The interviews will be audio recorded and will be literally and systematically transcribed. Identifying data of the informants in the transcripts will be anonymized. Moreover, images capturing significant psychosocial factors and elements concerning CKDu patients will be captured, following the hospital's approval and ensuring that no specific patients are depicted.

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2.6 Design and method

Semi-structured interviews with the first group (Sri Lankan) will be conducted by the principal investigator (PI) at the Hemodialysis unit of the Kandy Hospital, Sri Lanka. The semi-structured interviews with the second group (Polish) will be conducted by trained research assistants at the Hemodialysis unit of The University Clinical Center of the Medical University of Gdansk, Gdańsk, Poland. As a Sri Lankan Ph.D. student, the PI is not familiar with the Polish language. Therefore, MA students from the Institute of Psychology, University of Gdansk, will be recruited and trained for conducting interviews. The psychosocial approach to understanding the experience of CKD is a novel area of research. Thus, research assistants will be given an informed orientation into the research project and proper training in its methods before they enter the field.

2.7 Data management

The raw quantitative data will be entered into Microsoft Excel format to allow for statistical analysis via SPSS. Qualitative data will be stored on multiple hard drives such as USB and Google Drive and manual copies such as files and notebooks. Only researchers who belong to the project will have access to data and the data will be locked in a safe storage box at the university. However, the datasets and/or analyses related to the current study will be available from the corresponding author upon reasonable request.

2.8 Bias

As the data will be collected from hemodialysis units of the hospitals where the patients will be undergoing the procedure, some of them might have difficulties answering the questionnaires by themselves. On such occasions, the researcher will be reading the questions to the study participant and mark their answers on the paper questionnaire. This may lead to response bias. To minimize this effect, patients will be ensured of their anonymity. Furthermore, questions and answers options will be read to patients very clearly and repeated if not heard clearly.

3 Data analysis

3.1 Overview

The quantitative data obtained from the validated questionnaires (i.e., KDQOL-SF and BDI) will be analyzed with SPSS 25 (Statistical Package for Social Science). The variables will be computed using relevant scoring methods. Due to the sample size limitation, non-parametric methods will be employed (Altman and Bland, 2009).

The qualitative data will be analyzed using a conventional qualitative content analysis approach (Cho and Lee, 2014). The goal of this approach is to identify frequently reported themes/codes emerging from the data. Therefore, all the responses will be read multiple times as the first step of the analysis and an initial list of themes will be prepared by each graduate student. After that, each of the prepared separate lists of themes will be discussed, and a final list of themes (based on the most commonly reported themes) will be prepared. Finally, these themes will be analyzed further to identify emerging patterns that will finally lead to a deeper understanding of the psychosocial well-being of CKD patients and their caregivers.

3.2 Integration

The results of the quantitative and qualitative studies will be integrated by looking at common concepts and how qualitative data provide a deeper understanding of quantitative data. For instance, the KDQOL scale may address whether individuals with chronic kidney disease undergoing hemodialysis are affected by the disease by means of work or other regular activities and relationships. Participants are supposed to give answers as "Yes" or "No"; which will be not provided sufficient information about the experiences of individuals with chronic kidney disease undergoing hemodialysis. However, qualitative data will cover up the gap in the information as questions such as "How do you understand CKD?" and "How has your situation shaped your day-to-day life?" will allow participants to give in-depth descriptions of their experiences of the disease. Furthermore, while BDI screens the symptoms of depression, qualitative data may provide an in-depth understanding of individuals' suffering by asking open-ended questions about their feelings. Therefore, by integrating both quantitative and qualitative data, it is expected to be enriched the data about the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis and their caregivers.

3.3 Status and timeline of the study

The study is in the recruitment and data collection stage. Ethical approval for the study with group 1 (Sri Lankan sample) has been obtained from the Ethics Review Committee of the Open University Sri Lanka and ethical approval for group 2 (Polish sample) was obtained from the Ethics Committee of the University of Gdansk. Study instruments were finalized and data collection commenced in mid-October 2022, to be completed in September 2023.

4 Discussion

4.1 General discussion

The proposed study aims to focus on the psychosocial well-being of individuals with chronic kidney disease undergoing hemodialysis and their caregivers by using both quantitative and qualitative methods. Validated questionnaires and semi-structured interview guides will be employed for data collection.

The primary goal of this study is to explore and investigate the psychosocial well-being of CKD patients and their caregivers in both Sri Lanka and Poland. The knowledge gained from this research will be invaluable in promoting a holistic and systemic approach to planning, prevention, and intervention strategies tailored to the needs of CKD patients. By understanding the psychosocial well-being of this population, we can work toward enhancing their overall quality of life and well-being.

In line with the study's aim, we are committed to providing necessary support for participants identified as requiring psychological assistance. Any Sri Lankan patients in need will be referred to mental health services, ensuring that they receive the appropriate care and support during their journey with CKD.

Patients from Poland who participate in the study will be appreciated for their involvement, as they will receive written feedback on the project via email after the study concludes. This gesture ensures transparency and gratitude for their contribution to advancing research in this field.

A distinctive aspect of this study lies in its contribution to the research literature. While previous studies have explored the quality of life of ESRD patients, our research takes a step further by investigating the broader concept of psychosocial well-being using a mixed-method approach. By comparing the psychosocial well-being of two different ethnicities, Sri Lankan and Polish, we aim to uncover the influence of culture and ethnicity on the experiences of individuals with chronic kidney disease undergoing hemodialysis and their caregivers.

By delving into the factors associated with culture and ethnicity, we seek to gain a deeper understanding of how these elements shape the psychosocial well-being of the target group. This knowledge can inform more culturally sensitive and tailored approaches to support and care for CKD patients in both Sri Lanka and Poland.

Ultimately, the findings of this study will contribute to the development of specific guidelines for hospitals and clinics responsible for treating CKD patients. By considering the psychosocial aspects of CKD care and incorporating the insights gained from this research, healthcare facilities can improve their practices, ensuring that patients and their caregivers receive comprehensive and compassionate care throughout their journey with CKD.

In conclusion, this study aspires to make a significant contribution to the field of CKD research by exploring the psychosocial well-being of patients and their caregivers in Sri Lanka and Poland. By adopting a mixed-method approach and comparing different ethnicities, we seek to enrich our understanding of the cultural influences on psychosocial well-being. The ultimate aim is to use these findings to create guidelines that prioritize the holistic care and support of CKD patients, paving the way for better outcomes and improved well-being within this vulnerable population.

The findings will help to explore and investigate the psychosocial well-being of CKD patients and their caregivers in Sri Lanka and Poland. Gathering such knowledge will contribute to promoting a holistic and systemic approach to planning, prevention, and intervention strategies focused on CKD patients. Moreover, the findings of the study will help to enhance the psychosocial well-being of CKD patients and their caregivers. In addition, if during the study some Sri Lankan patients will be identified as in need of psychological support, they will be referred to mental health services (because the aim is to provide the guidelines). Patients from Poland will receive written feedback on the project via e-mail after the study ends (for those who will provide e-mail addresses).

4.2 Expected problems

Given that the proposed study is the first of its kind in the Sri Lankan context, it is likely that patients may have questions about the purpose and value of this project. An information sheet detailing the objectives and justification of the research will be prepared and handed over to the participants. The same information sheet will be prepared for the Polish participants.

In addition, prior to the study procedures, the project will be introduced to all participants, allowing them protected time to ask questions and clarify any doubts. It is essential to note that in the Sri Lankan context, CKD patients coming from families with low income receive monthly financial support from the government, along with occasional assistance from certain NGOs. Consequently, participants from these backgrounds might have specific expectations that the research study could offer similar financial benefits. To manage these expectations, it will be explicitly communicated at the beginning of the research that there will not be any direct monetary or material benefit associated with participation. Instead, the benefits lie in their contribution to enhancing the existing knowledge base on CKD. This research aims to have a significant impact on the psychosocial well-being of CKD patients and their families.

Another important problem is the potential of our sample being underpowered due to its size. The choice of minimum sample size takes into account the practical constraints associated with recruiting and managing patients in a clinical setting in two countries. We would like to acknowledge being aware of study limitations related to the sample size. First, we will use non-parametric tests to analyze the data, and what is a good practice while working with small samples (Altman and Bland, 2009). Second, sample size bias will be taken into account while processing the data and making conclusions while at the same time, we are mindful of resource limitations and the unique characteristics of our study population.

4.3 Ethical approval

The study proposal has been submitted to the Ethical Review Committee of the Open University of Sri Lanka and received the ethical clearance letter under the application number ER/2022/007 to conduct the first stage of the project. The approval from the Ethical Review Board of the Institute of Psychology, University of Gdańsk, has been obtained under inquiry number 03/2023 for conducting the second stage of the project in Poland.

The research will commence only with the informed consent of the informants to participate in the research project. Participants will be introduced to the research project and they will be offered an opportunity to raise any questions they have about the project before seeking their consensus. They will be provided with an information sheet with a description of the study. The participants will be allowed to withdraw from the study at any point of time during the research period, In case one wishes to withdraw, they will be asked to inform the principal investigator about it. Finally, the data received from the research will be kept in a locked filing cupboard and will be destroyed once the findings are ready to be published.

Ethics statement

The studies involving humans were approved by Ethical Review Committee of the Open University of Sri Lanka and Ethical Review

Board of the Institute of Psychology, University of Gdańsk. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

DB: study conceptualization, study design, data collection, statistical and qualitative analysis, and manuscript drafting. JB: study design, statistical analysis, and manuscript revision. AR: qualitative analysis and manuscript revision. MB: study conceptualization and design, data collection, manuscript revision, supervision, and mentorship. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpsyg.2023.1194991/full#supplementary-material

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THE CROSS-CULTURAL DIFFERENCES IN SHAME AND GUILT AMONG INDIVIDUALS WITH CHRONIC DISEASES – A SCOPING REVIEW

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Summary. This scoping review delves into the emotional complexities faced by individuals with chronic diseases, focusing on shame and guilt across diverse cultural contexts. This literature overview underscores the significant role of shame and guilt in the lives of individuals with chronic diseases and emphasizes the necessity of expanding the understanding of culturally related shame and guilt concerning chronic diseases. Findings underscore the need for targeted interventions in the emotional landscape of chronic illnesses and cultural sensitivity while talking about chronic conditions.

Key words: shame, guilt, shame-proneness, guilt-proneness, chronic diseases, culture

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Emotions are profoundly significant in human health and well-being (Vanderheiden & Mayer, 2017). According to researchers, basic emotions such as happiness, sadness, surprise, lust, and disgust are universally shared across cultures and linked to the physical survival of individuals. However, secondary or self-conscious emotions, including pride, shame, guilt, and embarrassment, are interconnected with specific cultures' values, morals, and anticipated behaviors, exhibiting substantial differences across societies (Yakeley, 2018). Furthermore, basic emotions are biologically driven and emerge within the first year of life, while self-conscious emotions develop later, beginning in the second year and continuing after that (Casimir & Schnegg, 2002; Yakeley, 2018). Thus, shame and guilt can be identified as negative social emotions particularly sensitive to culture.

The term "culture" refers to historically driven and socially transmitted things such as language, symbols, values, norms, rituals, laws, artifacts, and institutions (Tracy et al., 2007). Culture has a substantive influence on emotion, health, and well-being, as an individual's self is constructed by the culture (Kitayama & Park, 2007). For example, individuals in North American culture develop their "self " based on internal attributes such as abilities, talents, and personality traits. The culture's role is to facilitate the discovery, actualization, and confirmation of these internal attributes. Likewise, Western/individualistic cultures promote the "independent self". On the other hand, many Eastern/collectivist cultures introduced a set of different guidelines, beliefs, and norms; a major cultural task is to fit the individual' self into these norms. Hence, Eastern cultures promote the "interdependent self" (Kitayama et al., 2000). People in interdependent cultures define themselves in relation to others, while those in independent cultures do the opposite (Wong & Tsai, 2007).

Cultures may also be identified as guilt-based and shame-based cultures; using the criteria of internal and external sanctions (You, 1997). Based on this classification, Western/individualistic cultures are more integrated with guilt as these cultures are based on internalized value systems. On the other hand, Eastern /collectivist cultures are more integrated with shame, which is based on external social sanctions. Hence, individuals feeling shame are preoccupied with the way others are judging them, whereas individuals experiencing guilt are focused on the impact of their actions on others (Wolf et al., 2009).

The appropriateness of feeling certain emotions varies across cultures. Such variation exists due to the level of individualism and collectivism in particular cultures. For example, positive emotions such as pride and excitement are not highly encouraged in collectivistic cultures as those might detract the social harmony. On the other hand, in individualistic cultures, personal expression of positive emotions is very much

encouraged (Tov & Diener, 2013). Furthermore, cultural norms govern the expression of the way emotions are expressed and their intensity, impacting the overall well-being of society. This may explain why people from individualistic cultures report higher subjective well-being than individuals from collectivistic cultures (Diener & Lucas, 2004).

In both psychological and everyday contexts, people frequently use the terms shame and guilt interchangeably (Tangney, 1998; Wolf et al., 2009). Even though the term guilt and shame are confused as the same meaning in day-to-day language, they should not be understood as one homogeneous emotion (Cerna et al., 2022). The experiences of guilt and shame can be intertwined and distinct (Su & Hynie, 2019). Guilt can be identified as an awareness of having done something bad, committing a crime, or a feeling of responsibility for an offense whereas shame is a sense of inferiority or worthlessness. Therefore, guilt can be defined as "a negative, self-conscious, moral emotion which occurs when the individual admits that he has done something that transgresses a moral law. The focus is on inappropriate behavior". (Vanderheiden & Mayer, 2017, p. 81). Conversely, shame can be defined as "a negative, self-conscious moral emotion which occurs when someone sees *his person* as being deficient because something he did transgress a moral law. The focus is on the person." (Vanderheiden & Mayer, 2017, p. 81).

According to Su and Hynie (2019), experiencing guilt serves as a guide for healthier functioning of individuals in Western cultures, aiding in the strengthening of self-esteem, empathy, and perspective-taking. These adaptive functions, including coping with environmental challenges and prosocial behaviors such as helping others, are directly linked to the psychosocial well-being of individuals.

However, as Leith & Baumeister (1998) stated, shame is linked with personal distress and is harmful to human relationships because it arises as a result of real or imagined rejection from society. Hence, shame generates anger within an individual, and ultimately, it might cause internal blame, hostile criticism of others, insulting others, and withdrawal from social situations. Vanderheiden & Mayer (2017) also stated that shame is the affective component of subjective well-being, which produces negative affect. According to Crosskey et al. (2015), shame is associated with depression, alcohol and drug abuse, burnout, and self-rumination, whereas guilt is associated with social connectedness, hope, and empathy.

Nevertheless, according to You (1997) and Vanderheiden & Mayer (2017), shame can be identified as a valuable health resource. Shame motivates individuals to align themselves to connect with others. Shame acknowledges other people's norms and expectations, highlights one's own mistakes, and allows one to take steps to avoid repeating these mistakes in the future.

The emergence of a chronic illness marks a pivotal life event, indicating the commencement of what, for the majority, will be an enduring journey of adjusting to substantial alterations in physical, psychological, social, and environmental aspects. A wealth of research has shown that chronic illness significantly affects the mental, social, and physical well-being of patients (e.g., Trindade et al., 2018; Keles et al., 2006; Megari, 2013). Those with chronic conditions often experience reduced feelings of self-reliance, weakened quality in social connections, a sense of being misunderstood, isolation and vulnerability, and even the perception of burdening others (Taylor, 2006).

Shame and Guilt in the Context of Chronic Diseases

As previously indicated, shame is often seen as an uncomfortable emotion stemming from the perception that one's attributes are unfavorable. People facing chronic illnesses, especially those with evident symptoms or observable features, might theoretically be more prone to encountering feelings of shame (Trindade et al., 2016; Casati et al., 2000; Kellett & Gilbert, 2001). For example, individuals with inflammatory bowel disease (IBD) frequently communicate sensations of embarrassment, isolation, and diminished attractiveness due to the distinctive traits of the illness and its symptoms (Casati et al., 2000).

According to Dickerson et al. (2004), self-related emotions are directly linked with physiological processes. Specifically, prolonged exposure to evaluative and socially rejective conditions can trigger a cascade of physiological responses, including heightened cortisol levels and increased proinflammatory cytokine activity. These responses, in turn, contribute to the experience of shame and may ultimately lead to negative health outcomes (Dickerson et al., 2004). Moreover, some studies report the association of shame and guilt with chronic mental disorders. Exline et al. (2004) and Lee et al. (2001) have found a positive relationship between guilt and depression. Similarly, O'Connor et al. (2002) compared the self-focused motivations and other-focused motivations in submissive behavior and depression using depressive patients and students. The results revealed that depressed patients reached significantly higher scores in negative emotions, including guilt and fear, and lower scores in social comparison. The relationship between guilt and depression can be considered a special case, as highlighted by Cerna et al. (2022), who referenced the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV). They noted that excessive and inappropriate guilt is specifically identified as one of the symptoms indicative of major depressive disorder.

Many patients have their own perceptions, knowledge, and understanding of the nature of their disease (Abrams & Finesinger, 1953). As previously explained, culture plays a significant role in shaping individual thinking patterns. When it comes to chronic diseases, individuals comprehend the diseases and related treatments in the light of cultural knowledge rather than medical knowledge. According to a study by Earnshaw & Quinn (2012), the stigma associated with healthcare workers and people with chronic diseases can have harmful effects on the quality of life of those with chronic diseases. Therefore, by reducing stereotyping, prejudice, and discrimination in healthcare settings and encouraging people with chronic diseases to mitigate anticipated stigma, their quality of life can be preserved.

However, to the best of our knowledge, there is a lack of research that has been focused on the effect of shame and guilt on individuals with chronic diseases across cultures. Therefore, the objective of this study is to review and synthesize existing literature on shame and guilt in the context of chronic diseases across different cultures.

Method

The subsequent sections outline the procedures for acquiring the literature relevant to this review. The study applied a scoping review method. Contrary to systematic literature reviews (SLR), which address well-defined questions that often suggest the study design, a scoping literature review addresses broad questions and describes the literature widely, including diverse study methods and designs (Arksey & O'Malley, 2005). This approach fits the aim of our study due to the observational nature of the investigated studies that employ both qualitative and quantitative methods. Moreover, in the analyzed papers, a key variable – the culture, was often not considered/mentioned as the study variable but only sample characteristic. Therefore, applying the SLR method would lead to omitting some papers that described shame and guilt experienced by people with chronic conditions in many countries/ethnic groups but do not discuss the cultural context per se.

Search strategy – Initial Search

The search strategy for this scoping review involved a three-stage approach targeting different databases and search phrases. A search of electronic databases (PubMed, Academic Search Complete, APA PsycArticles, and APA PsycInfo) was performed on September 14th, 2023. The search phrase was as follows: 'life-long' OR 'chronic' OR 'long-term' OR 'continuing' OR 'incurable disease' OR 'illness' OR 'condition' OR 'disorder' AND 'culture' OR 'cultural' OR 'culture-based' AND 'shame and guilt' OR 'shame-based' OR 'shame proneness'. Articles available from the inception date until 14 September 2023 were included.

This search generated an initial set of 63 papers, from which a screening process led to a final selection. Additionally, Google Scholar was utilized, but no new studies meeting the inclusion criteria were found.

Search strategy – Title and Abstract Screening

After obtaining the initial yield of 63 papers, a review of the titles and abstracts was conducted. This phase involved assessing whether each was within the scope of the study. Due to the relatively low number of search results, the PI conducted screening by eye and then double-checked by another research team member. As a result of this step, 20 papers were selected for further evaluation.

Search strategy – Detailed Paper Screening

The detailed screening process involved a thorough review of 20 articles. Each of these articles underwent meticulous scrutiny based on specific inclusion criteria, ensuring alignment with the study's focus. The refined inclusion and exclusion criteria are outlined below:

Inclusion criteria:

a. Individuals with chronic diseases participated in the study.
b. Shame/ shame-proneness and/or guilt/ guilt-proneness were investigated within the study.
c. Sample's ethnicity/nationality was stated, which allowed for categorizing the culture as collectivistic or individualistic culture.
d. All observational empirical study designs, both qualitative and quantitative, were included (e.g., cohort studies, case-control studies, cross-sectional studies, and case studies).

Exclusion criteria.

Papers were excluded for the following reasons:

a. Full text in English could not be obtained.
b. The source was a theoretical or a review article, with no primary or secondary data analyzed.
c. The source was not peer-reviewed (book chapters, reports, theses/dissertations, conference proceedings).
d. Studies where the participant's background is not clearly stated.
e. Studies with heterogenous, culturally diverse participants analyzed jointly as one sample.
f. Studies on people experiencing chronic symptoms (e.g., chronic pain), not chronic diseases.

Study Categorization Process

Based on the ethnicity/nationality of study participants, the 20 selected studies were identified as either conducted within the shame-based culture (i.e., collectivistic culture) or guilt-based culture (i.e., individualistic culture). Subsequently, all 20 articles were further classified into five distinct categories based on the main focus of the study, namely: individual experiences, risk behaviors, patient care, social attitudes/ stigma, and self-perception in relation to chronic disease.

Results

The detailed results of the review and characteristics of the analyzed studies are summarized in Table 1. Across the span of 69 years, 20 studies have investigated the experience of self-conscious emotions (shame and guilt) among people with

chronic diseases. The identified studies have been classified based on their main focus using qualitative assessment of the paper's content performed by two members of the research team. There were five established categories as follows: individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception in relation to chronic disease.

In the next step, within each category, the studies were divided based on the cultural setting. Thus, across all five categories, we distinguished studies performed within the individualistic culture, within the collectivistic culture, and studies comparing individualistic and collectivistic cultures.

Category 1 – Individual Experiences

Seven studies that specifically delve into the experiences of individuals dealing with chronic diseases have been identified. These studies assess the cultural implications of chronic illnesses, particularly focusing on the emotions of shame and guilt. Five of these studies have been conducted with the participation of individuals living in individualistic cultures (Harrison et al., 2017; Furmańska et al., 2020; Ten Klooster et al., 2014; Robertson et al., 2021; Walker, 2017), while one study was conducted within a collectivistic culture (Taşkıntuna & Özçürümez, 2011). Additionally, one study, by El-Mansoury et al. (2008), examines a comparison between individualistic and collectivistic cultures.

Ten Klooster et al. (2014) studied feelings of guilt and shame in patients with rheumatoid arthritis (RA) in the individualistic culture of the Netherlands. This study aimed to investigate whether individuals diagnosed with rheumatoid arthritis (RA) tend to experience higher levels of general guilt and shame compared to those without RA. It involved 85 patients with rheumatoid arthritis and 59 individuals without RA. The most notable finding of this study was that patients with longstanding RA did not experience a greater general propensity for shame or guilt than their comparison group without RA. Furthermore, shame and guilt were only associated with the demographic and psychosocial characteristics of the patients and not with the clinical or physical aspects of the disease. The overall study results suggest that Dutch RA patients generally do not experience significant shame or guilt. According to the authors, several reasons might explain why shame and guilt were not notably higher in these patients. Firstly, RA is widely recognized as a medical condition by both doctors and the public. People seem to have realistic views about arthritis, understanding its seriousness and consequences and do not think patients can control the disease's course. This lack of stigma means RA patients likely do not feel the need to justify or hide their condition. Moreover, advances in understanding RA causes and effective treatments have made the disease milder compared to decades ago. RA patients today are generally less disabled, with fewer visible deformities or reliance on assistive devices. This contrasts with conditions like breast cancer, where visible signs may lead to bodily shame.

