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Experiences of women undergoing hemodialysis regarding family social support

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ABSTRACT

Introduction: Social support is defined as assistance offered by other people, which generates essential protective factors for individuals diagnosed with chronic kidney disease, especially those on hemodialysis. Women often face heightened challenges related to gender roles, which adversely affect their identity, quality of life, and social support.

Objective: To describe the experience of women on hemodialysis regarding family social support.

Material and Method: We conducted a descriptive, exploratory, qualitative study with 15 women on hemodialysis at a hospital in Maceió, Alagoas, Brazil. Interviews were conducted, subjected to thematic content analysis using categorical methods, and interpreted from the perspective of House's social support theory.

Results: The emerging categories show that family social support is presented in the following types: emotional, religious, instrumental, and informational. However, some interviewees reported distancing themselves from family members and individual isolation, revealing a barrier to receiving support.

Conclusion: The study shows that family social support manifests in the lives of women on hemodialysis in a variety of ways. Furthermore, it reinforces that separation from family members and individual isolation interfere with the delivery of support.

Keywords: social support; family structure; renal dialysis; women.

RESUMO

Experiência de mulheres em hemodiálise acerca do apoio social familiar

Introdução: O apoio social é definido como a assistência oferecida por outras pessoas na qual geram fatores protetivos essenciais para indivíduos diagnosticados com doença renal crônica, especialmente aqueles submetidos ao tratamento por hemodiálise. Em que pese as mulheres essas tendem a enfrentar desafios agravados considerando os papéis de gênero, impactando em sua identidade, qualidade de vida e apoio social.

Objetivo: Descrever a experiência de mulheres em hemodiálise acerca do apoio social familiar.

Material e Mètodos: Estudo descritivo, exploratório, qualitativo realizado com 15 mulheres que estavam realizando hemodiálise em um hospital de Maceió, Alagoas, Brasil. Foram realizadas entrevistas, submetidas à análise de

conteúdo temática, na modalidade categorial, e interpretadas a partir da perspectiva da teoria do apoio social de House.

Resultados: As categorias emergentes evidenciam que o apoio social familiar se apresenta nos seguintes tipos: emocional, religioso, instrumental e informacional. Contudo, algumas entrevistadas sinalizaram o afastamento de familiares e isolamento individual, revelando uma barreira na recepção de apoio.

Conclusão: O estudo evidencia que o apoio social familiar se manifesta na vida das mulheres submetidas à hemodiálise de diversas maneiras. Além disso, reforça que o afastamento de familiares e o isolamento individual interfere na concretização do apoio.

Descritores: apoio social; estrutura familiar; diálise renal; mulheres.

RESUMEN

Experiencias de mujeres en hemodiálisis respecto al apoyo social familiar

Introducción: El apoyo social se define como la asistencia ofrecida por otras personas, lo que genera factores de protección esenciales para las personas diagnosticadas con enfermedad renal crónica, especialmente aquellas en hemodiálisis. Las mujeres a menudo enfrentan mayores desafíos relacionados con los roles de género, lo que afecta negativamente su identidad, calidad de vida y apoyo social.

Objetivo: Describir la experiencia de las mujeres en hemodiálisis con respecto al apoyo social familiar.

Material y Método: Realizamos un estudio descriptivo, exploratorio y cualitativo con 15 mujeres en hemodiálisis en un hospital de Maceió, Alagoas, Brasil. Se realizaron entrevistas, se sometieron a análisis de contenido temático mediante métodos categóricos y se interpretaron desde la perspectiva de la teoría del apoyo social de House.

Resultados: Las categorías emergentes muestran que el apoyo social familiar se presenta en los siguientes tipos: emocional, religioso, instrumental e informativo. Sin embargo, algunas entrevistadas informaron distanciamiento de los miembros de la familia y aislamiento individual, lo que revela una barrera para recibir apoyo.

Conclusión: El estudio muestra que el apoyo social familiar se manifiesta en la vida de las mujeres en hemodiálisis de diversas maneras. Además, refuerza que la separación de los miembros de la familia y el aislamiento individual interfieren en la prestación de apoyo.

