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“A Living Dead”: A Qualitative Journey into Kidney Failure Experiences and Public Health Advocacy in Ghana

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Abstract

Individuals diagnosed with kidney failure often face the profound existential shock of feeling like the “living dead” due to a wide spectrum of serious, life-threatening complications. This study explored the lived experiences of individuals diagnosed with kidney failure who are undergoing haemodialysis in Ghana. Employing a purposive sampling and qualitative phenomenological research design, data were gathered through face-to-face semi-structured interviews with 15 participants (10 males, 5 females). The thematic analysis revealed a distinct narrative arc: the shock of initial diagnosis, intense emotional and psychological responses, complex healthcare experiences, adaptation to life after diagnosis, and active coping strategies coupled with a strong desire for public kidney health advocacy. The study concludes that while patients endure intense physical, emotional, and psychosocial distress throughout their treatment journey, they concurrently emerge as crucial voices for preventative health. To improve patient outcomes and honor this advocacy, there is an urgent need for intensified public awareness, lifestyle education, and subsidized early screening campaigns to promote early detection across Ghana.

1. INTRODUCTION

Kidney failure, or end-stage renal disease (ESRD), occurs when the kidneys lose their capacity to adequately filter metabolic waste products and maintain fluid and electrolyte balance. This systemic failure leads to uremia, severe fluid retention, and profound fatigue as toxins accumulate within the body. ESRD can manifest acutely or develop progressively over time, primarily driven by underlying chronic conditions such as diabetes mellitus and hypertension. For individuals surviving with this condition, renal replacement therapies principally haemodialysis or kidney transplantation become absolute mandates for survival (Majorowicz et al., 2024; Sevarakhon et al., 2024).

In Ghana, the landscape of managing kidney failure is fraught with severe systemic and financial bottlenecks. Despite growing public health interventions, low public awareness accounts for approximately 70% of kidney failure cases, contributing to a devastating 50% in-hospital mortality rate among admitted renal patients over the past decade (Kpene et al., 2024; Tannor et al., 2018; Tannor & Calice-Silva, 2022). Beyond deficit awareness, access to life-sustaining treatment is deeply restricted; over 90% of diagnosed individuals lack reliable access to renal replacement therapy (Tannor et al., 2023). This is reflected in Ghana’s haemodialysis treatment prevalence rate of just 38.8 patients per million populations a figure that sits woefully below both the African regional average of 79 per million and the global average of 296 per million.

Financially, the burden is catastrophic. A single haemodialysis session in Ghana averages $53.90. When juxtaposed against the national monthly minimum wage of approximately $55.70, the cost of regular, multiple-weekly treatments becomes completely prohibitive for the vast majority of citizens. While current discourse heavily advocates for the comprehensive integration of free haemodialysis into the National Health Insurance Scheme (NHIS) benefit package to offer financial relief (NHIA Report, 2024), patients currently navigate these costs out-of-pocket. This financial strain is compounded by severe

infrastructural deficits, including a critical shortage of specialists evidenced by a mere 0.44 nephrologists per million population compared to the low- and middle-income country (LMIC) average of 1.6 per million. Consequently, 57.5% of haemodialysis centers in Ghana operate without a resident or visiting nephrologist, placing the clinical management of patients under extreme scrutiny. Furthermore, geographical proximity to specialized centers and a reliance on over-the-counter self-medication severely delay timely diagnoses, particularly in resource-constrained regions like northern Ghana (Boateng et al., 2024).

Compounding these structural and economic hardships are the profound lifestyle disruptions demanded by continuous haemodialysis. Patients are forced into radical dietary, fluid, and social restrictions, which routinely trigger severe psychological distress, anxiety, and depressive symptoms (Amoako & Owusu-Ansah, 2021). This psychosocial burden significantly compromises treatment adherence and accelerates a decline in the patient's overall quality of life. Research consistently highlights the prevalence of these mental health challenges during intensive therapy; for instance, Bioma et al. (2019) demonstrated that haemodialysis patients exhibit significantly higher rates of anxiety and somatization compared to chronic kidney disease (CKD) patients who are not yet on dialysis. This reality underscores an urgent need for institutionalized clinical psychological support to mitigate the unaddressed mental health crises that patients endure throughout their treatment journey.

While existing literature thoroughly quantifies the epidemiological, financial, and clinical deficits of renal care in Ghana, there remains a critical gap in understanding the nuanced, subjective interiority of the patients themselves. The staggering structural barriers outlined above do not exist in a vacuum they are lived, felt, and navigated daily by human beings. To date, few studies have captured the rich, temporal depth of the patient journey: from the initial existential shock of the diagnosis where patients may perceive themselves as the "living dead" to the daily grinding mechanisms of coping, and ultimately, to how these individuals transform their suffering into active public health advocacy. Understanding these lived experiences through a qualitative lens is essential not only for optimizing patient-centered clinical care but also for informing public health frameworks grounded in the authentic voices of those on the front lines of the disease. Therefore, this study explores the lived experiences of individuals diagnosed with kidney failure undergoing haemodialysis in Ghana, seeking to illuminate their journey of shock, survival, and societal advocacy.

2. LITERATURE REVIEW

2.1 Conceptual and Epidemiological Foundation of Kidney Failure

2.1.1 The Concept of Kidney Failure

Kidney failure, structurally conceptualized as end-stage kidney disease (ESKD), represents the terminal stage of chronic kidney disease (CKD), wherein the kidneys lose their capacity to adequately filter blood,

clear metabolic waste, and maintain systemic homeostasis. According to Levin et al. (2020), the clinical threshold for kidney failure is characterized by the absolute requirement for renal replacement therapies such as haemodialysis or kidney transplantation or a persistent reduction in kidney function below a glomerular filtration rate (GFR) threshold of 15 mL/min/1.73 m². This condition signals a critical collapse of renal function that necessitates immediate, life-sustaining medical intervention.

The clinical manifestations of this physiological decline vary across different demographic strata. In older adults, Zhao et al. (2022) demonstrated that kidney failure is profoundly associated with a sharp deterioration in physical performance, including elevated risks of sarcopenia, diminished grip strength, and reduced walking speed, which severely compromise patient autonomy and overall health. Conversely, among pediatric and young adult demographics, Zahr et al. (2024) emphasized the severe implications of kidney failure in patients with sickle cell disease, noting that this cohort faces markedly reduced survival rates and significantly extended waiting times for transplantation compared to their non-sickle cell counterparts.

The operational definition of kidney failure has evolved over time to bridge clinical utility with patient-centered perspectives. Levey et al. (2020) highlighted the necessity of standardized nomenclature and consistent diagnostic thresholds, as advocated by the Kidney Disease: Improving Global Outcomes (KDIGO) guidelines, which streamline clinical trials, health policymaking, and cross-disciplinary medical communication. However, the application of a fixed GFR threshold across all demographics has faced scrutiny. Liu et al. (2021) argue for age-adjusted definitions of kidney disease, suggesting that rigid baseline cutoffs risk over-diagnosing older populations whose renal decline may be age-related, while simultaneously under-diagnosing younger adults, thereby complicating both epidemiological surveillance and individual clinical care.

Beyond purely biomedical frameworks, patients' lived experiences fundamentally shape their conceptual understanding of kidney failure. In a qualitative inquiry, Sledge et al. (2023) explored how patients perceive health while living with kidney failure, revealing holistic definitions of well-being that encompass physical functionality, emotional resilience, and social support systems perspectives that often stand in stark contrast to rigid clinical metrics. This patient-centered paradigm underscores the need to integrate subjective interiority into treatment planning. Furthermore, conservative kidney management has emerged as a core element of integrated care pathways. Davison et al. (2024) describe conservative kidney management and supportive care as essential models that prioritize symptom control, shared decision-making, and optimized quality of life over aggressive, life-prolonging interventions, presenting a vital alternative pathway for elderly or frail patients who opt out of haemodialysis.