Table 1. Study characteristics and results

No.	Study	Aim	Country/ Ethnicity
01	ten Klooster, P.M., Christenhusz, L.C., Taal, E., Eggelmeijer, F., van Woerkom, J.-M., & Rasker, J.J. (2014). Feelings of guilt and shame in patients with rheumatoid arthritis. *Clinical Rheumatology, 33*(7), 903–910, doi: 10.1007/s10067-014-2516-3	The study aimed to determine whether individuals with rheumatoid arthritis (RA) experience higher levels of general guilt and shame in comparison to those without RA, and to explore potential factors associated with these emotions in the context of RA	Netherlands
02	Harrison, S.L., Robertson, N., Goldstein, R.S., & Brooks, D. (2017). Exploring self-conscious emotions in individuals with chronic obstructive pulmonary disease. *Chronic Respiratory Disease, 14*(1), 22–32, doi: 10.1177/1479972316654284	The study aimed to investigate the manifestation of self-conscious emotions, examine potential correlations with adverse health outcomes, and compare the expression of these emotions between individuals with chronic obstructive pulmonary disease (COPD) and a healthy control group.	Canada
03	Walker, L. (2017). 'There's no pill to help you deal with the guilt and shame': Contemporary experiences of HIV in the United Kingdom. Health: *An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine, 23*(1), 97–113, doi: 10.1177/1363459317739436	The main aim of the study was to understand the impact of receiving and adjusting to an HIV diagnosis in today's UK society. Additionally, the study aimed to explore whether the social experiences of individuals living with HIV have changed or stayed consistent in response to biomedical advancements.	United Kingdom
04	Furmańska, J., Rzepa, T., Koziarska, D., Rutkowska, E., & Bulsa, M. (2020). Stereotypes vs. reality: Shame and coping strategies applied by healthy subjects and multiple sclerosis patients – preliminary research. *Postępy Psychiatrii i Neurologii, 29*(1), 11–24, doi: 10.5114/ppn.2020.94692	This study aimed to assess the degree of disease-related shame in individuals with multiple sclerosis (MS) in comparison to healthy individuals who identified with the stereotype of a chronic, incurable disease leading to disability.	Poland

Sample description	Methodology	Findings
Study participants included 85 outpatients (77% females, median age 62 years, median disease duration 11 years). A peer control group of 59 individuals was age and sex-matched for comparative analysis.	quantitative, cross-sectional comparative study	Individuals with longstanding RA did not undergo heightened general feelings or susceptibility to shame or guilt in comparison to their peers without RA. Additionally, the occurrences of shame and guilt were solely linked to the demographic and psychosocial characteristics of the patients, and not to the clinical or physical aspects of the disease.
Study participants included 15 individuals with COPD who participated in interviews. The quantitative component involved 70 patients diagnosed with COPD and 61 healthy controls.	mixed-methods study	Five interview-derived themes were discerned: grief, a range of blame, concern regarding external perceptions, concealment, and future-related apprehension. Quantitative results showed that individuals with COPD expressed reduced self-compassion, heightened shame, and diminished pride compared to their healthy counterparts.
The study participants included individuals aged 18–35 years who had received a diagnosis of HIV within the past 5 years.	qualitative study (online survey structured around open-ended questions and two interviews)	The data revealed a mix of experiences and expectations, highlighting that while HIV is considered ‚normal' in some aspects, there are still ongoing feelings of fear, shame, and stigma. This underscores its continued status as a highly ‚socially impactful' disease.
The study participants included 60 individuals, comprising 30 patients diagnosed with MS and 30 healthy subjects.	quantitative, cross-sectional comparative study	The study findings indicated no significant difference in the levels of disease-related shame between individuals with MS and healthy subjects. Both groups exhibited similar use of coping strategies such as avoidance, self-blame, and blaming others. Notably, MS patients were less inclined to employ withdrawal as a coping strategy compared to the healthy group. Within the MS patient group, a positive correlation was observed between the level of disease-related shame and the utilization of withdrawal and self-blame as coping mechanisms.

cont. table 1

No.	Study	Aim	Country/ Ethnicity
05	Robertson, N., Gunn, S., & Piper, R. (2021). The experience of self-conscious emotions in inflammatory bowel disease: A thematic analysis. *Journal of Clinical Psychology in Medical Settings, 29*(2), 344–356. doi: 10.1007/s10880-021-09778-0	The study aimed to explore the presence of self-conscious emotions in individuals with Inflammatory Bowel Disease (IBD).	United Kingdom
06	Taşkıntuna, N., & Özçürümez, G. (2011) End-stage renal disease and psychological trauma: Shame and guilt in hemodialysis patients, transplantation recipient and donor candidates, and controls. *Nöro Psikiyatri Arşivi, 48*(4), 249–254, doi: 10.4274/npa.y5846	The study aimed to investigate the impact of psychological trauma, specifically examining shame and guilt, on mood and health-related quality of life (HRQOL) among individuals with end-stage renal disease (ESRD).	Türkiye
07	Shahram, S.Z., Bottorff, J.L., Oelke, N.D., Kurtz, D.L., Thomas, V., Spittal, P.M., & and For the Cedar Project Partnership. (2017). Mapping the social determinants of substance use for pregnant-involved young Aboriginal women. *International Journal of Qualitative Studies on Health and Well-Being, 12*(1), 1275155, doi: 10.1080/17482631.2016.1275155	This study aimed to understand how young Indigenous women, engaged in pregnancy, conceptualize and grasp the interconnections of social determinants associated with substance use.	Canada
08	Lindqvist, G., & Hallberg, L.R.-M. (2010). 'Feelings of guilt due to self-inflicted disease.' *Journal of Health Psychology, 15*(3), 456–466, doi: 10.1177/1359105309353646	This study aimed to investigate the main challenges confronted by individuals living with chronic obstructive pulmonary disease (COPD) and explore their strategies for managing their daily lives.	Sweden
09	Mondia, S., Hichenberg, S., Kerr, E., Eisenberg, M., & Kissane, D.W. (2011). The impact of Asian American value systems on palliative care. *American Journal of Hospice and Palliative Medicine, 29*(6), 443–448, doi: 10.1177/1049909111426281	This study aimed to investigate the experiences of Asian American families in the context of palliative care, utilizing a cultural lens.	USA

Sample description	Methodology	Findings
The study included 15 participants from outpatient IBD clinics and patient groups.	qualitative study (semi-structured interviews)	The analysis identified themes that showed how people felt self-conscious emotions when their experiences threatened the identities they preferred.
The study participants included four groups: the hemodialysis group (56), the recipient candidate group (66), the donor candidate group (41), and 51 healthy individuals.	quantitative, cross-sectional comparative study	While the group differences for neither guilt nor shame reached statistical significance in the hemodialysis, recipient, and donor candidate groups, it was observed that hemodialysis patients exhibited the highest scores for depression, anxiety, and HRQOL.
The study participants included 17 young pregnant Indigenous women with experiences in substance use.	qualitative study (open-ended interviews)	Feelings of shame and guilt were strongly connected to low self-esteem, arising from the internalization of negative comments or behaviors from others, significantly affecting participants' emotional well-being.
The study participants included 23 individuals with COPD at different stages, from mild to severe.	qualitative study (interviews)	The study revealed a key theme focusing on feelings of guilt stemming from a self-inflicted illness due to smoking. This central aspect was connected to five coping strategies: making sense of existence, adapting to physical limitations, surrendering to fate, rationalizing the smoking-related cause, and ensuring adherence to daily medication.
The study involved 3 Asian American families.	qualitative study (case studies)	The themes identified from the interviews were encompassed family closeness, respect for hierarchy within the family, gender-defined roles, intergenerational tensions, preoccupation with shame, and limited emotional expressiveness.

cont. table 1

No.	Study	Aim	Country/ Ethnicity
10	Okazaki, S. (2000). Treatment delay among Asian-American patients with severe mental illness. *American Journal of Orthopsychiatry, 70*(1), 58–64, doi: 10.1037/h0087751	The study aimed to explore the degree of treatment delay and the factors linked to it among Asian-American patients seeking assistance for psychotic disorders at community outpatient mental health agencies.	USA
11	Abrams, R.D., & Finesinger, J.E. (1953). Guilt reactions in patients with cancer. *Cancer, 6*(3), 474–482, doi: 10.1002/1097-0142(195305) 6:3<474::aid-cncr2820060305 >3.0.co;2-p	The study aimed to evaluate the personality and emotional difficulties in cancer patients, shedding light on attitudes among patients and doctors.	USA
12	Cerna, A., Malinakova, K., Van Dijk, J.P., Zidkova, R., & Tavel, P. (2022). Guilt, shame and their associations with chronic diseases in Czech adults. *Psychology, Health & Medicine, 27*(2), 503-512, doi: 10.1080/13548506.2021.1903058	This study aimed to explore the possible association between feelings of guilt and shame and physical health, particularly in the context of chronic diseases and selected conditions.	Czech Republic
13	Gilbert, P. (2000). The relationship of shame, social anxiety and depression: The role of the evaluation of social rank. *Clinical Psychology & Psychotherapy, 7*(3), 174–189, doi: 10.1002/1099-0879 (200007)7:3<174::AID-CPP236> 3.0.CO;2-U	This study aimed to explore the links between shame, depression, and social anxiety using the social rank theory.	United Kingdom
14	Cantisano, N., Rimé, B., & Muñoz-Sastre, M.T. (2012). The social sharing of emotions in HIV/AIDS: A comparative study of HIV/AIDS, diabetic and cancer patients. *Journal of Health Psychology, 18*(10), 1255–1267, doi: 10.1177/1359105312462436	The study aimed to investigate variations in the social sharing of emotions among patients with HIV/AIDS, diabetes, and cancer.	Dominican Republic
15	Browne, J.L., Ventura, A., Mosely, K., & Speight, J. (2013). 'I call it the blame and shame disease': A qualitative study about perceptions of social stigma surrounding type 2 diabetes. *BMJ Open, 3*(11), doi: 10.1136/bmjopen-2013-003384	The study aimed to explore the social experiences of Australian adults dealing with type 2 diabetes mellitus (T2DM).	Australia

Sample description	Methodology	Findings
The study participants included a group of 62 Asian-American patients with psychotic disorders and 40 of their relatives.	mixed-methods study	In contrast to earlier observations of prolonged treatment delays in Asian Americans, this group demonstrated relatively low levels of stigma and shame. Extended treatment delays for patients were associated with elevated levels of shame and stigma experienced by their relatives.
The study included 60 participants with cancer.	qualitative study (interviews)	The study uncovered that patients' inclination to deny and avoid symptoms, hindering the pursuit of treatment, often stemmed from feelings of guilt.
The participants in the study comprised a nationally representative sample of 1000 Czech adults.	quantitative, cross-sectional correlational study	Respondents with elevated feelings of guilt, but not shame, were more prone to experiencing chronic diseases, including arthritis, back pain, cardiovascular disease, asthma, cancer, and depression or anxiety. The strongest association was observed in the case of cancer. No significant associations were found for diabetes and stroke, and feelings of shame were not correlated with chronic diseases.
The study included a group of 109 students and 50 individuals diagnosed with depression.	quantitative, cross-sectional correlational study	The results reveal a strong connection between shame, social anxiety, and depression (excluding guilt) with feelings of inferiority and submissive behavior.
The study participants included 35 HIV/AIDS outpatients, 35 diabetic outpatients, and 34 cancer outpatients.	quantitative, cross-sectional comparative study	The group with HIV/AIDS exhibited elevated levels of shame, guilt, and a reluctance to share illness-related emotions.
25 adults with T2DM were included as participants in the study.	qualitative study (interviews)	The study uncovered instances of social stigma experienced by individuals with T2DM.

cont. table 1

No.	Study	Aim	Country/ Ethnicity
16	Ho, L.P., & Goh, E.C. (2017). How HIV patients construct liveable identities in a shame based culture: The case of Singapore. *International Journal of Qualitative Studies on Health and Well-Being, 12*(1), 1333899, doi: 10.1080/17482631.2017.1333899	The study aimed to explore the process by which individuals diagnosed with HIV rebuild their identities after receiving the diagnosis.	Singapore
17	Dam, L., Cheng, A., Tran, P., Wong, S.S., Hershow, R., Cotler, S., & Cotler, S.J. (2016). Hepatitis B stigma and knowledge among Vietnamese in Ho Chi Minh City and Chicago. *Canadian Journal of Gastroenterology and Hepatology, 2016*, 1–8. doi: 10.1155/2016/1910292	The study aimed to define and contrast the comprehension and stigma linked to HBV within the Vietnamese communities in Ho Chi Minh City and Chicago. Simultaneously, it aimed to commence an evaluation of the cultural context surrounding HBV stigma.	Vietnamese people living in Ho Chi Minh City in Vietnam and Vietnamese people living in Chicago, USA
18	Walker, R.C., Walker, S., Morton, R.L., Tong, A., Howard, K., & Palmer, S.C. (2017). Māori patients' experiences and perspectives of chronic kidney disease: A New Zealand qualitative interview study. *BMJ Open, 7*(1), doi: 10.1136/bmjopen-2016-013829	The study aimed to uncover and articulate the experiences and viewpoints of Maori individuals living with chronic kidney disease.	New Zealand
19	Subandi, M.A., & Good, B.J. (2018). Shame as a cultural index of illness and recovery from psychotic illness in Java. *Asian Journal of Psychiatry, 34*, 33–37, doi: 10.1016/j.ajp.2018.04.005	The study aimed to explore the perceptions of shame in connection to psychotic illness among Javanese individuals.	Indonesia
20	El-Mansoury, T.M., Taal, E., Abdel-Nasser, A.M., Riemsma, R.P., Mahfouz, R., Mahmoud, J.A., El-Badawy, S.A., & Rasker, J.J. (2008). Loneliness among women with rheumatoid arthritis: A cross-cultural study in the Netherlands and Egypt. *Clinical Rheumatology, 27*(9), 1109–1118, doi: 10.1007/s10067-008-0876-2	The study aimed to explain loneliness as experienced by women with rheumatoid arthritis (RA) among Egyptian and Dutch female RA patients.	Egypt and the Netherlands

Sample description	Methodology	Findings
4 HIV patients (2 males and 2 females) participated in the study.	qualitative study (interviews)	The results revealed that even with the shift in the HIV trajectory from a terminal to a chronic condition, individuals living with HIV encounter challenges stemming from societal perceptions.
The sample included 842 participants from Ho Chi Minh City and 170 participants from Chicago.	quantitative, cross-sectional comparative study	Vietnamese residents in Chicago demonstrated heightened awareness of HBV but also exhibited higher stigma scores, including feelings of guilt and shame. Conversely, individuals in Ho Chi Minh City showed lower levels of HBV stigma.
The participants of this study included 13 Maori patients with CKD who were either nearing the need for dialysis or had started dialysis within the previous 12 months.	qualitative study (interviews)	The study uncovered that Maori concepts of whakama (disempowerment and embarrassment) and whakamana (enhanced self-esteem and self-determination) served as a comprehensive framework for interpreting the identified themes. These encompassed feeling disempowered by delayed CKD diagnosis, confronting the stigma of dialysis, developing and sustaining relationships to support treatment, and maintaining cultural identity.
The study included 6 psychotic patients and their family members as participants.	qualitative, ethnographic fieldwork	The data disclosed that participants utilized shame in three distinct ways. Firstly, it functioned as a cultural measure for illness and recovery; family members identified illness in the patient when a loss of shame was evident, and the return of shame was perceived as a sign of recovery. Secondly, shame was seen as a signal of relapse. Lastly, it was regarded as an obstacle to the recovery process.
The participants of this study included	quantitative, cross-sectional comparative study	The study found higher loneliness levels in Egyptian RA patients compared to Dutch. While low social support impacted loneliness in Dutch patients, it didn't in Egyptians. Egyptians also experienced more guilt about their condition than Dutch patients, despite similar pain and disability levels.

El-Mansoury et al. (2008) conducted a cross-cultural study comparing 36 Egyptian female RA patients with 140 female Dutch RA patients to explore loneliness within the context of rheumatoid arthritis (RA). The findings revealed that Egyptian patients reported higher levels of loneliness compared to their Dutch counterparts. Interestingly, while low social support was identified as a significant contributor to loneliness among Dutch RA patients, this association was not observed among Egyptian patients. Additionally, the study highlighted a comparison of RA patients in Egypt and the Netherlands, which found that Egyptian patients tended to experience greater feelings of guilt regarding their condition. Despite similar levels of pain and physical disability between the two countries, cultural influences, particularly feelings of guilt and shame, appeared to play a more prominent role in shaping the psychological experiences of RA patients in non-Western or developing nations.

Harrison et al. (2017) conducted a two-phase mixed-methods research endeavor to investigate the expression of self-conscious emotions, examining potential links to adverse health outcomes. The study aimed to compare these emotions between individuals with chronic obstructive pulmonary disease (COPD) and a control group of healthy individuals within a Canadian sample. The decision to choose questionnaires for assessing self-conscious emotions in individuals with COPD and healthy controls was guided by interviews conducted with 15 COPD participants. From these interviews, five main themes were identified: grief, a spectrum of blame, concern about the view of others, concealment, and worry about the future. Following this, the selected questionnaires were distributed to a total of 70 COPD patients and 61 healthy controls.

The qualitative results indicate that patients experience embarrassment due to concerns about how others perceive them. Consequently, individuals with COPD often worry about symptoms such as coughing and feel shame when coughing in front of others. In contrast, COPD patients described attempts to conceal their disability, often driven by guilt for contributing to their condition. According to the overall results of the study, COPD patients reported lower self-compassion, higher shame, and less pride than healthy controls.

Walker (2017) conducted a study on contemporary subjective experiences of people with HIV in the United Kingdom. This was a qualitative study that aimed to understand the experiences of being diagnosed and living with HIV. Furthermore, the author aimed to explore how the social experience of HIV changed in the light of biomedical development. A small-scale 40 online survey, structured around open-ended questions, was conducted alongside interviews with two individuals living with HIV who volunteered to participate. All participants had been diagnosed with HIV within the past five years. The analysis reveals three central themes: old narratives versus new knowledge; the experience of chronicity, manageability, and the impact of HIV on everyday life; and the societal perception of HIV as a 'social diagnosis,' including the pressures to normalize. The findings of the study revealed that there is a mixture of uncertain experiences and anticipated norms regarding people with HIV. Despite it

being a common health condition, there are still prevalent feelings of fear, shame, and stigma surrounding it, making it one of the most socially impactful diseases.

A comparative study on shame and coping strategies among individuals with multiple sclerosis (MS) and a control group was conducted in Poland by Furmańska et al. (2020). There were 60 people who participated in the study (30 patients with MS and 30 people in the control group. The study objective was to examine the extent of shame related to illness in individuals with MS compared to healthy individuals imagining themselves dealing with a chronic, incurable disease resulting in disability, a situation commonly perceived as challenging and exceptionally shameful. Additionally, the study aimed to assess the variations in coping strategies for shame between the two groups. The study found that both people with MS and the control group displayed similar levels of shame. Moreover, the coping strategies, including avoidance, self-blame, and blaming others, did not significantly differ between the groups. Although patients with MS were less inclined to use withdrawal as a coping mechanism compared to controls, their disease-related shame was linked to increased use of withdrawal and self-blame as strategies to cope with that shame.

Robertson et al. (2021) conducted a qualitative study investigating the experience of self-conscious emotions, including shame and embarrassment, among individuals with inflammatory bowel disease (IBD). Fifteen individuals with IBD were recruited from the clinic in the United Kingdom. The analysis of participant responses revealed two overarching themes, all centered around self-conscious emotions triggered by situations that challenged the participants' desired identities. The first theme, termed 'Lack of control,' highlighted the distress participants felt due to significant shifts in how they perceived themselves, and their efforts to regain a sense of stability in their identity. The second theme, named 'Lack of understanding,' encompassed the distress participants experienced when they became aware of being unfairly judged by others, adding to their emotional burden.

Taşkıntuna & Özçürümez (2011) conducted a study focused on end-stage renal disease (ESRD) and psychological trauma. This study was conducted in Turkey, a collectivistic country. There were four study groups: hemodialysis patients (56 individuals), transplantation recipients (66 individuals), donor candidates (41 individuals), and controls (51 individuals). The study aimed to assess whether the experience of shame and guilt has a negative effect on the mood and health-related quality of life among study groups. They hypothesized that individuals experiencing shame, stemming from negative self-evaluation, are likely to demonstrate higher scores in depression and anxiety, as well as lower health-related quality of life (HRQOL), compared to guilt, which is believed to result solely from a negative appraisal of one's behavior. However, according to the results of the study, hemodialysis patients reported higher depression, anxiety, and diminished HRQOL compared to the other three groups. However, there were no significant differences in shame and guilt. Interestingly, the control group in this study showed the highest shame scores. According to the author's interpretation of this result, the guilt and shame inventory (GSI) only assesses

the trait but not the state and it may not be appropriate in this kind of research. Furthermore, the Eastern culture-based self- consciousnesses is sensitive to seeing individuals confront hardships, such as organ loss and chronic diseases (Taşkıntuna & Özçürümez, 2011).

Summing up, the seven reviewed studies delve into the individual experiences of people with chronic diseases, particularly focusing on shame and guilt. Five studies were rooted in individualistic cultures. Among those, the Dutch study stood out by emphasizing the significance of demographic and psychological variables in assessing shame and guilt rather than disease-related factors, as the culture of the Netherlands is advanced in attitudes related to the longstanding RA. The cross-cultural study also underscored the significance of guilt and shame, which seemed to have a greater impact on shaping the psychological well-being of RA patients in non-Western or developing countries. Moreover, the Turkish study, representing a collectivistic culture, found no significant differences in shame and guilt scores among groups with end-stage renal disease but highlighted higher levels of depression, anxiety, and lower health-related quality of life in hemodialysis patients. This contrast underscores the need to understand cultural influences when examining emotions like shame and guilt in chronic illness contexts, offering valuable insights into both individualistic and collectivistic perspectives on coping with these emotions.

Category 2 – Risk Behaviors

There were two qualitative studies focused on shame and guilt and their relationship to risk behaviors. One was conducted in individualistic Swedish culture, with the participation of people with COPD (Lindqvist & Hallberg, 2010). Another was conducted among pregnant-involved indigenous women of Canada who were using psychoactive substances (Shahram et al., 2017).

According to Shahram et al. (2017), seventeen young Indigenous pregnant-involved women (defined as those who have experienced pregnancy between the ages of 14 and 30) and who had experienced substance use throughout their lives, including during pregnancy, were eligible to participate in a mapping activity called CIRCLES (Charting Intersectional Relationships in the Context of Life Experiences with Substances). During this activity, the women created maps and discussed how various social determinants affected their experiences with pregnancy and substance use. The women identified 10 themes to express the factors influencing their substance use. These themes included traumatic life histories, socioeconomic status, culture, identity and spirituality, shame and guilt, mental wellness, family connections, romantic and platonic relationships, strength and hope, mothering, and the intersections of these determinants. According to the findings, low self-esteem was closely related to feelings of shame and guilt. These emotions stemmed from internalizing negative remarks or actions from others, significantly impacting their emotional well-being. Actively working to reverse these internalizations was crucial for their wellness. Feeling judged

or unwelcome were major barriers to accessing community support, and some women hesitated to seek treatment due to shame from past attempts or fear of failure.

In the Swedish study, the data were obtained through interviews with 23 individuals at different stages of COPD, ranging from mild to severe. The resulting substantive theory highlighted the central concern of experiencing guilt attributed to a self-inflicted disease related to smoking habits. This core category was associated with five managing strategies termed making sense of existence, adjusting to bodily restrictions, surrendering to fate, making excuses for the smoking-related cause, and creating compliance with daily medication. Accordingly, the guilt was related to the participants' awareness of the strong association between smoking behavior and COPD. Moreover, they blamed themselves for bringing the disease into their own lives.

In conclusion, both studies, conducted in individualistic Swedish culture and in collectivistic indigenous Canadian culture, illustrate a pattern where individuals internalize guilt-associated with risky behaviors like substance abuse or smoking. This internalization of guilt and self-blame appears to be a common trend in these individualistic cultures, significantly impacting individuals' emotional well-being and their approach to seeking support or treatment.

Category 3 – Patient care

The literature review indicated three studies that were focused on patient care within the context of shame and guilt.

Mondia et al. (2011) conducted a qualitative exploration within the context of a randomized controlled trial focusing on family therapy initiated during palliative care and extending into bereavement. The study delved into the experiences of 3 Asian American families, aiming to understand the impact of the Asian American value system on palliative care dynamics. The findings revealed distinctive themes, including family closeness, respect for hierarchy within the family, gender-determined roles, intergenerational tensions, preoccupation with shame, and limited emotional expressiveness. These insights underscored the intricate nature of Asian American, collectivistic, cultural values. It emphasized the necessity for family therapists to thoughtfully consider and integrate these nuances into their approach, ensuring culturally sensitive care tailored to the unique needs of each family unit during palliative care and bereavement. Okazaki (2000) investigated treatment delay patterns in a less acculturated group of Asian Americans dealing with severe mental illness. In contrast to previous research, Okazaki's study discovered that these individuals and their families were thoughtful consumers of mental health services. However, the research revealed a paradoxical connection: higher levels of shame and stigma experienced by family members were associated with prolonged treatment delays for patients in a cohort of 62 Asian-American patients with severe mental illness and 40 of their relatives. This cohort reported relatively low levels of stigma and shame and a relatively short delay between the onset of psychiatric symptoms and the inception of treatment.

Additionally, Abrams & Finesinger's (1953) studied guilt reactions among cancer patients at Massachusetts General Hospital. The participants were a group of 60 patients with cancer. The study aimed to (1) assess the perspectives of both patients and their families regarding the diagnosis of a malignant tumor, (2) investigate how these attitudes impact the patients, and (3) propose a strategy for enhancing the care of individuals diagnosed with cancer. Their investigation revealed that patients' denial and avoidance of symptoms, significantly hindering treatment seeking, were often rooted in feelings of guilt.

Overall, these three studies underscore the imperative of recognizing culture-specific manifestations of guilt and shame in chronic diseases, particularly among diverse ethnic groups like Asian Americans. Understanding these cultural intricacies is crucial for tailoring healthcare interventions that effectively address emotional barriers and optimize treatment-seeking behavior among affected individuals and their families.

Category 4 – Social attitudes/ stigma

The literature review distinguished four works that described the effect of social attitudes/stigma related to chronic diseases. Two of them have been conducted in individualistic cultures (Browne et al., 2013; Cerna et al., 2022; Gilbert, 2000) and one in a collectivistic culture (Cantisano et al., 2012).

Cerna et al. (2022) conducted a study exploring the association between guilt and shame and chronic physical health conditions in Czech adults. The survey, which included 1000 participants, specifically examined eight selected chronic diseases: arthritis, asthma, back pain, cancer, cardiovascular disease, depression, diabetes, and stroke. The findings showed that feelings of guilt were associated with physical health, while feelings of shame were not. According to the authors, the impact of guilt on the quality of life of individuals with chronic diseases has been extensively explored in the literature. However, it is essential to recognize that guilt can also directly contribute to the onset and progression of the chronic disease. Therefore, it should be regarded as a significant subject within the clinical domain (Cerna et al., 2022).

Gilbert (2000) conducted a study in the UK that explored the associations between shame, depression, and social anxiety from the perspective of social rank theory. This theory argues that emotions and moods are significantly influenced by the perception of one's social status or rank. In this research, a group of 109 students and 50 individuals diagnosed with depression completed a set of self-report questionnaires specifically crafted to assess diverse facets of shame, guilt, pride, social anxiety, depression, and social rank (including self-perceptions of inferiority and submissive behavior). Results confirmed that shame, social anxiety, and depression (but not guilt) are highly related to feeling inferior and submissive behavior (Gilbert, 2000).

Cantisano et al. (2012) conducted a study in the collectivistic culture of the Dominican Republic to explore the nature of social emotion sharing among individuals living with HIV/AIDS. The study included 35 participants with HIV/AIDS, 35 with

diabetes, and 34 with cancer. According to the findings, the group of individuals with HIV/AIDS, comprising 35 participants, scored higher in shame, guilt, and reluctance to share emotions linked to their illness compared to individuals with diabetes or cancer. They also showed reduced instances of socially sharing these emotions and had fewer partners with whom they shared their feelings due to the nature of their chronic condition. The authors suggested that future research could focus on comparing how individuals living with HIV/AIDS are socially situated within individualistic and communal sociocultural settings.

A qualitative study (Browne et al., 2013) about perceptions of social stigma surrounding type 2 diabetes mellitus (T2DM) was conducted among individuals with T2DM living in Victoria State, Australia. The study included 25 participants who indicated that T2DM carried a social stigma or provided instances indicating the presence of such stigma. Key themes related to this stigma experience included feeling personally responsible for their condition and facing blame from others, encountering negative stereotypes, experiencing discrimination, and having limited life opportunities as a result.

These studies collectively demonstrate how individualistic and collectivistic cultural perspectives influence emotions like guilt, shame, and social stigma in the context of chronic diseases. Individualistic cultures emphasize personal responsibility and emotions' impact on health, while collectivistic cultures show how social attitudes and stigma affect individuals' experiences within the community.

Category 5 – Self-perception

The literature review indicated four articles centered on how people with chronic illnesses perceive themselves and their condition within the context of their collectivistic cultural backgrounds.

Accordingly, Ho & Goh (2017) conducted qualitative research on how patients with HIV construct liveable identities in a shame-based culture in Singapore. They interviewed four patients with HIV (two males and two females) and uncovered that the evolution of HIV from a terminal to a chronic illness has not eased the challenges faced by those living with it, especially in Asian societies where there is significant fear and stigma surrounding HIV. People diagnosed with HIV often experience profound shame initially and must navigate this by reshaping their identities, containing that sense of shame, reinforcing their usual selves, and building new identities.

The comparative study conducted by Dam et al. (2016) sought to examine the levels of knowledge on hepatitis B virus (HBV) and the related stigma among 842 Vietnamese individuals residing in Ho Chi Minh City and 170 individuals in Chicago. The aim was to compare these two groups living in distinct cultural contexts and explore their understanding of HBV as well as the associated stigma within their respective communities. According to the findings, Vietnamese residents in Chicago showed greater awareness about how HBV spreads and its potential to cause chronic

infection and liver cancer. However, they also exhibited higher levels of stigma associated with HBV, feeling more guilt and shame about the disease and being more inclined to believe that those with HBV could harm others and should be isolated. In contrast, individuals in Ho Chi Minh City displayed lower levels of HBV stigma compared to Vietnamese living in Chicago, indicating shifting cultural attitudes in Vietnam. Authors claim that to combat HBV stigma, there's a need for culturally tailored educational campaigns.