Palabras clave: apoyo social; estructura familiar; diálisis renal; mujeres.

INTRODUCTION

Social support is recognised as an important resource for individuals' health and well-being, especially for those living with long-term conditions, such as chronic kidney disease. It plays an essential role in mitigating the psychological impacts imposed by the illness, promoting resilience and mediating situations of stress and adversity[1].

According to House[2], social support can be understood as the assistance provided by others, involving expressions of empathy, affection, trust, concern, comfort, financial, instrumental, and informational assistance, as well as constructive feedback, helping individuals to self-evaluate and understand their behaviours and experiences. These elements are considered protective for patients with chronic kidney disease, particularly for those whose treatment requires haemodialysis, which imposes a series of challenges[3].

Haemodialysis aims to filter the blood through an extracorporeal circuit to remove uraemic (toxic) substances and excess fluid. It is the most common form of renal replacement therapy worldwide, accounting for approximately 69% of all renal replacement therapies and 89% of all dialysis treatments[4].

Despite its benefits, this therapy requires numerous adaptations, which may trigger physical, psychological, and social repercussions. Among the contextual changes are the demanding routine of haemodialysis sessions, transportation requirements, dietary and fluid restrictions, medication use, vascular access care, medical tests and periodic consultations, as well as frequent clinical changes[3]. All these factors are considered stressors and may negatively affect patients, leading to mood changes, depressive and anxiety disorders, and reduced quality of life[3].

The experience of women on haemodialysis is considered particularly complex, given the social and family roles often attributed to them. Restrictions on daily activities and reductions in productive and personal life may result in feelings of guilt, loss of identity, and decreased quality of life[5], highlighting the importance of understanding their experiences and social support needs.

Within this context, the following question arises: *How do women undergoing haemodialysis experience family social support?* Therefore, this study aims to describe the experience of women receiving haemodialysis regarding family social support, using House's Social Support Theory[2] as its theoretical framework. Understanding these experiences may provide valuable insights for implementing care strategies that address the specific needs of this group, promoting a more holistic and effective approach to chronic kidney disease management.

MATERIAL AND METHOD

We conducted a descriptive, exploratory, qualitative study in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ), ensuring methodological rigour at all stages. The study was carried out with women undergoing haemodialysis at a hospital within the complementary healthcare network (private) that also provides care for users of Brazil's Unified Health System (SUS), located in the city of Maceió, Alagoas, Brazil.

Initial contact with participants was established after authorisation from hospital administrators, approval by the research ethics committee, and subsequent researcher insertion into the field. Inclusion criteria were: being female, undergoing haemodialysis for more than six months, and possessing adequate cognitive and psychological conditions to participate. Women who initially agreed but could not be reached after 3 interview attempts were excluded.

Convenience sampling was adopted. Twenty-two women meeting the inclusion criteria were invited to participate and were informed about the study objectives, importance, and ethical guarantees. Two declined participation. Interviews were scheduled with the remaining participants at times of their choosing. Subsequently, five women were excluded after three unsuccessful interview attempts, resulting in a final sample of 15 participants.

Data collection occurred between August and September 2024. Interviews were conducted individually in a private space provided by the healthcare institution and led by the principal investigator, a nurse with a PhD in nursing and extensive experience in qualitative research, accompanied by two undergraduate nursing students who assisted with organisational tasks such as scheduling and preparing the interview setting. Neither the researcher nor the students had prior relationships with the participants. The relationship was established during initial contact. During each meeting, the Free and Informed Consent Form was read and signed before the interviews began.

Semi-structured interviews were conducted using a guide addressing participant characteristics (age, education, race/ethnicity, marital status, occupation, and time since diagnosis/treatment). The guiding questions were: *"After starting your treatment, did you receive any type of social support from your family?"*, *"What type of social support have you been receiving?"*, and *"Did any family member distance themselves from you?"* No pilot study was conducted. Data collection continued until saturation was reached[6], which occurred with the twelfth interview; however, three additional interviews were conducted as these participants expressed a desire to take part. Interviews lasted approximately 40 minutes, were audio-recorded, transcribed verbatim using Microsoft Word, reviewed, and validated by the participants prior to analysis.

