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Physical, Emotional, and Spiritual Coping in End-Stage Renal Failure: A Wilgamuwa, Sri Lanka IPA Study

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Abstract

End-stage renal failure (ESRF) profoundly disrupts patients' physical, emotional, and spiritual well-being. This paper presents a concentrated analysis of these responses, drawn from an initial study conducted in 2024 that consisted of three-themes recruiting the ESFR patients living in Wilgamuwa Divisional Secretariat, Mathale. An interpretative phenomenological analysis of semi-structured interviews with five purposively sampled ESRF patients, identified several key themes. Analysis demonstrated how severe fatigue and treatment side effects impede daily life and undermine work identity. It also revealed how guilt and fear of burdening family exacerbate emotional distress. And thirdly the study found that reframing illness in spiritual lens can foster acceptance and resilience among the participants. These findings highlight the urgent need for culturally sensitive palliative interventions in rural Sri Lanka, combining symptom management, family-centred psychosocial support, and spiritual counselling, to address the multifaceted challenges of ESRF.

Keywords: End-stage renal failure, physical decline, work identity, spiritual coping, resilience

Introduction

End-stage renal failure (ESRF) denotes the irreversible loss of kidney function requiring dialysis, transplantation, or comprehensive symptom management to sustain life. In Sri Lanka, ESRF precipitates severe toxin buildup, fluid imbalance, and cardiovascular complications (Abbasi et al., 2010; Brown et al., 2015). Beyond clinical sequelae, ESRF imposes profound socioeconomic and psychosocial burdens, particularly for patients who struggle to access or tolerate life-sustaining treatments (Levey et al., 2003). As outlined by the World Health Organization (WHO, 2012) Quality of life (QOL) in ESRF transcends mere clinical outcomes, encompassing physical comfort, emotional well-being, social relationships, independence, and spiritual beliefs.

Yet palliative care, specialized medical care aimed at relieving symptoms and psychosocial distress rather than curing disease, is critically underdeveloped in rural Sri Lanka (Ramadasa et al., 2023). Family

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members in agrarian communities often shoulder caregiving responsibilities with minimal formal support, leading to caregiver strain and inconsistent symptom management (Gonzalez et al., 2022; Silva et al., 2015). As highlighted by Abeywickrama et al., (2020) and Hewavitharane, (2021), predominantly smallholder-farming population of Wilgamuwa faces additional challenges: high rates of chronic kidney disease of unknown etiology (CKDu), long travel distances to treatment centers, and cultural barriers to seeking aid. Qualitative investigations in similar settings, such as Silva et al., (2015) have linked symptom burden and economic hardship to low QOL scores, underscoring the urgency of tailored palliative interventions. Hence, the present qualitative study was conducted adopting following theoretical framework to discuss the narratives of the people with ESRF.

Theoretical framework

This study uses a biopsychosocial-spiritual lens, drawing on WHO's multidimensional QOL, Pargament's religious-coping work, Park's meaning-making model, and Christiansen's occupational-identity perspective. Analysis focused on three linked constructs: (1) embodied symptom burden and functional limitation; (2) disrupted vocational/role identity; and (3) family-mediated emotional processes and spiritual meaning-making. These lenses guided interview prompts and IPA coding to answer following research questions:

1. How do ESRF patients describe symptoms and their effects on daily functioning and autonomy?
2. How does ESRF affect work/role identity, purpose, and community position?
3. How do emotional distress and family dynamics shape coping and help-seeking?
4. How do spiritual beliefs and meaning-making contribute to acceptance, resilience, or distress?

By exploring patients' experiences of physical decline, identity erosion, emotional distress (including its impact on family), and spiritual reframing, study aims to illuminate critical gaps in palliative provision and chart a roadmap for culturally sensitive interventions in rural ESRF care.

Materials and methods

Qualitative study design

A qualitative, exploratory design was selected to capture in-depth, contextually grounded experiences of ESRF patients. The selected design aligns with interpretative phenomenological analysis (IPA) by focusing on individual sense-making rather than generalizability. The Interpretative Phenomenological Analysis followed Smith et al. (2009) and comprised of (1) Immersion: repeated transcript readings; (2) Initial Noting: descriptive, linguistic, and conceptual comments; (3) Emergent Themes: clustering notes into themes; (4) Superordinate Themes: identifying patterns across cases; (5) Thematic Mapping: generating a thematic table Quirkos facilitated coding and organization of thematic nodes.

