

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.