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The Shrinking Social Horizon: Dialysis Impact on Autonomy and Identity

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Abstract

Background

Dialysis is a life-sustaining treatment for end-stage renal disease, yet it profoundly impacts patients' quality of life through physical limitations and psychosocial distress. This study explored the perceptions of patients on maintenance dialysis regarding their treatment needs, challenges, and lived experiences.

Methods

A descriptive qualitative design was employed. Individual, semi-structured face-to-face interviews were conducted with 42 adult participants (mean age 62.3 years; mean dialysis vintage 9.0 years). Data were analyzed using NVivo 15 software. Transcripts were coded for credibility, and results were synthesized into composite vignettes focusing on age-related challenges and functional capacity.

Results

Participants across all ages (26–82 years) reported a marked decline in quality of life driven by chronic fatigue and rigid treatment schedules. Key themes included the "burden of the machine," a shrinking social world, and identity loss. While some participants achieved acceptance or hope, many remained isolated and emotionally burdened by the loss of autonomy and identity.

Conclusions

Although life-saving, dialysis induces significant emotional dysregulation and physical limitations. Enhancing patient well-being requires a comprehensive approach that transcends medical needs to address emotional, relational, and existential challenges. Clinical care and supportive policies must integrate psychological support, flexible treatment options, and social inclusion to address the multifaceted needs of both adult and elderly patients.

Background

End-stage renal disease is a major global public health problem, with a steadily increasing prevalence in the adult and elderly population having a profound impact on their quality of life [1]. Chronic kidney disease’s irreversible progression requires complex treatments including dialysis, with significant implications for patients [2, 3]. In-center hemodialysis, the standard treatment option in most public health systems, aims to maintain life but entails major restructuring of daily routines and a decrease in autonomy, often accompanied by depression, anxiety, and chronic stress [4, 5]. Assessing the quality of life in patients undergoing in-center hemodialysis center is essential for understanding the real impact of treatment on daily life. By identifying the specific difficulties and subjective perceptions of patients,

interventions can be developed that focus on individual needs and contribute to improving well-being and optimizing renal care. This paper aims to explore the experiences of adult and elderly patients undergoing in-center hemodialysis center, with a focus on the physical, emotional, and social dimensions of quality of life. Current literature does not address in detail patients' experiences, coping mechanisms, and quality of life priorities. Qualitative investigations that explore the nuanced, lived experiences in the same research framework remain scarce. This gap limits our understanding of how treatment demands intersect with social support structures, and personal values. Addressing this gap, the present study provides an in-depth, qualitative analysis of adult and elderly patients on in-center hemodialysis center.

Dialysis is not just a technical procedure, but a radical lifestyle change severely affecting quality of life by significantly decreasing physical, emotional, social and professional functioning [6–10]. Among the elderly, loss of support networks and social isolation are major problems [11–14]. Although more commonly withdrawn from activity the elderly face more severe physical limitations, multiple comorbidities and increased emotional vulnerability. They tend to perceive dialysis as an extension of life, but sometimes also as a meaningless burden, sometimes opting for palliative care [15, 16].

Active working and family adults feel the disruption to their daily routine and loss of autonomy more acutely. The impact of dialysis on working life is severe, with less than 25% of patients being professionally active after treatment initiation [17, 18]. Financial problems and family restrictions deepen emotional distress [19, 20]. Dialysis interferes with work, career and parenthood, leading to frustration and sometimes social stigmatization [21]. Home dialysis offers benefits through flexibility, but for the elderly may be limited by cognitive or physical impairments, requiring additional support [22]. Faced with these challenges, an integrated approach addressing the psychosocial dimension including loss of identity and stigmatization, becomes essential [23]. QoL deterioration emphasizes the need for psychosocial interventions and constant monitoring of psychological status [24, 25].

This study conducts a comparative investigation of active adult and elderly patients undergoing dialysis. By using composite vignettes as a data presentation strategy offers a unique narrative perspective on lived experience, facilitating an integrated understanding of medical, emotional, and social factors. This approach complements existing research and provides valuable information for tailoring interventions to the cultural and demographic specificities of patients

Methods

This research adopts an exploratory qualitative approach, within the phenomenological paradigm, to understand the subjective experiences of adult and elderly patients undergoing in-center hemodialysis center in relation to their own quality of life. The choice of the qualitative method is motivated by the complex and deeply personal nature of this concept, which cannot be adequately captured by quantitative tools.