Data systematisation followed Bardin's thematic categorical content analysis framework[7]. The principal investigator and nursing students conducted the pre-analysis by organising the textual corpus through individual and collective floating readings. During the material exploration phase, meaningful units were identified and coded. Category grouping was supported using NVivo 12 qualitative analysis software, enabling more in-depth data exploration[8]. This stage was also carried out collaboratively to ensure shared understanding of category meanings.

Finally, data interpretation was guided by House's Social Support Theory[2], which identifies different sources of social support, including family and friends, and distinguishes emotional, religious, instrumental, informational, and appraisal support[2].

The study was approved by the Research Ethics Committee of the Maurício de Nassau University Centre in Maceió, Alagoas (Opinion No. 6.972.420), in accordance with Resolution No. 510/16 of Brazil's National Health Council. To ensure anonymity, alphanumeric codes were assigned: "E" for "Interviewee," followed by interview order numbers.

RESULTS

Fifteen women on haemodialysis at the study hospital participated in the research. Table 1 presents the participants' profile, describing age, educational level, self-declared race/ethnicity, marital status, occupation, and time since diagnosis.

The participants' statements were grouped into thematic categories, created inductively and anchored in the theoretical framework, expressing the meanings attributed to the object of study. Thus, 2 categories and six subcategories emerged, as shown in **table 2.**

The participants' accounts revealed that the family plays a fundamental role in coping with haemodialysis, offering different types of support that directly affect the women's physical and emotional well-being. This support is manifested in a multifaceted way, encompassing emotional, religious, instrumental, and informational dimensions, as described below.

SOCIAL SUPPORT PROVIDED BY THE FAMILY TO WOMEN UNDERGOING HAEMODIALYSIS

Emotional Support

The participants reported that when family members notice signs of sadness, they usually offer emotional support through constant presence. This support is expressed through increased visits, especially from children and grandchildren, and encouragement to go out, thereby fostering positive feelings.

Table 1. Profile of the women interviewed in the study.

PARTICIPANT	AGE	EDUCATION	RACE/COLOUR	MARITAL STATUS	OCCUPATION	TIME SINCE DIAGNOSIS (YEARS)
E1	29	Incomplete Secondary	Mixed race	Single	Unem-ployed	2
E2	39	Complete Secondary	Black	Single	Unem-ployed	3
E3	42	Incomplete Primary	Mixed race	Married	Homemaker	5
E4	82	Incomplete Primary	Black	Widowed	Retired	3
E5	37	Incomplete Primary	Mixed race	Single	Retired	3
E6	62	Incomplete Primary	Black	Married	Retired	5
E7	59	Incomplete Primary	Black	Married	Retired	4
E8	60	Incomplete Primary	Mixed race	Single	Retired	4
E9	54	Complete Secondary	Black	Married	Retired	5
E10	35	Complete Secondary	Mixed race	Single	Retired	5
E11	43	Incomplete Primary	Mixed race	Single	Homemaker	3
E12	66	Incomplete Primary	Mixed race	Divorced	Retired	4
E13	23	Complete Secondary	Black	Single	Unem-ployed	2
E14	62	Incomplete Primary	Mixed race	Single	Retired	4
E15	54	Incomplete Primary	Mixed race	Married	Retired	5

Source: Prepared by the authors (2025).

Table 2. Synthesis of the categories and subcategories according to the theoretical framework.

THEMATIC CATEGORIES	SUBCATEGORIES
SOCIAL SUPPORT PROVIDED BY THE FAMILY TO WOMEN ON HAEMODIALYSIS	EMOTIONAL
	RELIGIOUS
	INSTRUMENTAL
	INFORMATIONAL
BARRIERS TO THE PROVISION OF SOCIAL SUPPORT BY THE FAMILY TO WOMEN ON HAEMODIALYSIS	WITHDRAWAL OF RELATIVES
	INDIVIDUAL ISOLATION

Source: Prepared by the authors (2025).