2.1.2 Predisposing Factors of Kidney Failure

Predisposing factors of kidney failure encompass an array of underlying biological, genetic, and environmental conditions that accelerate progressive renal dysfunction. Chronic hypertension stands prominent among these etiologies, particularly in patients with pre-existing cardiovascular vulnerabilities. Burnier and Damianaki (2023) explain that uncontrolled systemic blood pressure

accelerates vascular and glomerular injury, significantly heightening the rate of renal impairment in individuals already predisposed to CKD.

In tandem with cardiovascular drivers, genetic determinants play a critical role. Pathogenic variants in the COL4A3–COL4A5 genes, typically associated with Alport syndrome, compromise the structural integrity of the glomerular basement membrane, precipitating progressive tissue damage and eventual organ failure (Savige & Harraka, 2021). Emerging genomic data further indicates that even individuals carrying heterozygous variants are heavily predisposed to early-onset CKD, though phenotypic progression to full end-stage kidney failure varies across individuals (Savige, 2022).

Environmental and therapeutic exposures also serve as significant predisposing vectors. Dieffenbach et al. (2021) highlighted that survivors of childhood cancers frequently present with late-onset kidney failure in adulthood, a consequence of chronic chemotherapeutic toxicity and historical radiation exposure. This drug-induced nephrotoxicity is a widespread concern; Kwiatkowska et al. (2021) outlined the cellular mechanisms such as prolonged oxidative stress, mitochondrial damage, and acute tubular necrosis that result from extended exposure to common nephrotoxic agents, including non-steroidal anti-inflammatory drugs (NSAIDs), specific classes of antibiotics, and systemic chemotherapies.

2.1.3 Prevalence of Kidney Failure

Globally, it is estimated that 8% to 10% of the adult population lives with some form of chronic kidney disease, with a critical volume of these cases advancing toward complete kidney failure due to delayed detection and suboptimal management (Thurlow et al., 2021). While Western Europe benefits from a relatively robust healthcare infrastructure with widespread access to haemodialysis and transplantation, the region faces an escalating incidence of kidney failure driven primarily by aging demographics and rising rates of diabetes mellitus and cardiovascular diseases (Pippias et al., 2024). In contrast, health systems in the Middle East contend with unique epidemiological pressures, including exceptionally high rates of diabetes-related kidney failure, fragmented health system integration, and profound disparities in access to renal replacement therapies (Karam et al., 2024). Latin America presents a similar dichotomy: despite incremental improvements in service delivery, the region continues to struggle with fragmented care networks, underfunded public health initiatives, and delayed diagnoses that disproportionately affect rural and low-income communities where specialized nephrology care is virtually absent (Wainstein et al., 2021).

Among pediatric populations, the epidemiological burden is rarely linked to lifestyle factors; instead, it is driven by congenital anomalies, hereditary nephropathies, and nephrotic syndrome. A global review of registry and cohort data indicates that pediatric kidney failure is severely underreported in resource-limited settings due to diagnostic deficits and the lack of standardized surveillance frameworks (Harada et al., 2022). Consequently, children in these regions often present to healthcare facilities only at advanced, irreversible stages of the disease when therapeutic options are exhausted.

Thurlow et al. (2021) observe that access to life-saving haemodialysis and kidney transplantation is unequally distributed on a global scale. High-income nations offer superior service availability and clinical quality, whereas in lower-income regions, patients routinely succumb to premature death due to the sheer unavailability or unaffordability of treatment. This disparity transcends technological gaps; it is fundamentally rooted in systemic policy priorities, economic underinvestment, and fragile healthcare infrastructure. Thus, kidney failure is as much a socioeconomic crisis as it is a medical one. Evans et al. (2022) note that managing kidney failure incurs catastrophic out-of-pocket expenditures for families in nations lacking universal healthcare coverage, positioning prevention and early screening as mandatory public health strategies. This imperative is further compounded by the secondary systemic complications of advanced renal failure; conditions such as chronic kidney disease-mineral and bone disorder (CKD-MBD) and accelerated vascular calcification frequently accompany kidney failure in aging populations, worsening global clinical management outcomes (Izzo et al., 2024).

In Africa, the surging prevalence of kidney failure within public health systems is characterized by rising rates of hypertension, diabetes mellitus, and chronic infections, coupled with deeply restricted healthcare access. However, inadequate data repositories, variations in diagnostic criteria, and pervasive underreporting derail efforts to establish accurate prevalence rates across the continent. Hariparshad et al. (2023) underscored these limitations, noting that the majority of prevalence data in sub-Saharan Africa, including South Africa, cannot be generalized due to methodological inconsistencies, small sample sizes, and an overwhelming research bias toward urban centers. Nonetheless, localized data paints a grim picture; community-based research in South Africa's North West Province revealed a substantial burden of kidney dysfunction among adults, primarily driven by underlying obesity, hypertension, and diabetes (Navise et al., 2023). Similarly, a multicenter cohort study across Malawi, South Africa, and Uganda by Fabian et al. (2022) exposed massive discrepancies in kidney function tracking, caused by the sparse availability of basic diagnostic tools such as serum creatinine testing or estimated glomerular filtration rate (eGFR) calculations. This technological deficit leaves chronic kidney disease hidden until it manifests in its final, terminal stages.

Within the Ghanaian context, this lack of robust epidemiological data remains a major challenge. The initial baseline data from the Ghana Renal Registry provided critical hospital-based insights, revealing that the vast majority of renal patients present at late stages of the disease, burdened by severe comorbidities of hypertension and diabetes mellitus, resulting in high mortality rates linked directly to inaccessible renal replacement therapies (Bioma et al., 2021). Tannor et al. (2023) detailed the historical evolution of haemodialysis services in Ghana, highlighting severe underutilization driven by stark geographic disparities and economic barriers. Although the country has expanded its commercial and institutional dialysis centers over the past few decades, cost remains an absolute barrier. Efforts to integrate cost-support frameworks through the National Health Insurance Scheme (NHIS) continue to face intense implementation and funding struggles (NHIA Report, 2024). Because the average monthly cost of maintaining haemodialysis far exceeds the national average income, many patients are forced into premature treatment cessation or incomplete regimens, resulting in early mortality (Tannor & Antwi, 2023).

This landscape of late-stage presentation and systemic delays is mirrored across various clinical sub-specialties in Ghana. For instance, Duah et al. (2022) reported severe comorbidities such as concurrent liver cirrhosis among kidney failure patients, which dramatically accelerates in-hospital mortality due to diagnostic delays. Pediatric renal care reflects a similarly worrying trajectory; a retrospective study at a major teaching hospital reported a rising trend in juvenile kidney diseases, with nephrotic syndrome and congenital anomalies identified as the leading drivers of late-stage pediatric admissions (Osei et al., 2025).

Furthermore, genetic predispositions introduce a layer of population-specific risk. Individuals of African ancestry carry a disproportionate burden of aggressive renal disease; insights from the KDIGO Controversies Conference on APOL1 kidney disease held in Accra, Ghana, confirmed the profound genetic susceptibility of West African populations including Ghanaians to APOL1-associated nephropathies (Ojo et al., 2025). This genetic risk factor complicates public health responses and demands targeted, localized screening strategies.

While hospital-based data consistently confirms an upward trajectory in ESRD nationwide, the lack of true national community prevalence data obscures the actual scope of the public health crisis. To combat this diagnostic delay, clinical researchers are investigating early-stage biomarkers. Danquah et al. (2023) explored the clinical utility of neutrophil gelatinase-associated lipocalin (NGAL) among hypertensive patients at a regional hospital in Ghana, demonstrating that NGAL could serve as a highly effective diagnostic tool for early detection before irreversible structural kidney damage occurs. The necessity for such holistic, early clinical interventions is further highlighted by the systemic, secondary complications that manifest in advanced cases. Seadey et al. (2024) documented widespread dermatological manifestations including severe uremic pruritus, hyperpigmentation, and xerosis (extreme dryness) among patients attending a tertiary kidney clinic in Ghana, illustrating how advanced kidney failure degrades every facet of a patient's physical existence and emphasizing the need for comprehensive, interdisciplinary management frameworks.