This cross-sectional study was conducted from January 2024 to June 2024 at a single dialysis center. It aims to assess the impact of dialysis on quality of life in adults and older adults. Purposive sampling

was used to select participants to identify those subjects who can provide the most relevant and detailed information. A dialysis vintage of at least three months was considered necessary to overcome the initial stage of adaptation and accumulate a considerable experience. Only patients able to communicate coherently, understand the nature of the study and give informed consent were included. Participation was voluntary, based on willingness to share individual experiences, in accordance with the ethical principles of qualitative research.

Patients in an unstable medical condition, with acute complications or severe psychiatric disorders that could impair the ability to participate consciously and coherently were excluded, thus respecting the protection of vulnerable individual. Patients within the first three months of treatment were also excluded to avoid biasing the data by the prospect of an incipient and unstable adjustment process. Lack of informed consent or withdrawal of informed consent was a firm exclusion criterion.

Data was collected through semistructured, face-to-face, individual interviews conducted in a dedicated space within the dialysis center that provided privacy and comfort for the participants. The interviews were guided by a list of open-ended questions, designed to explore patients' perceptions, experiences and strategies for coping with life on dialysis. Data collection was conducted by a single, trained researcher to maintain consistency and depth. The flexible interview guide allowed adaptation to emerging responses and themes. Interviews continued until theoretical saturation was reached, with no new themes emerging. To ensure trustworthiness, two independent researchers coded the transcripts separately and resolved any discrepancies through consensus, reducing bias. All interviews were fully transcribed, preserving participants’ language to support thorough qualitative analysis and theme identification.

The semi-structured interviews were conducted based on a thematic guide consisting of nineteen open-ended questions. After a brief ethical introduction regarding the voluntary and anonymous nature of participation, the interview begins with a section of socio-demographic data (age, duration of diagnosis, dialysis vintage). Questions are thematically organized into seven areas: perception of illness and treatment (4 questions), changes in personal and professional life (3 questions), independence and autonomy (2 questions), social relationships (3 questions), psycho-emotional support (2 questions), affective experiences related to dialysis (5 questions).

Data analysis was conducted using the thematic analysis method, following the approach proposed by Braun and Clarke [26], allowing the systematic identification, organization and interpretation of recurrent themes in the participants' discourses. Interview transcripts were fully verbatim transcribed immediately after each session, and the data were further processed manually, in parallel with the use of NVivo software. The analysis was conducted in parallel by researchers, who discussed and reconciled any differences in interpretation. In addition, methodological triangulation techniques (field notes, contextual observations) and internal validation by checking themes against the whole dataset were applied.

To authentically and nuanced render the participants' experiences, the qualitative analysis was complemented by the construction of composite vignettes. These are synthesized narratives, based on

the statements of multiple interviews, reflecting recurring themes and common experiences identified in the interviews. Each vignette depicts a fictional" character" constructed based on thematic coding and data triangulation, illustrating typical perspectives on the impact of dialysis on personal, professional, relational and emotional life. This approach allows the humanization of the results, without compromising the anonymity of the participants, and supports a deeper understanding of the subjective dimension of the experiences analyzed.

Results

The study included 42 adult patients on dialysis replacement therapy with a mean age of 62.31 years, 50% men and 50% women. The youngest participant was 26 years and the oldest 82 years, showing a wide age distribution. The socio-demographic and clinical characteristics of the participants show significant diversity with more than half retired, and the rest professionally active or without formal employment. Educational levels ranged from primary to higher education, and most patients were married or in stable relationships. The most reported comorbidities were hypertension and diabetes mellitus. This socio-demographic heterogeneity provides a useful framework for understanding the variability of perceptions and experiences related to dialysis. The mean dialysis vintage was 9.02 years, with extremes ranging from 2 to 32 years, reflecting significant variability in individual experience with end-stage renal disease and adaptation to the long-term therapeutic regimen. NVivo-assisted thematic analysis revealed five overarching themes and several sub-themes (Table 1).