Walker et al. (2017) looked into and described how Maori people, New Zealand's indigenous population, experience and perceive chronic kidney disease (CKD). This qualitative study aimed to uncover more about what CKD means for indigenous groups, which has not been widely studied before. Thirteen CKD patients who were near to or undergoing dialysis participated in interviews. Regret and self-blame, confronting the stigma of kidney disease, associated multigenerational fear, as well as shame and embarrassment were some of the themes identified in this study. Moreover, the authors have used two concepts of Maori, which are whakama (disempowerment and embarrassment) and whakamana (enhanced self-esteem and self-determination), as an overarching framework for interpreting the identified themes. The findings of the study highlighted that Maori individuals with CKD felt pushed to the sidelines in the New Zealand healthcare system because of late diagnoses. Moreover, problems such as the focus on individuals instead of families, longstanding concerns about dialysis across generations, and patient's belief that healthcare providers were not considering their cultural beliefs and values when making decisions, were identified.

An exploratory study was conducted on the complex Javanese meaning of shame in relation to psychotic disorders by Subandi & Good (2018). The study involved six individuals with psychosis and their families, and the research was carried out through ethnographic fieldwork conducted in Yogyakarta, Indonesia. The thematic analysis revealed that participants saw shame in three distinct ways. Initially, it served as a cultural measure for gauging illness and recovery; when someone lost their sense of shame, family members considered them ill, and the return of shame indicated recovery. Secondly, shame was seen as a sign of relapse. Lastly, it was perceived as an obstacle hindering the path to recovery.

The studies conducted by Ho & Goh (2017), Dam et al. (2016), Walker et al. (2017), and Subandi & Good (2018) provide nuanced insights into how individuals with chronic illnesses perceive their conditions within diverse cultural contexts. Ho & Goh's (2017) research on patients with HIV in Singapore illuminates the ongoing challenges faced by individuals with HIV, emphasizing the significant role of shame in shaping their identities in a culture marked by stigma. Dam et al.'s (2016) comparative study between Vietnamese communities in Ho Chi Minh City and Chicago highlights the differing levels of awareness and stigma associated with the hepatitis B virus, shedding light on cultural influences on disease perception. Walker et al.'s (2017) exploration of chronic kidney disease among Maori individuals in New Zealand unveils

themes of regret, shame, and systemic marginalization within the healthcare system, emphasizing the importance of cultural considerations in healthcare delivery. Finally, Subandi & Good's (2018) study on Javanese perspectives of shame regarding psychotic disorders demonstrates multifaceted cultural interpretations of shame as a gauge for illness, recovery, relapse, and as a barrier to recovery. Altogether, these studies underscore the intricate interplay between cultural backgrounds and self-perception of chronic illnesses, emphasizing the necessity of culturally sensitive approaches in healthcare as well as understanding and addressing the experiences of individuals living with chronic conditions. The studies also underscore the challenges of changing perceptions within collectivistic cultures and the importance of considering whole families and self-conscious emotions, like shame, in addressing chronic diseases within cultural contexts.

Discussion

The scoping review of 19 papers highlights the significant role of cultural influences in shaping emotional responses to chronic diseases. More specifically, the effect of culture on individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception has been considered.

When considering the cultural influence of shame-proneness and guilt-proneness among individuals with chronic diseases, specific features associated with individualistic cultures have been identified. These include the influence of awareness (being educated of their disease, including its symptoms, treatments, and management strategies), personal and social factors (social support networks and personal beliefs) over clinical factors, access to advanced treatments, and the advantage of guilt over shame. Moreover, feelings of fear, shame, and stigma despite certain chronic diseases being common health conditions were noticed.

The influence of one's cultural background on the perception of chronic diseases seems to persist even after changing the place of residence. It is observed that individuals who have experienced stigma-associated diseases in their native culture may continue to experience heightened levels of guilt and/or shame in a host culture, even if the latter is perceived as more secure for them (Dam et al., 2016).

The studies conducted in the Netherlands by Tom Klooster et al. (2014), El-Mansoury et al. 2008) and Harrison et al. (2017) in Canada have underscored that shame and guilt related to chronic diseases are primarily linked to the psychosocial and demographic characteristics of individuals rather than solely to the clinical and physical aspects of the disease. Additionally, these studies have emphasized that advancements in treatments and increased societal awareness can contribute to reducing the stigma associated with chronic diseases. Consequently, tailored interventions considering these sociocultural nuances could potentially alleviate the emotional impact of chronic conditions. Nonetheless, individuals with chronic diseases tend to experience guilt more frequently than shame in individualistic societies (Cerna et al., 2022; Abrams & Finesinger, 1953; Lindqvist & Hallberg, 2010), which is a finding supported by the research of You (1997) and Wolf et al. (2009).

According to Walker (2017) and Cantisano et al. (2012), individuals living with HIV/AIDS in the United Kingdom and the Dominican Republic, respectively, continue to experience shame and guilt and are often reluctant to share illness-related emotions due to the highly socially impactful nature of the disease, irrespective of the individualistic nature of the society. This underscores that certain chronic diseases remain deeply stigmatized regardless of the societal context, emphasizing the persistent challenges faced by individuals living with such conditions.

Moreover, the studies conducted by Okazaki (2000), Mondia et al. (2011), and Dam et al. (2016) draw attention to the influence of native culture over host culture in determining shame proneness and guilt proneness in chronic diseases. For instance, Okazaki (2000) and Mondia et al. (2011) found that Asian American families were preoccupied with shame, limited emotional expressiveness, and delays in seeking treatment for chronic diseases, regardless of their residence in individualistic societies. Furthermore, Dam et al. (2016) highlighted a higher sense of shame, guilt, and stigma experienced by Vietnamese people living in Chicago, USA, compared to those residing in Ho Chi Minh City, Vietnam specifically regarding HBV. These findings underscore the enduring impact of cultural norms and values on individuals' experiences of shame and guilt, regardless of their geographical location.

Considering the cultural influence of shame proneness and guilt proneness related to chronic diseases encountered by individuals in collectivistic cultures, it has been observed that individual well-being is determined by social perception, even though illness trajectories have improved positively over time. Specifically, Ho & Goh (2017) provided an example of the social challenges faced by individuals with HIV, notwithstanding medical advancements. Furthermore, some collectivistic cultures employ shame as a cultural index for chronic diseases. According to Subandi & Good (2018), shame has been identified as an indicator of recovery, relapse, and inhibitors to the recovery of psychotic illness. This research finding emphasizes the complex role of shame in chronic diseases within collectivistic cultures.

Moreover, in collectivist cultures, there tends to be a greater emphasis on interconnectedness and concern for others within the community. Therefore, individuals from these cultures may be more sensitive towards those dealing with chronic diseases or facing challenges such as the loss of an organ, potentially leading to heightened feelings of shame (Taşkıntuna & Özçürümez, 2011).

Clinical Implication

Understanding the significant role of cultural influences in shaping emotional responses to chronic diseases has important implications for clinical practice. Healthcare professionals need to recognize the diverse cultural backgrounds of their patients and the impact that these cultural factors can have on the experiences of shame and guilt

related to living with chronic illnesses. Tailored interventions that take into account sociocultural nuances, such as awareness of cultural attitudes towards shame and guilt, can help mitigate the emotional impact of chronic conditions on patients. Additionally, increased societal awareness and advancements in treatments can contribute to reducing the stigma associated with chronic diseases. Clinicians should prioritize cultural competence and sensitivity in their approach to patient care, ensuring that individuals from all cultural backgrounds receive appropriate support and treatment for their chronic illnesses. By acknowledging and addressing the cultural dimensions of shame and guilt-proneness, healthcare providers can better support patients in coping with the emotional challenges of living with chronic diseases.

Study strengths

The study excels in conducting a cross-cultural analysis of shame and guilt experiences among individuals with chronic diseases. It encompasses a diverse range of chronic conditions, providing a broad examination of shame and guilt. Utilizing a qualitative approach, the study deeply explores individual experiences, risk behaviors, patient care, social attitudes/stigma, and self-perception. The current scoping review allowed to form clinical implications, emphasizing the need for culturally-tailored interventions.

Furthermore, the study highlights cultural nuances, recognizing the impact of individualistic values in societies like Canada and Sweden, as well as the role of collectivistic values in family-centered support. Despite cultural differences, the research identifies commonalities in emotional experiences, challenging the notion that cultural collectivism solely dictates responses in chronic diseases. The study also provides insights into societal attitudes, uncovering how broader cultural beliefs influence the emotional landscape of individuals with chronic diseases.

Limitations and future directions

The current review had some limitations that need to be underlined. Firstly, our review was not a systematic literature review (SLR). Instead, we employed the scoping review method as it allowed us to include more studies than the SLR would include (Arksey & O'Malley, 2005). In 8 out of 19 reviewed studies culture was not one of the studied constructs, yet it was specified in the sample description (as ethnicity or nationality). Therefore, we could put the results of the studies on chronic conditions and feelings of shame and guilt into specific cultural contexts. Although we employed a different methodological approach, we believe that it would be beneficial if future studies on feelings of shame and guilt among people with chronic conditions across various cultures could employ SLR.

Secondly, the reviewed studies' designs were cross-sectional. Therefore, inferring causality in studied relations is not possible. Thirdly, many of these studies were

conducted with a small number of participants; therefore, their results were underpowered. However, one should note that while studying chronic conditions it is often difficult or even impossible to reach a big sample (e.g., in case of rare genetic conditions). Fourthly, the analyzed studies concerned people with various chronic conditions; therefore, their results are characterized with low generalizability. Regardless of that, the review of these studies provides valuable information that may inspire future studies, foster the understanding of the emotional challenges of people with chronic conditions across cultures, and thus help in organizing culturally tailored patient care, support, and decreasing the disease-related stigma.

Conclusion

The current literature review underscores the intricate interplay between cultural backgrounds, emotional experiences, and perceptions of chronic diseases. While individualistic cultures seem to influence the manifestation of self-conscious emotions, like shame and guilt, these responses are also shaped by demographic and psychosocial factors. In contrast, collectivistic cultures seem to exhibit more universal and deeply rooted perceptions influenced by familial and societal values.

The findings underscore the importance of tailoring interventions to accommodate cultural diversities, promoting comprehensive family-centered support within collectivistic cultures, and addressing nuanced emotional dynamics in individualistic societies. Recognizing these subtleties is crucial in fostering a more inclusive and empathetic environment for individuals with chronic diseases, transcending cultural barriers to provide holistic care and support.

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MIĘDZYKULTUROWE RÓŻNICE W ZAKRESIE PRZEŻYWANIA WSTYDU I POCZUCIA WINY PRZEZ OSOBY Z CHOROBAMI PRZEWLEKŁYMI – PRZEGLĄD ZAKRESU LITERATURY

Streszczenie. Niniejszy przegląd zakresu literatury zgłębia złożoność emocji, jakich doświadczają osoby z chorobami przewlekłymi, koncentrując się na wstydzie i poczuciu winy w różnych kontekstach kulturowych. Analiza literatury zwraca uwagę na ważną rolę jaką pełnią wstyd i poczucie winy w życiu osób z chorobami przewlekłymi oraz na konieczność zwiększania świadomości uwarunkowań kulturowych towarzyszących tym emocjom. Wyniki wskazują na konieczność tworzenia dopasowanych kulturowo interwencji oraz włączania wrażliwości kulturowej podczas rozważań na temat wstydu i poczucia winy w chorobach przewlekłych.

Słowa kluczowe: wstyd, poczucie winy, skłonność do przezywania poczucia wstydu, skłonność do przeżywania poczucia winy, choroby przewlekłe, kultura

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All Good Without Anything Good. Beyond Survival: Understanding the Psychosocial Experiences of Individuals With Chronic Kidney Disease and Their Caregivers in Sri Lanka

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ABSTRACT

Aim: This study aims to explore the experiences of individuals with chronic kidney disease (CKD) undergoing haemodialysis and their caregivers, focusing on the disease's impact and the treatment process.

Background: In Sri Lanka, CKD is a growing health concern, particularly affecting farming communities and contributing to the strain on the biomedical healthcare system. Despite increasing awareness of CKD's physical implications, its psychosocial impact remains underexplored. This study seeks to fill this gap, aiming to inform culturally sensitive interventions and improve the healthcare system's responsiveness to the unique needs of Sinhala Buddhist individuals with CKD and their caregivers.

Design: An exploratory qualitative study.

Method: Semistructured interviews were conducted with 10 individuals undergoing haemodialysis and 5 caregivers at a dialysis unit. The interviews were audio-recorded, transcribed and analysed using conventional qualitative content analysis.

Findings: The analysis revealed three interrelated main themes: (1) impact on standard of living (quality of life), (2) coping strategies and (3) medical experience, with a notable influence of traditional beliefs and practices.

Conclusion: The findings highlight the need for a holistic approach to CKD management that integrates physical, emotional, psychological and social aspects, considering the significant role of traditional influences. Further research is essential to develop effective interventions that can enhance the quality of life for CKD.

Patient or Public Contribution: The lived experiences of Sinhala Buddhist individuals with CKD and their caregivers served as a cornerstone, providing profound insights into the impact of the condition on their lives. Throughout the study, these participants played an instrumental role in refining the research's cultural sensitivity and relevance. Their engagement extended beyond the data collection phase to encompass feedback sessions, where they actively shared their perspectives. This ongoing collaboration ensured the study's depth and applicability to real-world experiences. By actively involving those directly affected by CKD, this collaborative approach safeguards that the study remains rooted in their voices and addresses their unique needs.

Reporting Method: This study adhered to relevant EQUATOR guidelines (the COREQ checklist).

Trial Registration: This study is not a clinical trial, and thus, registration is not applicable.

1 | Introduction

Chronic Kidney Disease (CKD) represents a significant global health challenge, impacting millions of individuals worldwide, including in Sri Lanka [1, 2]. Over the past three decades, the prevalence of CKD in Sri Lankan farming communities has notably increased, primarily due to two factors: the emergence of Chronic Kidney Disease of Unknown Aetiology (CKDu) and a rise in non-communicable diseases such as hypertension and diabetes mellitus within the population [3].

CKD is defined as a decline in kidney function, characterized by a glomerular filtration rate (GFR) below 60 mL/min per 1.73 m^2, or evidence of kidney damage that persists for at least 3 months, irrespective of the underlying cause [4]. The increasing prevalence of CKD is predominantly driven by hypertension and diabetes [5, 6].

As of 2017, the global incidence of CKD was reported to be increasing by approximately 8% annually [7], and it is listed among the top 20 causes of death worldwide [8]. Developing countries are experiencing a significant surge in end-stage renal disease (ESRD), with a reported 70% increase, largely attributed to the high costs associated with treatment [9]. Moreover, in these nations, access to adequate dialysis facilities is often limited, which adversely affects survival rates for many individuals with CKD [10].

Abraham et al. [11] highlighted the impact of ethnicity on CKD prevalence, observing lower rates in white populations compared to Asians. They pinpointed South Asia as an ESRD 'hotspot', attributing this to several challenges, including limited access to healthcare, inadequate patient registries and deficiencies in early disease detection and management.

CKD typically progresses insidiously, often leading to the loss of up to 90% of kidney function before symptoms become apparent, eventually resulting in end-stage kidney disease (ESKD) or ESRD [12]. According to the National Kidney Foundation's criteria (2002), CKD is categorized into five stages based on the degree of kidney function, with Stage 5 being ESRD. Conservative management is generally recommended through the earlier stages, but by Stage 5, when ESRD is reached, renal replacement therapies such as dialysis or kidney transplantation become necessary [13].

Haemodialysis, a primary treatment for CKD globally, presents significant challenges due to its demanding schedule, typically requiring lengthy sessions three times a week [14, 15]. While it extends life, haemodialysis often leads to a diminished quality of life for both patients and their families, affecting them physically, psychologically, and socially [16, 17]. ESRD, in particular, profoundly impacts various aspects of patients' lives, including familial relationships, education, finances, professional activities, physical health, social interactions and mental wellbeing [15].

Mckercher et al. [18] emphasize CKD as a global health threat that has not been adequately addressed. The journey of the disease is marked by disabling symptoms, dietary restrictions, social limitations and stigma, all of which significantly impact patients' lives [19]. CKD also adversely affects mental health, thereby influencing the overall Health-Related Quality of Life (HRQOL) [20]. Research by Adejumo et al. [8] underscores the critical role of caregivers in patient care, highlighting that they often face unmet psychological needs. Notably, female caregivers are particularly susceptible to depression, anxiety and a sense of burden. Therefore, integrating supportive interventions for caregivers into treatment guidelines is essential to improve patient outcomes.

In Sri Lanka, the health sector, already under significant strain, faces potential cutbacks in critical services such as dialysis and transplants [21]. Senanayake et al. [20] indicate that Sri Lankan CKD patients experience high levels of psychological distress and depression. Ranasinghe and Ranasinghe [22] emphasize the necessity for enhanced psychosocial support, improved financial allowances and optimized resource utilization in the fight against CKD. Liyanage [23] advocates for an ethno-medical approach, stressing the importance of cultural competency in healthcare to effectively bridge the gap between communities and hospitals. Furthermore, Wijayath [24] acknowledges the benefits of the global human rights framework in addressing CKD but points out that Sri Lanka's local capacity to deal with the disease is currently inadequate.

During the British colonial era, Sri Lanka's healthcare system underwent a significant transformation with the adoption of biomedicine, a shift that Mills [25] notes was largely insensitive to the country's traditional cultural practices. Liyanage [23] further critiques this approach, highlighting its neglect of the psychosocial and cultural dimensions of health risks. She emphasizes the need for more comprehensive research to understand the bio-psychosocial needs of CKD patients, advocating for a more integrated approach in healthcare delivery.

The primary objective of this study is to delve into the psychosocial experiences and treatment journeys of individuals diagnosed with CKD and their caregivers. By gaining a deeper understanding of their unique bio-psychosocial needs, the study aims to identify ways to more effectively integrate these needs into the current healthcare framework, thereby enhancing the overall quality of life for these individuals.

2 | Materials and Methods

2.1 | Procedure

This qualitative research is part of a broader mixed-method study that investigates the psychosocial wellbeing of individuals with CKD undergoing haemodialysis, as well as their caregivers, across Sri Lanka and Poland. Before their participation, all participants received an informational document detailing the study's objectives, and their explicit consent was duly obtained. The data collection phase involved conducting semi-structured interviews, based on prepared schedules, within the haemodialysis unit of the National Hospital, Kandy, Sri Lanka. The interviews were conducted by the principal investigator, an accomplished female researcher experienced in qualitative research, a university lecturer with an MSc and a psychologist. The data collection

period spanned from 1 October to 31 October 2022. The research team's deep interest in the research topic, particularly the wellbeing of individuals with chronic diseases, motivated a nuanced exploration, ensuring a comprehensive understanding of the participants' experiences. All team members had backgrounds in psychology and/or psychotherapy, enabling them to offer appropriate debriefing and, when necessary, provide patients with psychological support. This study was reported using the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist [26] (File S1).

2.2 | Participants

The study involved a total of 15 participants, comprising 10 patients with CKD and 5 caregivers of individuals suffering from CKD. Among these participants, there were 8 females (53%) and 7 males (47%), with an average age of 48 years. The demographic characteristics of the sample are presented in Tables 1 and 2. Purposive sampling, aimed at meeting specific research outcomes, was conducted in line with the criteria defined by Bulathwatta et al. [27]. The inclusion criteria for the study were individuals diagnosed with stage V CKD, currently undergoing haemodialysis treatment, aged between 18 and 70 years and having received CKD treatment for more than 6 months. Additionally, participants were selected based on nationality and religion, specifically those of Sinhala nationality and Buddhist faith. This study is part of a larger mixed-method project aimed at comparing individuals of Sinhala nationality with Buddhist faith and Polish nationality with the Catholic faith. The inclusion criteria specifying Sinhala nationality and Buddhist faith were chosen for the Sri Lankan segment of the study to ensure cultural and religious homogeneity, which is crucial for the validity of the comparisons being made. By focusing on these specific criteria, we aim to control for cultural and religious variables, making it more convenient and consistent to gather data in Sri Lanka. This approach allows us to isolate the effects of nationality and religion on the study outcomes more effectively.

It is important to note that the presence of comorbidities was not considered in the inclusion criteria.

Conversely, the exclusion criteria for the study include individuals who do not meet the aforementioned inclusion criteria, those who are unwilling to provide consent and individuals who lack the physical or mental capacity to participate in the study.

For caregivers, the inclusion criteria include being identified by individuals with CKD as significant supporters, irrespective of the nature of their relationship (such as friend, spouse, child, sibling or parent), and being aged 18 years or older. Similar to the participants, caregivers who do not meet these inclusion criteria, who refuse to provide consent or who lack the necessary physical or mental capacity are excluded from the study.

TABLE 1 | Demographic characteristics of the participants (patients).

Participant code	Age (years)	Sex	Religion	Employment	Duration of the disease	Marital status
1	54	Female	Buddhist	Unemployed	2 years	Single
2	47	Male	Buddhist	Cemetery worker	9 months	Married
3	58	Male	Buddhist	Farmer	1 year	Married
4	61	Male	Buddhist	Unemployed	1 year	Married
5	59	Female	Buddhist	Retired Clerk	1 year	Married
6	57	Female	Buddhist	Traditional Sinhala Medicine practitioner	7 months	Married
7	39	Male	Buddhist	Unemployed	1 year	Single
8	24	Male	Buddhist	Unemployed	3 years	Single
9	45	Female	Buddhist	Unemployed	10 years	Single
10	58	Male	Buddhist	Retired Postman	1 year	Married

TABLE 2 | Demographic characteristics of the participants (caregivers).

Participant code	Age (years)	Sex	Religion	Employment	Caregiver relationship	Months of caregiving	Marital status
11	23	Male	Buddhist	Unemployed	Son	1 year	Single
12	47	Female	Buddhist	Factory worker	Wife	9 months	Married
13	52	Female	Buddhist	Unemployed	Mother	3 years	Married
14	52	Female	Buddhist	Factory worker	Wife	1 year	Married
15	51	Female	Buddhist	Unemployed	Wife	1 year	Married

2.3 | Data Collection

The data collection phase consisted of face-to-face interviews conducted using semi-structured interview schedules. These interviews, which ranged in duration from 35 to 60 min, were focused on exploring the participants' experiences with CKD. The process of data collection was continued until data saturation was reached, ensuring a comprehensive understanding of the participants' perspectives.

All interviews were audiotaped and initially transcribed verbatim in Sinhala. Subsequently, these transcripts were translated into English by an experienced researcher. To ensure accuracy and reliability, the English translations were then retranslated back into Sinhala. Independent researchers within the research team cross-checked these translations to confirm that all nuances were accurately captured in the English version. For quality assurance, the transcribed materials were returned to the participants, allowing them the opportunity to comment and correction to ensure the fidelity of their narratives. Following this feedback loop, the finalized transcripts were utilized for the content analysis of the interviews.

2.4 | Data Analysis

In this study, we employed an inductive approach, utilizing conventional content analysis to scrutinize the narratives derived from interviews, among other sources. This method entails a thorough examination of the content or contextual meaning within the text data, aiming to extract insights and deepen our understanding of the phenomenon being studied. We can characterize it as a systematic procedure of coding textual data to identify patterns, themes and relationships. Such analysis is highly versatile and can be applied to a wide range of written materials, regardless of the data collection techniques used. It is crucial in enhancing our grasp of individuals' perceptions and their lived experiences. Furthermore, the employment of open-ended questions as an analytical tool significantly contributed to the depth of the study, aligning with a manifest analytical approach [28, 29].

Coding was carried out independently by two experienced researchers, each working to develop themes, categories and sub-categories. This method, known as triangulation, aims to reduce potential biases that might arise from varying interpretations of the data by different researchers. In line with the guidelines proposed by Elo and Kyngäs [30] having at least two people encode the data independently is crucial for ensuring a more objective analysis. After completing their independent analyses, the researchers then convened to finalize the organization of the data and to reach a consensus on their findings.

2.5 | Ethical Considerations

All participants were provided with comprehensive information regarding the scope and procedures of the study. Participation was entirely voluntary, and they were assured that they could withdraw at any time without any repercussions. To ensure confidentiality, each participant was assigned a unique encrypted identifier, guaranteeing their anonymity. Access to the collected data was strictly limited to members of the research team. The study received ethical approval from the Ethical Review Committee of the Open University of Sri Lanka, under the application number ER/2022/007.

3 | Findings

After analyzing data from individuals with CKD and their caregivers, three main themes emerged: (a) standard of living (quality of life), (b) coping strategies and (c) medical experience (refer to Table 3). Notably, these themes were found to be mutually interconnected. Interestingly, the 'power of tradition' was observed to influence all three themes (see Figure 1).

3.1 | Theme 1: Standard of Living (Quality of Life)

The quality of life for individuals with CKD and their caregivers is impacted by three factors: work life, family life and everyday life.

3.1.1 | Work Life

The work lives of individuals with CKD and those undergoing dialysis treatment have been significantly impacted. Nearly all respondents discussed how their jobs were affected by these conditions. Some faced difficulties in continuing their jobs, while others had to stop working altogether, leading to early retirement. For example: participant 8 expressed: *While I am capable of working, the necessity of undergoing dialysis twice a week makes maintaining regular employment unfeasible. Taking two days off every week is not something I can afford.*

3.1.2 | Family Life

The impact of CKD on family dynamics varies depending on the patient's role within the family. Half of the patients surveyed (5 out of 10) spoke directly about the negative effects of the disease on family relationships. Primarily, the results highlighted how the disease impacts family members and intimate relationships. Unmarried individuals often feel isolated, receiving limited support from siblings due to their family commitments and economic constraints. The participants noted that some of their close relatives and friends distanced themselves after they fell ill, avoiding close relationships due to the disease. For example: participant 3 expressed: *I have two younger brothers who live nearby; one resides just half a kilometer away, and the other is even closer. Yet, despite the short distance of less than 1 kilometer, they haven't visited me since I became ill. This is in stark contrast to our previously close relationship, as they have distanced themselves from me after my illness.*

TABLE 3 | Themes, categories and subcategories that emerged from the data.