Sampling

Participants (n=5) were purposively sampled at the Wilgamuwa renal care center based on: confirmed ESRF diagnosis, ≥6 months on dialysis, ability to articulate experiences, and consent. Recruitment continued until thematic saturation occurred.

Ethical considerations

Approval was obtained from the Pro tem Ethics Committee of SLIIT School pf Psychology. Written informed consent was secured, participants were free to withdraw at any time, and anonymity was protected through pseudonyms and secure data storage.

Table 1: *Participant information*

Pseudonym (Name)	Age	Diagnosis	Carer/s
Participant 1 - AG	75	2023	none
Participant 2 - BG	67	2010	Wife & Two Sons
Participant 3 - TJ	74	2018	Wife
Participant 4 - WG	65	2018	Wife
Participant 5 - WH	82	2004	Wife

Data collection

Semi-structured interviews (45–60 minutes) were conducted in Sinhala by the lead researcher in private clinic rooms. Interviews were audio-recorded, transcribed verbatim, and supplemented with field notes capturing non-verbal cues and contextual details.

Ensuring credibility and trustworthiness

Credibility was enhanced through member checking, peer debriefing, and maintaining an audit trail of coding decisions. Triangulation of interview transcripts and field notes strengthened interpretive validity. The lead researcher kept a reflexive journal to document assumptions, emotional responses, and methodological decisions, ensuring transparency of interpretative choices.

Results

Given the methodology's idiographic emphasis on rich, individual accounts, each participant's unique narrative was initially explored in depth. However, succinct interpretations of the sample extracts were subsequently included in the proceeding sections to substantiate generated themes. Table 2 below depicts the categorized themes and subthemes explored in the original study. This paper limits the in-depth discussion at this conference paper to the first theme.

Table 2: *Themes and Subthemes Identified in the Study*

Theme	Subthemes
1. Physical, Emotional, and Spiritual Responses to Illness	1. Physical decline and perception of illness 2. The erosion of work identity and role

	3. Spiritual beliefs as coping mechanisms
	4. Acceptance of fate and resilience
2. Family Dynamics and Caregiving	1. Complex family dynamics
	2. Caregiving as burden and bond
3. Financial and Social Struggles	1. Financial burden and survival strategies
	2. Social perception and discrimination

Analysis of the Theme 1 data yielded four interrelated subthemes, each illustrated by participant excerpts and pseudonyms.

Physical decline and perception of illness

Participant WG described unrelenting fatigue that permeates every moment of his day: *"Most of all is this sleepiness… Always have this urge to sleep… I get these headaches, and as soon as I lay my head down for a bit, I fall asleep."* He further highlighted environmental triggers: *"I can't stay in A/C rooms, my legs tighten up… The muscles in my chest give me the worst pain, I lose my breath."* Such vivid accounts reveal how physical symptoms constrain daily functioning and erode autonomy, transforming mundane tasks, walking to the market or tending a small garden, into insurmountable challenges. These embodied limitations foster dependency on caregivers and amplify the psychosocial burden of illness.

Erosion of work identity and role

Participant TJ's reflections mourn the collapse of a lifetime's vocation: *"I was a farmer… now I can only swing the hoe twice before getting dizzy, and I start to go almost blind."* In an attempt to reclaim agency, he crafted hoes *"just for my enjoyment… Rs. 3750! … You know… I want to use it like I used to, but I can't."* This poignant symbolism underscores how ESRF dismantles vocational identity and diminishes self-worth, depriving individuals of both economic agency and the dignity derived from productive labor.

Emotional distress within family context

Participant WG also disclosed a profound sense of guilt: *"My daughter works two jobs to pay for my medicines; I try to hide my pain, so she won't worry."* He recounted moments of humiliation, explaining, *"I've thought about carrying one of those plastic bottles… so I can urinate in that… keep it under the seat… the buses don't stop, you know?"* This protective silence and desperation amplify emotional suffering, as patients balance their own needs against the perceived burden on kin, perpetuating isolation even within close-knit families.