Table 1. Thematic structure and frequency of occurrence among participants.

Main Theme	Sub-theme	No. of references	No. of participants	% of participants
Perception of illness and treatment	Initial physical symptoms	58	36	85.7
	Initial emotional reactions	74	39	92.8
	Acceptance/resignation	42	28	66.7
Changes in personal life	Physical limitations and fatigue	83	40	95.2
	Social restrictions	61	33	78.6
Independence and autonomy	Loss of functional independence	55	34	80.9
	Family support	47	32	76.2
Social relationships	Emotional support from family	69	35	83.3
	Social isolation	38	21	50.0
Affective experiences related to dialysis	Fear and anxiety.	63	37	88.1
	Hope and optimism	27	18	42.8

The qualitative analysis highlights several interconnected themes reflecting the multifaceted impact of dialysis on patients' quality of life. Most participants experienced significant initial physical symptoms (85.7%) and strong initial emotional reactions (92.8%) to their diagnosis and treatment. A majority also expressed acceptance or resignation toward their condition (66.7%), indicating a complex emotional adjustment process. Physical limitations and fatigue emerged as the most frequently referenced challenges, affecting 95.2% of participants. Social restrictions were also notable, reported by 78.6% of participants, underscoring how dialysis imposes constraints on daily activities and social engagement. A substantial portion of participants (80.9%) reported a loss of functional independence, reflecting the physical toll of dialysis. However, family support was significant for many (76.2%), supporting the vital role of close social networks in helping patients cope. Emotional support from family was highlighted by 83.3% of participants, emphasizing the importance of familial bonds during treatment. Nonetheless, social isolation affected half of the participants (50%), pointing to the need for broader social support mechanisms. Fear and anxiety were prevalent, reported by 88.1% of participants, illustrating the psychological strain associated with ongoing treatment. Yet, hope and optimism were present in 42.8%, indicating resilience and a positive outlook in some patients.

Figure 1 provides an integrative summary of the main themes and their interrelations, highlighting how loss of autonomy, emotional responses, family support, and social participation, interact to shape patients' quality of life.

At its core, psycho-emotional support or the lack of it shapes patients' emotional reactions, loss of independence, and ability to cope with restrictions and medical demands. Perception of illness and treatment influences how patients adapt, whether through acceptance, resignation, or negotiating autonomy amid personal and professional changes. Affective experiences range from hope and support to resignation, shaped by friends, social relationships, and the stigma they sometimes carry. Fear, linked to loss of roles, can lead to isolation, while optimism and fatigue reflect contrasting outcomes of the dialysis journey. Together, these elements form a web where each factor influences and amplifies the others, defining the lived experience of dialysis.

A word cloud visually represents key concepts and experiences related to the impact of dialysis on patients' lives (figure 2).

At the center, highlighted in larger and bolder text, are the most prominent themes: diagnosis, dialysis, social impact, limitations, and perception. These core ideas reflect the central concerns shaping patients' journeys. Surrounding these main terms are other significant aspects of the dialysis experience. Emotional dimensions include hope, fear, shock, anxiety, resignation, and optimism, showing the range of feelings that accompany the treatment. Psychological aspects such as understanding, acceptance, and autonomy point to the mental and adaptive processes patients go through. Practical and social elements like professional, personal, independence, family, support, resources, and social impact reveal the ways dialysis affects daily functioning, relationships, and societal interactions. Medical and treatment-related terms including disease, symptoms, treatment, initial reaction, and adaptation highlight the clinical side of the experience, from diagnosis to ongoing care. Overall, the word cloud captures a multidimensional picture of life with dialysis, blending medical realities, emotional responses and social consequences into one interconnected view.

Composite vignettes of participants with ESRD

1. *Perception of illness and treatment*

The onset of dialysis was most associated by participants with the appearance of persistent physical symptoms such as fatigue, nausea, or swelling indicators that prompted medical consultation and eventual diagnosis. The resulting theme is that end-stage renal disease often goes unnoticed, frequently requiring emergency intervention due to lack of preventive care or follow-up. In our study some diagnoses were incidental, occurring during unrelated medical investigations, while others were delayed by patient recourse to alternative treatments or medical mistrust highlighting the influence of cultural beliefs and systemic gaps.

