Home-Based Self-Care and Facility-Based Caregiver Support for Patients with End-Stage Kidney Disease

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Abstract

Background: End-Stage Kidney Disease (ESKD) is a major global public health challenge. Patients receiving renal replacement therapy (RRT) often experience poor quality of life, frequent complications, and high healthcare costs due to inadequate self-management and fragmented continuity of care. **Objective:** This mixed-methods study aimed to examine home-based self-care and healthcare facility-based caregiver support for patients with ESKD undergoing RRT. **Methods:** The study was conducted at the Sriratanakosin Foundation and the KDKC Peritoneal Dialysis Center, Thailand. Quantitative data were collected from 148 patients receiving hemodialysis or peritoneal dialysis using standardized measures of self-management behaviors, functional status (Karnofsky Performance Status), and health-related quality of life (9-THAI). Qualitative data were obtained through in-depth interviews with eight key informants, including patients, family caregivers, and healthcare professionals. **Results:** Regarding home-based care (Objective 1), while patients adhered well to medications and appointments, significant deficits remained in exercise and dietary modifications, which correlated with reduced quality of life scores, further exacerbated by economic constraints. For facility-based care (Objective 2), multidisciplinary teams effectively functioned as clinical coaches, offering essential guidance to manage hyperkalemia, fluid overload, and septicemia. Crucially, this clinical support was complemented by psychosocial reinforcement from families and peer networks, which helped alleviate burnout and reinforce self-efficacy. **Conclusion:** The integrated mixed-methods findings provide empirical evidence that supports patient empowerment, strengthens self-management capacity, reduces clinical complications, and offers sustainable strategies for improving the quality of life of patients with End-Stage Kidney Disease.

Keywords: Hemodialysis (HD), Peritoneal Dialysis (PD)

Introduction

Chronic Kidney Disease (CKD) represents a critical global public health challenge. As the condition progresses to End-Stage Kidney Disease (ESKD), life-sustaining Renal Replacement Therapy (RRT) primarily Peritoneal Dialysis (PD) or Hemodialysis (HD) becomes inevitable. Although these treatments prolong survival, they concurrently introduce severe clinical complications, such as intradialytic hypotension, cardiovascular events, fluid retention, and peritonitis. Beyond physiological burdens, patients experience profound psychological distress and a diminished Quality of Life (QoL). Previous empirical literature

consistently demonstrates that the health-related QoL among ESKD patients remains confined to low-to-moderate levels. (Wongsaree & Phahuwatanakorn, 2019)

Crucially, these adverse clinical outcomes are often driven by a pervasive lack of disease-specific knowledge, insufficient skills, and low self-efficacy in home-based self-care among both patients and family caregivers. This vulnerability is further exacerbated by the absence of standardized, continuous, and multidisciplinary care pathways within the existing healthcare infrastructure. Therefore, an urgent necessity exists to explore comprehensive care models that bridge clinical facilities and home environments.

Guided by the Individual and Family Self-Management Theory (Ryan, P., & Sawin, K. J. 2009), this mixed-methods research aims to systematically investigate the characteristics and implementation of home-based self-care alongside facility-based caregiver support for ESKD patients undergoing RRT. The scope of this study is contextualized within two premier institutional settings in Thailand: The Sriratanakosin Foundation, a high-volume facility with extensive Hemodialysis expertise, and the KDKC Peritoneal Dialysis Center, a pioneering private center operating under the Universal Health Coverage scheme.

Ultimately, the potential benefits of this research are substantial. By providing an empirical foundation on the critical success factors and socioeconomic barriers in care delivery, the findings will inform the development of standardized multidisciplinary care pathways. In doing so, this study aims to foster patient empowerment, enhance self-management capacity, minimize clinical complications, and sustainably elevate the overall quality of life for individuals living with ESKD.

Research Objectives

1. To examine the characteristics of home-based self-care for patients with End-Stage Kidney Disease.
2. To examine the characteristics of facility-based caregiver support for patients with End-Stage Kidney Disease.

Scope of the Research

1. Population Scope

Investigation of current home-based self-care and facility-based caregiver support for patients with End-Stage Kidney Disease (ESKD) undergoing renal replacement therapy (RRT) at the Sriratanakosin Foundation and the KDKC Center.