Themes	Categories	Subcategories	Supported evidence/narratives
Standard of living (quality of life)	Work-life	Looking for a job	Participant 8, despite having qualified for university through a competitive examination, was compelled to discontinue their education owing to the challenges posed by CKD and the demands of haemodialysis treatment. Additionally, his health condition significantly hindered his ability to find employment. *Beyond these challenges, my ability to focus on education has been severely impacted, and I deeply miss engaging in my studies. The nature of my condition prevents me from undertaking strenuous work. Additionally, I frequently experience fatigue, which significantly affects my capacity to work at the same level as others. While I am capable of working, the necessity of undergoing dialysis twice a week makes maintaining regular employment unfeasible. Taking two days off every week is not something I can afford.*
			Participant 11, a 23-year-old son and a caregiver to his father, explained the difficulty of finding a job because he has to take care of his father. *In his words, 'I have so many challenges. Useless to tell (He was smiling). This is the time I should be starting my life. I have many challenges such as earning money, building a house, buying a car—everything. I do not have anything. I have to start from zero'.*
		Difficulties in keeping the job	Participant 1, who was formerly a practitioner of traditional Sinhala medicine, encountered significant challenges in transitioning to a life with dialysis. The demands of the dialysis treatment led to the closure of her shop, where she previously sold traditional remedies. Now, she has adapted by offering treatments at her home to those who visit her. *I lost my job, and life has become more difficult since I could no longer work. Managing expenses became challenging; for instance, I had to pay Rs. 20,000* [$ 62] in *rent for my shop per month, along with electricity bills, which led me to close it. Now, if someone seeks treatment, I provide it at home. However, the cost of bus fares to get to my treatments is high. I need to dedicate around 20 days each month to treatment and tests, which is quite stressful. This situation was a key factor in my decision to close the shop. As a result, my income has significantly decreased.*
			Participant 2 expressed that his wife stopped the job as she has to take care of him. *My wife stopped going to work after working for about 11 or 12 years. She stopped because of my condition. I have been requesting her to go back, but she isn't listening to me. For the past week, she has been firmly telling me that she will not go back to work. She is refusing because she wants to take care of me.*
		Losing the job	Participant 5, along with her husband, resigned from their jobs due to the demands of her illness and treatments. As she explained; *I did not retire. I faced many obstacles at once, so I resigned. First, I had some difficulties such as a poor appetite and vomiting. I also had high blood sugar. But no one told me that I had a problem with my kidneys. It was only at this hospital that I found out about my kidney problem. Since then, I have been coming here for medications and treatments.*
			Her husband, who has been an excellent caretaker, took on the responsibility of managing all household chores effectively. *He limits his outings to only essential errands, like buying groceries and medicine. Apart from that, he is always by my side, assuring me to call him whenever I need anything. He was previously employed at the electricity board and had the option to continue working there until the age of 65. Yet, due to my illness, he felt compelled to resign as well, since there was no one else available to assist me. He became the one to take me to the hospital for my treatments* [Her voice conveyed a sense of depression as she spoke].
		Family life	Intimacy	Participant 4 explained his wife's response once he was diagnosed with the disease. *We'll get through this together. We'll adjust our diet, and prioritize your medications, and I'll be here to support you every step of the way. We'll face this challenge as a team. And remember, we have a wonderful support system with our family and friends too.*
			Isolation	Participant 1 [unmarried] expressed this: *They also feel sorry for me. One sibling lives in Mathara* [a district in Sri Lanka] *and the other in Seeduwa* [a city in Sri Lanka]. *They have young children. I have another sister in Gampaha* [a district in Sri Lanka]. *who calls me, but it's hard for her to visit frequently When I was healthier, I supported my siblings' kids by having them stay with me. I did this without expecting anything in return. If I can help now, I still will.*
				participant 9 [unmarried] explained: *They* [siblings] *face their own difficulties. They've made mistakes, but what can be done? They have children, and they need to take care of them. So, I don't hold their mistakes against them.*
				Participant 3 shared feelings of detachment from his siblings, a contrast to the significant support he had provided them before he fell ill. *I have two younger brothers who live nearby; one resides just half a kilometer away, and the other is even closer. Yet, despite the short distance of less than 1 kilometer, they haven't visited me since I became ill. This is in stark contrast to our previously close relationship, as they have distanced themselves from me after my illness.*
			Impact on family members	Participant 8 explained the impact of his disease on his siblings. *They are very upset and depressed. I was selected for the university as well, which makes them sad as I cannot attend. The only relief is going for a transplant, so they are trying to arrange a transplant*
				Participant 13 described the impact on her family when her son was diagnosed with CKD and began dialysis. *Following my son's health crisis, my husband was also diagnosed with high blood pressure. Initially, he had intended to donate his kidney to our son. Unfortunately, he, too, was later diagnosed with diabetes and high blood pressure, conditions he had never experienced before. His health deteriorated due to the mental strain caused by our son's illness. The bond between my husband and our son is profound. Whenever our son's condition worsens, my husband becomes anxious and exhibits symptoms akin to a heart attack.*
				Participant 12 emphasized her role in supporting her husband through the challenges of the dialysis process. *It's a challenge for my husband to handle the dialysis on his own due to his condition, and it's not practical for me to depend on others to accompany him. He has a strong preference for either me or our son to be with him during these times. While I can't ask my*

(Continues)

TABLE 3 | (Continued)

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Themes	Categories	Subcategories	Supported evidence/narratives
			husband to forgo his treatments, it's also important for both my son and me to focus on our futures. My son needs to carve out his own path, secure a job, and not be confined to staying at home to care for his father.
	Everyday life	Diet	Participant 1 shared that her financial constraints made it difficult for her to afford the diet recommended by the hospital: *To be honest, affording the diet recommended by the hospital is beyond my means. I simply don't have the financial resources to purchase protein-rich foods like meat, eggs, or milk. Currently, I weigh only 45 kg, and the hospital advises a daily intake of 40–50 grams of protein. Unfortunately, meeting this requirement is just not feasible for me.*
			Participant 7 mentioned the adherence to the hospital's prescribed timetable and strict dietary regimen, abstaining from unnecessary food items like tea and outside meals: *I have fully embraced the hospital's prescribed diet plan. I maintain a stringent adherence to both my dietary requirements and medication regimen, consciously avoiding unnecessary indulgences such as tea and dining out.*
		Financial issues	Participant 2 mentioned that his job is not sufficient to cover his medical and travel expenses. According to his words: *The current situation in the country is not good, so I fear my job won't be enough.* [The patient was emotional]. *We anticipate spending more than RS 1500* [approximately $5] *on travel expenses for the treatment.*
			Participant 5 explained her financial difficulties in her treatment process. *We have financial problems. We do not have a pension because we were working on a board. We spent all the money we saved on building a house and on my treatment process. Now our financial situation is zero. Without spending money, how can I recover myself? I also have to spend money on transportation. I come by a hired three-wheeler for dialysis.*
			Participant 11 explained the expenses for drugs and the need for government revisions in selecting criteria for allowances. *Due to the economic crisis in the country, there is a shortage of drugs here. Some drugs are not available locally, so we have to buy them from outside. There is a specific drug needed for dialysis. We were advised to purchase it from outside, which costs about RS 1600 (6 $). I met a person who works as a development officer in his area. He said that he could get an allowance of RS. 20,000 (66 $). However, people like my father only receive a pension. The government should take action for people like my father. I think it would be better if there were a program for patients who have retired. They can properly analyze the situation and help people like my father. I do not expect a large amount. Some amount can be used for traveling for treatment, etc.*
		Social isolation	Participant 9 expressed her experience: *I can't hang out with friends because they're either busy with work or have moved away. Additionally, some people avoid me because of my sickness. This includes even some family members, who fear that my illness might cause problems for them. It's challenging because my condition isn't something that goes away quickly, like a cold. As a result, some people keep their distance. It's disheartening to witness this in our society—where sick individuals like myself are left out. It feels unjust.*

(Continues)

TABLE 3 | (Continued)

Themes	Categories	Subcategories	Supported evidence/narratives
		Adaptation	Participant 1 shared her adaptation to the disease due to prolonged suffering. She remarked: *I didn't find out about my condition all at once, so it didn't shock me. I learned about it gradually, which helped me prepare mentally. Yes, I've been dealing with diabetes for a long time; I found out when I was 23.*
			Participant 14 disclosed her emotional turmoil, saying: *I was utterly shocked and mentally distressed. I lack the words to fully articulate it. Yes, at times, I experience anger easily. Sometimes, I lose my temper. But I have to consider my children, so I strive to maintain a calm state of mind.*
Coping strategies	Attitudes	Helplessness and hopelessness	Participant 3 explained that he feels helpless as he does not have children and no one is there to look after his wife if something happens to him. *It's hard, and sometimes the helplessness is overwhelming, but we have to keep going.*
			Participant 9, who had worked abroad before getting this disease, explained her helplessness due to the lack of social support. *I think they may believe they will face troubles because of me. This is trouble. It is not cured. This condition is not going to be cured like a cold or a fever. It exists forever. That is why they separate from us. This is a wrong thing that is happening in our society. People maintain a distance from us.*
			Participant 2 elucidated the difficulties in finding a suitable kidney for transplantation, stating: *I believe that if I find a donor, it should ideally be a family member, as external individuals may not be as inclined to donate. Additionally, being blood group O+ makes it more challenging to find a compatible kidney. Consequently, I've decided to continue with treatments like dialysis, while resigning myself to the possibility of a shorter life expectancy. Now, at 47 years old, the future seems uncertain. I am aware that beyond the age of 50, our physical strength tends to decline significantly.*
			Participant 3 explained that he feels helpless as he does not have children and no one is there to look after his wife if something happens to him. *I cannot explain, miss. I was so sad. We both do not have anyone else, and it felt like the world was falling apart.*
		Being focused on finding solutions	Participant 5 highlighted that her husband had assumed all household responsibilities while caring for her, due to the lack of external assistance. She explained: *My husband expressed that hiring help for me would incur expenses we currently cannot afford. Consequently, he manages all household chores, including cooking, washing, and cleaning. He diligently takes care of the tasks I used to handle, like washing clothes, preparing meals, and more.*
			Participant 3 explained that he sold a house to deposit money for their future expenses. *I did not have money when I got this disease. All the jewelry was in a bank. I had land with a house. As I was farming, I built another house. So I wanted to sell that house and the land. No one was buying. But, before 4 months, I could manage to sell it. Now I have 30 lakhs in my bank. Now we are living with the interest on that amount. I will get about 60000 every three months. So, it is enough to have a normal life.*

(Continues)

TABLE 3 | (Continued)

Themes	Categories	Subcategories	Supported evidence/narratives
	Psychosocial support	Relatives' support	Participant 8 explained how he received family support, stating: *They only prepare appropriate food for me. My family's food pattern has completely changed due to my disease. They've shifted to eating more fruits and using less oil in cooking. They make sure that any food they bring home is good for me. Everyone has adapted to this. My sister, a midwife, also helps me a lot, even though she lives separately after getting married. She regularly visits and assists me in various ways.* In contrast, Participant 3, who has no children and no support from siblings, expressed deep sadness, saying: *I can't quite put it into words. I've felt a profound sadness. My wife and I are alone. Over time, I've adjusted somewhat.*
		Friendship	Participant 4 explained the support he receives from his friends, saying: *I frequently meet with my friends and talk to them. They have been a great help to me, even in my search for a kidney. They make sure I'm never alone when I come home; someone always accompanies me and ensures I am safely dropped off.* Participant 9 has a different experience with friends: *I can't hang out with friends because they're either busy with work or have moved away.*
		Government support	Participant 7 stated: *I receive Rs 5,000* [about $ 15] *per month from the government. Additionally, my friends are also helping me.* On the other hand, Participant 8 mentioned his lack of government support despite being qualified. He said: *I did not receive anything from the government, even though some patients are receiving Rs. 5,000. My mother inquired about this with the GS officer* [a government officer who works for the village], *who refused it because we own a truck. The hospital recommended me for this support, saying I could get Rs 5,000 as all patients should, but I still did not receive it. So, I have not received any assistance from the government.*
	Spirituality/ religion	Religious and cultural practices	Participant 6 expressed gratitude for her recovery and vowed to visit spiritual places to fulfill promises made to God. She said: *I've experienced immense benefits through cultural rituals. My daughter prayed for my health at the Temple of the Tooth, and I recovered. In gratitude, she gifted me a pendant for divine protection. I've made numerous promises to various spiritual places due to my recovery and am planning a journey to Ruwanwelisaya* [a stupa in Anuradhapura]. Participant 14 also mentioned finding relief by attending Bodhi Puja: *I regularly attend Bodhi Puja, and although my family doesn't join as often, they do participate during significant events like Katina* [the offering of new robes to Buddhist priests]. Participant 1 discussed her reliance on Buddhist philosophy, finding peace in life's impermanence through meditation, as she explained: *I find relief in Buddhism. Its teachings on impermanence resonate with me. Through meditation, I constantly remind myself of this, helping me to relax.* Participant 5 shared her perspective on embracing Buddhism until death, stating:

(Continues)

TABLE 3 | (Continued)

Themes	Categories	Subcategories	Supported evidence/narratives
			I aim to live without troubling anyone. Contemplating my Buddhist faith helps make my pain vanish. Dying with a spiritual mindset causes no trouble to others. Participant 13 finds solace in meditation, a core teaching of Buddhism that helps him endure suffering: *Meditation is my solace against suffering. I've lived righteously and wish for my son's recovery.*
		Meaning of life	Participant 2 was trying to understand the psychological and physical aspects of the disease condition through the core Buddhist belief of 'letting go'. *The solution is to practice letting go. Then we do not have problems* Participant 10 explained suffering is a compulsory thing in life. *I think the whole life is suffering.* Participant 4 expressed a serene acceptance of life's limitations, stating: *I'm not overly concerned. I'm 61 now. What's the point in expecting a longer life?*
	Perception of the disease	Cause of the disease	Participant 1 reflected on her efforts to protect herself, saying: *Since 2009, I've tried to protect myself. But perhaps this is my destiny.* Participant 7 shared his thoughts on life and unfulfilled desires, stating: *At my age, people usually marry and have children. I long for that life, and sometimes, I feel sorrow. It's like I've committed past wrongs (paw), and this feels like a punishment for something I did in a previous birth. I mourn the life I've missed—especially playing with kids. It feels like a consequence of past sins.* Participant 9 contextualized her current situation with a perspective on fate: *I see this as my fate, possibly due to misdeeds in a previous life. I acknowledge that others face even greater challenges. Some endure sudden losses, like limbs, or even their lives in accidents. I still have functional limbs and can earn a living, which brings me happiness. But ultimately, we all face mortality.* Participant 6 prompted contemplation and connected her disease with the Buddhist concept of karma, observing: *None of my family members have this disease. It seems I alone have this karmic disease* ['karma lede' in Sinhala].
		Better to live with fewer expectations	Participant 4 expressed a serene acceptance of life's limitations, stating: *I'm not overly concerned. I'm 61 now. What's the point in expecting a longer life?*
Medical experience	Process of diagnosis	Examinations	Participants undergo continuous check-ups until their transplantation. As Participant 9 elaborated on her transplantation process: *I asked a doctor, who mentioned it might be possible, but I'll need to consult with a surgeon. The surgeon is the one who decides if I'm a suitable candidate. After that, a consultant will refer me for a transplant.*
		Insecurity	Participant 13 shared her experience when her son unexpectedly began dialysis, saying: *The doctors informed me that they initiated dialysis due to my son's elevated creatinine levels and revealed that his kidneys had*

(Continues)

TABLE 3 | (Continued)

Themes	Categories	Subcategories	Supported evidence/narratives
			been damaged. We were completely unaware of this disease. When we inquired about treatments, they provided no information.
		Other chronic diseases	Participant 7 mentioned his long history with diabetes. He stated: *I have been suffering from diabetes since I was 18 years old.* Participant 4 also shared his health struggles, stating: *I have been treated for diabetes and hypertension for a long time*
	Gaining knowledge	Looking for information	Participant 1 expressed frustration with doctors who appeared reluctant to provide information beyond prescribing medication, leaving patients with a limited understanding of the disease. She explained: *Doctors aren't open to answering our questions. They seem unwilling to engage beyond just medication. As a result, we lack comprehensive knowledge about the disease. The nurse only advised on dietary changes in the later stages, when my creatinine levels increased. Before that, clinic visits were just about blood and urine tests with no additional advice. I was under their care for a long time but received no earlier guidance.*
		Health literacy	Participant 7 admitted his confusion about the disease, citing the varying information he received. He said: *I'm not sure what this disease exactly is. Some say the kidneys are melting; others say they're shrinking.* Participant 3, who was unaware of the effects of dialysis, questioned its impact, stating: *I don't even know what dialysis is, even though I'm undergoing it. Does dialysis make people weak?*
	Treatment	Difficulties with travelling	Participant 11, a caregiver for his father undergoing dialysis, detailed the challenges they faced due to long-distance travel. He described the post-dialysis routine, saying: *There is a dialysis shift from 7 p.m. to 12 a.m. Patients arriving for that shift, especially those from distant places, can't leave immediately; they stay overnight. We often end up sleeping on chairs or even on the floor. Many of us manage somehow, with some laying cardboard for comfort. You can see how people make sleeping arrangements. There's a bus from Colombo to Nuwara Eliya, arriving in Kandy around 3 a.m. We could take that bus and get off at Walapane. From there, another bus takes us to our village, reaching home by 7:30 a.m. However, that bus is incredibly crowded, making it difficult to take my father. As a result, we're compelled to stay until morning. Many others are in the same situation, making makeshift arrangements to sleep. As I mentioned, you can see how people adapt here.*
		Lack of effectiveness	Participant 9 shared her experience with a kidney transplant, stating: *I had a kidney transplant, but it was rejected after 8 years.*
		Lack of availability of medicine	Participant 9 also spoke about the challenges due to medicine shortages, saying: *We often can't find basic medicines here. Sometimes, we even have to provide the hospital with supplies like plasters because they run short. It's really tough. For instance, the pills I need for my blood pressure are sometimes unavailable at the hospital, forcing me to buy them elsewhere. I also have to purchase other items, like plasters, myself. Dialysis has become increasingly difficult these days.*

(Continues)

TABLE 3 | (Continued)

Themes	Categories	Subcategories	Supported evidence/narratives
		Attitude towards medical procedures	Participant 2 expressed frustration with the dialysis process, preferring to continue with haemodialysis due to its fewer safety measures compared to peritoneal dialysis. He explained: *Today, a doctor asked me about my plan. I told him I did not want to do CAPD* [peritoneal dialysis]. *I'd rather continue with hemodialysis.* Participant 10 mentioned that he has little hope of being qualified to receive a kidney from the cadaver list. *They (the hospital) will not consider me because I am old and will give priority to younger patients* Participant 9 was not satisfied with the service provided by the dialysis unit. She expressed her concerns as: *I think they do this service just as a job. There is nothing beyond that. There are only a few who work with good motivation. They don't care about us. Not everybody, but the majority. You can see many doctors and nurses here in this unit. It requires a close relationship with the patient for them to feel comfortable. It helps with mental development too. Here, it is difficult, and they do not provide such a service. We are not getting satisfactory service.*
		Attitude towards transplantation	Participant 1 is considering dialysis due to difficulties in finding a suitable kidney donor. She expressed her concerns: *I don't have any family members who can donate a kidney to me. My blood group is O+. I'm hesitant to receive a kidney from someone else because I worry they might suffer health consequences because of it. I don't want anyone else to suffer on my account.* Participant 2 expressed that due to the difficulty and delay in finding a kidney, he decided to stay on dialysis for the rest of his life. *I made a decision that I would stay remaining short period of life by getting a treatment like dialysis. Now I am about 47 years old. So. after 50 years we are almost weak.* Participant 5 expressed that he would not receive any support from his siblings for kidney transplantation. *I cannot even imagine it. Who will give? I have two younger brothers. They did not come to my house, not even to see me.* Participant 6 stated that she does not want to put her children in trouble by searching for money for transplantation. *Anyhow, I will die. There is no need to put my children through the trouble of collecting money for donors. I do not want to be a burden to my family members*
		Attitude towards healthcare system	Participant 5 praised the hospital staff for their attentive and prompt assistance. She stated: *I think there's no need to complain. The hospital staff are commendable, always considering the patient's needs. Whenever I ask for help, they're readily available.* Participant 14 also expressed appreciation for the dedication of the medical staff and nurses, noting a contrast with the doctors in other wards. He said: *I feel everything is going smoothly. All the medical staff, particularly the nurses, are very dedicated. They differ from doctors in other wards in that we can ask nurses anything about the patient, and they always provide clear explanations.*

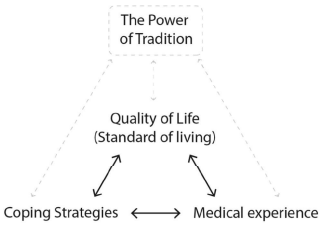

FIGURE 1 | A model illustrating the mutual relationship among three identified themes and the influence of the power of tradition on them.

3.1.3 | Everyday Life

The daily lives of participants are affected in various ways, including diet, financial issues, social isolation and the need for adaptation. Each of these factors significantly influences their day-to-day experiences and overall wellbeing. Both individuals undergoing dialysis and their caregivers highlighted the numerous challenges associated with the disease, particularly in terms of dietary restrictions. While striving to adhere to medical guidelines, many face financial constraints that hinder their ability to follow recommended dietary plans. For example: participant 1 explained: *To be honest, affording the diet recommended by the hospital is beyond my means. I simply don't have the financial resources to purchase protein-rich foods like meat, eggs, or milk. Currently, I weigh only 45 kg, and the hospital advises a daily intake of 40–50 grams of protein. Unfortunately, meeting this requirement is just not feasible for me.* A significant majority of individuals (9 out of 10) with CKD reported facing financial difficulties. These challenges include the high costs of travelling for treatments, medication expenses and managing basic living costs. Additionally, some individuals grappling with CKD have gradually acclimated to the progression of the disease, which is often linked with comorbid conditions like diabetes and hypertension.

3.2 | Theme 2: Coping Strategies

The coping strategies employed by individuals with the disease and their caregivers include attitudes, psychosocial support, spirituality/religion and perception of the disease.

3.2.1 | Attitudes

The experience of chronic illness has elicited a range of attitudes among those affected. As noted earlier, individuals recounted numerous challenges resulting from their conditions, often leading to a sense of helplessness. These attitudes are intricately linked with the nature of the disease, influencing the patients' outlooks. For example: Participant 9 stated *I think they may believe they* (siblings and relatives) *will face troubles because of me. This is trouble. It is not cured. This condition is not going to be cured like a cold or a fever. It exists forever.* Remarkably, despite a majority expressing feelings of hopelessness and helplessness, with 4 out of 10 patients explicitly articulating this sentiment, some participants demonstrate a remarkable ability to focus on practical solutions. For instance, one individual emphasized the importance of adhering to the hospital's timetable, being meticulous about dietary habits and consistently taking prescribed medications. They follow a strict dietary regimen, abstain from unnecessary food and beverages like tea, and avoid meals outside their home. Additionally, they limit social interactions, including with friends visiting their house, as part of a dedicated effort to rebuild their lives in the face of these challenges. Because some patients strictly adhere to the health precautions recommended for individuals on dialysis. They were advised to minimize exposure to external people to prevent infections, which led them to avoid inviting friends to their homes. The primary aim here is to prioritize their health.

3.2.2 | Psychosocial Support

Despite facing numerous obstacles, individuals with CKD and their caregivers often receive support from various sources, including close relatives, friends and government programs. The data reveals that only 2 out of 10 individuals with CKD received government allowances. Furthermore, 7 out of 10 participants reported receiving satisfactory family support to cope with the disease. In addition, assistance from friends plays a vital role for some participants. For instance, Participants 4 and 7 mentioned that their friends were instrumental in helping them find a kidney for transplant. For example: Participant 4 mentioned: *I frequently meet with my friends and talk to them. They have been a great help to me, even in my search for a kidney.*

3.2.3 | Spirituality/Religion

Apart from relying on conventional healthcare systems, individuals coping with CKD and their caregivers frequently turn to their traditions for support. Religious beliefs, cultural practices and the personal meanings they assign to life provide considerable relief and serve as coping mechanisms to mitigate the stress associated with this challenging health condition. Many patients find solace in Buddhist teachings, which help ease the burdens of the chronic disease. They believe that focusing on religious thoughts can dissipate pain, ensuring a peaceful passing that will not burden others. Cultural practices aimed at alleviating mental and physical distress, such as Bodhi Puja—which involves worshiping the Bodhi tree and the presiding deity—and wearing protective pendants with mantras, are prevalent among these individuals.

The meaning of life for individuals with CKD and their caregivers is significantly influenced by religious and cultural perspectives, alongside their adherence to conventional medical treatments. According to Buddhism, letting go, suffering and the impermanent nature of life are emphasized. The relevant quotes related to the 'meaning of life' indicate that participants have had the shadow of Buddhism in their interpretation of life. For example: Participant 2 stated: *The solution is to practice letting go. Then we do not have problems.*

3.2.4 | Perception of the Disease

The majority of participants expressed surprise upon being diagnosed with CKD. Despite the disease's common association with diabetes and hypertension, there was a notable lack of awareness about it among the participants. This lack of knowledge led to confusion at the time of diagnosis. Furthermore, due to difficulties in accessing appropriate treatment, participants reported a diminished expectation of life. Additionally, none of the participants had a family history of CKD, leading them to ponder and attempt to reconcile their condition with the Buddhist concept of karma. They often view their suffering as a part of their destiny, a belief deeply ingrained in Buddhist culture. For example: Participant 1 expressed: *Since 2009, I've tried to protect myself. But perhaps this is my destiny.* This understanding intertwines the present suffering with notions of karma and destiny, thus shaping their perspectives on their current situation.

3.3 | Theme 3: Medical Experience

This theme encompasses the processes of diagnosis, gaining knowledge and treatment as experienced by individuals with CKD.

3.3.1 | Process of Diagnosis

Participants with CKD reported various experiences with their diagnosis process. Some had been suffering from diabetes or hypertension for a long time, which eventually led to CKD. Others progressed to ESRD without prior awareness and suddenly began dialysis. The frequent testing required for dialysis and transplantation has caused feelings of insecurity among some participants. For example: Participant 13 explained: *The doctors informed me that they initiated dialysis due to my son's elevated creatinine levels and revealed that his kidneys had been damaged. We were completely unaware of this disease.*

3.3.2 | Gaining Knowledge

Participants expressed a need for more comprehensive information about CKD. They felt that doctors often limited their engagement to prescribing medication, without providing in-depth explanations or additional guidance. Moreover, several participants reported gaps in their understanding and knowledge of the disease, leading to confusion due to inconsistent or unclear information from various sources. For example: Participant 7 stated: *I'm not sure what this disease exactly is. Some say the kidneys are melting; others say they're shrinking.*

3.3.3 | Treatment

The treatment of CKD involves various challenges, categorized into difficulties with travelling, treatment effectiveness, medication availability, procedural complexities, transplantation challenges and healthcare system interactions.