Emotional reactions were diverse, often combining fear with a reluctant acceptance of the dialysis treatment. *"It was like a shock at first, but I knew it was something I had to do to stay alive." (P3, male, 54) "I didn't understand much in the beginning; it felt like a punishment." (P9, female, 49).* Patients reported a wide range of initial responses, most commonly fear and acceptance, often coexisting in a fragile

balance. Emotional disorganization, denial, and shock were also frequently described, particularly in the absence of adequate information or psychological support. Some individuals reported courage and mental preparation, reflecting the participants' heterogeneous coping capacities.

The diagnosis and indication of dialysis triggered an existential crisis involving loss of meaning, identity fragmentation, and disruption of life goals. A recurrent theme was that of cognitive-emotional resignation or passive acceptance, often shaped by insufficient understanding of the disease due to its inherent complexity or suboptimal medical communication. Although dialysis was widely recognized as a life-saving intervention, many viewed it as a burdensome yet necessary routine. Gradual normalization and emotional adjustment were supported by familial support and spiritual reinterpretation, with a few patients integrating dialysis into their existential narratives.

2. *Changes in personal and professional life*

Dialysis imposed significant restrictions on daily routines, especially due to fatigue after treatment sessions. Many participants reported withdrawal from social or recreational activities: *"I feel I can't do anything after the session. For three hours I just lie down with no energy." (P14, male, 58) "I used to travel a lot, now I can't plan anything freely." (P27, female, 61).* The participants' narratives reveal that living with dialysis involves a deeply transformative personal, professional and functional experience, often marked by limitation, identity restructuring, and emotional adaptation. Among physical limitations fatigue and reduced autonomy were frequently described as a progressive loss that redefined daily roles and responsibilities. Despite this, some participants internalized their condition and displayed acceptance and resilience, suggesting the activation of functional coping mechanisms while others reported anxiety and emotional shock in the preliminary stages.

At the occupational level, many patients experienced career disruptions such as premature retirement or job loss, reflecting a break between their professional identity and the new demands of chronic illness. However, several participants continued working, often supported by flexible schedules, accommodating roles, or strong family systems. Others were already retired or had no formal employment, which modulated the perceived impact of dialysis on professional life. These diverse experiences highlight how prior employment history and individual valuation of work play a role in how the disease is experienced and integrated.

Functionally, most patients reported substantial physical limitations (chronic fatigue, reduced mobility), inability to engage in social and domestic activities though some denied any major loss of capacity, reflecting effective adaptation or preexisting low activity levels.

3. *Independence and autonomy*

Loss of autonomy emerged as a central concern, with participants describing increased dependence on family members for transportation, daily tasks, and emotional support: *"I used to be independent, now I depend on my daughter for almost everything." (P22, female, 72)*. Patients frequently report a reduction in

their ability to perform everyday activities, with common statements including “I can no longer do what I used to do” or “tiredness won’t let me move”. Despite these challenges, many individuals demonstrate resilience by restructuring their daily lives to align with treatment schedules and physical capabilities, thereby preserving a degree of autonomy.

The transition to dialysis often coincides with a perceived rupture in identity, particularly regarding the ability to function independently. Patients describe a shift toward informal support systems, involving family members who assist with transportation, personal care, and emotional support. While some individuals integrate this support as part of a new life routine commonly referred to as "negotiated autonomy" others perceive it as infantilizing or degrading, with negative consequences for self-esteem and interpersonal relationships.

Variability in patients’ experiences of autonomy loss appears to be influenced by factors such as age, educational level, prior functional status, family support, and psychological coping strategies. While some adapt successfully, particularly those with pre-existing limitations, others experience frustration, helplessness, or emotional withdrawal. Patients who are actively involved in managing their treatment often report a more favorable and balanced perception of autonomy, retaining a sense of agency in the face of chronic illness.