1.1 Quantitative Sample: 148 patients

1.2 Qualitative Sample: 8 informants (3 patients, 2 relatives, 3 medical professionals)

2. Variable Scope

2.1 Independent Variables: Patient's personal information (gender, age, income, underlying medical conditions, education, residence, environment, duration of treatment, treatment costs) multidisciplinary care practices, and local community support.

2.2 Dependent Variable: Characteristics of Home-based self-care and facility-based caregiver support for patients with End-Stage Kidney Disease (ESKD) undergoing renal replacement therapy (RRT)

3. Time Scope

Data collection from January 2026 to April 2026 at the Sriratanakosin Foundation and the KDKC Peritoneal Dialysis Center

Literature Review

Empirical evidence consistently indicates that patients with end-stage kidney disease (ESKD) undergoing renal replacement therapy (RRT) experience a suboptimal quality of life (QoL) within the low-to-moderate range across physical, psychological, and social domains. While immediate symptom management is often rated favorably, the chronic burden of kidney disease and severe clinical complications remain profound areas of concern, frequently exacerbated by comorbid depression, anxiety, and a loss of functional autonomy. (Wongsaree & Phahuwatanakorn, 2019) To mitigate these challenges, structured self-management frameworks are pivotal. Grounded in Ryan and Sawin's Individual and Family Self-Management Theory, (Ryan, P., & Sawin, K. J. 2009) successful health management is conceptualized not as a solitary endeavor, but as a collaborative process linking the patient, family caregivers, and multidisciplinary healthcare teams. Literature substantiates that systematic caregiver support directly enhances patient self-efficacy and adherence to complex treatment regimens. Complementing this behavioral approach, the Chronic Care Model (CCM) (Wagner et al., 2001) serves as a theoretical foundation for integrated renal care. Evidence shows that combining self-management support with community resource linkages significantly reduces emergency hospital admissions.

However, a critical knowledge gap persists: most existing literature focuses exclusively on rigid facility-based clinical protocols or passive educational materials, largely overlooking the logistical, economic, and psychosocial realities of home-based environments within the Thai healthcare context. By synthesizing individual self-management theory with the Chronic Care Model, this proposed research directly addresses these limitations to establish a sustainable, patient-centered home care framework.

Research Methodology

1. Research Methodology

This study employed a mixed-methods research approach using a convergent design to investigate the characteristics of Home-based self-care and facility-based caregiver support for patients with End-Stage Kidney Disease (ESKD)

Population and Sample

The study population consists of end-stage chronic kidney disease patients receiving Hemodialysis (HD) and Peritoneal Dialysis (PD) at the Sriratanakosin Foundation and the KDKC at Peritoneal Dialysis Center. Participants were selected via accidental sampling from January 2026 to April 2026.

Inclusion Criteria

1) Aged 18 years or older.

2) Diagnosed with End-Stage Kidney Disease ESKD) undergoing renal replacement therapy (RRT) for at least 3 months.

3) Cognitively intact and able to communicate/write in Thai.

4) Voluntarily consented to participate.

5) Hemodynamically stable (no dyspnea, arrhythmia, diaphoresis, or palpitations).

Exclusion Criteria

1) Inability to communicate or provide information independently.

2) Currently diagnosed with depression or receiving antidepressant therapy.

3) Diagnosed with other severe psychiatric disorders.

Sample Size

Quantitative Sample consisted of 148 patients by convenient sampling from 200 patients.

Qualitative Sample consisted of 8 informants (3 patients, 2 relatives, 3 medical professionals).

2. Data Collection

The research employed five instruments:

1) General Demographic Record: Patient and caregiver profile, socioeconomic status, and medical history.

2) Quality of Life Questionnaire 9-THAI: Health-related quality of life assessment for ESKD patients. (Sukthongsa, S., & Thinkhamrop, B. 2011)

3) Karnofsky Performance Status (KPS): Assessment of physical functional capacity. (Karnofsky & Burchenal, 1949).