2.2 Cultural and Religious Perception of Kidney Failure

2.2.1 Global Perspectives on Illness Meaning and Coping

Advanced chronic kidney disease (CKD) patients heavily rely on cultural and spiritual values to make sense of their illness. Many conceptualize kidney failure as a spiritual test, ancestral punishment, or divine will, a duality that directly shapes health-seeking behaviors and treatment adherence (Nair et al., 2021). Highly religious patients often prioritize comfort and spiritual support over aggressive medical interventions (Scherer et al., 2021). Furthermore, chronic patients frequently define "health" holistically as the ability to fulfill religious duties, maintain spiritual peace, and sustain social roles, utilizing their beliefs as a primary cognitive coping mechanism to navigate physical suffering and clinical uncertainty (Sledge et al., 2023).

2.2.2 Empirical Evidence on Clinical Outcomes and Spiritual Interventions

Empirical literature confirms a positive correlation between spirituality and patient well-being during renal replacement therapy. Adherence to religious practices like prayer and scriptural reading helps patients tolerate suffering while reducing their perception of pain and despair (Okhli et al., 2022). Spirituality-oriented counseling significantly reduces the fear of death among chronically ill cohorts (Hosseini et al., 2022), while higher spiritual well-being correlates with lower depression rates and increased life satisfaction in end-stage kidney disease (Fradelos, 2021). Consequently, structured clinical protocols like the “sound heart model” (Asadzandi et al., 2022) and integrated spiritual care in nephrology services have been strongly linked to elevated quality of life among haemodialysis patients (Fradelos et al., 2021).

2.2.3 The Socio-Cultural and Religious Landscape in Ghana

In Ghana, cultural and religious belief systems fundamentally dictate how individuals perceive and cope with kidney failure. Patients routinely interpret the illness as a test of faith, ancestral punishment, or fate, which directly influences their emotional responses and drives them to blend traditional practices with biomedical treatments (Kisseih-Kwao, 2020). Religiously, patients depend heavily on prayer, fasting, and the counseling of religious leaders to find meaning during haemodialysis, which reduces psychological distress but can sometimes delay critical medical decisions (Asaah, 2020). Socio-cultural coping mechanisms including extended family support, traditional healing, and communal decision-making profoundly dictate quality of life and guide treatment choices (Anang, 2014). Family and religious elders often act as primary decision-makers, leading some patients to alternate between spiritual interventions and medical protocols (Boateng et al., 2018). Because local beliefs regarding illness causation frequently center on spiritual curses or moral failings, patient engagement with renal treatments is deeply impacted (Nyante et al., 2019). These pervasive realities underscore the urgent need for culturally sensitive healthcare frameworks in Ghana that respect patients’ spiritual values while actively promoting adherence to life-sustaining medical regimens.

2.3 The Lived Patient Experience

2.3.1 Post-Haemodialysis Life Experiences and Complications

Navigating kidney failure fundamentally destabilizes a patient’s physical, emotional, and social normalcy. The transition to life-sustaining haemodialysis or the prolonged wait for transplantation deeply disrupts identity, autonomy, and basic functional capacity (Morgan, 2024; Roberti et al., 2023). Both peritoneal and in-center hemohaemodialysis carry an immense secondary burden that severely compromises quality of life (Brown et al., 2021), requiring rigorous adaptation to medicalized routines and strict fluid boundaries (Wong et al., 2024). Although transplantation offers a definitive beacon of hope for long-term

survival, severe systemic bottlenecks and extensive waitlist durations restrict this pathway for many (Chaudhry et al., 2022).

Physically, patients endure a cascade of chronic complications. Uremic pruritus stands out as an intensely distressing symptom that directly correlates with profound sleep fragmentation, intractable insomnia, daytime exhaustion, and heightened anxiety (Almutary, 2024; Ege et al., 2024; Lyons, 2024; Manenti & Leuci, 2021; Świerczyńska et al., 2021; van der Willik et al., 2022; Vendeville et al., 2025). This physical deterioration is compounded by systemic fatigue stemming from chronic anemia and sustained inflammatory pathways (Gregg et al., 2021). Furthermore, patients routinely battle muscle cramps, debilitating bone pain, gastrointestinal distress, and anorexia (Butt et al., 2022; Rasyid et al., 2022), alongside dialysis-specific burdens like post-treatment exhaustion, severe hypotension, and vascular access discomfort (Coyne et al., 2023). In resource-constrained landscapes like Ghana, these symptoms manifest acutely as severe mobility deficits and fluid retention (swollen feet), forcing absolute reliance on family caregivers and stripping individuals of occupational roles (Bioma et al., 2021; Mehra et al., 2023).

2.3.2 Occupational, Socioeconomic, and Dietary Disruptions

The rigid therapeutic schedules of end-stage renal disease enforce severe economic and social marginalization. Employment rates among dialysis and post-transplant cohorts remain drastically lower than the general population (Kirkeskov et al., 2021), a reality that contributes to a broader systemic neglect of renal care within global public health priorities (Vanholder et al., 2021). Debilitating fatigue, muscle wasting, and progressive physical deconditioning frequently exacerbated by institutional policy gaps that deprioritize active physical rehabilitation severely restrict workforce productivity (Bennett et al., 2022; Wilkinson et al., 2021). Although variations in physical engagement exist based on modality, with peritoneal dialysis patients occasionally demonstrating higher baseline activity than hemodialysis patients, the overarching disease burden restricts sustained labour across both groups (Kim et al., 2021).

Dietary restriction constitutes another major front of daily behavioral friction. Patients must constantly navigate highly personalized dietary constraints targeting sodium, potassium, phosphate, and protein intake (MacLaughlin et al., 2022). However, clinical literacy does not automatically translate into adherence (Betz et al., 2021); complex socioeconomic, psychological, and cultural variables drive widespread dietary non-compliance globally (Vijay & Kang, 2022). While hospital-based nutritional support is recommended to mitigate these patterns (Fiaccadori et al., 2021), access is highly restricted in low-resource clinics, leaving patients to navigate chronic nausea, poor appetite (Kalantar-Zadeh et al., 2022), and emerging forms of disordered eating completely unassisted (Puckett, 2023).

2.3.3 Medical Routines, Stigmatization, and Caregiver Burdens

The standard hemodialysis regimen imposes exhausting time demands and complex polypharmacy profiles to manage concurrent hypertension, mineral imbalances, and anemia, significantly elevating the risk of adverse drug reactions and clinical non-adherence (Anding-Rost et al., 2023; Arcoraci et al., 2021; Hall et al., 2024; Vilar et al., 2022). This medicalized existence is frequently worsened by low health literacy (Eckardt et al., 2023) and intense social stigmatization. Hemodialysis patients routinely report profound perceived stigma linked directly to altered bodily appearance (fistulas, surgical scars), perceived unproductivity, and structural dependency (Li et al., 2023; Li et al., 2024). These community misconceptions often manifest as blame and social exclusion (Campos et al., 2015). Young adults and adolescents feel this isolation acutely, frequently missing vital developmental milestones (Oberdhan et al., 2022). This rigid lifestyle induces a state of existential alienation often described by patients as "living normally without being oneself" (de la Cuesta-Benjumea et al., 2023) fostering a severe cycle of loneliness and reduced social participation that erodes clinical compliance (Al Salmi et al., 2021; Diao et al., 2023; Sluiter et al., 2024; Zhou et al., 2025).