Spiritual beliefs and acceptance of fate

Participant BG offered a stance of pragmatic acceptance: *"Yes, this illness is a major debilitating pain, but what can I do about it? … It just happened naturally… So, I don't waste my thoughts on thinking about my illness."* Rather than attributing his illness to divine will, BG's words reflect a stoic, almost fatalistic outlook, resigned to the realities of his condition and choosing mental detachment as a form of psychological preservation. While this may not constitute overt spiritual framing, it nonetheless illustrates a quiet form of resilience, suggesting that acceptance, whether spiritually or practically rooted, can be a powerful coping mechanism.

WG reflects on the notion of fate: *"There is a thing called fate, we can't change it… so we have to be happy with what we're given, what's the point in loathing… we must accept it."* His acceptance goes beyond passive endurance; it is coupled with an effort to cultivate contentment. In his view, resistance or sorrow would be futile in the face of forces beyond his control. His resilience lies in this deliberate choice to find peace with whatever life presents, no matter how challenging it might be.

Collectively, these narratives trace a journey from embodied decline and identity disruption to emotional negotiation within familial relationships and, finally, spiritual reconciliation. This focused lens highlights precise targets for palliative care: environment sensitive symptom management, vocational rehabilitation to rebuild purpose, family centered counseling to address hidden emotional burdens, and culturally aligned spiritual support, offering a roadmap for holistic ESRF care in rural Sri Lanka.

Discussion

This study’s concentrated exploration of physical, emotional, and spiritual responses underscores several critical implications. First, the profound physical limitations described by participants such as persistent fatigue, pain, and mobility loss, mirror findings in broader ESRF research, which show how such symptoms constrain daily functioning and erode autonomy, transforming routine tasks into insurmountable challenges and fostering dependency on caregivers (Levy et al., 2003). These embodied limitations gain particular urgency in resource-limited, rural Sri Lankan settings. Traditional palliative frameworks must incorporate locally feasible symptom-management strategies, such as community-based rehabilitation and mobile dialysis services, to mitigate daily functional decline.

Second, erosion of work identity emerges as a core psychosocial burden. The symbolic attachment to farming tools and routines highlights patients’ struggle to maintain dignity and purpose. This resonates with previous work showing that chronic illness dismantles vocational identity and diminishes self-worth, depriving individuals of both economic agency and the dignity derived from productive labor (Christiansen, 1999; Reeve et al., 2014). Palliative care in Wilgamuwa should therefore include vocational rehabilitation components and psychosocial support groups that enable identity reconstruction and meaningful engagement within community roles.

Third, emotional distress filtered through family contexts reveals both the strength and strain of kinship networks. While protective silence preserved family morale, it also perpetuated isolation, an effect noted in studies of family caregiving and chronic illness (Gonzalez et al., 2022). Interventions must balance respect for familial values with structured counseling programs that empower patients to communicate needs and reduce caregiver burden.

Finally, spiritual reframing served as a powerful resilience mechanism. Participants demonstrated a range of responses, from stoic acceptance to quiet spiritual coping, echoing evidence that acceptance, whether spiritually or practically rooted, can buffer psychological distress (Pargament, 1997; Park, 2010). Integrating local religious practices and spiritual counseling into palliative care plans can strengthen coping resources, provided they are delivered in culturally congruent ways. Collaborating with community faith leaders may enhance acceptance and adherence to care regimens.

By homing in on Theme 1, this distills actionable insights from a larger investigation. Future research should evaluate targeted interventions derived from these findings and expand focus to the other original themes - family caregiving and socioeconomic challenges; to develop comprehensive palliative care models for rural Sri Lanka.

Conclusion

This focused exploration of physical, emotional, and spiritual responses among end-stage renal failure patients in rural Wilgamuwa reveals a deeply embodied experience of decline, where the loss of physical function erodes not just daily routines but fundamental aspects of identity, particularly for those rooted in agrarian labour. Emotional burdens, intensified by feelings of guilt and perceived familial dependency, underscore the hidden psychological toll of chronic illness in care systems reliant on kin. Yet, amid this suffering, participants displayed profound resilience through spiritual reframing, drawing on culturally embedded beliefs to restore meaning and acceptance. These findings highlight the urgent need for context-sensitive palliative care interventions in rural Sri Lanka that address more than clinical symptoms: policies must encompass vocational rehabilitation, emotional support attuned to family dynamics, and integrated spiritual care delivered in culturally resonant forms. In doing so, we move closer to a palliative model that honours the full human experience of illness.

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