- Travel difficulties: Most participants reported significant difficulties travelling to receive treatments, citing high costs, long distances and physical discomfort as primary concerns.
- Treatment effectiveness and complexity: Many participants expressed disappointment with both the complexity of treatment procedures and their perceived lack of effectiveness.
- Medication shortage: Exacerbated by Sri Lanka's current economic crisis, a shortage of medication has become a significant burden for patients undergoing dialysis. Essential drugs, often unavailable locally and costing around RS 1600 ($5) each, have led patients to pool resources for joint purchases.
- Transplantation challenges: All 10 individuals with CKD faced considerable obstacles in securing a suitable kidney for transplantation. The primary challenge was finding a donor, particularly from within their families. Financial hurdles frequently led to seeking donors who expect monetary compensation, with some external donors demanding up to $6000. As an alternative, many patients are considering inclusion on the hospital's cadaver list for potential deceased donor kidneys.
- Community support: The community's support for these individuals was notable, with reports of friends initiating fundraising efforts to help finance their transplants. Hesitancy with non-relative donors: Some individuals expressed reluctance to seek kidneys from non-relatives, concerned about the potential harm or discomfort to the donors.
- Patient experience in dialysis units: While those receiving care in dialysis units expressed overall satisfaction, there was a desire for a more personable and engaging approach from medical staff. Patients long for interactions filled with humour and human connection, seeking temporary respite from the stress of their illness. For example: As participant 9 mentioned: *I think they do this service just as a job. There is nothing beyond that. There are only a few who work with good motivation. They don't care about us. Not everybody, but the majority.*

4 | Discussion

CKD represents a significant health challenge in Sri Lanka, marked by its high prevalence and extensive psychosocial impacts on patients and their caregivers. This qualitative study was conducted to explore the psychosocial experiences of these two groups. The content analysis revealed three main areas requiring intervention: standard of living (quality of life), coping strategies and medical experience. A particularly important factor identified was the power of tradition, encompassing

general attitudes, beliefs and religious practices. These elements are integrated into the constructed model presented in Figure 1.

The study underscored the difficulties individuals face in managing daily activities and maintaining overall well-being while living with CKD. Though this research was conducted in Sri Lanka, similar challenges are observed in other countries, as indicated by the analysis of Maguire, Hanly and Maguire [31]. They highlight the crucial role of social support, loneliness and psychological appraisals in sustaining wellbeing in a population-based European sample, suggesting that positive appraisals may help individuals cope better with their conditions and mitigate daily life limitations. This aligns with findings from a systematic review by Roberti et al. [32], which encompassed 260 studies from 30 countries, involving 5115 patients and 1071 caregivers. This review emphasized socioeconomic status as a pivotal factor in the CKD experience, especially in advanced stages requiring renal replacement treatment. Challenges identified included underfunded healthcare, reliance on emergency care, risk of unemployment and insurance issues and financial strain. Patients often struggled with transportation to haemodialysis centres, particularly those in nonurban areas, or those with young children or limited resources. Uninsured or underinsured patients faced additional burdens, such as the need for fundraising. Post-transplant patients contended with uncertainties regarding financial management and responsibilities. A common concern across the board was the lack of information about the disease, treatment options and side effects of immunosuppressants. Living with end-stage kidney disease was described as highly burdensome, involving time-consuming, invasive and exhausting tasks that affect all aspects of patients and caregivers.

Individuals with CKD and their caregivers utilize various coping strategies to manage the disease-related challenges, as observed in our study. A systematic review by Shahin, Kennedy and Stupans [33] emphasized the significant influence of personal and cultural beliefs on medication adherence among patients with chronic diseases like hypertension and diabetes. This review highlighted the critical role of patients' individual perceptions and beliefs about their illnesses in adhering to prescribed medications. Similarly, Nair et al. [34] stressed the importance of considering patients' perspectives and beliefs when providing healthcare guidance and treatment. In our study, we noted that patients from diverse racial, ethnic and sociocultural backgrounds view advanced CKD as a substantial limitation in their lives, often experiencing a loss of control over the disease's progression. This leads to various psychological and emotional challenges, including anxiety about death, uncertainty regarding their prognosis and existential distress. To cope with these challenges, patients employ strategies such as accepting their condition, avoiding the implications of the disease, seeking solace in spiritual beliefs or finding support within religious communities. Notably, a preoccupation with and fear of death were identified as new factors contributing to psychological distress among individuals with CKD. Furthermore, several studies [35–37] have identified religion and acceptance of illness as important coping mechanisms. These findings, consistent with our study, suggest that individuals often rely on their religious beliefs and acceptance of their condition to cope with the psychosocial burden of CKD.

Our findings revealed that participants engage in meditation, a core teaching of Lord Buddha, and perform bodhi puja ceremonies at the bodhi tree. Some individuals wear jewellery (known as 'Sura' in Sinhala) with hopes of warding off negative influences. Moreover, many pray for recovery at religious sites, promising offerings upon regaining health. However, despite these cultural practices, all participants primarily trust mainstream medicine. They diligently follow medical guidelines despite facing considerable challenges. These results echo the findings of Wimalasena and Marks [38], indicating that while Sri Lanka is steeped in tradition, cultural practices are often habitual rather than reflective, lacking reliable guidance in social actions.

Interestingly, many participants in our study perceive CKD as a 'karmic disease', associating it with the concept of destiny. This viewpoint stems not just from religious beliefs but also from practical circumstances, as some participants link their condition to limited access to timely treatment, often due to poverty. Thus, the label of 'karmic disease' is partly influenced by their socioeconomic challenges. In their attempts to cope, several participants embrace the Buddhist teaching of the 'impermanence of life'. This perspective is not solely a product of blind faith; rather, it reflects a coping mechanism influenced by their restricted access to healthcare resources. The inadequacy in accessing psychosocial support further encourages reliance on traditional health and life beliefs. Joshi [39] emphasizes the importance of addressing these subjective elements, including spiritual and religious belief systems, in enhancing the quality of life for ESRD patients. This highlights the need for a holistic approach to patient care that considers not only the medical but also the psychosocial and spiritual aspects of chronic illness management.

As demonstrated in our study, the medical experience of individuals with CKD plays a pivotal role in their psychosocial wellbeing, aligning with findings by Kalantar-Zadeh et al. [40]. CKD requires continuous medical management, including a strict medication regimen, dietary limitations and, in some cases, the need for dialysis. These treatments often demand significant time and physical effort from patients. Our study highlighted that participants experienced a sense of ineffectiveness, lack of knowledge and frustration with the procedural aspects of their disease, leading to diminished perceptions of disease benefits. This was reflected in their minimal expectations regarding their condition's outcome. In contrast, a study by Rymon Lipińska and Nowicka-Sauer [41] found a significant association between perceived benefits of the disease and more favourable illness perceptions among individuals with type 1 diabetes, indicating a critical link between disease benefit perception and mental wellbeing. This finding contrasts with the challenges faced by our study participants, who struggled with inadequate perceptions of their treatments. Furthermore, Hedayati et al. [42] identified a significant correlation between major depressive episodes and critical events such as the initiation of dialysis, hospitalization or death in patients with CKD. Their study noted that depression affects up to 20% of CKD patients even before dialysis initiation, underscoring the importance of addressing mental health issues to improve overall wellbeing in this population. Recommendations by Senanayake et al. [19] stress the need for periodic screening of all CKD patients in the rural districts of Sri Lanka for depression and psychological distress.

They also suggest the necessity for policymakers to support an organized psychological health service, aimed at enhancing the mental wellbeing of individuals with CKD.

4.1 | Research Strengths

- Comprehensive examination of both patients and caregivers: The study's approach included an in-depth examination of the experiences of both patients with CKD and their caregivers, providing a holistic understanding of the disease's impact.
- Focused patient group: All participants were patients treated at a single centre in Sri Lanka, ensuring consistency in the treatment environment and healthcare delivery.
- Uniform disease severity: The study specifically focused on patients diagnosed with the same severity of CKD, all undergoing dialysis. This uniformity allows for more focused insights into this particular patient group.
- Rigorous medical diagnostics: The psychological examination of participants was preceded by a reliable medical diagnosis, ensuring that the psychological assessments were grounded in accurate and comprehensive medical understanding.

4.2 | Study Limitations

This study faced several limitations that should be acknowledged. First, the sample size was small and included both patients with CKD and their caregivers. Given the qualitative nature of this research, the primary aim was not to generalize the findings but to provide an in-depth understanding of the participants' experiences. Therefore, generalizability is not applicable to this type of study. Instead, the insights gained can serve as a basis for further research and potential interventions.

Additionally, the study focused on Sinhala Buddhist individuals, which may limit the relevance of the findings to other ethnic and religious groups in Sri Lanka. This specificity should be considered when interpreting the results and planning broader applications.

Data were collected retrospectively, requiring participants to recall their experiences at different stages of the illness. This approach may introduce recall bias, potentially affecting the accuracy of the reported experiences. While this limitation is inherent in qualitative research, the rich, detailed accounts provided by participants still offer valuable perspectives on the psychological and social challenges faced by patients with CKD and their caregivers in Sri Lanka.

Despite these limitations, the study provides important insights that can inform future research and interventions aimed at supporting patients with CKD and their caregivers.

4.3 | Directions for Further Research

Future research should prioritize understanding the long-term effects of CKD on the quality of life of both individuals with the disease and their caregivers. Longitudinal studies would be beneficial for assessing changes in psychosocial wellbeing over time and evaluating the effectiveness of coping strategies, including religious practices and acceptance of the illness. There is a significant need to explore the role of healthcare providers in supporting individuals with CKD and their caregivers. Investigating the experiences and perspectives of healthcare professionals can offer crucial insights into enhancing the medical experience and psychosocial support for those living with CKD.

We believe it would also be valuable to conduct studies with larger sample sizes, which would increase the robustness and generalizability of our results. This approach would enable a more comprehensive understanding of the psychological and social challenges faced by patients with CKD and their caregivers.

5 | Conclusion

This study highlights the significant psychosocial impact of CKD on individuals and their caregivers in Sri Lanka. The findings underscore the necessity for comprehensive support systems that address the challenges encountered in everyday life, work life and family life. Future research should prioritize addressing the identified knowledge gaps to enhance our understanding of the psychosocial experiences of individuals with CKD and develop effective interventions to improve their quality of life, taking into account the specific influence of tradition and its power. A holistic approach to managing CKD is imperative, encompassing not only the physical aspects but also the emotional, psychological and social dimensions of the disease.

Author Contributions

Darshika Thejani Bulathwatta: conceptualization, methodology, investigation, formal analysis, writing–original draft, data curation, visualization, writing–review and editing. **Agata Rudnik:** conceptualization, methodology, data curation, investigation, writing–original draft, writing–review and editing, formal analysis, visualization. **Mariola Bidzan:** conceptualization, supervision, project administration, methodology, writing–review and editing, formal analysis, investigation, funding acquisition.

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Ethics Statement

The study received ethical approval from the Ethical Review Committee of the Open University of Sri Lanka, under the application number ER/2022/007.

Consent

Informed consent was obtained from all participants included in the study. The participants were briefed about the nature of the research, its purpose, procedures, potential risks and benefits. They were informed

about their voluntary participation and the confidentiality of their identity. Permission was obtained to reproduce any copyrighted material from other sources used in this article.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.

Publication 4

This publication is included as part of the thesis in its published format.

Original Research Article

Contrasting Cultures, Shared Struggles: A Qualitative Analysis of the Experiences of End-Stage Kidney Disease Patients and Their Caregivers in Poland and Sri Lanka

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Abstract

Introduction: End-stage kidney disease (ESKD) represents the final stage of chronic kidney disease, profoundly impacting patients and their caregivers through a wide range of physical, psychological, and social challenges. Cultural values and healthcare system disparities often shape these experiences, but comparative cross-cultural perspectives remain limited.

Objective: This study explores the psychosocial experiences and treatment processes of individuals with ESKD and their caregivers in Sri Lanka and Poland, focusing on cultural, systemic, and personal influences on wellbeing.

Methods: An exploratory qualitative design was employed, utilizing semistructured interviews with 27 participants, including 18 individuals undergoing hemodialysis (10 from the Sri Lankan sample and eight from the Polish sample) and nine caregivers (five from the Sri Lankan sample and four from the Polish sample). The interviews were analyzed using conventional qualitative content analysis, identifying thematic similarities and differences across the two cultural contexts.

Results: Three interconnected themes emerged: quality of life, coping strategies, and medical experiences. In Poland, the "Power of (My)Self" reflected individual resilience and personal agency as dominant factors influencing wellbeing. In contrast, the Sri Lankan context was shaped by the "Power of Tradition," with cultural practices, religious rituals, and communal values playing pivotal roles. Participants in Sri Lanka faced significant resource limitations and infrastructural challenges, while Polish participants benefited from more comprehensive healthcare systems but reported challenges such as depression and emotional isolation.

Conclusion: The findings highlight the profound impact of cultural frameworks and systemic disparities on the lives of individuals with ESKD and their caregivers. While Polish participants emphasized autonomy and self-management, Sri Lankan participants relied heavily on traditional and familial support systems. The proposed conceptual model encapsulates these dynamics, providing a framework for culturally sensitive interventions that address both universal and context-specific needs.

Keywords

kidney failure, hemodialysis, quality of life, coping strategies, healthcare systems, medical experience, cross-cultural comparison

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Introduction

End-stage kidney disease (ESKD) marks the final stage of chronic kidney disease, with kidney function dropping below 15%. It significantly affects patients' and caregivers' quality of life, posing physical, psychological, and social challenges. While hemodialysis prolongs life, it often leads to lifestyle restrictions and emotional burdens (Gerogianni & Babatsikou, 2014a; Tchape et al., 2018).

Globally, ESKD management varies with healthcare resources, cultural beliefs, and economic conditions. High-income countries have advanced care, while low- and middle-income countries (LMICs) struggle with limited access and infrastructure (Thurlow et al., 2021; Crews et al., 2019). In Sri Lanka, a LMIC with strong Buddhist traditions, health and illness are often viewed through karmic beliefs, providing psychological coping mechanisms (Ananda & Ali, 2022). Despite free public healthcare, patients face high out-of-pocket expenses and systemic challenges due to economic crises and resource shortages (Kumar, 2019; Weerakoon et al., 2024). In contrast, Poland's universal healthcare system covers ESKD treatment, including dialysis and transplantation (Rój, 2020; Dębska-Ślizień et al., 2021). However, Polish patients still face psychological difficulties like depression and emotional isolation.

While some research addresses the psychosocial impact of ESKD in specific countries (Ćwiek et al., 2017; Senanayake, 2018), comparative cross-cultural studies are scarce. This study aims to explore and compare the psychosocial experiences of patients with ESKD and caregivers in Sri Lanka and Poland, highlighting how cultural and systemic factors shape their challenges and coping strategies.

Literature Review

Living with ESKD poses significant psychosocial challenges. Patients commonly experience anxiety, depression, social withdrawal, and diminished self-esteem (Finnegan-John & Thomas, 2013; Gerogianni & Babatsikou, 2014b). Caregivers also face substantial pressures, including emotional fatigue, financial hardship, and overwhelming responsibilities (Adejumo et al., 2019; Brunier & McKeever, 1993; Low et al., 2008).

Cultural beliefs strongly influence how individuals interpret illness and choose coping mechanisms. In collectivist contexts like Sri Lanka, religious and spiritual views, particularly Buddhist concepts such as karma and impermanence, shape illness narratives, offering either a source of comfort or passive resignation (Kleinman, 1980; Ananda & Ali, 2022). These beliefs often emphasize shared suffering and communal support.

Despite the growing body of national studies, few have compared how cultural values and healthcare systems together shape the psychosocial experiences of patients with ESKD and their caregivers. This study addresses that gap by exploring lived experiences in both Sri Lanka and Poland, to inform culturally sensitive, context-aware psychosocial interventions.

Methods

Design

This study employed a qualitative design as a part of a mixed-method project on the psychosocial wellbeing of patients with ESKD undergoing hemodialysis and their caregivers in Sri Lanka and Poland. All participants gave written informed consent after receiving detailed study information. Semistructured interviews were conducted in hemodialysis units: in a hospital in Sri Lanka's central province (October 2022) and a hospital in northern Poland (October 2023–May 2024). One Polish caregiver interview was conducted online due to logistical issues. In Sri Lanka, interviews were conducted by the principal investigator, a female experienced qualitative researcher and university lecturer. In Poland, data were collected by a trained female psychology master's student and a female assistant professor, both experienced in qualitative research and chronic illness care. The research team ensured ethical conduct, offering debriefing and psychological support when needed, with a focus on participants' wellbeing.

Sample

Participants were selected using a purposive sampling approach (Palinkas et al., 2015) aligned with the research objectives outlined by Bulathwatta et al. (2023). The study included 10 individuals with ESKD from Sri Lanka and eight from Poland. Two Polish participants were excluded after initial interviews because they identified as Jehovah's Witnesses rather than Catholics, which did not meet the inclusion criteria. Additionally, five caregivers from Sri Lanka and four from Poland participated. One Polish caregiver was excluded after the initial interview for not meeting the Catholic background criterion.

Inclusion criteria for patients with ESKD required a diagnosis of chronic kidney disease (CKD) stage G5 (ESKD), active hemodialysis treatment, age between 18 and 84 years, and CKD treatment duration exceeding 6 months. Participants were also required to meet specific nationality and religious criteria: Sinhala Buddhist for Sri Lanka and Polish Catholic for Poland. These criteria were established to ensure cultural and religious homogeneity, enabling meaningful cross-cultural comparisons. Although religion was included as a criterion in the study, it was not explicitly stated in the protocol. Comorbidities were not considered for inclusion.

Exclusion criteria included individuals who did not meet the inclusion criteria, declined consent, or lacked the physical or mental capacity to participate. Caregivers were eligible if they were identified by patients with CKD as significant

Table 1. Demographic Characteristics of Sri Lankan Participants (Patients).

Participant code	Age (years)	Sex	Religion	Employment	Duration of the disease	Marital status
1	54	Female	Buddhist	Unemployed	2 years	Single
2	47	Male	Buddhist	Cemetery worker	9 months	Married
3	58	Male	Buddhist	Farmer	1 year	Married
4	61	Male	Buddhist	Unemployed	1 year	Married
5	59	Female	Buddhist	Retired Clerk	1 year	Married
6	57	Female	Buddhist	Traditional Sinhala Medicine practitioner	7 months	Married
7	39	Male	Buddhist	Unemployed	1 year	Single
8	24	Male	Buddhist	Unemployed	3 years	Single
9	45	Female	Buddhist	Unemployed	10 years	Single
10	58	Male	Buddhist	Retired postman	1 year	Married

supporters and were at least 18 years old. Caregivers who declined consent or lacked the necessary capacity were excluded.

Data Collection

Two semi-structured interview guides were developed—one for patients with ESKD, one for caregivers—based on literature and study objectives. Each included 27 questions (12 general, 15 open-ended) covering experiences, emotions, relationships, social support, and medical care. Data saturation determined the final sample size for both groups. Interviews (35–60 min) were conducted by experienced researchers, with field notes taken. All interviews were recorded, transcribed verbatim (in Sinhala and Polish), and translated into English. Translations were cross-checked through back-translation and reviewed by independent researchers to ensure cultural and linguistic accuracy. Participants reviewed their transcripts (member checking) to verify accuracy. Researchers practiced reflexivity throughout the process. Triangulation was employed by combining multiple data sources (interviews, field notes, member checks, and translations reviewed by independent researchers) and involving multiple researchers in data analysis to enhance the credibility and trustworthiness of the findings (Nowell et al., 2017). Verified transcripts formed the basis for content analysis.

Data Analysis

An inductive content analysis approach (Joffe et al., 2004; Hsieh & Shannon, 2005) was used to explore interview narratives and identify patterns, meanings, and themes. Open-ended questions enabled a detailed examination of participants' experiences. Four researchers conducted the analysis: two analyzed the Sinhala data, while three analyzed the Polish data. Researchers independently read transcripts, coded key phrases, and grouped codes into subcategories, categories, and overarching themes. Triangulation ensured reliability by having at least two researchers code each dataset independently (Elo & Kyngäs, 2008). Analytic notes documented coding decisions and reflections, guiding team discussions. Findings were compared, refined, and validated collaboratively to ensure consistency and credibility.

Ethical Considerations

Participants received detailed information about the study's objectives, scope, and procedures beforehand. Participation was voluntary, with the right to withdraw at any time without repercussions. Anonymity was ensured by assigning unique encrypted identifiers, and data access was restricted to the research team.

Ethical approval for the study was obtained from the Ethical Review Committee of the Open University of Sri Lanka, under the application number ER/2022/007 and from the Ethical Review Board of the Institute of Psychology, University of Gdańsk, under inquiry number 03/2023. These measures underscore the study's adherence to ethical research standards, prioritizing participant autonomy, confidentiality, and data security.

Results

Basic demographic information of the participants is presented below. The Sri Lankan sample consisted of eight females (53%) and seven males (47%), with an average age of 48 years. The adjusted Polish sample included nine females (75%) and three males (25%), with an average age of 29 years. Tables 1 and 2 present the demographic details of the Sri Lankan sample, while Tables 3 and 4 outline those of the Polish sample.

After analyzing the data from individuals with ESKD and their caregivers in both countries, three main themes emerged: (a) quality of life, (b) coping strategies, and (c) medical experiences (refer to Table 5). These themes appeared to be interconnected, highlighting the complex interplay of factors affecting participants' experiences.

Notably, the "Power of tradition" emerged as a significant influence across all three themes in the Sri Lankan results, reflecting the role of cultural and communal values in shaping participants' lives. In contrast, the "Power of (my)self" was a predominant influence in the Polish results, emphasizing individual autonomy and self-reliance as key factors shaping their experiences (see Figures 1 and 2).

Table 2. Demographic Characteristics of the Participants (Sri Lankan Caregivers).

Participant code	Age (years)	Sex	Religion	Employment	Caregiver relationship	Duration of caregiving	Marital status
11	23	Male	Buddhist	Unemployed	Son	1 year	Single
12	47	Female	Buddhist	Factory worker	Wife	9 months	Married
13	52	Female	Buddhist	Unemployed	Mother	3 years	Married
14	52	Female	Buddhist	Factory worker	Wife	1 year	Married
15	51	Female	Buddhist	Unemployed	Wife	1 year	Married

Table 3. Demographic Characteristics of Polish Participants (Patients).

Participant code	Age (years)	Sex	Religion	Employment	Duration of the disease	Marital status
1	53	Female	Catholic	Unemployed	20 years	Married
2	45	Female	Catholic	Unemployed	10 years	Married
3	42	Female	Catholic	Tutor	10 years	Divorced
4	45	Female	Catholic	Patient works online, did not mention the profession	29 years	Widow, currently engaged
5	48	Female	Catholic	Unemployed	9 years	Married
6	35	Male	Catholic	Tatoo artist	10 months	Single
7	37	Female	Catholic	Works in university administration	12 years	Informal relationship
8	47	Male	Catholic	Entrepreneur	16 years	Married

Table 4. Demographic Characteristics of the Participants (Polish Caregivers).

Participant code	Age (years)	Sex	Religion	Employment	Caregiver relationship	Duration of caregiving	Marital status
9	53	Male	Catholic	Unemployed	Husband	20 years	Married
10	65	Female	Catholic	Retired	Mother	3 years	Widow
11	69	Female	Catholic	Retired	Mother	10 years	Widow
12	57	Female	Catholic	Nurse	Wife	15 years	Married

Theme 1: Quality of life

The quality of life for both the Sri Lankan and Polish samples was shaped by four key factors: financial hardship, work life, family life, and everyday life.

Financial Hardship. Financial hardship emerged as a distinct and pervasive concern, influencing multiple aspects of participants' daily lives, particularly among the Sinhalese sample. Participant 1, a traditional Sinhala medicine practitioner, had to close her clinic due to mounting costs. "*I had to pay Rs. 20,000 [$62] in rent for my shop per month, along with electricity bills, which led me to close it. Now, if someone seeks treatment, I provide it at home.*" Sinhalese participant 2 was fearful and mentioned that his job is insufficient to cover his medical and travel expenses. As he put it *"The current situation in the country is not good, so I fear my job won't be enough. [The patient was emotional]. We anticipate spending more than RS 1500 [approximately $5] on travel expenses for the treatment."* Sinhalese participant 1 also shared that her financial constraints made it difficult to afford the hospital-recommended diet: In her words: *"to be honest, affording the diet recommended by the hospital is beyond my means. I simply don't have the financial resources to purchase protein-rich foods like meat, eggs, or milk…"*

Sinhalese participant 5 described the financial difficulties she faced during her treatment process. She stated *"Now our financial situation is zero. Without spending money, how can I recover myself? I also have to spend money on transportation."*

Polish participants also reported financial strain, especially those who lost jobs due to the demands of treatment. Polish participant 10 explained, "I lost my job, and now I have to rely on a pension; I can't earn extra. It has had a big impact. It's not that my parents can't manage financially, but there's a difference between what could have been and what is. We have to support each other financially." Some Polish

Table 5. Themes, Categories, and Subcategories That Emerged from the Data.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
Theme 1: Quality of life	Category 1: Financial hardship	Participant 1, a practitioner of traditional Sinhala medicine, explained the demands of the treatment forced her to close her shop, where she used to sell traditional remedies. She has since adjusted by providing treatments at home for those who come to see her. As she explained,	Many patients declare that their budget has been severely affected by the illness. For instance,
		"I had to pay Rs. 20,000 [$ 62] in rent for my shop per month, along with electricity bills, which led me to close it. Now, if someone seeks	Participant 10 explained,
		treatment, I provide it at home. However, the cost of bus fares to get to my treatments is high. I need to dedicate around 20 days each month to treatment and tests, which is quite stressful. This situation was a key factor in my decision to close the shop. As a result, my income has significantly decreased".	"Sure, I lost my job, and now I have to rely on a pension; I can't earn extra. It has had a big impact. It's not that my parents can't manage financially, but there's a difference between what could have been and what is. We have to support each other financially."
		Participant 2 mentioned that his job is insufficient to cover his medical and travel expenses. According to his words,	Some patients lose their jobs due to the inability to combine employment with dialysis treatments. Participant 10 explained,
			"I lost my job, and now I have to rely on a disability pension; I can't earn extra."
		"The current situation in the country is not good, so I fear my job won't be enough. [The patient was emotional]. We anticipate spending more than RS 1500 [approximately $5] on travel expenses for the treatment."	Participant 6 explained,
		Participant 1 shared that her financial constraints made it difficult for her to afford the diet recommended by the hospital:	"In reality, I don't receive any support from the government, just this 215 PLN care allowance, and that's it. […] If I were to be left alone, it wouldn't cover my bills or anything."
			Some of the participants were dissatisfied with the government support. According to participant 8,
		"To be honest, affording the diet recommended by the hospital is beyond my means. I simply don't have the financial resources to purchase protein-rich foods like meat, eggs, or milk. Currently, I weigh only 45 kg, and the hospital advises a daily intake of 40–50 g of protein. Unfortunately, meeting this requirement is just not feasible for me."	"No, I think they're not helping [the government]. As I read on forums, patients, whether post-transplant or with other issues, constantly have to fight to keep their medications on the reimbursement list."
		Participant 5 explained her financial difficulties in her treatment process:	Participant 5 expressed satisfaction with his financial situation.
		"We have financial problems. We do not have a pension because we were working on a board. We spent all the money we saved on building a house and on my treatment process. Now our financial situation is zero. Without spending money, how can I recover myself?	He said:
		I also have to spend money on transportation. I come by a hired three-wheeler for dialysis."	"I would describe my financial status as good; I manage well, have two loans, and can afford luxuries and trips, so this disease… I can't say it doesn't limit me because I could probably have more, but what I have is great."