This multi-layered crisis directly spills over into the immediate support network. Family caregivers operate under severe emotional, logistical, and physical distress, acting as transport coordinators, financial safety nets, and primary emotional anchors (Driehuis et al., 2025; Hejazi et al., 2021). The relentless chronicity of the disease triggers high clinical baselines of anxiety and depression among caregivers, particularly when care demands force the abandonment of personal career goals (Vovlianou et al., 2023). In rural areas, these logistical strains and emotional fatigue reach catastrophic proportions due to geographic isolation from urban dialysis centers (Kpekura et al., 2025; Scholes-Robertson et al., 2022). Ultimately, these steep out-of-pocket expenses for treatments, medications, and transport trigger severe economic vulnerability (Roberti et al., 2022), frequently driving families in lower-income settings like Ghana to abandon life-saving care entirely (Kumah et al., 2022; Osei Appiah et al., 2022).

2.3.4 Emotional Landscapes and Coping Dimensions in Ghana

Psychologically, kidney failure triggers an intense trajectory of shock, grief, and emotional adaptation, with clinical depression and anxiety consistently affecting 30% to 40% of the hemodialysis population (Duan et al., 2021; Ma et al., 2021; Nair et al., 2021). In Ghana, this emotional distress is deeply interwoven with cultural taboos and spiritual apprehensions; for instance, many patients express intense hesitation regarding life-saving kidney transplantation due to deep-seated spiritual fears (Bioma et al., 2021). Using a Heideggerian phenomenological approach, Manookian et al. (2022) revealed that Ghanaian renal patients interpret their condition as an existential disruption, marked by overwhelming uncertainty, forced structural dependency, and acute spiritual conflict. To survive, patients implement a mix of emotion-focused, cognitive, and problem-focused coping mechanisms (Shahrokhi et al., 2014; Soponaru et al., 2016; Woei Ling et al., 2024).

Emotion-focused strategies predominantly intensive prayer, fasting, and seeking divine intervention are universally deployed across low-resource sectors where formal psychosocial infrastructure is absent

(Imran et al., 2023; Melo et al., 2016). Concurrently, Ghanaian patients lean heavily on highly communal, culture-specific coping networks, leveraging extended family support and religious elders to preserve hope and maintain complex treatment schedules (Anang, 2014; Dowou et al., 2023; Kisseih-Kwao, 2020). Conversely, maladaptive coping patterns such as clinical denial or complete self-isolation act as severe accelerators for clinical depression and suicidal ideation (Keskin & Engin, 2011; Zweiryadinda et al., 2023).

Research indicates that patients facing high anxiety profiles typically default to emotion-based avoidance, whereas those backed by strong social infrastructure transition into adaptive, problem-focused behaviors like active health literacy tracking and strict regimen adherence (Ibrahim et al., 2013; Silva et al., 2016; Soeli et al., 2022). Over extended treatment durations, surviving patients gradually build highly structured coping habits and emotional resilience, allowing them to systematically process illness-related stressors (Dewayani et al., 2022; Ling et al., 2021; Sulistyanto et al., 2022). Crucially, targeted support from healthcare professionals driven by deliberate, compassionate nurse-patient communication and structured patient education serves as the primary catalyst for expanding these adaptive coping capacities and mitigating psychological collapse (Akpakli Addo & Senoo-Dogbey, 2025).

2.4 Awareness Campaigns and Community Engagement Strategies on Kidney Failure

Public awareness campaigns and strategic community engagement are critical catalysts for elevating kidney health literacy and driving preventative behavioral modifications. Globally, the dissemination of targeted kidney health messages through mobile health (mHealth) interventions and digital platforms has proven highly effective; for instance, Sarker et al. (2022) demonstrated that mobile-driven narrative education in Bangladesh yielded significant improvements in patients' clinical knowledge, lifestyle choices, self-motivation, and long-term behavioral changes (Matias & Sousa, 2017). To maximize the efficacy of these public information sources which span healthcare provider counseling and mass media campaigns interventions must be intentionally designed to be culturally relevant to the target population (Afzal et al., 2024; Okpongkpong et al., 2025). Furthermore, prominent health advocates argue that kidney health must be systematically integrated into global health agendas to actively reduce systemic inequities in care access, directly linking persistent awareness disparities to broader, structural social determinants of health and a lack of baseline kidney risk education (Anafi, 2023; Francis et al., 2024; Iroegbu et al., 2022; Li et al., 2020).

In resource-limited settings, advocating for inclusive, grassroots public health drives and community-level screening is essential for accelerating early detection and fostering positive treatment-seeking behaviors among at-risk populations (Ogieuhi et al., 2024; Tannor & Calice-Silva, 2022). Across the African continent, large-scale initiatives like the International Society of Nephrology (ISN) Global Kidney Atlas project are actively enhancing community-level engagement and mapping data infrastructure to broaden the scope of early clinical interventions (Tannor et al., 2024). Ultimately, these evolving public

health frameworks underscore the exact paradigm shift your study highlights: transitioning from passive, top-down institutional messaging to active, culturally grounded community engagement.

3. METHODS

3.1 Research Settings

This study was conducted at the Kidney Specialist Center (KSC) in Kumasi and the Sunyani Teaching Hospital (STH) in the Bono Region. Selected for their comprehensive renal services, these sites capture both private and public healthcare experiences in Ghana. KSC is a specialized private facility in Asokwa offering multidisciplinary care, where sessions cost GHC 620 to GHC 700. STH is a public tertiary hospital serving Ghana's middle and northern sectors, providing subsidized dialysis at GHC 550 per session. Both settings require substantial out-of-pocket payments, highlighting the diverse socioeconomic realities of patients navigating kidney failure.

3.2 Study Design and Sampling

This qualitative study employed an interpretive phenomenological approach to explore depth over breadth regarding the lived experiences of individuals diagnosed with kidney failure (Creswell & Creswell, 2023; Terrell, 2022; Yadav, 2023). Purposive sampling was used to select information-rich cases from the Kidney Specialist Centre (KSC) and the Sunyani Teaching Hospital (STH) (Ahmad & Wilkins, 2024; Nyimbili & Nyimbili, 2024). This non-probability technique is highly suitable for health-related qualitative inquiries aiming to capture detailed insights into specific clinical conditions (Robinson, 2024; Thomas, 2022).

The target population comprised individuals clinically diagnosed with kidney failure actively undergoing haemodialysis at the two selected sites. At the time of data collection, the active patient pool included 132 individuals at KSC (private) and 3 individuals at STH (public). Selecting a well-defined, contrasting population from both private and public healthcare environments provides a diverse range of lived experiences and support structures, enhancing the contextual applicability of the findings (Creswell & Creswell, 2023; Lewis et al., 2023; Rahman, 2023; Zickar & Keith, 2023).

Inclusion and Exclusion Criteria

To participate, individuals had to be at least 18 years old, clinically diagnosed with kidney failure, actively receiving haemodialysis at KSC or STH, and capable of providing independent, informed consent. Patients were excluded if they were cognitively impaired, unable to communicate effectively due to severe illness, or declined participation. These criteria maintained ethical integrity and ensured that participants could reflect meaningfully on their care and support systems.

Sample Size

The final sample consisted of fifteen participants drawn across both facilities. This sample size was determined by the principle of data saturation, where recruitment and interviewing ceased once no new themes, patterns, or insights emerged from the data (Hennink & Kaiser, 2022; Rahimi, 2024). Saturation serves as the definitive criterion for sample adequacy in in-depth qualitative research (Ahmed, 2025; Daher, 2023). Recruitment was carefully paced to respect the clinical vulnerability of the patients (Islam & Aldaihani, 2022). All eligible individuals who were approached agreed to participate, resulting in a 100% response rate.

3.3 Research Instrument, Data Collection and Ethical Considerations

Semi-structured interviews served as the primary data collection tool for this study. This approach utilizes a flexible guide of open-ended questions, allowing the researcher to probe deeper based on participant responses and explore sensitive, complex aspects of their experiences (Adeoye-Olatunde & Olenik, 2021; Ruslin et al., 2022). The tool was designed to elicit rich, narrative data regarding emotional responses to diagnosis, treatment perceptions, and personal challenges (Belina, 2023; Price & Smith, 2021).