4. *Social relationships*

For most, family provided the main source of emotional stability and motivation. However, some reported social isolation and reduced contact with friends due to stigma or fatigue: *“My family supports me, but outside of that, people have distanced themselves.” (P11, male, 66)*. Patients’ accounts of how family and friends responded to their diagnosis, the evolution of close relationships, and the perceived quality of support reveal a complex dynamic of social adjustment in the context of chronic kidney disease. Thematic analysis identifies three core dimensions: the nature of immediate social reactions, transformations in interpersonal relationships, and the perceived level and quality of social support.

Most patients describe affective and empathetic responses from family and close friends, characterized by encouragement and emotional availability. This initial support functions as a critical buffer in the initial stages of adaptation, offering a stabilizing relational framework amid the uncertainties of chronic illness. However, some narratives reflect reactions of shock or rejection, particularly when the illness is framed as catastrophic a finding consistent with literature on the disruptive impact of chronic illness on social systems. In some instances, stigma or emotional overwhelm led to distancing or withdrawal by others, exacerbating patients’ suffering and promoting social isolation.

Relationally, two divergent trajectories emerge. One reflects the strengthening of familial bonds, aligning with evidence that highlights the protective role of family in chronic illness contexts. In these cases, patients report continuity or deepening of emotional ties. The other trajectory describes increasing social withdrawal or reliance exclusively on the family unit, indicative of a contraction of broader social

networks. This retreat is attributed to both physical limitations and perceived stigmatization or emotional fatigue.

While most patients report feeling supported and understood correlated with more adaptive coping and improved QoL a minority experience partial support or social isolation, especially in less responsive environments.

5. *Psycho-emotional support*

The psycho-emotional support dimension in dialysis patients reveals a complex interplay of coping strategies involving individual, familial, and systemic resources. Participants overwhelmingly identify the family as the primary source of emotional support, providing understanding, validation, and a sense of security amidst the upheaval of chronic illness. While extended support occasionally includes friends or dialysis center staff, a minority of patients cite themselves as the main source of emotional support, reflecting intrapersonal coping and self-regulation strategies consistent with the cognitive appraisal theory of stress. In these cases, the patient emerges not merely as a recipient of care but as an active agent in reinterpreting their condition and maintaining emotional equilibrium.

Access to psychological counseling reveals ambivalence. Some patients benefited and found it helpful, while others dismissed the need, potentially reflecting denial, self-reliance, or sociocultural norms discouraging vulnerability. For others, psychological services were unavailable due to infrastructural or financial barriers, despite the well-documented association between chronic kidney disease and psychological distress, including anxiety and depression. Statements like *"I felt the need but didn't do it"* are common and reflect systemic shortcomings in addressing mental health needs.

A subset of patients explicitly rejected psychological counseling, expressing distrust or cultural resistance to mental health care responses that may serve as defensive strategies to preserve autonomy and identity in the face of chronic illness.

6. *Affective experiences related to dialysis.*

Initial feelings of fear and anxiety often gave way to acceptance or even hope. Some participants reframed dialysis as a second chance in life: *"I think it's a gift from God that I'm still alive, even if it's hard." (P7, female, 65) "You just have to be strong and take it one day at a time." (P16, male, 59).* In the initial stages of dialysis treatment, patients frequently report intense negative emotions, primarily fear, anxiety, and emotional shock. A prevailing "fear of the unknown" often stems from uncertainty about the medical procedures and prognosis. A subset of patients displays early emotional resilience, transforming anxiety into adaptive behaviors such as cognitive reframing and seeking emotional support mechanisms aligned with coping theory. Social support, particularly from family, but also from healthcare professionals and peers, emerges as a critical resource that mitigates distress and fosters psychological adjustment. In contrast, some individuals employ avoidance strategies denial, emotional suppression, or minimization

of illness severity which, while temporarily protective, are associated with long-term emotional disengagement and increased psychological vulnerability.

Narratives also reflect the presence of positive psychological resources, particularly hope and optimism. Many patients interpret dialysis as a “second chance” or a transformative life opportunity, resonating with the concept of “benefit finding” in chronic illness. Acceptance of illness is a dominant theme in the data, with patients consciously integrating their condition into daily life an active and intentional stance consistent with acceptance and commitment therapy principles. However, partial or ambivalent acceptance also emerges, reflecting emotional stagnation or denial, as conceptualized in the transtheoretical model of change.