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
	Category 2: work life	Participant 5, together with her husband, left their jobs because of the demands of her illness and treatments. As she shared,	Participant 8 described how she transitioned from full-time work to part-time in order to better manage her time for treatment. She said:
		"I did not retire. I faced many obstacles at once, so I resigned."	"I obtained permission to work remotely. […] Besides, I work part-time, so I manage my day better and am glad to be back at work, as it keeps my mind occupied."
		Her husband, a devoted caregiver, assumed the responsibility of efficiently handling all the household chores.	
		"[…] He was previously	
		employed at the electricity board and had the option to continue working there until the age of 65. Yet, due to my illness, he felt compelled to resign as well, since there was no one else available to assist me."	
	Category 3: family life	Participant 4 explained his wife's response once he was diagnosed with the disease:	Participant 8 emphasized the crucial role of her partner, who takes on household duties and financially supports the family.
			According to him,
		"We'll get through this together. We'll adjust our diet, and prioritize your medications, and I'll be here to support you every step of the	"My partner is my biggest supporter. I'm glad he stayed with me [despite the illness], especially since we're not formally married; it's a decision we both made."
		way. We'll face this challenge as a team. And remember, we have a wonderful support system with our family and friends too."	Participant 10 explained the nature of her family support, She said:
		Participant 8 explained the impact of his disease on his siblings:	"Our relationship has become closer. I mean with my parents because it hasn't changed with my brother. My relationship with my parents has strengthened a lot. […] I live with my parents."
		"They are very upset and depressed. I was selected for the university as well, which makes them sad as I cannot attend. The only relief is going for a transplant, so they are trying to arrange a transplant."	Participant 1 explained her dependency on the family,
		Participant 13 described the impact on her family when her son was diagnosed with CKD and began dialysis:	She said:
			"I am now so weak that without the help of my husband and son, I can't do anything. Sometimes I just cry because I want to do something when I'm sitting and feel good, but I just can't manage—everything falls from my hands, and there's no chance."
		"Following my son's health crisis, my husband was also diagnosed with high blood pressure. Initially, he had intended to donate his kidney to our son. Unfortunately, he, too, was later diagnosed with diabetes and high blood pressure, conditions he had never experienced before."	Participant 1 added:
			"I currently have a twenty-year-old son at home, and he's probably my anchor to keep living. Honestly, more than my husband, yes. [smiles]. That's how it is. I'm glad I have him."

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
	Category 4: everyday life	Participant 9 expressed her experience about social relationships: "I can't hang out with friends because they're either busy with work or have moved away. Additionally, some people avoid me because of my sickness. This includes even some family members, who fear that my illness might cause problems for them. It's challenging because my condition isn't something that goes away quickly, like a cold. As a result, some people keep their distance. It's disheartening to witness this in our society—where sick individuals like myself are left out. It feels unjust."	Most patients adhere to medical recommendations, are knowledgeable about their condition. Participant 1 explained, "It's not easy; we're supposed to follow a diet that restricts almost everything. Drink as little as possible—I had a huge problem with this because of diabetes… and I still drink too much." For some patients, the illness has not significantly impacted their life situations. Participant 2 said, "You can't say that this kidney disease has had such a significant impact because we live at the same level as we did before I got sick. We don't have to give up anything specific to afford medications or anything like that." Participant 2 mentioned about her social relationships: "I definitely miss contact with people, like with friends, over small, trivial things. Not anything particular, just to… Since I'm feeling bad, I sometimes just want to hear about something, like someone chatting, but not even to participate in the conversation, just to listen." Some patients some people found social support in people they met at the hospital: Participant 1 said, "Right now, we have this group; we've become more outgoing with a few women. We bake cakes, bring them, share them with the nurses, talk, and cook; it helps us escape from it all, and that's probably a good thing." According to Participant 4, "There are friends I met here in the hospital. Staying in various departments, these are women who were patients or are nurses, and they know about it and come to see me. They support me a lot." Opinions on government support vary. Some patients express dissatisfaction while others are satisfied. According to participant 4, 'yes, [the government] helps in some way. As a pensioner, I get the so-called '13th' and '14th' payments. There are reimbursed medications, which would otherwise cost me a lot. These are lower costs. I can take advantage of rehabilitation and sanatoriums. Regarding dialysis itself, the advantage is that it's free. I don't need

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
			to seek private treatment. I don't think there's much more I'd ask for." Participant 3 explained his satisfaction with the government support, "In general, yes [I rate the access to free dialysis positively], the only drawback is sometimes the long wait times for certain tests or procedures. But it's understandable, given the number of doctors compared to the number of patients."
Theme 2: Coping strategies	Category 1: Adaptive	Participant 1 shared her adaptation to the disease due to prolonged suffering. She remarked: "I didn't find out about my condition all at once, so it didn't shock me. I learned about it gradually, which helped me prepare mentally. Yes, I've been dealing with diabetes for a long time; I found out when I was 23." Participant 3 explained, "….As I was farming, I built another house. So I wanted to sell that house and the land. No one was buying. But, before 4 months, I could manage to sell it. Now I have 30 lakhs in my bank. Now we are living with the interest on that amount. I will get about 60000 every three months. So, it is enough to have a normal life." Participant 8 explained how he received family support, stating, "They only prepare appropriate food for me. My family's food pattern has completely changed due to my disease. They've shifted to eating more fruits and using less oil in cooking. They make sure that any food they bring home is good for me. Everyone has adapted to this. My sister, a midwife, also helps me a lot, even though she lives separately after getting married." Participant 4 explained the support he receives from his friends, saying: "I frequently meet with my friends and talk to them. They have been a great help to me, even in my search for a kidney. They make sure I'm never alone when I come home; someone always accompanies me and ensures I am safely dropped off."	Some patients have found positive ways to cope with their illness using Humor and Maintaining a Positive Attitude. As Participant 1 explained, "I try to think positively." Participant 7, "I'm a cheerful person." Participant 6—Accepted his illness and said, "I've befriended my illness." Participant 1 said, "I try to change my thinking and focus on positive things, pushing away thoughts that make me feel trapped. It's intense. […] I push away thoughts about feeling unwell by turning on the TV or engaging with my pets, so I can distract myself." Participant 1 explained his positive hopes regarding the third transplant, "There's a possibility that I might not be able to undergo a third transplant, and that's incredibly difficult. However, being on the list—even if I'm just going through the process without yet receiving the transplant—gives my mind a positive outlook. […] But I hope [laughs] that I'll still manage to get another transplant and maybe breathe a little easier." Most patients see themselves as believers but do not actively practice or associate with the Catholic Church. Participant 1 explained, "I mean, I believe in God and that He exists. […] I don't believe in priests, don't believe in earthly beings, as I think we're all sinful." Participant 4 explained,

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
		Participant 7 stated that the government's support manage the disease, "I receive Rs 5,000 [about $ 15] per month from the government. Additionally, my friends are also helping me. On the other hand, Participant 8 mentioned his lack of government support despite being qualified. He said: I did not receive anything from the government, even though some patients are receiving Rs. 5,000." Participant 6 expressed gratitude for her recovery and vowed to visit spiritual places to fulfill promises made to God. She said: "I've experienced immense benefits through cultural rituals. My daughter prayed for my health at the Temple of the Tooth, and I recovered. In gratitude, she gifted me a pendant for divine protection. I've made numerous promises to various spiritual places due to my recovery and am planning a journey to Ruwanwelisaya [a stupa in Anuradhapura]. Participant 14 also mentioned finding relief by attending Bodhi Puja." Participant 2 was trying to understand the mental and physical aspects of the illness through the main Buddhist idea of "letting go." "The solution is to practice letting go. Then we do not have problems." Participant 10 explained suffering is a compulsory thing in life. "I think the whole life is suffering."	"Although I don't go to church, I believe in God deep down and usually pray. […] Faith and prayer help me; I feel more spiritually uplifted and stronger." Some patients mention "superstitions" or esoteric experiences. Participant 2 explained, "I have certain superstitions, like carrying a chimney sweep's button, which I bring with me to exams or important events." Participant 8 explained, "These esoteric explorations, among other things, help me stop being afraid."
	Category 2: maladaptive	Participant 9, who had worked abroad before getting this disease, explained her helplessness due to the lack of social support. She said: "I think they may believe they will face troubles because of me. This is trouble. It is not cured. This condition is not going to be cured like a cold or a fever. It exists forever. That is why they separate from us. This is a wrong thing that is happening in our society. People maintain a distance from us." Participant 2 explained the difficulties in finding a suitable kidney for transplantation, stating:	Some patients behaved as if desire for control and distrust of Doctors. According to participant 8, "I want to be able to have some control, which isn't always a good trait. It caused me to refuse anesthesia for a procedure that usually requires sedation, as I insisted on watching what they were doing. Over time, doctors got used to my personality and stopped having issues with sending me test results or discussing things with me. I even started writing down my questions and going to them with a list." Some patients are isolated from others as a result of Depression, loss of purpose, and feelings of uselessness and boredom.

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
		"I believe that if I find a donor, it should ideally be a family member, as external individuals may not be as inclined to donate. Additionally, being blood group O+ makes it more challenging to find a compatible kidney. Consequently, I've decided to continue with treatments like dialysis, while resigning myself to the possibility of a shorter life expectancy. Now, at 47 years old, the future seems uncertain. I am aware that beyond the age of 50, our physical strength tends to decline significantly." Participant 3 explained that he feels helpless as he does not have children and no one is there to look after his wife if something happens to him. He said: "I cannot explain, miss. I was so sad. We both do not have anyone else, and it felt like the world was falling apart."	Participant 2 said, "When I feel bad, or something terrible happens, I cut myself off from distant people. I don't want to involve them." Participant 1 said, "Family, friends… I rarely participate in social life these days, not meeting up much at all." As Participant 6 explained, "I don't mention that I'm sick. […] I mostly stay at home, barely going anywhere, so you could say I have little contact with people." Some individuals are reluctance to discuss their Illness. Participant 4 mentioned, "I have friends who, as I mentioned, don't know about my illness, so they can't support me because they don't understand what's wrong with me. Patient 2 added, "I can't even say that my illness caused me to lose friends or anything because that was my choice. I'm just like that. I prefer not to be seen in this state to feel comfortable." Some patients are focusing excessively on suffering, leading to despair and abandoning efforts to improve well-being. Participant 2 said, "Honestly, I've thought about suicide a few times [voice breaks], knowing that not much is left for me. That things will only get worse. But I couldn't do that to my family, nor am I brave enough. I don't expect it to get better, not unless I get a transplant, but kidney disease has done so much damage that I'm unsure if it can all be reversed. It's not just kidney disease anymore but all the complications."
Theme 3: Medical Experience	Category 1: Knowledge and self-management	Most patients did not fully grasp the nature of this disease. Participant 7 acknowledged feeling confused about the disease due to the conflicting information he had received. He said: "I'm not sure what this disease exactly is. Some say the kidneys are melting; others say they're shrinking". Participant 3, who was unaware of the effects of dialysis, questioned its impact, stating:	Most patients understand the mechanism of chronic kidney disease: Participant 2 explained, "My kidneys don't remove toxins, don't filter, don't work, which is why I'm on dialysis." Most patients adhere to medical recommendations, are knowledgeable about their condition, and understand the necessary self-care guidelines, including dietary restrictions. As Participant 8 explained,

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
			"I no longer feel like I used to, where I was seen as a sort of know-it-all."
		"I don't even know what dialysis is, even though I'm undergoing it.	Participant 2 mentioned that she strictly follows her diet and knows what positively influences her health. He said:
		Does dialysis make people weak?"	"If I'm not supposed to eat something, I just don't eat it. I can refuse myself, just like with drinking."
		Some patients were dissatisfied with the information provided by doctors, with Participant 1 expressing frustration over doctors' reluctance to offer details beyond prescribing medication.	Many patients have some background in health-related fields. They supplement their knowledge by consulting with doctors and verifying information on social media forums dedicated to their illness. They are actively engaged in their treatment process.
		As she said,	Participant 8 explained,
		"Doctors aren't open to answering our questions. They seem unwilling to engage beyond just medication. As a result, we lack comprehensive knowledge about the disease. The nurse only advised on dietary changes in the later stages, when my creatinine levels increased. Before that, clinic visits were just about blood and urine tests with no additional advice. I was under their care for a long time but received no earlier guidance."	"Even though I was also doing my doctorate, but in a different field, I'm passionate about these things, so I read scientific articles, dig around, and try to organize things in my mind. When I go to the doctor, I might come across as a bit of a smart aleck for asking questions about things I found, so I was probably viewed as a patient who talks too much and wants to know too much. I've always tried to ask questions to piece together the cause-and-effect relationships because I like to understand things."
	Category 2: Treatment	Most patients complained about the difficulties of long-distance traveling for dialysis. Participant 11, a caregiver for his father undergoing dialysis, detailed the challenges they faced due to long-distance travel. He described the post-dialysis routine, saying:	Most patients express a positive view of the medical support they receive, describing it as modernized and patient-centered.
			Participant 6 explained, "Compared to other facilities, I rate them very highly here; it's a well-qualified team."
			Patient 4 shared, "Honestly, I feel safe here. Sure, the building is now renovated, but even before, in the old building, the sense of security from the staff mattered more to me."
		"There is a dialysis shift from 7 p.m. to 12 a.m. Patients arriving for that shift, especially those from distant places, can't leave immediately; they stay overnight. We often end up sleeping on chairs or even on the floor."	However, some patients share difficult experiences with healthcare services. According to Participant 2,
		Some patients highlighted the shortage of medication and the difficulties they faced.	"The only thing I resent about my doctors here is that sometimes, when I speak up, I feel brushed off, like no one is listening. And then it turns out I was right, and it could have been dealt with a month, two, or even half a year earlier, but now it's too late."

(continued)

Table 5. Continued.

Theme	Category	Sri Lanka (quotes/evidence)	Poland (quotes/evidence)
		Participant 9 also spoke about the challenges due to medicine shortages, saying:	According to patients, the medical staff generally respond to questions and approach each patient individually.
		"We often can't find basic medicines here. Sometimes, we even have to provide the hospital with supplies like plasters because they run short. It's really tough. For instance, the pills I need for my blood pressure are sometimes unavailable at the hospital, forcing me to buy them elsewhere."	Patient 2 said: "Every time, the doctors have taken a highly individual approach, showing care and concern."
		Participant 2 expressed frustration with the dialysis process, preferring to continue with hemodialysis due to its fewer safety measures compared to peritoneal dialysis. He explained:	According to Participant 4, Nurses are friendly and often provide a source of support.
			He said:
		"Today, a doctor asked me about my plan. I told him I did not want to do CAPD [peritoneal dialysis]. I'd rather continue with	"The nurses are always so welcoming and helpful."
		Hemodialysis."	Most patients don't need to travel far for dialysis sessions—they typically come from nearby areas. For those from farther away, receiving treatment in Gdańsk is a personal choice.
		Participant 10 mentioned that he has little hope of being qualified to receive a kidney from the cadaver list.	Participant 5 said, "I'm from Gdynia, so I'm closest to the station in Gdynia, but I would never want to go." there. Here… Here, I feel safe".
		"They [the hospital] will not consider me because I am old and will give priority to younger patients."	
		Participant 9 was not satisfied with the service provided by the dialysis unit. She expressed her concerns as:	
		"I think they do this service just as a job. There is nothing beyond that. There are only a few who work with good motivation. They don't care about us."	

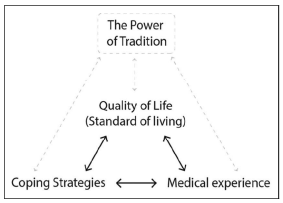

Figure 1. A model illustrating the mutual relationship among three identified themes and the influence of the power of tradition on them.

Figure 2. A model illustrating the mutual relationship among three identified themes and the influence of the power of (my) self on them.

participants expressed dissatisfaction with government support. As Polish participant 8 noted: "*I think they're not helping [the government]. As I read on forums, patients, whether post-transplant or with other issues, constantly have to fight to keep their medications on the reimbursement list.*"

However, not all experiences were negative. Polish participant 5 described financial stability: *"I would describe my financial status as good; I manage well, have two loans, and can afford luxuries and trips, so this disease… I can't say it doesn't limit me because I could probably have more, but what I have is great."*

Work Life. Work life changes emerged as a distinct aspect of participants' experiences, separate from financial hardship. While financial strain was a consistent backdrop, participants specifically described how their ability to engage in work, retain employment, or adjust their careers was directly impacted by ESKD and caregiving duties. For example, participant 5 from the Sinhalese sample resigned from her job due to the disease, and her husband retired to become her full-time caregiver. . As she explained: "*I did not retire. I faced many obstacles at once, so I resigned […] He was previously employed at the electricity board and had the option to continue working there until the age of 65. Yet, due to my illness, he felt compelled to resign as well, since there was no one else available to assist me.*"

Similarly, Polish participants highlighted disruptions in their professional life. Some transitioned to part-time or remote work due to the physical burden of treatment and time required for dialysis. Polish participant 8 shared: "*I obtained permission to work remotely. […] Besides, I work part-time, so I manage my day better and am glad to be back at work, as it keeps my mind occupied.*" Meanwhile, many participants mentioned that their financial situation has been severely affected by the treatment and some of them lost their jobs due to the difficulty of managing work alongside dialysis.

Family Life. The family has been recognized as the purpose of living for all the participants in both samples. The statement of "*We'll get through this together. We'll adjust our diet, and prioritize your medications, and I'll be here to support you every step of the way. We'll face this challenge as a team…*" given by participant 4 from the Sinhalese sample to her husband shows her intimacy with him.

Sinhalese participant 8 explained the impact of his disease on his siblings. "*They are very upset and depressed. I was selected for the university as well, which makes them sad as I cannot attend. The only relief is going for a transplant, so they are trying to arrange a transplant.*"

Sinhalese participant 13 described the impact on her family when her son was diagnosed with CKD and began dialysis. "*Following my son's health crisis, my husband was also diagnosed with high blood pressure.*"

Participant 8 from the Polish sample emphasized the crucial role of her partner, who takes on household duties and financially supports the family. "*My partner is my biggest supporter. I'm glad he stayed with me [despite the illness], especially since we're not formally married…*" Polish participant 10 explained the nature of her family support: *"Our relationship has become closer. I mean with my parents because it hasn't changed with my brother. My relationship with my parents has strengthened a lot. […] I live with my parents.*"

Polish participant 1 explained her dependency on the family: "*I am now so weak that without the help of my husband and son, I can't do anything. Sometimes I just cry because I want to do something…*"

Everyday Life. Participants from both samples discussed their everyday lives in terms of the diet they are required to follow, their financial situation, and their isolation.

Participant 1 from the Sinhalese sample shared that her financial constraints made it difficult to afford the diet recommended by the hospital. In her words: "*to be honest, affording the diet recommended by the hospital is beyond my means. I simply don't have the financial resources to purchase protein-rich foods like meat, eggs, or milk…*"

Sinhalese participant 5 described the financial difficulties she faced during her treatment process. She stated: *"Now our financial situation is zero. Without spending money, how can I recover myself? I also have to spend money on transportation."*

Sinhalese participant 9 mentioned that she is losing social contact with friends due to this disease. She stated: *"I can't hang out with friends because they're either busy with work or have moved away. Additionally, some people avoid me because of my sickness…"*

Participant 1, from the Polish sample, described her challenges with dietary restrictions: "*It's not easy; we're supposed to follow a diet that restricts almost everything. Drink as little as possible – I had a huge problem with this because of diabetes… and I still drink too much.*"

For some patients in the Polish sample, the disease has not significantly impacted their financial situation. Polish participant 2 stated: "*You can't say that this kidney disease has had such a significant impact because we live at the same level as we did before I got sick…*"

Many patients regardless of their gender and age, experience social isolation, avoid social interactions, refrain from sharing their health status outside the family, and watch relationships often diminish. Polish participant 2 described her experience of isolation*: "I definitely miss contact with people, like with friends, over small, trivial things. Not anything particular, just to… Since I'm feeling bad, I sometimes just want to hear about something, like someone chatting…"*

Coping Strategies

The coping strategies of both samples included both adaptive and maladaptive approaches.

Adaptive Coping Strategies. In both the Sinhalese and Polish samples, adaptive coping strategies were used to manage the challenges of ESKD. These strategies included maintaining family harmony, engaging in social support networks, managing finances, and participating in religious or cultural practices.

Family harmony, meeting friends, managing finances, and following religious rituals were identified as most common adaptive coping mechanisms in the Sinhalese sample. As Sinhalese participant 8 stated: "*my family's food pattern has completely changed due to my disease. They've shifted to eating more fruits and using less oil in cooking. They make sure that any food they bring home is good for me…*"

Sinhalese participant 4 explained the support he receives from his friends, saying: "*I frequently meet with my friends and talk to them. They have been a great help to me, even in my search for a kidne.y.*

Sinhalese participant 7 stated that the government's support manages the disease: "*I receive Rs 5,000* [about $15] *per month from the government. Additionally, my friends are also helping me.*"

Sinhalese participant 6 expressed gratitude for her recovery and vowed to visit spiritual places to fulfill promises made to God. She said: "*I've experienced immense benefits through cultural rituals. My daughter prayed for my health at the Temple of the Tooth, and I recovered…*"

Sinhalese participant 2 was trying to understand the psychological and physical aspects of the disease condition through the core Buddhist belief of "letting go." He expressed: "*The solution is to practice letting go. Then we do not have problems.*"

Positive thinking, acceptance of the illness, setting goals (such as a kidney transplant), finding solace in learning about their illness, and engaging in distraction techniques through hobbies were common adaptive coping strategies among the Polish sample. As Polish participant 1 mentioned: "*I try to change my thinking and focus on positive things, pushing away thoughts that make me feel trapped. It's intense. […] I push away thoughts about feeling unwell by turning on the TV or engaging with my pets, so I can distract myself.*"

For some patients, the crisis served as a catalyst for personal growth, inspiring them to seek and acquire new knowledge. Polish participant 2 mentioned, "*Since being diagnosed with diabetes, I've been in this medical world. Then I chose my studies and work in this area, so I find it easier to understand what doctors are telling me.*"

A few patients maintained a supportive group and engaged in enjoyable activities. Polish participant 1 mentioned: "*Right now, we have this group; we've become more outgoing with a few women. We bake cakes, bring them, share them with the nurses…*"

Polish participant 3 explained her positive hopes regarding the possible transplant: "*My goal now is to get a transplant, go through the tests, get the certificates I need, and persist in pursuing that goal.*"

Polish participant 7 mentioned the support he receives from his friends*: "That's exactly it, I stick more with my friends than with my family, so we've been through a lot together, and one friend even offered—well, most of them, every other one, said they would give me a kidney if they could. And one of them got so involved that he personally checked everything to find out what he needed to do."*

Most patients see themselves as believers but do not actively practice or associate with the Catholic Church. Polish participant 1 explained: *"I mean, I believe in God and that He exists. […] I don't believe in priests, don't believe in earthly beings, as I think we're all sinful."* Some patients described their disease as "superstitions" or esoteric experiences. Polish participant 2 explained*, "I have certain superstitions, like carrying a chimney sweep's button, which I bring with me to exams or important events."*

Polish participant 4 admitted: *"Although I don't go to church, deep down I believe in God and usually pray when I have moments of doubt, moments of despair, when I don't understand why so many bad things are happening around me, why I still don't have my health. Faith and prayer help me; they make me feel more spiritual and stronger."*

Maladaptive Coping Strategies. Helplessness, hopelessness, withdrawal, and mistrust were identified in both samples and are presented here as maladaptive coping strategies. These behaviors or emotional states appeared to reduce individuals' ability to actively manage the challenges of ESKD and were often linked to passivity, emotional distress, or isolation. While such responses are understandable given the burden of the illness, we grouped them separately due to their recurring presence and impact on participants' overall wellbeing.

Helplessness and hopelessness identified in the Sinhalese sample are considered maladaptive coping strategies. Most of them feel helpless and hopeless particularly those facing challenges related to caregiving responsibilities or finding suitable organ donors. Sinhalese participant 3 explained that he feels helpless as he does not have children, and no one is there to look after his wife if something happens to him. *"It's hard, and sometimes the helplessness is overwhelming, but we have to keep going."* Similarly, Sinhalese participant 2 expressed a sense of limitation and reliance on close kin for life-saving support, stating: *"I believe that if I find a donor, it should ideally be a family member, as external individuals may not be as inclined to donate."* While not overtly emotional, this belief may reflect a sense of constrained possibility and reduced perceived support, which could contribute to feelings of hopelessness.

Some individuals in the Polish sample exhibit mistrust of healthcare providers, experience depression, withdraw from relationships, struggle with hopelessness, and thoughts of suicide. According to Polish participant 8: *"I want to be able to have some control, which isn't always a good trait. It caused me to refuse anaesthesia for a procedure that usually requires sedation, as I insisted on watching what they were doing…"*

Some patients are isolated from others as a result of depression, loss of purpose, and feelings of uselessness and boredom. Polish participant 2 stated: *"When I feel bad, or something terrible happens, I cut myself off from distant people. I don't want to involve them…"*

Some individuals are reluctant to discuss their illness, which can be considered a passive coping response and may hinder emotional expression. Polish participant 4 said, *"I have friends who, as I mentioned, don't know about my illness, so they can't support me because they don't understand what's wrong with me…"*

Some patients are focusing excessively on suffering, leading to despair and abandoning efforts to improve wellbeing. Polish participant 2 expressed: *"Honestly, I've thought about suicide a few times [voice breaks], knowing that not much is left for me…"*

Medical Experience

The medical experience of both the sample includes the knowledge of the disease, self-management and attitudes toward the treatment process.

Knowledge and Self-Management. Most of the Sinhalese individuals did not fully understand the nature of the disease. Sinhalese participant 7 acknowledged feeling confused about the disease due to the conflicting information he had received. He said: *"I'm not sure what this disease exactly is. Some say the kidneys are melting; others say they're shrinking."*

Sinhalese participant 3, who was unaware of the effects of dialysis, questioned its impact, stating: *"I don't even know what dialysis is, even though I'm undergoing it. Does dialysis make people weak?"*

Some patients were dissatisfied with the information provided by doctors. Sinhalese participant 1 expressed frustration over doctors' reluctance to offer details beyond prescribing medication. She said: *"Doctors aren't open to answering our questions. They seem unwilling to engage beyond just medication…"*

Unlike the Sinhalese, Polish individuals generally appreciate the high quality of medical care and individualized attention from healthcare professionals. Polish participant 2 remarked, *"Every time, the doctors have taken a highly individual approach, showing care and concern,"* emphasizing the importance of tailored care.

Similarly, Polish patient 4 added, *"Honestly, I feel safe here. Sure, the building is now renovated, but even before, in the old building, the sense of security from the staff mattered more to me,"* highlighting how the supportive environment created by the staff fosters a sense of safety and trust among patients.

Polish participant 2 explained, *"My kidneys don't remove toxins, don't filter, don't work, which is why I'm on dialysis."*

Some Polish patients demonstrate a strong curiosity to deepen their understanding of their condition and are motivated to pursue knowledge that supports self-management. For instance, Polish Participant 2 shared, *"Since being diagnosed with diabetes, I've been in this medical world. Then I chose my studies and work in this area, so I find it easier to understand what doctors are telling me."*

This highlights how gaining knowledge about their illness can empower patients, enabling them to better comprehend medical advice and actively participate in managing their health.