Data collection spanned a three-week period from April 4, 2025, to April 25, 2025. Following the submission of official introductory letters to secure institutional access, face-to-face interviews were conducted at the Kidney Specialist Centre from April 4 to April 21, 2025 and at the Sunyani Teaching Hospital from April 22 to April 25, 2025. The interviews were conducted in person using the Twi language to accommodate participant preference. With the participants' prior permission, each session was audio-recorded to ensure structural accuracy and completeness during transcription.

Ethical approval

was granted by the Committee on Human Research, Publication and Ethics (CHRPE) at the Kwame Nkrumah University of Science and Technology (Reference Number: CHRPE/AP/546/25), alongside formal administrative permission from both health facilities. Participation was entirely voluntary. Signed or verbal informed consent was obtained after explaining the study's objectives, risks, and benefits in both Twi and English. To safeguard identities, strict anonymity and confidentiality protocols were maintained through the use of pseudonyms across all transcripts and research reports. Participants were explicitly informed of their right to withdraw from the study at any point without penalty or consequence to their routine clinical care.

3.4 Data Analysis

The data analysis process adopted reflexive thematic analysis to systematically identify, analyze, and report patterns grounded within the participants' narratives (Braun & Clarke, 2006; 2019; 2021). This approach provided a rich, detailed account of the meanings individuals assign to their lived experiences with kidney failure. The analysis followed five iterative stages. First, familiarization and preparation

involved transcribing all audio-recorded interviews verbatim to ensure accurate representation. The researcher repeatedly read the transcripts, field observation notes, and categorized institutional documents to achieve deep immersion, recording preliminary reflections (Christou, 2023; Goldsmith, 2021). Second, generating initial codes utilized open coding to label meaningful segments of text addressing diagnosis, emotional experiences, treatment routines, and systemic support, systematically organizing data in line with the study objectives (Allsop et al., 2022). Third, searching and clustered coding for themes required clustering related codes into hierarchies and broader categories to isolate emerging explicit and implicit patterns across participant narratives. Fourth, interpretation of findings synthesized the generated themes within the context of existing literature, the conceptual framework, and the structural socio-cultural realities of kidney care in Ghana. Fifth, presentation structured the final themes narratively, integrated with verbatim quotations to maintain authenticity and support the validity of the interpretations.

3.5 Coding Procedures for Qualitative Data

To maintain close textual engagement with the raw narratives, manual coding was conducted using Microsoft Word without the use of qualitative software. The data was processed through a rigorous three-stage coding framework. Open coding began by breaking down textual data to identify discrete ideas, descriptions, and initial conceptual labels relevant to the research objectives. Next, axial coding systematically integrated these initial open codes, exploring conceptual relationships and grouping them into interconnected thematic categories and hierarchies (Al-Eisawi, 2022; Riazi et al., 2023). Finally, selective coding refined and integrated the core categories to form the final overarching themes encapsulating the central findings on lived experiences, support structures, and patient intervention needs.

3.6 Ensuring Trustworthiness

To establish the authenticity, reliability, and academic rigor of the qualitative findings, this study adhered to the four-dimensional trustworthiness framework established by Lincoln and Guba (1985). Credibility ensures confidence in the truth of the findings and verifies that they accurately represent the participants' realities. This was enhanced through member checking by sharing thematic summaries with participants for validation (Shenton, 2004). Additionally, peer debriefing was utilized, where experienced colleagues and supervisors critically reviewed the coding systems and thematic development to minimize subjective researcher bias. Transferability addresses the applicability of the findings to other contexts. While qualitative research does not claim universal generalizability, transferability was advanced by providing thick, rich descriptions of the healthcare settings, participant demographics, and the broader socio-cultural contexts of Ghana (Polit & Beck, 2010; Flanagan & Beck, 2024), allowing readers to determine applicability to similar environments. Dependability emphasizes the stability and consistency of the processes over time. To ensure this, a transparent audit trail was maintained to chronologically record every methodological step taken, tracking participant recruitment, data collection protocols, transcription, manual coding frameworks, and final interpretive decisions (Nowell et al., 2017; Nowell & Albrecht, 2019). Confirmability relates to the clinical neutrality and

objectivity of the findings. This was strengthened through continuous reflexive journaling to document thoughts, decisions, and potential biases (Shufutinsky, 2020). This conscious bracketing process allowed the researcher to systematically identify, record, and isolate personal assumptions throughout the analytical cycle, ensuring the findings remain strictly grounded in the participants' actual experiences (Tufford & Newman, 2012; Habibullah et al., 2023).

3.7 Reflexivity

To ensure a rigorous and transparent inquiry, the research team practiced continuous reflexivity and critical self-awareness, managing how personal backgrounds, values, and assumptions might shape the research process (Finlay, 2024). In line with the descriptive phenomenological approach, the primary researcher employed bracketing to consciously set aside preconceptions about kidney failure and haemodialysis during data collection and analysis (Giorgi, 2009; Moustakas, 1994). This deliberate management of prior knowledge ensured that the participants' voices remained central to the study. To maintain transparent oversight, a reflexive journal was kept throughout the research process to document observations, methodological choices, and emotional responses to the interviews. This collaborative practice established a clear audit trail of our thought processes, ultimately enhancing the credibility and confirmability of the findings while safeguarding the data against researcher bias.

3.8 Data Storage and Security

All data were handled with the highest standards of security. Electronic copies of interview transcripts and notes were stored on password-protected devices accessible only to the research team. Hard copies of signed consent forms and field notes were secured in a locked cabinet within a secure office environment. Audio recordings were encrypted during storage and will be permanently deleted once transcripts are fully verified for accuracy. These measures ensured the confidentiality and integrity of participant information, minimizing any risk of unauthorized access, loss, or misuse.

4. RESULTS

4.1 Demographic Information of Participants

The study involved fifteen participants medically diagnosed with Stage 5 kidney failure, drawn from two healthcare facilities in Ghana: the Kidney Specialist Centre (a private dialysis unit in Kumasi) and the Sunyani Teaching Hospital (a public tertiary facility). To maintain strict ethical standards and protect participant privacy, all names were anonymized throughout this analysis. Table 1 outlines the comprehensive demographic characteristics of the cohort, including gender distribution, age ranges, duration on dialysis, and treatment facility distribution, which collectively establish the contextual baseline for interpreting the subsequent qualitative findings.

Table 1
Demographic Characteristics of Participants

Demographic Characteristics	Category	Frequency
Gender	Male	10
	Female	5
Age	41–50	5
	51–60	6
	61–70	3
	71–80	1
Marital Status	Married	10
	Single	3
	Widow	2
Education	No Formal	3
	Basic	3
	Secondary	4
	Tertiary	5
Facility	KSC	14
	STH	1
Year Diagnosed & Treatment	2022	2
	2023	3
	2024	8
	2025	2

Table 1 reveals a male predominance among participants, with most aged 41–71. This concentration suggests that renal failure diagnosis often occurs during peak working years, amplifying socioeconomic vulnerability. Most participants had been on dialysis for under two years.

Methodologically, the study shows a stark institutional skew; most participants preferred the private Kidney Specialist Centre in Kumasi over the public Sunyani Teaching Hospital, citing superior infrastructure and consistent scheduling. This division fundamentally shaped participants' lived experiences: the public sector cohort faced systemic delays and resource shortages, while the private facility cohort endured severe financial strain due to out-of-pocket costs.

Despite these contrasting settings, a definitive commonality emerged: formal institutional support was perceived as inadequate. Consequently, participants relied heavily on informal networks comprising immediate relatives, friends, and religious communities for the emotional, logistical, and financial sustenance required to survive regular haemodialysis.

4.2 Thematic Overview

The qualitative analysis identified five primary themes and twenty interconnected subthemes, tracing the chronological trajectory of patients navigating kidney failure and haemodialysis in Ghana (Fig. 1). This thematic progression moves from initial clinical discovery through the existential and emotional weight of chronic illness. The analysis then explores the structural realities of healthcare navigation and the daily physical, occupational, and lifestyle disruptions experienced post-diagnosis. Finally, the framework concludes with the survival mechanisms and resilience strategies constructed by patients in the absence of institutional safety nets. Collectively, these themes offer a multi-dimensional understanding of the renal patient experience within the contemporary Ghanaian socio-cultural and medical landscape.