Of particular significance are patients’ messages to others beginning dialysis, often centered on courage, trust, and hope. These responses illustrate a form of narrative altruism, where personal suffering is reframed as a resource for communal support. Overall, patients’ emotional trajectories oscillate between vulnerability and resilience. While fear dominates initially, many progress toward conscious acceptance, supported by social networks, introspective capacity, and future-oriented optimism. Conversely, avoidance and hopelessness may impede adaptation.

Discussion

The findings of this study confirm that dialysis, while lifesaving, profoundly reshapes patients’ daily life by limiting autonomy, reducing functional capacity, and generating significant emotional distress. Fear and anxiety dominated the early stages of treatment, often linked to uncertainty about procedures and prognosis, while hope and resilience were less frequent but meaningful responses [27–29]. Loss of autonomy emerged as a central theme, consistently associated with fatigue, reliance on family members, and social restrictions [30–32]. When compared with existing literature, our results align with previous reports emphasizing the psychosocial burden of dialysis and the protective role of social support [3, 33]. At the same time, this study highlights important differences between age groups: younger patients perceived dialysis as a disruption of professional and social identity, whereas older patients experienced it more as an existential challenge, oscillating between gratitude for prolonged survival and the perception of treatment as a burden [11, 29, 34–36]. These findings complement global evidence suggesting that conservative management may sometimes offer comparable survival with better quality of life in elderly patients [37, 38].

From a clinical perspective, the results underscore the importance of integrating psychosocial and psychological care into nephrology practice. Family-centered interventions, stigma reduction, and improved access to counseling could mitigate distress and enhance adaptation. Particular attention should be paid to elderly patients, whose comorbidities and functional decline compound the impact of dialysis, while younger adults require support in maintaining social and occupational roles. Implementing patient-reported outcome measures (PROMs) and flexible treatment approaches would support more person-centered care [39, 40].

This study has several limitations. The monocentric sample and relatively small number of participants limit transferability to broader populations. All interviews were conducted by a single researcher, introducing potential bias despite triangulation in coding. The cross-sectional design prevents capturing long-term trajectories of adaptation, and socio-demographic factors such as education or occupational status were not explored in depth. Future research should employ multicenter, longitudinal, and mixed method approaches to better capture the complexity of dialysis patients lived experiences.

Conclusions

This study provides an in-depth qualitative exploration of the complex and multidimensional ways in which dialysis shapes the lived experience of adult and elderly patients with chronic kidney disease, revealing a profound reconfiguration of physical autonomy, emotional equilibrium, social identity, and daily functionality. Far from being merely a life-sustaining medical intervention, dialysis emerges as a central axis around which patients must reorganize not only their routines, but their sense of self and relational world. The findings emphasize the coexistence of vulnerability and resilience, showing how individuals navigate suffering, dependence, and uncertainty through adaptive strategies, familial support, and the gradual internalization of new meanings of life and health. While patients manage to integrate treatment into a newly redefined normality, others remain emotionally destabilized, socially isolated, or existentially disoriented, highlighting the limitations of a purely biomedical approach. In this context, the imperative for personalized, holistic, and ethically anchored care becomes evident. Enhancing quality of life for dialysis patients requires a change in basic assumptions in clinical nephrology, one that embraces not only technological efficacy, but also emotional support, decisional autonomy, social inclusion, and the recognition of patients' narratives as valid forms of knowledge in the construction of care.

Declarations

Ethical approval:

The questionnaire and methodology for this study was approved by the Ethics Committee of the "1 Decembre 1918" University of Alba Iulia (23/05/2024). The procedures used in this study adhere to the tenets of the Declaration of Helsinki and its later amendments and of the national legislation governing research involving human participants.

Consent for publication

Not Applicable

Consent, confidentiality and privacy

All patients gave their free and informed consent to participate in the study.

Participant confidentiality was ensured by assigning unique codes to each interview transcript and securely storing data on password-protected institutional servers accessible only to the research team.

Funding, Competing interests

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author Contribution

A.B.G. oversaw the creation of the questionnaire, conducted the interviews, and supervised all statistical analyses and the writing of the manuscript. A.M.B. and A.I.B. created the questionnaire, conducted the qualitative analysis and the creation of the composite vignettes, and drafted the manuscript.