"They (family members) are always on alert […] when they realise I am sad they do everything they can to motivate and cheer me up. They visit me, take me out for walks and distract my mind […] they say I will be cured." (E2/SF)

"My children give me a lot of affection, they support me emotionally […] when they realise I am sad, they always come close, they do not leave me alone." (E6/SF)

"When my children and grandchildren come to my house it is a joy […] I feel very happy. I forget that I am ill and I am rarely sad. I feel welcomed." (E7/SF)

"After I was diagnosed and started treatment (dialysis), my family has always been present, taking care of me […] giving me support in every way […] that is why I am alive." (E3/SF)

Religious Support

Religious support provided by family members was also reported. This emerges through encouragement for women to attend religious institutions and to engage in prayer in the search for healing.

"They encourage me to pray […] they say they are always asking God to cure me." (E2/SF)

"My son and my husband are always praying for me […] they take me to church so that I can seek God."(E12/SF)

Instrumental Support

Although most women receive a fixed income from retirement benefits, this income is often insufficient to cover food, medication, and transportation costs. Thus, instrumental family support was evidenced through financial assistance.

"Even though I am retired and have my own income, after I was diagnosed it became harder to support myself financially because of medication and transport costs […] my children help me, they give me money every month to supplement my income." (E8/SF)

"Sometimes, when I ask, they give me some money so I can buy food and medicine […] the pension I receive is too little for so many expenses." (E4/SF)

Informational Support

Participants reported that their families demonstrate concern and vigilance regarding food and fluid intake, which characterises informational support. This support is provided through dietary counselling, preparation of meals according to restrictions, and monitoring fluid intake. However, some women admitted not following the restrictions, believing they would die because of the disease.

"They (family members) worry a lot about me, about everything I do [...] especially about food and water consumption. They are always warning me because I eat everything and do not follow the diet. I say I will eat because I am going to die." (E12/SF)

"After my disease was discovered, my family became very concerned about my diet [...] they tell me not to eat very salty foods and to avoid drinking too much water [...] my daughter prepares my lunch controlling the seasoning and monitors everything I drink." (E1/SF)

Despite the positive aspects, barriers to social support also emerged, particularly family distancing and self-imposed isolation among some women. These situations reveal fragility in family support, generating feelings of disappointment and loneliness.

BARRIERS TO FAMILY SOCIAL SUPPORT FOR WOMEN UNDERGOING HAEMODIALYSIS

Family Distancing

The absence of social support was reported through the distancing of relatives who had previously been close, visited frequently, and engaged in leisure activities together. This distancing generated feelings of disappointment.

"Some relatives who were always at my house moved away after my disease was discovered [...] I was very disappointed, because I thought they would be with me not only in good times, but also in bad times." (E1/SF)

"I never received their support [...] now it seems they have moved even further away." (E9/SF)

"Before the illness we got along well, we were always together, went out to bars and restaurants [...] after the diagnosis they moved away. Today they no longer come to my house [...] I can only count on my husband and my daughter." (E5/SF)

Self-Imposed Isolation

The narratives reveal that due to embarrassment about oedema and catheters, and exhaustion from the treatment routine, the women refuse visits from relatives, preferring to remain isolated at home. The statements also show fear of disrupting family routines because of their health condition.

"My relationship with my family has changed a lot. Before becoming ill, I used to visit friends and family [...] after I was diagnosed and started treatment (haemodialysis) I do not like going out or receiving visits, I prefer to stay isolated [...] I am ashamed of the swelling and the catheter, and I feel very tired [...] I prefer to stay at home watching TV." (E10/SF)

"I distanced myself from all of them (family) [...] I said I did not want to receive anyone, that I wanted to be alone. I do not want anyone to change their routine because of me. Besides, I am ashamed to go out with my swollen face and legs." (E14/SF)

DISCUSSION

The narratives of women on haemodialysis reveal that family emotional support is primarily manifested through the frequent presence of children and grandchildren in their homes. Companionship and the involvement of family members in coping with chronic illness are widely recognised in the literature as beneficial to the maintenance of patients' physical and mental health. Emotional support provided by relatives within the home is understood as a subjective expression of awareness regarding the severity of both the illness and its treatment. Such understanding encourages the expression of affection and care through words conveying hope and healing, thereby contributing substantially to the preservation of patients' mental health[9].