4.3 Theme 1: Diagnosis and Initial Reactions

4.3.1 Subtheme 1.1: Signs and Symptoms

Before receiving a formal clinical diagnosis, participants endured a cascade of persistent, debilitating physical symptoms. These primary markers included systemic fatigue, fluid retention leading to swollen feet, generalized body pains, painful finger cramps, and intense, unremitting itching. The diagnostic pathway was frequently complicated by initial clinical misdiagnoses and a cycle of multiple hospital visits across various tiers of the healthcare system, which severely delayed appropriate nephrology interventions. As one participant recalled:

“I went through many tests. Eventually, I realised I had low body fluid levels and started feeling constantly tired. After reviewing my lab report, the doctor asked me to come to the hospital for admission because my health was rapidly declining.” (P6)

4.3.2 Subtheme 1.2: Predisposing Factors

When reflecting on the underlying etiology of their condition, participants consistently identified long-standing chronic comorbidities as the primary drivers of renal failure. Chronic hypertension and diabetes mellitus were the most frequently reported predisposing conditions within the cohort. Additionally, several individuals identified a known family history of these metabolic cardiovascular conditions, pointing to hereditary patterns that went unmanaged or unlinked to renal risk until the onset of organ failure. One participant noted:

“High blood pressure and diabetes are contributing factors. I have both maybe it’s hereditary, but I never thought they could lead to this.” (P9)

4.3.3 Subtheme 1.3: Initial Reactions

The formal disclosure of a kidney failure diagnosis triggered intense, immediate psychological trauma among participants. These initial emotional responses were universally characterized by acute existential shock, deep disbelief, profound despair, and paralyzing fear. Because renal failure is widely misunderstood within the broader socio-cultural landscape, the diagnosis was immediately interpreted by patients as an imminent, irreversible death sentence rather than a manageable chronic pathology. This immediate psychological collapse is captured by one participant's account:

"I was shocked and frightened when I was told I had a kidney condition. I started shivering and thought I was already dead." (P2)

4.4 Theme 2: Emotional and Psychological Responses

4.4.1 Subtheme 2.1: Fear and Presumption of Death

The overarching emotional landscape for participants was defined by severe clinical anxiety, deep sadness, hopelessness, and fear as they adjusted to life-sustaining haemodialysis. The initial phase of this navigation was heavily dominated by the fear of premature mortality, with patients routinely equating the diagnosis with an immediate cessation of life. This psychological distress is illustrated by one participant's recollection:

"It was very scary at the beginning. I thought I wouldn't even live beyond that year." (P1)

4.4.2 Subtheme 2.2: Chronic Nature of the Disease

As the immediacy of the initial diagnosis subsided, the gradual realization that kidney failure is an irreversible, lifelong condition triggered profound frustration and emotional exhaustion. Participants experienced an existential crisis when contrasting renal failure with acute pathologies, noting that the relentless nature of dialysis offered only maintenance rather than a definitive cure. One participant expressed this weariness:

"This illness has given me hell. With other illnesses, treatment brings healing but not this one." (P9)

4.4.3 Subtheme 2.3: Spiritual Connotations

Socio-cultural frameworks heavily influenced how participants rationalized their diagnosis. Several individuals interpreted their condition through metaphysical lenses, attributing the onset of organ failure to supernatural interventions, divine testing, or ancestral punishment. This spiritualization of a chronic medical condition is reflected in community perceptions:

"Many people believe this illness is a curse." (P5)

4.4.4 Subtheme 2.4: Stigma, Secrecy, and Loneliness

Social vulnerability was severely compounded by community-level stigmatization, misconceptions, and malicious gossip. To insulate themselves from public scrutiny and social discrimination, multiple

participants adopted strict secrecy regarding their diagnosis. While this defensive hiding protected their privacy, it directly induced profound social isolation, alienation, and loneliness. As one participant shared:

"People spread your story like gossip. They wonder how I'm still alive." (P6)

4.4.5 Subtheme 2.5: Caregiver Burden

Even in the presence of robust, highly supportive family structures, participants experienced deep psychological distress regarding the secondary physical, logistical, and financial toll imposed on their immediate support networks. This sense of dependency eroded personal autonomy and created persistent feelings of guilt, as patients watched loved ones' sacrifice personal and professional goals to sustain their care. One participant noted:

"My daughter is a nurse and helps monitor my medication, but I feel like I'm burdening them." (P1)

4.5 Theme 3: Healthcare Experiences

4.5.1 Subtheme 3.1: Financial Burden and Accessibility

The catastrophic out-of-pocket costs associated with routine haemodialysis sessions and specialized pharmaceuticals constituted the primary structural barrier to continuous care. Because public health insurance coverage remains inadequate for long-term renal therapy, participants faced severe financial exhaustion, frequently forcing them to ration, delay, or entirely skip their life-sustaining treatments. This pervasive economic vulnerability affected even gainfully employed individuals, as illustrated by one participant's account:

"Sometimes you're due for treatment but can't afford it. Even though I work, I sometimes get financially stuck." (P4)

4.5.2 Subtheme 3.2: Haemodialysis and Logistical Challenges

Beyond the direct medical costs, the physical and logistical infrastructure required to sustain a tri-weekly dialysis regimen imposed a severe daily burden. Participants struggled with the friction of frequent long-distance travel to specialized centers, the recurring expenses of temporary accommodations near the facilities, and the profound, debilitating post-dialysis physical exhaustion that compromised their mobility. One participant detailed the compounding logistical and financial demands:

"Coming for treatment three times a week is not easy; I have to be financially prepared." (P3)

4.5.3 Subtheme 3.3: Healthcare System Experiences

Participants' interactions with the broader healthcare infrastructure during the pre-diagnostic and early symptomatic phases were frequently characterized by systemic friction. Narratives revealed a pattern of

initial clinical misdiagnoses, fragmented referral pathways, and poor or non-existent communication from frontline clinical staff. This lack of transparent patient education left individuals navigating complex therapeutic regimens without a basic understanding of their underlying pathology, as shared by one participant:

"During my early visits, I was given medications, but no one explained what was actually wrong with me." (P7)

4.5.4 Subtheme 3.4: Kidney Donor Concerns

When evaluating definitive therapeutic options beyond maintenance dialysis, participants expressed profound anxiety and defeatism regarding renal transplantation. This distress stemmed from the acute shortage of viable organs, the absence of centralized, institutionalized donor registries, and the immense difficulty of securing a compatible match within informal family networks. Consequently, the prospect of transplantation was viewed with deep skepticism, as captured by one participant:

"It's difficult to get a donor. You might die waiting for one." (P9)

4.6 Theme 4: Life After Diagnosis

4.6.1 Subtheme 4.1: Physical Health Symptoms

Sustaining life on maintenance dialysis did not fully alleviate the systemic burden of renal failure; instead, participants navigated a baseline of continuous, debilitating physical impairments. Ongoing systemic weakness, chronic fatigue, unremitting uremic itching, and severe insomnia were universally reported as disruptive somatic challenges. These persistent symptoms compromised their physical comfort and eroded the energy reserves required to execute basic activities of daily living. This was expressed by one participant saying:

"After my diagnosis, I found it difficult to have sound sleep. My appetite was gone, and even when I try to eat, I can only take in very little." (P8)

4.6.2 Subtheme 4.2: Lifestyle and Occupational Disruption

The profound physical decline and the demanding schedule of clinical treatments forced radical, involuntary shifts in participants' socioeconomic roles. The majority of individuals suffered complete occupational marginalization, losing their capacity to maintain steady employment, manage businesses, or serve as primary economic providers for their households. This abrupt loss of productivity triggered severe financial distress and a compromised sense of identity, as detailed by one participant:

"All my work has collapsed, and now I just stay home." (P3)

4.6.3 Subtheme 4.3: Dietary Restrictions and Medication Dependence

Daily life after diagnosis was heavily regulated by rigid medical imperatives, specifically complex pharmaceutical regimens and strict fluid and dietary limitations. Participants experienced severe psychological friction when trying to suppress basic biological impulses such as thirst and food preferences to avoid acute clinical complications. This highly policed lifestyle created an environment of constant deprivation, which one participant described as emotionally chaotic:

"Everything becomes chaotic. You want to eat or drink but can't. You're always restricted." (P6)

4.6.4 Subtheme 4.4: Loss of Autonomy and Hospital Routines

The relentless cadence of multi-weekly clinical appointments systematically stripped participants of their personal independence, subordinating their personal, familial, and social schedules to institutional demands. This total loss of autonomy and the constant immersion in clinical environments blurred the boundaries between domestic life and medical spaces. One participant reflected on this institutional dependency:

"Sometimes I feel like the hospital has become my second home." (P12)

4.7 Theme 5: Coping Strategies and Healthcare Advocacy

4.7.1 Subtheme 5.1: Dietary Caution and Restrictions

To navigate the physical demands of kidney failure, participants cultivated strict dietary adaptations, transitioning from enforced clinical restrictions to proactive nutritional management. Guided by specialized dietitians, individuals emphasized rigorous moderation and the elimination of dietary triggers specifically reducing sodium intake, avoiding alcohol, and abstaining from processed or commercially prepared street foods. One participant offered practical guidance regarding these modifications:

"People should check their salt intake, avoid street food, and minimize spices." (P8)

4.7.2 Subtheme 5.2: Early Diagnosis and Regular Health Checks

Reflecting on their complex diagnostic pathways, participants frequently channeled their lived experiences into advocacy for preventative healthcare. They strongly emphasized the critical importance of routine clinical screenings, metabolic monitoring, and early medical intervention, noting that timely detection is vital to arresting asymptomatic renal decline before it advances to end-stage disease. This perspective was summarized by one participant:

"It's advisable to check your health regularly to detect problems before they get worse." (P7)

4.7.3 Subtheme 5.3: Emotional, Psychosocial, and Spiritual Strength

Psychological survival and resilience within this cohort were deeply tethered to internal coping mechanisms, primarily personal faith and emotional endurance. When formal healthcare frameworks and economic resources proved insufficient, participants relied heavily on spiritual anchoring to maintain the psychological stamina required to endure routine dialysis, viewing their continued survival as an interplay of medical management and divine intervention. As one participant shared:

"Sometimes surviving depends on a miracle. Personally, I believe only God keeps me going." (P6)

4.7.4 Subtheme 5.4: Lifestyle Discipline and Accountability

A critical component of long-term survival involved balancing spiritual hope with strict clinical adherence and rigorous personal accountability. Participants identified self-discipline as an essential requirement for navigating the disease, explicitly warning against abandoning proven medical therapies in favor of unverified alternative or spiritual cures. One participant highlighted this need for behavioral discipline:

"Some stop coming to the hospital because they believe in miracles. But we must take care of ourselves before it's too late." (P6)

5. DISCUSSIONS

The study explored the lived experiences of individuals with kidney failure undergoing haemodialysis in both a public and a private facility in Ghana. The findings revealed complex emotional, financial, social, and behavioural responses that directly influenced coping mechanisms and treatment adherence. Unlike earlier Ghanaian studies that focused narrowly on isolated psychosocial or biomedical outcomes (Amoako & Owusu-Ansah, 2021; Bioma et al., 2019), this research provides a holistic perspective by demonstrating how the institutional facility type actively mediates the patient experience.

5.1 Diagnosis and Initial Reactions

The clinical disclosure of diagnosis was characterized by participants as shocking, confusing, and deeply destabilizing, a finding that aligns with Manenti and Leuci (2021). Across both institutional settings, patients immediately associated the diagnosis with premature mortality or an irreversible bodily decline. However, the comparative analysis reveals different structural emphases: private facility patients expressed acute frustration at the high costs and complex batteries of diagnostic tests, whereas public hospital patients highlighted systemic delays and structural mistrust in laboratory service delivery.

The Health Belief Model (HBM) (Rosenstock, 1974a; 1974b; Janz & Becker, 1984) explains these responses through the lenses of perceived susceptibility and perceived severity. The immediate recognition of the lethal nature of end-stage renal failure triggered acute existential fear, while the distinct institutional inefficiencies shaped how patients calculated their ongoing clinical risk.

5.2 Emotional and Psychological Impact

Participants across both cohorts experienced intense anxiety, despair, and deep-seated social stigma, mirroring the qualitative patterns documented by Hansen et al. (2022) and Abbas and Ali (2023). However, unlike in resource-rich Western contexts where professional psychiatric counseling is routinely integrated into renal care, Ghanaian patients navigated this profound psychosocial strain without structured mental health support.

Facility-based variations were distinct: at the private center, emotional despair was inextricably tied to the anticipation of unsustainable out-of-pocket costs, while at the public hospital, psychological distress stemmed from unpredictable treatment delays and overcrowding. Within the HBM framework (Rosenstock, 1974a; 1974b; Janz & Becker, 1984), these distinct experiences demonstrate that perceived barriers whether financial or systemic directly undermine a patient's confidence in long-term treatment adherence. Furthermore, the prominent emergence of caregiver burden confirms previous calls by Abbas and Ali (2023) to explicitly recognize family-level strain as a core component of renal care in sub-Saharan Africa.

5.3 Healthcare Experiences

Participants' interactions with health services exposed stark systemic inequalities. Financial strain and resource exhaustion dominated private care, whereas prolonged delays, broken referral pathways, and severe overcrowding characterized the public sector experience. These findings mirror the broader assessments by Francis et al. (2024) and Kelly et al. (2021), who document underfunded, understaffed dialysis services across sub-Saharan Africa.

The comparative perspective offered by this study adds a novel dimension to the literature: it demonstrates that while both healthcare settings produce high levels of patient distress, the structural nature of the barriers differs fundamentally by facility type. In the context of the HBM (Rosenstock, 1974a; 1974b; Janz & Becker, 1984), these distinct operational barriers dictate whether patients view continuous clinical treatment as highly beneficial or ultimately futile.

5.4 Life After Diagnosis

Daily routines, established occupational roles, and baseline physical well-being were severely disrupted for all participants, validating the chronic illness trajectories outlined by Bennett et al. (2022) and McLean et al. (2024). A key point of divergence from resource-rich global settings is that Ghanaian patients faced total loss of income and occupational marginalization without state-sponsored disability benefits or social safety nets. This lack of institutional compensation severely amplified complete dependency on immediate family networks.

The extreme perceived severity of kidney failure, compounded by unremitting uremic symptoms, rigid hospital schedules, and the constant psychological friction of strict dietary and fluid restrictions, forced a passive resignation to highly restricted lifestyles. This loss of autonomy and the blurring of boundaries between home and clinical spaces reflect a significant perceived barrier within the HBM (Rosenstock, 1974a; 1974b; Janz & Becker, 1984). Ultimately, these findings confirm that the oppressive, chronic

nature of the illness is not merely physiological but is fundamentally amplified by the lack of institutional support and the totalizing nature of the dialysis routine.

5.5 Lifestyle Adjustment, Health Advice, and Coping Mechanisms

To survive the daily demands of renal failure, participants relied on strict lifestyle discipline, active health advocacy, and deep spirituality. The emphasis on dietary modifications and fluid restrictions echoes nutritional adherence patterns found by Chen et al. (2018), while participants' strong advice regarding early medical screening and public campaigns supports the preventative healthcare arguments of Danquah et al. (2023). Spiritual resilience was exceptionally prominent, echoing Firmawati et al. (2024), and aligns directly with the HBM's cues to action (Rosenstock, 1974a; 1974b; Janz & Becker, 1984). Within this cohort, personal faith, perceived miracles, and family encouragement served as powerful internal motivators that drove treatment adherence despite severe socioeconomic adversity.