4) Self-Management Behavior Assessment: A standardized tool for ESKD patients. (Wongsaree, C., & Phahuwatanakorn, W. 2019)

5) In-depth Interview Guide: Semi-structured interviews addressing
(a) facilitators and barriers,
(b) self-management processes, and
(c) clinical outcomes.

Instrument Validity and Reliability

Content Validity

Standard instruments (1–4) were utilized. The interview guide (5) was validated by 5 experts to ensure content accuracy, clarity, and linguistic appropriateness. The Content Validity Index (CVI) was calculated for each item.

Quantitative data: Participants completed the questionnaires in a private, quiet setting (approximately 30–40 minutes per session). Data were audited for completeness upon completion.

Qualitative data: Semi-structured, open-ended interviews were conducted (40–60 minutes per session). Data were recorded via audio/visual media and supplemented with field notes

1. Data Analysis

Quantitative Data: Descriptive statistics, including frequency, percentage, mean, and standard deviation, were employed.

Qualitative Data: Content Analysis was utilized to synthesize findings.

2. Research ethics

The research proposal was approved by the Chairman of Ethics Panel 1 at Suan Sunandha Rajabhat University with Certificate Number: COA.1-041/2025

Research Result

General Demographic Profile: Among the 148 participants in the sample, the majority were male (54.05%), aged 60–69 years (31.08%), and married (52.38%). Regarding educational attainment and economic status, 42.18% had completed only primary school, 42.57% reported a monthly household income below 10,000 THB, and 60.81% were currently unemployed. These baseline characteristics indicate that the majority of the cohort consists of elderly individuals facing significant socioeconomic constraints.

Health-Related Quality of Life (9-THAI Questionnaire): At the individual item level, most patients reported experiencing no difficulties in self-care (66.89%), physical mobility (52.03%), and performing activities of daily living (58.11%). However, mild-to-moderate impairments were frequently reported regarding bodily pain/discomfort (56.75%), fatigue/decreased concentration (47.29%), and psychological distress (28.38% reporting mild anxiety or depression). Conversely, when individual scores were converted into standardized norm-referenced metrics, a sharp disparity emerged: the vast majority fell significantly below standard population norms in both the Physical Health Component (87.16%) and the Mental Health Component (94.59%), with absolute zero (0.00%) achieving a normal quality of life score.

Physical Functional Capacity (Karnofsky Performance Status - KPS): The assessment indicated that the majority of patients (83.79%) maintained functional physical independence and self-sufficiency. The largest single subgroup comprised patients who performed normal activities with only minor symptoms of the disease (29.05%), followed closely by those who were entirely asymptomatic (27.03%). Only 16.22% required occasional caregiver assistance, and no patients were found to be severely ill or completely dependent (0.00%).

Self-Management Behavior Assessment: Overall, 68.24% of the participants demonstrated a "good" level of general self-management. Domain analysis revealed strong compliance in passive adherence behaviors, such as strict medication adherence (77.70%) and keeping scheduled clinical appointments (83.78%). However, critical gaps persisted in proactive lifestyle modifications, including performing no physical exercise whatsoever (44.59%), adhering to renal-specific dietary restrictions only "sometimes" (40.54%), never discussing dry-weight adjustments with their physicians (48.65%), and failing to note down clinical questions before appointments (54.73%).

In-Depth Interviews (8 Key Informants): Qualitative thematic analysis revealed four core dimensions. Intrinsic motivation and health beliefs drive patient self-care, where clinical burnout can be strategically mitigated by introducing a designated weekly "rest day" (achieved by keeping the dialysate dwelling statically in the peritoneal cavity for a full 24-hour period). Socioeconomic factors impact quality of life more significantly than chronological age, and the presence of a "peer patient network" serves as a vital psychological buffer, allowing low-income patients to achieve higher emotional resilience than isolated, wealthier peers. Structurally, healthcare providers act as "clinical coaches," families function as the primary care backbone, and peer groups provide critical psychosocial validation. Essential home-care competencies include proper fluid-exchange techniques, nutrition, and recognizing early complications, which prompted recommendations for telehealth platforms, automated peritoneal dialysis (APD) expansion, and targeted mental health programming.