Many patients with diverse educational backgrounds actively engage in their treatment by consulting doctors and verifying information on social media forums. Polish participant 8 explained: *"even though I was also doing my doctorate, but in a different field, I'm passionate about these things, so I read scientific articles, dig around, and try to organize things in my mind…"*

Treatment. The Sinhalese sample expressed satisfaction with dialysis but highlighted inadequate infrastructure. Sinhalese participant 11 described his father's postdialysis routine, stating: *"there is a dialysis shift from 7 p.m. to 12 a.m. Patients coming for that shift, especially those traveling from distant places, cannot leave immediately and have to stay overnight. We often end up sleeping on chairs or even on the floor."*

Some patients highlighted difficulties caused by medication shortages. Sinhalese participant 9 elaborated, stating: *"We often can't find basic medicines here. Sometimes, we even have to provide the hospital with supplies like plasters because they run short. It's really tough."*

Compared to the treatment facilities of Sinhalese, Polish individuals are generally more satisfied with the available services. Polish individuals are not traveling long distances for dialysis. They typically come from nearby areas. For those from farther away, receiving treatment in Gdańsk as a personal choice with satisfaction. Polish participant 5 said: *"I'm from Gdynia, so I'm closest to the station in Gdynia, but I would never want to go there. Here… Here, I feel safe."*

Polish participant 6 stated, *"Compared to other facilities, I rate them very highly here; it's a well-qualified team,"* reflecting confidence in the expertise of the medical staff.

According to Polish participant 4, nurses are friendly and often provide a source of support. *"The nurses are always so welcoming and helpful."*

According to Polish patients, the medical staff generally respond to questions and approach each patient individually. Polish patient 2 stated: *"Every time, the doctors have taken a highly individual approach, showing care and concern."*

Discussion

This study offers a unique cross-cultural comparison of the psychosocial experiences and treatment processes of individuals with ESKD and their caregivers in Sri Lanka and Poland. The findings identified three core themes—quality of life, coping strategies, and medical experiences—each deeply influenced by the cultural, economic, and healthcare contexts specific to each country.

Quality of Life

Participants from both countries reported a diminished quality of life as a result of the physical, psychological, and financial burdens associated with ESKD. In Poland, some participants were able to maintain financial stability due to systemic healthcare support, whereas Sri Lankan participants universally faced significant economic hardships. These findings are consistent with previous studies emphasizing the critical role of resource availability in managing chronic illnesses (Senanayake, 2018; Ziętalewicz & Bargiel-Matusiewicz, 2024).

Despite these differences, family support emerged as a universal factor in fostering resilience, highlighting the pivotal role of familial networks in coping with chronic disease.

Coping Strategies

Coping strategies varied significantly between the two cultural contexts. Polish participants predominantly employed adaptive strategies such as autonomy, goal-setting, and cognitive reframing, reflecting the individualistic cultural orientation characteristic of Western societies. In contrast, Sri Lankan participants relied on communal support, religious rituals, and adherence to traditional values, consistent with the collectivist societal norms typical of Eastern cultures. These findings align with existing literature on cultural influences on coping, which underscores the emphasis on individual agency in Western cultures versus communal interdependence in Eastern contexts (Maguire et al., 2021; Fischer & Grønning, 2021).

Notably, maladaptive strategies, including feelings of helplessness and depression, were observed in both groups. This shared experience highlights the universal need for targeted psychosocial interventions to support individuals with ESKD and their caregivers.

Medical Experiences

The medical experiences of participants reflected systemic disparities between the two contexts. Polish participants reported satisfaction with the quality and accessibility of healthcare services, benefiting from structured and individualized care within a well-established healthcare system. In contrast, Sri Lankan participants encountered significant infrastructural challenges, including long travel distances and limited resources. These findings are consistent with previous research highlighting the essential role of systemic support in managing chronic illnesses (Boonstra et al., 2022).

Addressing these disparities requires the development of culturally adaptive strategies that consider local resource constraints while prioritizing the specific needs of patients and caregivers.

Cross-Cultural Insights

The conceptual model proposed in this study encapsulates the dynamic interplay between cultural frameworks, coping strategies, and medical experiences. The "Power of (My)Self" framework identified in the Polish context underscores the importance of resilience and autonomy, while the "Power of Tradition" observed in Sri Lanka emphasizes the role of communal and religious influences. These frameworks provide a foundation for designing culturally tailored interventions

that respect and integrate cultural values while addressing the universal challenges associated with ESKD.

Previous research aligns with these findings in distinct ways. For example, Eloia et al. (2021) highlighted the significance of religious coping and spirituality in CKD, which resonates with the "Power of Tradition" framework seen in the Sri Lankan context. Similarly, Siqueira et al. (2019) emphasized the role of religiosity and a sense of coherence in improving survival quality among patients with CKD—an aspect closely related to resilience, reinforcing the "Power of (My)Self" framework in the Polish context.

Together, these studies demonstrate how cultural, spiritual, and psychological factors shape coping mechanisms and influence the wellbeing of individuals living with CKD.

Study Strengths

This study's cross-cultural design compares the experiences of patients with ESKD and caregivers in Sri Lanka and Poland, revealing both universal challenges and culturally specific factors. Its comprehensive scope examines multiple life dimensions—quality of life, coping, and medical experiences—offering a holistic understanding of ESKD's impact on patients and families. Including caregivers alongside patients is a key strength, highlighting the reciprocal influence of chronic illness within family systems. The qualitative methodology, using semistructured interviews, allows for in-depth exploration of lived experiences, while methodological rigor (triangulation and reflexivity) enhances the credibility of findings, despite the common limitation of recall bias.

A strong focus on cultural sensitivity ensures findings are relevant and respectful of participants' contexts, promoting culturally informed healthcare practices. The study also provides practical recommendations for improving patient education, psychosocial support, and addressing healthcare disparities, particularly in underserved settings like Sri Lanka.

Finally, the research lays a foundation for future mixed-method studies, contributing to global discussions on health equity and culturally sensitive care. Its innovative design, methodological rigor, and practical focus offer valuable insights for improving ESKD management across diverse populations.

This study's strengths lie in its cross-cultural design, comparing the experiences of patients with ESKD and caregivers in Sri Lanka and Poland. It reveals universal challenges while highlighting culturally specific factors, offering insights that are both globally significant and contextually relevant. The study also demonstrates methodological rigor through reflexivity, triangulation, and credibility-enhancing strategies, which strengthen the trustworthiness of its findings.

Another strength lies in the study's comprehensive scope, which examines multiple dimensions of life affected by ESKD, including quality of life, coping strategies, and medical experiences. By addressing such a wide range of psychosocial factors, the research offers a holistic understanding of the impact of ESKD on patients and their caregivers, emphasizing the interconnected influences of personal, familial, and systemic factors.

The inclusion of caregivers alongside patients is particularly noteworthy. This dual focus enables the study to explore the interrelated dynamics of chronic illness management within family systems, illuminating the reciprocal impact of ESKD on both patients and their support networks. By integrating caregivers' perspectives, the research underscores their critical role in patient wellbeing and enriches the overall analysis.

The study's qualitative methodology is another significant strength. The use of semistructured interviews facilitates an in-depth exploration of participants' lived experiences, capturing the complexity and nuance of their psychosocial and medical realities. This approach yields insights often overlooked in quantitative research, offering a detailed and personal perspective on the challenges faced by individuals living with ESKD. Furthermore, the application of rigorous triangulation methods, with data independently coded by multiple researchers, enhances the credibility and reliability of the findings. While rich in depth, this method may also be subject to recall bias—a common limitation in retrospective qualitative interviews.

A strong emphasis on cultural sensitivity further distinguishes this research. By tailoring the study design and interpreting results within the cultural and religious contexts of the participants, the researchers ensure that the findings are both relevant and respectful of participants' worldviews. This cultural sensitivity not only strengthens the applicability of the study's conclusions but also underscores the importance of contextually informed healthcare practices.

In addition, the study generates practical implications for healthcare providers and policymakers. It identifies actionable recommendations, such as enhancing patient education, expanding psychosocial support services, and addressing systemic disparities in healthcare access. By focusing on underserved populations, particularly in Sri Lanka, the research highlights systemic inequalities and advocates for targeted improvements in healthcare infrastructure and resources.

Finally, the study establishes a strong foundation for future research. Its findings can inform larger-scale, mixed-methods studies that further examine the interplay between cultural, systemic, and psychosocial factors in chronic disease management. Its contribution to the global discourse on health equity and culturally sensitive care is particularly significant, emphasizing the need for inclusive healthcare strategies that cater to diverse patient populations.

The study's innovative design, rigor, cultural inclusivity, and practical focus offer valuable insights into ESKD, enhancing academic knowledge and guiding improvements in patient and caregiver wellbeing across cultures and healthcare settings.

Study Limitations

This study encountered several limitations that should be considered when interpreting its findings.

First, although the sample size may seem limited, it aligns with qualitative research priorities, which focus on depth rather than generalizability. Data saturation was monitored during collection and deemed achieved when no new codes or themes emerged, based on ongoing comparisons and team discussions confirming the richness of the data.

Second, the study focused exclusively on two specific cultural groups: Sinhalese Buddhists and Polish Catholics. While this cultural specificity allows for a rich exploration of the interplay between cultural, religious, and systemic factors, it may limit the applicability of the findings to other ethnic or cultural groups. These specific contexts should be carefully considered when interpreting the results and applying them to broader populations.

The data were collected through semistructured interviews, which effectively captured detailed experiences but were prone to recall bias, as participants reflected on different stages of their illness. This highlights the importance of incorporating complementary methods, such as longitudinal or mixed-method approaches, in future studies to enhance accuracy and validate these findings.

Implications for Practice

This study highlights the importance of developing culturally sensitive interventions that align with the unique values and coping mechanisms of patients and caregivers. In contexts such as Sri Lanka, where traditional practices and communal support systems are deeply embedded, integrating cultural resources into healthcare delivery can significantly enhance patient engagement and outcomes. For example, organizing short retreats for patients and caregivers focused on relaxation, mindfulness, and spiritual healing could provide emotional relief and foster resilience. Similarly, establishing social clubs where patients and caregivers can connect, share experiences, and support one another would cultivate a sense of community and mutual understanding, further bolstering coping mechanisms and overall wellbeing.

These findings are relevant to nursing practice, as nurses are often at the frontline of chronic illness management and long-term patient care. Through culturally competent care, nurses can bridge the gap between medical treatment and psychosocial support, ensuring that patients receive care that respects their beliefs and coping mechanisms. Strengthening both nursing education and clinical practice to include psychosocial and cultural dimensions, particularly in contexts like Sri Lanka, where such integration may be limited, can better equip nurses to deliver holistic, patient-centred care. Improving access to healthcare and psychological support is vital for patients with ESKD in resource-limited settings. Healthcare policymakers should prioritize addressing systemic disparities, including logistical barriers and infrastructure gaps, to ensure equitable care.

In cultures that emphasize individual strength and autonomy, such as Poland, fostering resilience and self-reliance is essential. Tailored mental health interventions, patient education on adaptive coping strategies, and structured support groups can play a pivotal role in enhancing psychological wellbeing and empowering patients to navigate the challenges of ESKD more effectively.

A multidisciplinary, collaborative care approach is essential for addressing the complex medical and psychosocial needs of patients with ESKD and their caregivers. Prioritizing patient-centred care and integrating physical, psychological, and cultural aspects ensures responsive and supportive healthcare that empowers patients and caregivers.

Conclusions

This study explored the psychosocial experiences and treatment processes of individuals with ESKD in two distinct cultural contexts—Eastern (Sri Lanka) and Western (Poland). As the first study to compare these cultural perspectives in relation to the psychosocial wellbeing of patients and their families, it uncovered significant influences on quality of life, coping strategies, and medical experiences.

A key finding was the contrasting frameworks shaping participants' wellbeing. Among Sinhalese participants, *the power of tradition*, rooted in communal values and cultural practices, emerged as a central factor influencing their experiences. In contrast, Polish participants emphasized *the power of (my) self*, characterized by autonomy and self-determination. These divergent paradigms underscore the profound interplay between cultural norms and individual coping strategies in managing chronic illness.

The findings contribute to the development of a conceptual model that integrates these cultural dynamics, offering a robust framework for designing culturally sensitive healthcare interventions. By incorporating these insights into clinical practice, healthcare providers can enhance patient and caregiver wellbeing while addressing systemic disparities across diverse cultural and healthcare settings.

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Ethical Considerations

The study received ethical approval from the Ethical Review Committee of the Open University of Sri Lanka, under the application number ER/2022/007 and from the Ethical Review Board of the Institute of Psychology, University of Gdańsk, under inquiry number 03/2023.

Author Contributions

DB was involved in study conceptualization, data curation, study design, data collection, qualitative analysis, and manuscript drafting; AR in study conceptualization, data curation, study design, qualitative analysis, manuscript drafting, and revision; JB, AZ, ADŚ, BB, and LT in data collection; SZ in data collection and qualitative analysis; MT in qualitative analysis; JR in data collection and manuscript revision; MB in study conceptualization and design, data collection, manuscript revision, supervision, and mentorship. All authors contributed to the article and approved the submitted version.

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Data Availability Statement

The data that support the findings of this study are available upon request from the corresponding author.

Supplemental Material

Supplemental material for this article is available online.

Patient Consent Statement

Informed consent was obtained from all participants included in the study. The participants were briefed about the nature of the research, its purpose, procedures, potential risks, and benefits. They were informed about their voluntary participation and the confidentiality of their identity.

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Clinical Trial Registration

This study is not a clinical trial, and thus, registration is not applicable.

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Publication 5

This publication is under review, thus included as a submission file.

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Psychosocial well-being among individuals with end-stage kidney disease undergoing hemodialysis treatment in Sri Lanka and Poland: an explorative study

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Authors	Thejani Bulathwatta, Judyta Borchet, Agata Rud nik, Jakub Ruszkowski, Agnieszka Zakrzewska , Alicja M. Dębska-Ślizień, Bogdan Biedunkiewic z, Leszek Tylicki, Ewelina Puchalska-Reglińska, Mariola Bidzan

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Psychosocial well-being among individuals with end-stage kidney disease undergoing hemodialysis treatment in Sri Lanka and Poland: an explorative study

Running Head: Psychosocial Well-being in ESKD

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Declarations

ETHICAL APPROVAL AND CONSENT TO PARTICIPATE: The study received ethical approval from the Ethical Review Committee of the Open University of Sri Lanka, under the application number ER/2022/007 and from the Ethical Review Board of the Institute of Psychology, University of Gdańsk, under inquiry number 03/2023. All participants gave their informed consent to participate in the study.

AUTHOR CONTRIBUTION: DB: study conceptualization, study design, data collection, statistical analysis, and manuscript drafting. JB: study design, statistical analysis, and manuscript revision. AR: manuscript revision. JR: data collection, statistical analysis, manuscript revision. AZ: data collection, manuscript revision. ADŚ: data collection, manuscript revision. BB: data collection, manuscript revision. LT: data collection, manuscript revision. EPR: data collection, manuscript revision. MB: study conceptualization and design, data collection, manuscript revision, supervision, and mentorship. All authors contributed to the article and approved the submitted version.

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Psychosocial well-being among individuals with end-stage kidney disease undergoing hemodialysis treatment in Sri Lanka and Poland: an explorative study

Running Head: Psychosocial Well-being in ESKD

Abstract:

Background: End-stage kidney disease (ESKD) is the final stage of chronic kidney disease (CKD), severely affects quality of life. Understanding its psychosocial impact is crucial, particularly when comparing populations across diverse cultural contexts. This study examines the psychosocial well-being of individuals with ESKD in Sri Lanka and Poland, comparing how cultural differences influence psychological experiences and quality of life.

Methods: This study employed a cross-sectional quantitative design to examine the psychosocial well-being of individuals with ESKD undergoing hemodialysis. Data were collected using validated questionnaires: the Kidney Disease Quality of Life Short Form Questionnaire, the Beck Depression Inventory, and the Acceptance of Illness Scale. Health records were reviewed for demographic and medical information. The study involved 50 patients from Sri Lanka and 43 from Poland.

Results: Common challenges included symptoms, sleep issues, cognitive impairments, and disease burden. However, Sri Lankan patients reported higher depression, lower quality of social life, and less social support than Polish patients.

Conclusions: Cultural context significantly influences the psychosocial experiences of individuals with ESKD. These findings highlight the need for culturally sensitive interventions to improve psychosocial support for this population.

Keywords:

chronic kidney disease, psychosocial well-being, health-related quality of life, depression, acceptance of illness, cross-cultural comparison

Background

Chronic kidney disease (CKD) is recognized as a leading non-communicable disease affecting millions worldwide [1, 2]. It is estimated that approximately 11 to 13% of the global population suffers from CKD, a rise linked to increasing rates of hypertension, diabetes, and an aging population [3]. Over the past three decades, the prevalence of CKD has notably increased, with contributing factors including the rise of CKD of unknown etiology and the growing incidence of non-communicable diseases such as hypertension and diabetes, particularly in Sri Lanka [4, 5, 6]. In Poland, CKD is not only a major risk factor for cardiovascular disease [7] but also a widespread condition among the elderly, affecting roughly one-third of the senior population [8].

Patients with CKD often progress to end-stage kidney disease (ESKD), requiring a kidney transplant or dialysis for survival [9]. Hemodialysis (HD), while life-extending, significantly impacts patients' quality of life (QoL) due to the physical, psychological, and social burdens it imposes on both patients and their families [10]. ESKD is a complex health issue that affects family dynamics, education, finances, physical and social functioning, and mental health [11, 12].

While health-related quality of life (HRQoL) is widely used to assess well-being in ESKD-capturing symptoms, treatment effects, functional limitations, and perceived health [13,14], it may not fully reflect the complex psychological and social burdens patients face. In contrast, psychosocial well-being encompasses emotional health (e.g., depression, anxiety), illness acceptance, relationships, social integration, and existential meaning [15–17]. It is not merely the absence of distress but also includes resilience, social role maintenance, and a sense of purpose despite chronic illness [17,18]. Notably, ESKD patients report psychosocial distress levels comparable to those with terminal cancer [19].

ESKD occurs 3 to 5 times more frequently among South Asians than White Europeans, yet few studies explore depression and its impact among South Asian hemodialysis patients [20]. This gap stems from limited registries and weak health policies in many developing countries [21]. South Asian patients often view ESKD as a social burden, even post-transplant, with psychological well-being shaped by distinct cultural contexts - area underexplored in renal research [22]. In Sri Lanka, most CKD patients are informal-sector farmers, and despite free public healthcare, they face high out-of-pocket costs and systemic challenges due to economic instability [23–25]. Cultural beliefs such as karma, spirituality, and divine will further shape illness perceptions and coping [26]. In contrast, Poland's universal healthcare system covers dialysis and transplantation, easing financial pressures on ESKD patients [27,28].

Insights from countries like Poland, which follow Kidney Disease: Improving Global Outcomes (KDIGO) standards, can guide practitioners in Sri Lanka. Given that low socioeconomic status (SES) affects health, social support, and depression [15], these factors must be addressed. Cross-country comparisons of psychosocial well-being and healthcare systems can help develop context-specific recommendations to enhance ESKD care in Sri Lanka.

Cross-country differences in healthcare access and cultural coping highlight the need to consider context when addressing ESKD patients' broader needs. Despite growing focus on quality of life, research and care often neglect psychosocial dimensions, especially in culturally diverse, low-resource settings [22]. Current models remain largely biomedical, with limited mental health and social support integration [15]. Consequently, issues like cultural stigma,

existential distress, and caregiver burden are often ignored clinically and in policy. This gap between patient needs and system responses calls for holistic, context-sensitive ESKD care.

Objectives

The study's primary objective is to investigate the psychosocial well-being of individuals with ESKD undergoing hemodialysis in Sri Lanka and Poland. Its specific objectives are as follows:

1. To identify the main social (i.e., age, gender, education, occupational status, marital status, religion) and medical factors (i.e., self-reported time since CKD diagnosis, self-reported diabetes, self-reported hypertension, hemoglobin level, and hemodialysis treatment adequacy) that might be associated with the psychosocial well-being of ESKD patients undergoing hemodialysis in Sri Lanka and Poland.

2. To compare the psychosocial well-being (i.e., HRQoL, depression, acceptance of illness) among ESKD patients undergoing hemodialysis in Sri Lanka and Poland.

Method

Study design

This current study is part of a broader mixed-methods project that combines qualitative and quantitative approach (see study protocol: MASKED FOR REVIEW). This paper presents the results of the quantitative investigation. It employs questionnaires and medical records to assess the psychosocial well-being of individuals with ESKD undergoing hemodialysis,

focusing on measurable insights into HRQoL, depression, and illness acceptance. The design allowed for structured data collection and analysis, facilitating comparisons between groups and evaluating medical and social factors associated with psychosocial well-being. The data were analyzed to align with the study's objectives, integrating findings into a cohesive understanding of these aspects.

Study setting

This study was conducted in Poland and Sri Lanka, focusing on two purposively selected hemodialysis units: the Hemodialysis Unit at the District Teaching Hospital in Kandy, Sri Lanka, and the Hemodialysis Unit at the University Clinical Center of the Medical University of Gdańsk, Poland. Kandy was chosen for its central location, providing access to patients from across Sri Lanka, while Gdańsk was selected to match the sample, as it is the only Polish Nephrology Clinic for adults included in the European Reference Network for Rare Kidney Diseases and is situated in a well-connected urban setting.

Data Collection

Data collection occurred between October 2022 and March 2024. In Sri Lanka, questionnaires were administered by the principal investigator (PI). In Poland, due to PI's lack of fluency in the Polish language, the questionnaires were distributed to patients with the assistance of the dialysis unit staff. This inconsistency in data collection needs to be noted as a study limitation. Notably, in both sites, all participants were informed about the anonymity of the study, its scope and procedures, as well as the voluntary nature of participation and the option to withdraw at any time without consequence. Each participant was assigned a unique encrypted identifier to maintain anonymity, and data access was restricted to the research team. Ethical approval was granted by the Ethical Review Committee of the Open University of Sri Lanka and the Ethical Review Board of the University of Gdansk (ER/2022/007 and 03/2023).

Participants

Participants were selected through purposive sampling, ensuring matching demographic composition (i.e., age and gender) between the two countries. Inclusion criteria were: diagnosed CKD in stage G5D, undergoing hemodialysis, over 18 years old, and of Sinhalese nationality for the Sri Lankan sample or Polish nationality for the Polish sample. Because of the explorative nature of the study, the most prevalent nationalities/ethnicities in the studied countries were set as inclusion criteria in order to ensure the homogeneity of the samples (Polish, composing 97% of Poland's inhabitants, and Sinhala, 75-77% of Sri Lanka's inhabitants; add references). Future studies should include more ethnically-diverse samples. Comorbidities were not considered for inclusion due to limited sample size. Exclusion criteria included: failure to meet inclusion criteria, refusal to provide informed consent, or lack of physical/mental ability to participate.

Measure

All participants completed the Kidney Disease Quality of Life - Short Form (KDQOL-SF) Version 1.3 , [29] Beck Depression Inventory (BDI), [30] and Acceptance of Illness Scale (AIS) [31] to measure the variables of HRQoL, depression, and acceptance of illness, respectively.

The KDQOL-SF Version 1.3 demonstrates strong construct validity and test-retest reliability [29]. This instrument comprises two main components: the Kidney Disease-Specific Component and the SF-36. In total, it includes 81 questions across 19 domains. The Kidney Disease-Specific Component consists of 11 domains assessed through 43 items, while the SF-36 component evaluates general health-related aspects through 36 items. Higher scores reflect a better quality of life.

The 11 domains specific to kidney disease cover various aspects, including symptom/problem list (12 items), the effect of kidney disease on daily life (8 items), and the burden of kidney disease (4 items). Other domains assess cognitive function (3 items), quality of social interaction (3 items), sexual function (2 items), sleep (4 items), social support (2 items), work status (2 items), patient satisfaction (1 item), and dialysis staff encouragement (2 items) [32]. The SF-36 component consists of eight domains: physical function (10 items), role limitations due to physical health (4 items), role limitations due to emotional health (3 items), pain (2 items), general health perceptions (5 items), social function (2 items), emotional well-being (5 items), and energy/fatigue (4 items). Additionally, the final item evaluates overall health on a scale from 0 to 10. The KDQOL-SF has been culturally validated and adapted for use in both Sri Lankan [32] and Polish [33] populations. Higher scores represent better health status and well-being.

The Beck Depression Inventory (BDI) was used to assess the depression of individuals with chronic kidney disease undergoing hemodialysis. It is a 21-item, self-administered questionnaire that covers the full spectrum of depressive symptomatology [30, 34]. Furthermore, studies have proven the validity of the BDI for measuring depression in patients with ESKD [35, 36]. In the Polish cultural setting, the Polish adaptation of BDI-II was used [37]. In the Sri Lankan cultural setting, the BDI-II adaptation prepared by Rodrigo et al [38], was used.

The AIS questionnaire comprises 8 statements that outline adverse outcomes of compromised health, encompassing evaluations of limitations imposed by the illness, reduced self-sufficiency, a sense of dependence on others, and diminished self-esteem. The overall assessment of illness acceptance is calculated as the cumulative score of all the statement points, with total scores ranging from 8 (extremely low acceptance/adjustment) to 40 (extremely high acceptance/adjustment). A lower score signifies a lack of adaptation to the illness and a strong sense of psychological discomfort, while a higher score indicates acceptance of one's medical condition and is accompanied by a lack of negative emotions tied to the illness. The AIS scale

exhibits the reliability of Cronbach's α at 0.83 [31]. The Sri Lankan translation of the scale produced a satisfactory reliability score both in this study (α=0.69) and in the scale adaptation study (α=0.90; MASKED FOR REVIEW).

Apart from the instruments mentioned above, a sociodemographic survey was distributed to all study participants. The survey measured independent variables. The following information was collected via the sociodemographic survey: nationality, age, gender, education, occupational status, marital status, and religion.

Information related to health conditions came from two sources: self-reports and hospital records. Information on time since CKD diagnosis, having or not having diabetes, and having or not having hypertension was self-reported. Medical information such as hemoglobin and hemodialysis treatment adequacy measured as Kt/V levels were retained from hemodialysis units records.

Data Analysis

All analyses were conducted using SPSS Version 29 (IBM Corp., Armonk, N.Y., USA). To assess group differences, an independent sample Student's *t*-test was employed. In the case of non-parametric analyses, Mann–Whitney *U* test, chi-square test, and Fisher's test were used. Statistical significance was set at two-tailed $p<0.05$. The effect size of group differences was measured with Cohen's *d* (with $d>0.8$ indicating a high effect size, and $d>0.5$ indicating a moderate effect size) [39]. To ensure equity-relevant context during data interpretation, following the PROGRESS-Plus framework [40], factors such as nationality/ethnicity, age, gender, education, occupational status, marital status, and religion were measured.