From a psychological perspective, the presence of family members in shared environments contributes to emotional regulation and serves as a protective distraction from negative thoughts that may emerge. The scientific literature indicates that women, regardless of health status, are more susceptible to mental health disorders, particularly affective disorders, a vulnerability that may be significantly exacerbated by chronic illness and aggressive treatments[10].

Living with chronic kidney disease (CKD) and undergoing haemodialysis may generate a wide range of mental health problems, particularly depression. A study conducted in Jordan involving 66 patients on haemodialysis aimed at measuring the prevalence of depression, anxiety, and quality of life found that women undergoing haemodialysis had significantly higher depression scores (mean=6. ±3.77) compared with men (mean=2.9±2.8)[11]. A similar study in the province of Córdoba, Spain, showed that 27.9% of 186 patients presented depressive disorders[12]. In this context, family emotional support strengthens well-being, promotes subjective relief, reduces feelings of loneliness, and enhances resilience in the face of adversity[2], thus fulfilling a protective and therapeutic role[13].

The process of coping with illness through adherence to treatment is further reinforced when the religious dimension is present. This aspect emerged in participants' accounts as a form of family support, particularly expressed through encouragement to attend religious institutions and seek spirituality and closeness to the divine through prayers. This type of support integrates with emotional care by

transcending physical assistance and incorporating affective and spiritual elements essential to psychological well-being[2].

Family social support expressed through religiosity functions as a strengthening mechanism for coping with the adversities imposed by chronic illness. This perspective is corroborated by a qualitative study conducted with 18 women on haemodialysis in two public hospitals in Central–Western Brazil, which highlighted that spiritual support provided by family members improves patients' mental health and quality of life[14]. In this sense, such support plays a significant role in fostering hope and sustaining the strength necessary for survival.

Beyond the elements already described, the participants' narratives revealed that family social support also manifested in an instrumental form, through financial assistance for medications, food, and transportation. A large proportion of individuals with CKD undergoing haemodialysis experience financial toxicity, defined as the harmful impact resulting from the inability to afford additional expenses related not only to healthcare but also to family and social needs[15]. This context is particularly aggravated when patients lack a stable income, as occurs among some women engaged in informal employment or entirely financially dependent on their partners.

Of note, in cases of disease progression requiring permanent medical care that precludes employment, Brazilian legislation provides for disability retirement benefits[16]. However, even with this or other forms of assistance, maintaining adequate nutrition, paying household expenses, transportation costs, and purchasing medications becomes difficult due to the low monthly minimum wage[17]. A systematic review exploring financial hardship and its relationship with symptom burden in dialysis patients found across 57 studies that financial toxicity is associated with difficulties in sustaining treatment and meeting basic needs such as food and housing, as well as increased incidence of anxiety, depression, sleep disorders, clinical deterioration, and higher hospitalisation rates[18].

Therefore, financial assistance provided by family members significantly reduces economic stress, improves access to necessary resources for individual and collective care, and positively influences clinical outcomes and overall well-being. Instrumental support is identified by House[2] as vital to preserving core aspects of social care, directly influencing survival and quality of life among individuals with chronic illness. This form of family support is often decisive in ensuring treatment adherence, particularly for patients in socioeconomically vulnerable conditions[19].

In addition to financial assistance, family members demonstrated concern by monitoring participants' food and fluid intake, thereby expressing informational support. Several dietary restrictions, such as reduced phosphorus and sodium intake, are imposed on individuals undergoing haemodialysis to optimise clinical outcomes[20]. However, many patients struggle to modify dietary habits due to cultural practices, physical symptoms, and excessive personal choices[21]. Failure to implement these changes increases the risk of complications such as fluid overload, symptom worsening, and reduced quality of life, often necessitating family involvement.

Within this context, family members exercise instrumental support through direct care practices such as preparing adapted meals, controlling fluid intake in accordance with dietary requirements, and providing health-related counselling[2]. They thus assume two strategic roles in maintaining patient health: as educators, transmitting information to encourage behavioural change, and as monitors, closely observing patients' needs and adaptations[22].