Conclusion and Discussion

Home-Based Self-Care

Quantitative data indicated high physical independence (KPS: 83.79%), yet the 9-THAI manual classified 94.59% of patients with below-normal mental health QoL. Qualitative findings successfully bridged this gap, demonstrating that the invisible "cumulative burden of chronic illness," unremitting treatment distress, and existential anxiety impact psychological well-being far more heavily than overt physical limitations.

Patients demonstrated excellent passive compliance (medication and appointments) driven by external institutional monitoring. However, a significant deficit was identified in

active lifestyle modifications (diet, exercise, proactive communication). Qualitative insights revealed this stems from low self-efficacy, limited health literacy, and time constraints during clinical consults.

While low income directly restricts access to disease-specific nutrition and care logistics, qualitative data unveiled a powerful protective factor: the "patient community.". Shared peer experiences mitigate isolation, allowing low-income patients with strong peer support networks to achieve greater emotional resilience than affluent but isolated individuals.

Facility-Based Care

Qualitative data highlighted a shift among clinicians toward becoming "clinical coaches" who focus on cultivating hands-on care competencies. However, the quantitative finding that nearly half of the patients lacked bidirectional communication reflects a systemic barrier. Clinicians face high administrative burdens (wearing "multiple hats"), which reduces the time available for thorough, patient-centered coaching.

The finding that high physical independence (KPS) contrasts sharply with low psychological QoL (9-THAI) due to cumulative disease burden is strongly supported by Miskulin et al. (2002). Their study on dialysis cohorts confirmed that while clinician-rated scales like KPS capture overt physical stability well, they systematically fail to detect the invisible, progressive emotional attrition and existential distress associated with long-term renal replacement therapy.

The divergence where patients exhibit high passive adherence (medication/appointments) but fail in proactive lifestyle changes due to low self-efficacy and clinician time constraints is validated by Curtin et al. (2008). They demonstrated that institutional monitoring enforces passive compliance, whereas proactive self-care requires intensive, bidirectional clinical coaching which is often obstructed by the high administrative burdens ("multiple hats") placed on healthcare professionals.

A "patient community" acts as a protective buffer mitigating burnout for low-income individuals is highly consistent with Wongsaree (2021). Wongsaree emphasized that within the Thai healthcare framework, integrating structured peer-support groups creates a resilient psychosocial network that enhances emotional adaptation, successfully offsetting material and financial vulnerabilities.

Recommendations

1. Recommendations for Clinical Practice

Integrate standardized health-related quality of life (HRQoL) and mental health screenings into routine clinical follow-ups to detect anxiety, depression, and burnout early.

Develop structured, proactive educational programs for patients and caregivers that focus on practical, cost-effective renal nutrition, safe physical activity guidelines, and pre-appointment question preparation.

Deploy multidisciplinary teams (physicians, nurses, dietitians, psychologists, pharmacists) to target chronic pain, uremic fatigue, and cognitive deficits, promoting functional independence.

2. Recommendations for Healthcare Policy

Mandate the inclusion of mental-health-related QoL indices as standard national key performance indicators for chronic kidney disease management alongside traditional biochemical markers.

Expand national subsidy schemes for Automated Peritoneal Dialysis (APD) machines to alleviate daytime caregiver strain, and allocate budgets for secure telehealth (Televisit) platforms and home-visit initiatives to reduce financial travel barriers.

Implement structural reforms to reduce administrative overlap for clinical staff, and fund the integration of formal "Peer-to-Peer Networks" within primary healthcare infrastructure.

3. Recommendations for Future Research

Conduct quantitative studies utilizing advanced statistical modeling to map the causal relationships between socio-demographic factors, health literacy, and psychosocial variables on long-term clinical outcomes.

Implement 1-to-2-year longitudinal studies to monitor fluctuations in KPS and 9-THAI scores relative to the onset of acute complications, establishing definitive temporal relationships.

Interventional trials evaluating structured self-management and peer-support protocols, measuring success through reductions in emergency readmissions and peritonitis rates.

Undertake qualitative phenomenological studies across diverse age cohorts and health insurance schemes to capture lived experiences and home-care barriers, informing patient-centered care models within the Thai healthcare context.

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