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Figures

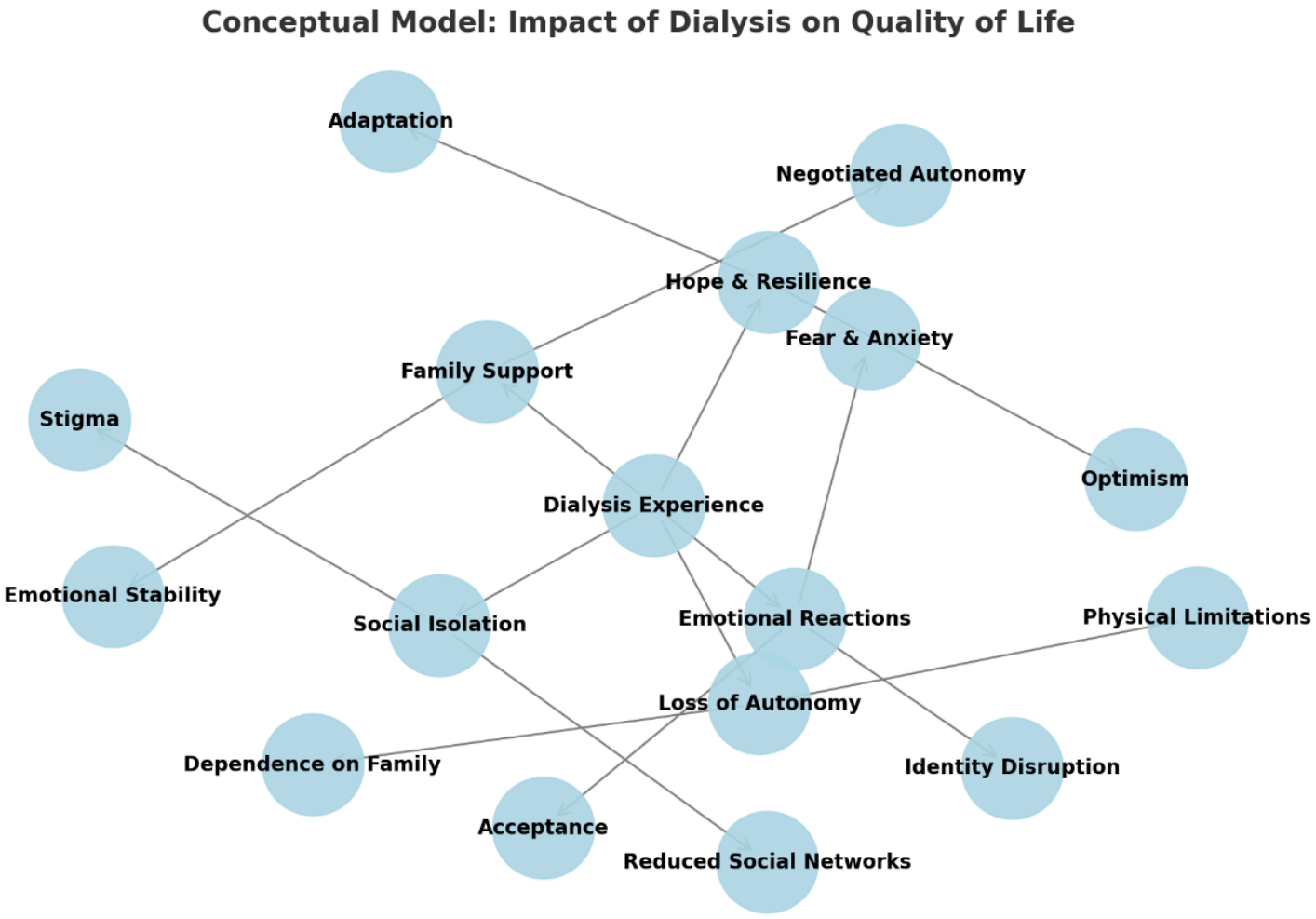


Figure 1

Thematic Model: Impact of Dialysis on quality of life (NVivo-assisted thematic analysis)



Figure 2

Word cloud with key concepts and experiences (NVivo-assisted thematic analysis)