National and international evidence highlights the relevance of family involvement in the care of dialysis patients. In Brazil, studies show that family participation in dietary control is one of the most common forms of instrumental support, facilitating adherence to dietary restrictions and improving clinical conditions[19]. Internationally, family monitoring of food and fluid intake is also recognised as essential, particularly when patients have difficulty understanding and following nutritional guidance[23]. Such involvement, motivated by concern and affection, reinforces the family's role as mediator between professional recommendations and everyday practice, contributing significantly to healthy habit formation, treatment adherence, and quality of life.

Despite the presence and importance of emotional, religious, instrumental, and informational support, some participants reported the distancing of relatives who had previously been actively involved in their social lives, revealing fragility or absence of support following the onset of illness. It is common for patients facing complex diagnoses and treatments such as haemodialysis to experience negative impacts on family relationships, often marked by tension, misunderstanding, and emotional insensitivity[24]. This scenario generates stressful experiences that may promote emotional and physical distancing, leading to natural separation.

Family distancing may be understood as a failure of social support, particularly when previously reliable social networks become indifferent or absent. This experience fosters feelings of abandonment, exclusion, and disappointment, negatively affecting both illness experience and emotional state[25]. A qualitative study in Zhengzhou, China, involving 12 haemodialysis patients found that prolonged illness and treatment often lead to a reorganisation of social relationships, frequently characterised by withdrawal from family and friends, thereby increasing the risk of social isolation and exacerbating anxiety and depression[26].

It is important to recognise that family social support is not confined to favourable moments; rather, its true value emerges most strongly during adversity. The absence or breakdown of these bonds symbolises a failure in the support network, weakening disease coping mechanisms and compromising

overall well-being. The dissolution of these ties represents not merely the loss of companionship but the disruption of a vital psychological resource. Experiencing the collapse of relationships during periods of greatest vulnerability underscores the importance of sustained social support and the cultivation of enduring, compassionate bonds[27].

Self-imposed isolation driven by shame, insecurity regarding body image, and physical exhaustion was also reported as a factor distancing participants from their families. Participants expressed a desire not to burden relatives due to their health condition, stating that they did not wish their family members to alter their routines to accommodate them. Refusal of visits and reluctance to "disturb" others reflect a protective behaviour in which individuals attempt to preserve family normality, even at the expense of their own psychological suffering[26].

Although often silent, this reality constitutes a significant barrier to receiving social support, as conceptualised by House[2]. When patients voluntarily isolate themselves, the opportunity to receive and even recognise family social support is interrupted. Self-withdrawal reflects psychological responses to vulnerability, low self-esteem, and bodily stigma resulting from invasive or visible procedures such as haemodialysis catheters or oedema, particularly among female patients.

A qualitative study involving renal patients demonstrated that perceived bodily changes directly affect social interactions, leading to voluntary withdrawal from contact with friends and family[28]. Such factors promote self-censorship and social avoidance, undermining emotional well-being and the maintenance of affective bonds[1]. Consequently, psycho-emotional interventions should encourage family interaction to preserve social support and enhance coping.

In conclusion, this study demonstrated that family social support for women undergoing haemodialysis manifests in emotional, religious, instrumental, and informational forms. Nonetheless, family distancing and social isolation were also reported by some participants. Understanding the nature of family support is fundamental to improving treatment adherence and quality of life. Therefore, psychosocial and emotional support should be provided and strengthened within healthcare services for both patients and their families, employing therapeutic and educational strategies that foster self-esteem and social belonging.

Health care professionals must remain attentive to signs of weakened family support and intervene promptly, recognising the profound psychological consequences that may affect treatment outcomes. In addition to clinical indicators, behavioural characteristics should be carefully observed to identify insufficient family social support.

This study was limited to women's experiences due to difficulties in recruiting male participants, which may have restricted the breadth of perspectives. Furthermore, although the findings elucidate the types of family support and associated challenges, the small sample size precludes generalisation, though this is not an objective of qualitative research.

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Conflicts of interest

None declared.

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