Crucial facility differences emerged within these behavioral adaptations: private center patients benefited from highly structured, dietitian-led nutritional regimens, whereas public hospital patients leaned far more heavily on spiritual anchoring due to weaker institutional support and limited access to specialized allied health professionals. This structural divergence represents an important contribution to contemporary Ghanaian renal research.

6. CONCLUSION AND RECOMMENDATIONS

6.1 Contribution of the Study

This study makes a distinct contribution to sub-Saharan renal literature by providing a comparative, dual-facility analysis of how institutional settings public versus private actively mediate the lived experiences of patients navigating Stage 5 kidney failure in Ghana. While existing local research typically aggregates patient experiences or focuses strictly on clinical or psychosocial outcomes, our findings uncover a critical structural divergence: private facility care induces deep emotional despair driven by catastrophic out-of-pocket costs, whereas public facility care generates psychological trauma stemming from systemic delays, infrastructure deficits, and overcrowding. Furthermore, by framing these distinct structural realities through the Health Belief Model, this study provides a novel theoretical mapping of how institutional barriers directly alter patient perceptions of treatment utility and adherence, offering a concrete blueprint for targeted healthcare policy interventions.

6.2 Limitations of the Study

Although this study provides rich, contextualized insights into the trajectory of renal care, several limitations must be noted. First, the qualitative sample consists of fifteen participants recruited from two specific centers in Kumasi and Sunyani; therefore, the findings reflect the localized operational realities of these facilities and cannot be statistically generalized to all dialysis units across Ghana. Second, the

cohort exhibited a stark institutional imbalance, with the vast majority of participants drawn from the private center, which may minimize some of the systemic nuances unique to long-term public healthcare utilization. Finally, because data collection relied on retrospective self-reports, participants' accounts of their initial pre-diagnostic symptoms and reactions are subject to recall bias.

6.3 Conclusion

This study demonstrates that navigating kidney failure and maintenance haemodialysis in Ghana is an existential, financial, and structural crisis that extends far beyond individual biomedical management. The disclosure of a diagnosis inflicts immediate psychological trauma, which is subsequently compounded by the grueling daily realities of a life-sustaining treatment regimen. Crucially, the patient experience is not uniform; it is profoundly shaped by the type of healthcare facility accessed. Patients face a precarious trade-off between the financial exhaustion of private care and the hazardous systemic inefficiencies of public care. Ultimately, as formal institutional safety nets remain inadequate, patients must rely on strict personal discipline, spiritual anchoring, and informal socio-familial networks to survive, highlighting an urgent need for systemic healthcare reform in national renal care delivery.

6.4 Recommendations

Based on the empirical findings, the research team proposes several targeted recommendations for policy and practice. First, the Ministry of Health should urgently expand National Health Insurance Scheme (NHIS) coverage to fully or partially subsidize the cost of routine haemodialysis sessions and essential nephrology pharmaceuticals, thereby mitigating the catastrophic financial burden on families. Second, public tertiary facilities, such as the Sunyani Teaching Hospital, require immediate infrastructural expansion, including the acquisition of functional dialysis machines and the deployment of specialized nephrology personnel, to reduce diagnostic delays and treatment bottlenecks. Third, healthcare administrators in both public and private sectors should establish structured, institutionalized counseling and psychiatric support units within dialysis centers to address the pervasive anxiety, existential dread, and caregiver burden experienced by patients and their families. Finally, public health directorates should launch targeted community screening and educational initiatives focused on early metabolic monitoring, specifically hypertension and diabetes management, to curb the rising incidence of end-stage renal disease.

6.5 Suggestions for Further Study

To build upon the insights generated by this inquiry, further research should consider several pathways. Future studies should execute a large-scale, mixed-methods survey across all sixteen regions of Ghana to statistically validate the facility-based disparities identified in this qualitative cohort. Additionally, a dedicated qualitative investigation is needed to explore the long-term physical, psychological, and financial impacts of renal care specifically on immediate family caregivers over an extended trajectory. Finally, conducting an empirical cost-benefit analysis of national dialysis subsidies versus the integration of institutional renal transplantation programs would provide vital data to guide sustainable healthcare financing policies in Ghana.

Declarations

Ethics Approval and Consent to Participate:

Ethical approval was granted by the Committee on Human Research, Publication and Ethics (CHRPE) at the Kwame Nkrumah University of Science and Technology (Reference Number: CHRPE/AP/546/25), with formal administrative permission obtained from both participating health facilities. All participants provided verbal informed consent in consultation with their caregivers prior to being interviewed.

Consent for Publication:

Participants consented to the use of their interview data for publication, provided that all personal identifiers were anonymized to facilitate public awareness campaigns.

Competing Interests:

The authors declare that they have no competing interests.

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Author Contribution

GKA and EAB conceptualized the study. GKA and TK were responsible for data collection. GKA and TK led the data analysis and the drafting of the results, with significant intellectual contributions from EAB, and AK-AD. All authors contributed to the drafting of the manuscript and have approved the final version for publication.

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Data Availability

The datasets generated and analyzed during the current study are available from the corresponding author upon reasonable request.

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Figures

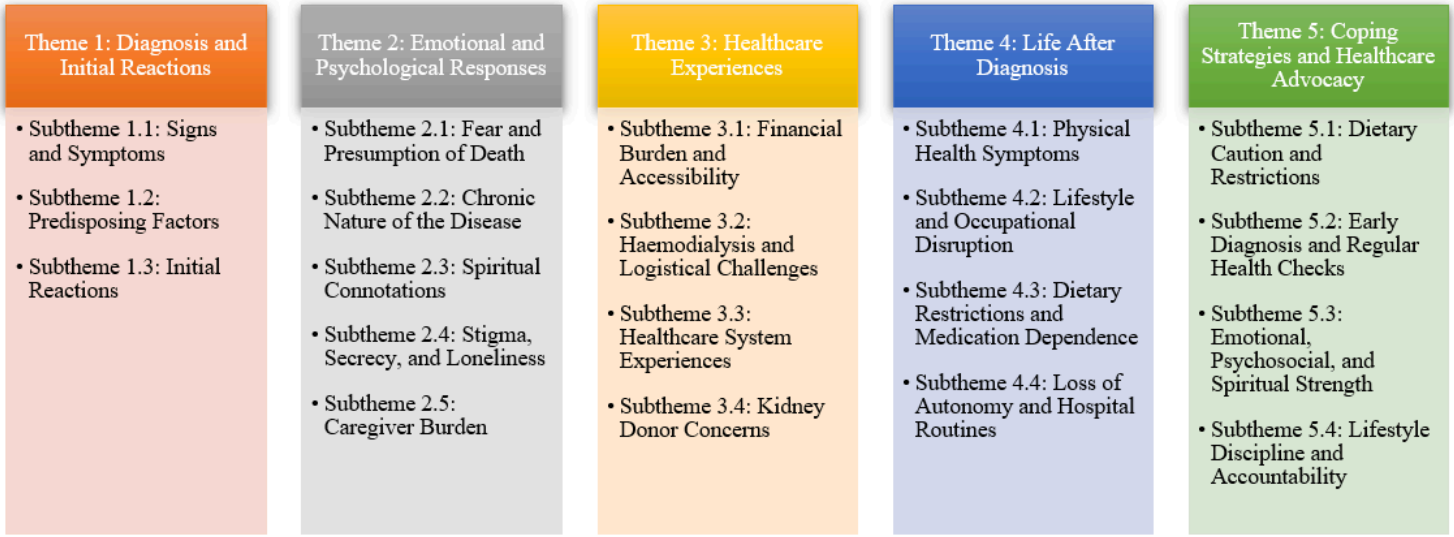

Figure 1

Thematic Brief of the Study

Source: Researchers' Construct (2025)