Results

Study group description

A total sample of 93 individuals with CKD undergoing hemodialysis were recruited. There were 50 patients recruited in Sri Lanka (Sinhalese) and 43 participants recruited in Poland (Polish). The Sri Lankan sample consisted of 68% men and 32% women, aged 24 to 75 (M=51.08 years, SD=10.99). Their CKD was diagnosed from 6 to 169 months (approximately 14 years) ago. The mean time since the CKD diagnosis was approximately above 3 years (M=37.90 months, SD=37.60). The Polish sample was more gender-balanced (51.2% male, 41.9% female, 7% omitted the question about their gender; no info). Time from CKD diagnosis extended from less than a month to approximately 30 years (M=102.16 months, SD=123.03). Further sample description by nationality is presented in Table 1.

<Table 1 here>

The first goal of the study was to identify the main social (i.e., age, gender, education, occupational status, marital status, religion) and medical factors (i.e., self-reported time since CKD diagnosis, self-reported diabetes, self-reported hypertension, hemoglobin level, and hemodialysis treatment adequacy) that might be associated with the psychosocial well-being of ESKD patients undergoing hemodialysis in Sri Lanka and Poland. As expected, there were no significant differences in gender and age between groups, due to applying the matching sampling method. Given the subsamples limited sizes ($n_{SL}=50$; $n_{PL}=43$), the studied factors were not tested as predictors for psychosocial well-being. We used these information to characterize the and seek for potential differences among the samples that might be considered in further investigations. We identified high disparities in education, marital status, religion ($p<0.001$), and occupational status ($p=0.02$). These social differences may be attributed to both cross-cultural variations [40, 41], and systemic challenges, particularly those faced by the Sri Lankan healthcare system in managing non-communicable and chronic diseases [42].

Additionally, the groups were similar concerning the time since CKD diagnosis (p=0.50), self-reported hypertension (p=0.31), and the dialysis adequacy (Kt/V; p=0.480). Interestingly, when compared to Sinhalese participants, Polish HD patients had diabetes ($p<0.05$) and cardiovascular disease ($p<0.001$) more frequently. This result is interesting, as Polish patients have better access to healthcare compared to Sri Lankan patients [42]. Additionally, Polish patients presented higher serum concentration of haemoglobin ($p<0.001$).

The second goal of the study was to compare the psychosocial well-being (i.e., HRQoL, depression, acceptance of illness) among ESKD patients undergoing hemodialysis in Sri Lanka and Poland. The results of the analyses are presented in Table 2.

<Table 2 here>

When compared to Polish HD patients, Sinhalese HD patients reported significantly lower social support, patient satisfaction, emotional well-being, social function, and general health perceptions ($d > 0.8$), indicating poorer quality of life in these positive domains. Additionally, they reported significantly higher levels of depression, role limitations due to physical and emotional problems, greater pain, and more fatigue ($d > 0.8$), reflecting a higher burden of these negative domains. Moreover, the Sinhalese group experienced a moderately higher burden of kidney disease and poorer quality of social interactions ($d > 0.5$). On the other hand, they reported moderately better sexual function ($d > 0.5$). Interestingly, we did not identify significant differences ($p > 0.5$) in the effect of kidney disease in daily life, symptom levels, sleep, physical and cognitive functioning, work status, and dialysis staff encouragement. Also, the level of acceptance of illness was moderate in both groups and no significant differences were detected ($p = 0.20$). These results suggest the universality of some challenges faced by patients with ESKD.

Summing up, while both groups accept their illness to a similar extent, the Sri Lankan ESKD patients reported a higher CKD burden, more pain and role limitations, higher depression levels, and lower social support and functioning. Therefore, one might conclude that Sri Lankan ESKD patients presented lower psychological well-being than their Polish counterparts.

Discussion

The findings of this study, based on quantitative analysis, identified both culture-specific and universal impacts of ESKD among Sri Lankan and Polish participants.

Common challenges included illness acceptance, symptoms, physical and cognitive difficulties, sleep problems, and CKD's impact on daily life. These findings align with global patterns from a systematic review of 199,000 CKD patients across 62 countries, reporting high rates of fatigue, depression, sleep disturbances, pain, and poor physical and mental QoL in both dialysis and non-dialysis groups [43]. In Sri Lanka, a cross-sectional study of 1,118 CKD patients (many in stages 4–5, some on dialysis) found most experienced five or more symptoms, including fatigue, sleep issues, pain, cognitive complaints, and emotional distress [44]. Another study linked symptom burden to poor daily functioning in HD patients [45].

In this study, illness acceptance did not differ significantly between Sri Lankan and Polish groups. This similarity, despite marked differences in other QoL dimensions, may reflect a universal coping response to life-threatening illness [31]. However, culturally embedded worldviews, particularly among Sri Lankans, may also influence acceptance. Theravāda Buddhist beliefs emphasize karma (moral causality) and anicca (impermanence), promoting acceptance of suffering as part of life. While these beliefs may encourage resignation, they do not necessarily improve QoL [46, 47]. As Ananda and Ali [48] noted, many Buddhists view illness as karmic retribution, suffering as a moral consequence rather than a biological

misfortune. This may explain similar illness acceptance despite poorer well-being among Sri Lankan participants.

Improving the QoL of individuals with ESKD requires addressing the physical, emotional, and socioeconomic burdens of HD. A meta-analysis [49] reported that peritoneal dialysis (PD) patients often show better QoL in areas like physical functioning and emotional role limitations. While our study did not include PD patients, the disease-related challenges highlighted in that review align with those reported by our HD participants. However, PD remains less feasible in Sri Lanka due to high costs, self-management demands, and infrastructure limitations [50], leading to continued reliance on HD despite its drawbacks. Supporting evidence from Malawi [51] also showed HD-related physical symptoms impair patients' ability to work. Additionally, a Sri Lankan study [52] found that many HD patients experience poor nutrition due to financial hardship, worsening their physical health. These findings underscore the multidimensional struggles of HD patients in low-resource settings.

While illness acceptance, symptoms, physical and cognitive difficulties, sleep issues, and daily life disruptions affected both groups similarly, notable psychosocial and QoL differences emerged between Sinhalese and Polish participants, reflecting cultural and systemic influences. Using the PROGRESS-Plus framework [40], disparities in psychological outcomes relate to socioeconomic status, residence, culture, and healthcare access. Sri Lankan patients face a heavier burden from these inequalities. Poland's healthcare offers more comprehensive rehabilitation, while Sri Lankan cultural beliefs may hinder recovery. For example, rural patients often misattribute CKD symptoms like facial swelling or breathing difficulties to anemia, malnutrition, or demonic forces [53]. Some view CKD as karma or destiny [54]. Misconceptions such as kidneys "melting" or "shrinking" indicate limited disease understanding, worsening the burden. Factors like residence, culture, socioeconomic status, and education strongly shape health outcomes [55], highlighting the need for culturally sensitive,

systemic interventions such as psychological support integration, social workers in dialysis units, and culturally relevant education to combat stigma.

In the current study, the Sinhalese group reported significantly higher depression levels compared to the Polish group. This suggests a greater psychological and functional burden among Sinhalese participants, possibly due to differences in healthcare access, support systems, or coping mechanisms. A large Sri Lankan study of advanced-stage CKD patients found 65% had clinically significant depressive symptoms and 75% experienced high psychological distress [56]. In contrast, Polish studies report lower, but still concerning-rates, with around 35.7% of HD patients affected according to BDI assessments [57]. These comparisons highlight a heavier depression burden in Sri Lanka, likely due to systemic, economic, and geographic stressors.

The Polish group reported better social interactions and support, highlighting the influence of social factors on quality of life. Social functioning showed a similar pattern, possibly due to cultural norms, stronger welfare systems, or better integration of psychosocial care. These findings align with earlier research [58], which showed that CKD affects livelihoods, domestic roles, and social participation, disrupting family dynamics and community relationships. The literature review [11] also supports this, linking social support from family and friends to reduced depression, more positive illness perceptions, greater life satisfaction, and better treatment adherence in ESKD patients.

This study found significant differences in emotional well-being and role limitations due to emotional and physical issues. Polish participants reported fewer limitations and better emotional health, likely reflecting systemic or cultural resilience. They also rated their general health higher than Sinhalese participants. Marked pain differences highlight the need for improved pain management in the Sinhalese group. Although ESKD affects both populations,

Sinhalese patients reported poorer HRQoL, consistent with earlier findings [59, 56]. CKD remains a global issue, with greater burdens in developing countries [59]. The PROGRESS framework helps identify and address such disparities..

Notably, Polish participants did not report better HRQoL in all domains. Lower sexual function scores may reflect co-morbidities (e.g., diabetes) and conservative cultural factors, including limited access to sexual education [60] and Catholic influences [61].

Although Sinhalese patients reported better overall health despite lower QoL in most domains, they rated their health worse than the previous year, suggesting complex cultural and contextual influences. Stigma around expressing difficulties may partly explain this [62]. These findings reflect psychosocial and QoL disparities shaped by cultural, systemic, and social forces. As structural violence theory suggests [63], limited psychological care, dialysis access, rural poverty, and inadequate health education worsen Sri Lanka's burden. Culturally tailored interventions are essential.

Strengths and Limitations

This study's strength lies in its cross-cultural comparison of CKD patients on hemodialysis in Poland and Sri Lanka, showing how cultural, social, and healthcare factors influence psychosocial well-being. It underscores the need for culturally sensitive policies and tailored education for patients, caregivers, and providers.

Limitations include small sample sizes, reducing generalizability. The cross-sectional design provides only a snapshot, while longitudinal studies could better capture psychosocial changes. Self-reported data may also reflect cultural bias, affecting validity.

Conclusion

Symptoms and daily life impacts affect CKD patients universally, but some factors are culture-specific. Sinhalese patients report higher depression and weaker social support than Polish patients, highlighting the need for culturally tailored care. Despite better reported overall health, stigma and shame may mask true struggles among Sinhalese patients. These psychosocial differences reflect social determinants shaped by structural violence, emphasizing the need for systemic interventions to address inequities and cultural barriers and improve psychosocial support and well-being in CKD care.

Declarations

- **Ethics approval and consent to participate**

The study received ethical approval from the Ethical Review Committee of the Open University of Sri Lanka, under the application number ER/2022/007 and from the Ethical Review Board of the Institute of Psychology, University of Gdańsk, under inquiry number 03/2023. The research was conducted in accordance with the ethical principles of the Declaration of Helsinki. Informed consent was obtained from all participants included in the study. The participants were briefed about the nature of the research, its purpose, procedures, potential risks, and benefits. They were informed about their voluntary participation and the confidentiality of their identity.

- **Consent for publication**

Not applicable, as no identifiable personal data is included in the manuscript.

- **Availability of data and materials**

The data and materials of this study are available upon request from the corresponding author.

- **Competing interests**

The authors declare no conflict of interest concerning the research, writing, and/or publication of this article.

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- **Authors' contributions**

DB: study conceptualization, study design, data collection, statistical analysis, and manuscript drafting. JB: study design, statistical analysis, and manuscript revision. AR: manuscript revision. JR: data collection, statistical analysis, manuscript revision. AZ: data collection, manuscript revision. ADŚ: data collection, manuscript revision. BB: data collection, manuscript revision. LT: data collection, manuscript revision. EPR: data collection, manuscript revision. MB: study conceptualization and design, data collection, manuscript revision, supervision, and mentorship. All authors contributed to the article and approved the submitted version

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Table 1

Sample characteristics (N= 93)

Variable		Sinhala (N = 50)	Polish (N = 43)	*P* value
Gender	Man, n (%)	34 (68)	22 (55)	0.296 (chi-sq 2 x 2)
	Woman, n (%)	16 (32)	18 (45)	
	Not reported, n	0	3	
Age	Mean (SD)	51.08 (10.99)	53.23 (14.78)	0.490 (U Mann-Whitney)
	Not reported	0	4	
Education	Primary, n (%)	6 (12.0)	3 (7.7)	**<0.001** (Fisher 4x2)
	Junior secondary, n (%)	28 (56.0)	6 (15.4)	
	Senior secondary, n (%)	15 (30.0)	17 (43.6)	
	Collegiate & tertiary, n (%)	1 (2.0)	13 (33.3)	
	Not reported	0	4	
Occupational status	Employed, n (%)	19 (38.0)	23 (76.7)	**0.022** (chi-sq 2 x 2)
	Unemployed, n (%)	31 (62.0)	7 (23.2)	
	Not reported, n	0	13	
Marital status	Married, n (%)	39 (81.3)	20 (48.8)	**<0.001** (Fisher 5x2)
	Single, n (%)	9 (18.8)	7 (17.1)	
	Informal relationship, n (%)	0	6 (14.6)	
	Widowed, n (%)	0	4 (9.8)	
	Divorced, n (%)	0	4 (9.8)	
	Not reported	2	2	
Religion	Buddhist, n (%)	50 (100.0)	0	<0.001 (Fisher 6x2)
	Christian (not specified), n (%)	0	3 (15%)	
	Catholic, n (%)	0	13 (30.2%)	
	Atheist, n (%)	0	1 (5%)	
	Muslim, n (%)	0	1 (5%)	
	Jehowah's witness, n (%)	0	2 (10%)	
	missing data	0	23	
Diabetes	Present, n (%)	32 (64.0)	14 (37.8)	0.028 (chi-sq 2 x 2)
	Not reported, n	0	6	
Hypertension	Present, n (%)	43 (86.0)	27 (75%)	0.311 (chi-sq 2 x 2)
	Not reported, n	0	7	
Cardiovascular disease	Present, n (%)	4 (8.0)	16 (45.7)	<0.001 (chi-sq 2 x 2)
	Not reported, n	0	8	
Time since CKD diagnosis	Mean (SD), months	37.90 (37.60)	102.12 (123.03)	0.504 (U Mann-Whitney)
	Not reported	0	10	
Haemoglobin level	Mean (SD), g/dL	9.1 (1.3)	10.7 (0.7)	
	Not reported	33	26	
				<0.001 (U Mann-Whitney)
Kt/V	Mean (SD)	1.64 (0.31)	1.61 (0.25)	0.480 (U Mann-Whitney)
	Not reported	33	27	

Note: *Kt/V* = hemodialysis treatment adequacy

Table 2

Psychosocial well-being among Sri Lankan (SL) and Polish (PL) ESKD patients

Parameters	Subsample (n)	M	SD	t/Z value	p-value	effect size (Cohen's d)
KDQOL symptom	SL (50)	69,50	14,76	-,257	,798	-,053
	PL (43)	70,44	20,57			
KDQOL effect of kidney disease on daily life	SL (50)	53,19	12,41	-,858	,393	-,180
	PL (42)	56,65	25,16			
KDQOL burden of kidney disease	SL (50)	25,00	19,19	-3,538	<,001***	*-,736*
	PL (43)	43,12	29,74			
KDQOL work status	SL (50)	18,00	33,14	**-1,782**	,078	-,371
	PL (43)	31,40	39,37			
KDQOL cognitive function	SL (50)	71,60	16,21	-,538	,592	-,113
	PL (41)	73,98	25,73			
KDQOL quality of social interactions	SL (50)	57,33	16,82	-2,842	,006*	*-,616*
	PL (41)	69,43	22,61			
KDQOL sexual function	SL (46)	70,38	30,32	2,742	,008*	*,626*
	PL (33)	49,24	38,14			
KDQOL sleep	SL (50)	42,53	14,59	-1,043	,300	-,220
	PL (43)	46,03	17,42			
KDQOL social support	SL (50)	55,33	22,45	-4,474	<,001***	**-,935**
	PL (42)	76,19	22,13			
KDQOL dialysis staff encouragement	SL (50)	67,25	16,34	-1,704	,093	-,368
	PL (41)	74,09	20,99			
KDQOL patient satisfaction	SL (50)	4,02	0,65	-6,342	<,001***	**-1,336**
	PL (41)	5,32	1,25			
SF36 physical functioning	SL (50)	44,20	15,82	-1,723	,088	-,358
	PL (43)	52,67	30,32			
SF36 role limitations caused by physical problems	SL (50)	1,50	10,61	-5,891	<,001***	**-1,241**
	PL (41)	38,21	42,53			
SF36 pain	SL (50)	39,21	18,40	-4,418	<,001***	**-,925**
	PL (42)	62,14	30,76			
SF36 general health perceptions	SL (50)	18,90	10,51	-5,366	<,001***	**-1,116**
	PL (43)	36,52	20,28			
SF36 emotional wellbeing	SL (50)	37,44	19,37	-7,093	<,001***	**-1,482**
	PL (43)	66,98	20,57			
SF36 role limitations caused by emotional problems	SL (50)	11,39	26,58	-8,884	<,001***	**-1,872**
	PL (41)	72,36	38,66			
SF36 social function	SL (50)	36,50	15,74	-4,848	<,001***	**-1,015**
	PL (42)	61,01	31,38			
SF36 energy or fatigue	SL (50)	31,40	16,78	-4,580	<,001***	**-,953**
	PL (43)	50,81	23,90			
BDI	SL (49)	18,04	6,26	4,079	<,001***	**,852**
	PL (43)	11,56	8,89			
AIS	SL (33)	22,85	3,73	-1,296	,199	-,301
	PL (42)	24,81	8,03			

Note: Kidney Disease Quality of Life = KDQOL-SF, Beck Depression Inventory = BDI, Acceptance of Illness Scale = AIS; t = t-test value, Z = Z test value, *p<0.05; **p=0.01; ***p<0.001

Declarations of Co-authors of the Publications

Publication #1: Bulathwatta, D. T., Borchet, J., Rudnik, A., & Bidzan, M. (2023). Psychosocial well-being among individuals with chronic kidney disease undergoing hemodialysis treatment and their caregivers: A protocol of a mixed method study in Sri Lanka and Poland. *Frontiers in Psychology*,14. https://doi.org/10.3389/fpsyg.2023.1194991

Name of the candidate: Darshika Thejani Bulathwatta

We, the undersigned, co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.

Statement indicating the candidate's contribution to the publication: The candidate contributed to study conceptualization, conducting literature review, study design and manuscript drafting.

The contribution of co-authors: The co-authors contributed to the conception of the study and to drafting and revising the manuscript.

Name: Mariola Bidzan

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Institution: University of Gdansk

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Title: Doctor of Psychology

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Institute of Psychology

Date: 20.01.2026

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Signature: 

Name: Agata Rudnik

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Institution: University of Gdansk

Institute of Psychology

Date:20.01.2026

Signature: 

Publication #2: Bulathwatta, D. T., Borchet, J., Rudnik, A., & Bidzan, M. (2024). The cross-cultural differences in shame and guilt among individuals with chronic diseases — A scoping review. *Polish Psychological Forum (Polskie Forum Psychologiczne), 29*(2), 135–164. https://doi.org/10.34767/PFP.2024.02.02

Name of the candidate: Darshika Thejani Bulathwatta

We, the undersigned co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.

Statement indicating the candidate's contribution to the publication: concept, assumptions, research methodology, literature review, analysis, conclusion)

The contribution of co-authors: The co-authors contributed to the conception of the study, analysis, conclusion and revising the manuscript. JB (analysis, conclusion), AR (conclusion), MB (concept, conclusion)]

Name: Mariola Bidzan

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Date: 20.01.2026

Signature: 

Publication #3: Bulathwatta, D. T., Rudnik, A., & Bidzan, M. (2024). All good without anything good. Beyond survival: Understanding the psychosocial experiences of individuals with chronic kidney disease and their caregivers in Sri Lanka. *Health Expectations, 27*(4), e14157. https://doi.org/10.1111/hex.14157

Name of the candidate: Darshika Thejani Bulathwatta

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We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.

Statement indicating the candidate's contribution to the publication: study conceptualization, study design, data collection, qualitative analysis, and manuscript drafting).

The contribution of co-authors: The co-authors contributed to study conceptualization, study design, qualitative analysis, manuscript drafting, supervision, and mentorship.

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Publication # 4 : Bulathwatta, D. T., Rudnik, A., Borchet, J., Zelechowska, S., Treppner, M., Ruszkowski, J., Zakrzewska, A., Dębska-Ślizień, A. M., Biedunkiewicz, B., Tylicki, L., & Bidzan, M. (2025). Contrasting cultures, shared struggles: A qualitative analysis of the experiences of end-stage kidney disease patients and their caregivers in Poland and Sri Lanka. *SAGE Open Nursing, 11*, Article 23779608251360594. https://doi.org/10.1177/23779608251360594

Name of the candidate: Darshika Thejani Bulathwatta

We, the undersigned, co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.

Statement indicating the candidate's contribution to the publication: study conceptualization, data curation, study design, data collection, qualitative analysis, and manuscript drafting.

The contribution of co-authors: AR: study conceptualization, data curation, study design, qualitative analysis, manuscript drafting, and revision. JB: data collection, SZ: data collection, qualitative analysis. MT: qualitative analysis. JR: data collection, manuscript revision. AZ: data collection. ADŚ: data collection. BB: data collection. LT: data collection. MB: study conceptualization and design, data collection, manuscript revision, supervision, and mentorship.

Name: Mariola Bidzan

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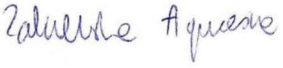
Signature: 

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Name: Bogdan Biedunkiewicz

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Name: Leszek Tylicki

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Institution: Medical University of Gdansk

Faculty of Medicine

Date: 21.01.2026

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Publication #5 : Bulathwatta, D. T., Borchet, J., Rudnik, A., Ruszkowski, J., Zakrzewska, A., Dębska-Ślizień, A. M., Biedunkiewicz, B., Tylicki, L., Puchalska-Reglińska, E., & Bidzan, M. (2025). Psychosocial well-being among individuals with end-stage kidney disease undergoing hemodialysis treatment in Sri Lanka and Poland: An explorative study [Manuscript under review].

Name of the candidate: Darshika Thejani Bulathwatta

We, the undersigned co-authors of the above publication, confirm that the above publication has not been submitted as evidence for which a degree or other qualification has already been awarded.

We, the undersigned, further indicate the candidate's contribution to the publication in our joint statement below.

Statement indicating the candidate's contribution to the publication: study conceptualization, study design, data collection, statistical analysis, and manuscript drafting.

The contribution of co-authors: JB: study design, statistical analysis, and manuscript revision. AR: manuscript revision. JR: data collection, statistical analysis, manuscript revision. AZ: data collection, manuscript revision. ADŚ: data collection, manuscript revision. BB: data collection, manuscript revision. LT: data collection, manuscript revision. EPR: data collection, manuscript revision. MB: study conceptualization and design, data collection, manuscript revision, supervision, and mentorship. All authors contributed to the article and approved the submitted version.

Name: Mariola Bidzan

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Institute of Psychology

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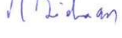
Signature: 

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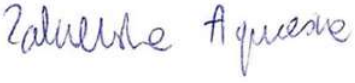
Signature: 

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Date: 21.01.2026

Signature: 

Name: Ewelina Puchalska-Reglińska

Title: Doctor of Medicine

Institution: 7 Navy Hospital in Gdansk,

Date: 22.01.2026

Signature: 

Grant Sri Lanka – Confirmation

විශ්වවිද්‍යාල ප්‍රතිපාදන කොමිෂන් සභාව
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20, வார்டு இடம், கொழும்பு 7, இலங்கை.
20, Ward Place, Colombo 07, SriLanka.

08.03.2021

Mrs. B.D.D.T. Bulathwatta
Lecturer (Probationary)
Department of Psychology and Counseling
Faculty of Health Sciences
The Open University of Sri Lanka

Thro' Vice Chancellor / Open University of Sri Lanka

Thro' Dean/ Faculty of Health Sciences

Thro' Head/ Department of Psychology and Counseling

Financial Assistance to University Teachers for Higher Studies- 2020

This has reference to your application dated 07.05.2020 for the above grant.

I am pleased to inform you that the Commission at its 1048th meeting held on 11th February 2021 considered the recommendation of the Selection Committee and approved to provide financial assistance to pursue your postgraduate studies (PhD) at University of Gdansk, Poland subject to submit following documents on or before 11th February 2022.

i. IELTS certificate with relevant scores
ii. Declaration regarding the other funding sources through proper channel

Further, please note that the Commission at its 1001th meeting held on 10.01.2019 decided that, "A selected candidate for a UGC award under the UGC postgraduate Research Grants should fulfill all the requirements and make a formal request to release of the first installment of the grant within a period of one year. If any candidate fails to fulfill this requirement his or her grant will automatically come to cease after one year from the award of the grant."

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Therefore, please make necessary arrangements to submit the above documents and the hardcopies of the application & the project proposal, which you have already sent to UGC via email with original signatures & official stamps at your earliest convenience in order to proceed further.

Senior Professor Chandana P. Udawatte
Vice Chairman

Cc: Accountant /UGC
Bursar / The Open University of Sri Lanka

Ethical Clearance Certificates

මගේ අංකය
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THE OPEN UNIVERSITY OF SRI LANKA

Office of Director Research

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அஞ்சல் பெட்டி 21,
நாவல,
நுகேகொட.

P.O.Box 21,
Nawala,
Nugegoda.

15.07.2022

Ms. B.D.D.T.Bulathwatta,
Department of Psychology & Counseling,
Faculty of Health Sciences,OUSL.

Through: Head/ Department of Psychology & Counseling,

Dear Ms.Bulathwatta,

Ethical Clearance Application

This refers to the Ethical Clearance Application you submitted to the Research Unit/OUSL. (Title: Psychosocial wellbeing of patients with chronic kidney disease and their families: A comparative study).
The Ethics Review Committee (ERC) members have evaluated your application and I wish to inform that Ethics Review Committee has given approval for your Ethical Clearance Application to conduct the research in Kidney Unit-Kandy and the National Hospital of Nephrology, Polonnaruwa Sri Lanka.

(Your application number – ER/2022/007)

Thank you,

Prof. Sicily Weerakoon
Director/Research

Director Research
Research Unit
The Open University of Sri Lanka
Nawala, Nugegoda.

Uniwersytet Gdański

WYDZIAŁ NAUK SPOŁECZNYCH UNIWERSYTETU GDAŃSKIEGO

Ethics Board for Research Projects
at the Faculty of Social Sciences
University of Gdańsk

Gdańsk, 13.03.2023

Ethics Board Opinion in response to inquiry no. 03/2023

The Ethics Board for Research Projects at the Faculty of Social Sciences, University of Gdańsk, having acquainted itself with the documentation of the planned research project submitted for external ethical evaluation by

MA Thejani Bulathwatta

entitled

Psychosocial well-being and depression among patients with chronic kidney disease and their close relatives: a mixed method study in Sri Lanka and Poland

issues a positive opinion.

As presented by Thejani Bulathwatta the research project, if carried out following the presented procedures and fulfilling the commitment to obtain the surveyed persons' conscious consent to participation in the research, is ethically acceptable.

Ethics Board for Research Projects, composed of:
dr hab. Krystyna Adamska, prof. UG – chairperson
dr hab. Anna Kłonkowska, prof.UG – member
dr hab. Michał Harciarek, prof. UG – member

Chairperson of the Ethics Board
for Research Projects

Krystyna Adamska

Chairwoman of the Ethics Committee
for Research Projects
at the Institute of Psychology
of the University of Gdańsk

dr hab. Krystyna Adamska, prof. UG

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