

PERCEPTION OF OLDER ADULT WOMEN WITH CHRONIC KIDNEY DISEASE ABOUT THEIR EXPERIENCES AND SOCIAL SUPPORT NETWORKS

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ABSTRACT

Objective: to investigate the perception of older women with chronic kidney disease regarding their experiences and social support networks.

Method: A descriptive qualitative study was conducted with 21 older women undergoing conservative treatment for CKD, followed at an outpatient clinic. Data were collected through individual interviews using a semi-structured questionnaire comprising three parts: sociodemographic and economic information; the guiding question “What is it like to live with chronic kidney disease?”; and the question “What is your support network like?” The interviews were recorded, transcribed, and analyzed using the Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires software, through Descending Hierarchical Classification and similarity analysis. The study was approved by a Research Ethics Committee.

Results: The participants had low levels of education and income and reported feelings of resignation, emotional instability, and difficulty adapting to the restrictions imposed by the disease. The support network revealed contrasts between loneliness, lack of support, and the presence of family support marked by dependence. The statements showed that a negative perception of the disease affects the capacity to live with well-being and quality of life.

Conclusion: The study uncovers the challenges experienced by older women with CKD undergoing conservative treatment and contributes to improving self-care by providing input for the (re)formulation of health education strategies targeting this population.

DESCRIPTORS: Perception. Women. Older adults. Chronic kidney disease. Social support.

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PERCEPÇÃO DE MULHERES IDOSAS COM DOENÇA RENAL CRÔNICA SOBRE SUAS VIVÊNCIAS E REDES DE APOIO SOCIAL

RESUMO

Objetivo: desvelar a percepção de mulheres idosas com Doença Renal Crônica sobre suas vivências e redes de apoio social.

Método: Estudo qualitativo descritivo realizado com 21 mulheres idosas em tratamento conservador para DRC, atendidas em ambulatório. Os dados foram coletados por meio de entrevistas individuais, utilizando um questionário semiestruturado composto por três partes: informações sociodemográficas e econômicas; a questão norteadora “Como é viver com a Doença Renal Crônica?”; e a questão “Como é sua rede de apoio?”. As entrevistas foram gravadas, transcritas e analisadas no software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*, por meio da Classificação Hierárquica Descendente e da análise de similitude. O estudo foi aprovado por Comitê de Ética em Pesquisa.

Resultados: As participantes apresentaram baixa escolaridade e renda, e relataram sentimentos de conformismo, instabilidade emocional e dificuldade de adaptação diante das restrições impostas pela doença. A rede de apoio revelou contrastes entre solidão, falta de suporte e presença de apoio familiar permeado pela dependência. As falas evidenciaram que a percepção negativa da doença influencia a capacidade de viver com bem-estar e qualidade de vida.

Conclusão: O estudo desvela os desafios vivenciados por mulheres idosas com DRC em tratamento conservador e contribui para a melhoria do autocuidado, oferecendo subsídios à (re)formulação de estratégias de educação em saúde voltadas a esse público.

DESCRIPTORIOS: Percepção. Mulheres. Pessoa idosa. Doença renal crônica. Apoio social.

PERCEPCIÓN DE MUJERES MAYORES CON ENFERMEDAD RENAL CRÓNICA SOBRE SUS VIVENCIAS Y REDES DE APOYO SOCIAL

RESUMEN

Objetivo: revelar la percepción de mujeres mayores con Enfermedad Renal Crónica sobre sus vivencias y redes de apoyo social.

Método: Estudio cualitativo descriptivo realizado con 21 mujeres mayores en tratamiento conservador para ERC, atendidas en consulta externa. Los datos fueron recolectados mediante entrevistas individuales, utilizando un cuestionario semiestructurado compuesto por tres partes: información sociodemográfica y económica; la pregunta orientadora “¿Cómo es vivir con la Enfermedad Renal Crónica?”; y la pregunta “¿Cómo es su red de apoyo?”. Las entrevistas fueron grabadas, transcritas y analizadas en el software *Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*, mediante la Clasificación Jerárquica Descendente y el análisis de similitud. El estudio fue aprobado por un Comité de Ética en Investigación.

Resultados: Las participantes presentaron bajo nivel de escolaridad e ingresos, y reportaron sentimientos de conformismo, inestabilidad emocional y dificultad de adaptación frente a las restricciones impuestas por la enfermedad. La red de apoyo reveló contrastes entre la soledad, la falta de soporte y la presencia de apoyo familiar permeado por la dependencia. Los testimonios evidenciaron que la percepción negativa de la enfermedad influye en la capacidad de vivir con bienestar y calidad de vida.

Conclusión: El estudio revela los desafíos experimentados por mujeres mayores con ERC en tratamiento conservador y contribuye a la mejora del autocuidado, ofreciendo insumos para la (re)formulación de estrategias de educación en salud dirigidas a este público.

DESCRIPTORIOS: Percepción. Mujeres. Persona mayor. Enfermedad renal crónica. Apoyo social.

INTRODUCTION

Chronic kidney disease (CKD) is characterized by the presence of structural or functional damage to the kidneys, or by a reduction in the glomerular filtration rate for a period of three months or longer, regardless of cause. It is a serious public health problem affecting millions of people worldwide, with a negative impact on quality of life and high costs associated with treatment and hospitalization¹.

Advanced-stage CKD is more common among women beyond reproductive age. It is estimated that 195 million women worldwide have some degree of the disease, with evident inequality in access to appropriate treatment. Among older women, notable challenges include difficulty with early diagnosis and the absence of systematic screening in primary healthcare services, particularly among those with arterial hypertension and diabetes mellitus, the main conditions associated with CKD development^{2,3,4}.

The scientific literature focuses primarily on studies of the dialytic phase and women of reproductive age^{1,2,5,6}, with limited research on conservative treatment in older women in the Brazilian context⁶. Conservative treatment encompasses clinical interventions, medication use, dietary modifications, and lifestyle changes, intending to slow disease progression, reduce symptoms, and prevent complications. Although CKD is progressive and irreversible, its course can be slowed or stabilized with this treatment, promoting survival and quality of life in patients⁷.

During conservative treatment, individuals experience significant changes in their daily lives and require support from a multidisciplinary team to meet their biopsychosocial needs. Given the limiting nature of the condition, resistance to accepting the diagnosis is common, which can trigger negative emotional experiences and compromise quality of life, making family and emotional support indispensable⁸.

Qualified listening and a close relationship between healthcare providers and patients are essential for understanding the illness process and fostering therapeutic bonds. It is the nurse's responsibility to identify, understand, and contextualize the feelings expressed by patients, in order to promote coping and the development of self-care^{9,10}. In this context, nurses play an essential role in promoting autonomy and treatment adherence by providing explanations about the disease and guidance for conservative management, encouraging the active participation of older women.

Experiences related to CKD are deeply connected to the social support network, which influences both coping and adherence to therapeutic guidelines. Family, emotional, and community support contribute to reframing the illness experience and strengthening the capacity to live with a better quality of life¹¹.

Given the above, it is important to broaden the perspective beyond renal function, valuing comprehensive care, the strengthening of self-care, and the social support network as essential dimensions of care for older women with CKD. This perspective aligns with Sustainable Development Goal (SDG) 3, Health and Well-Being, which proposes ensuring a healthy life and promoting well-being for all, at all ages. Accordingly, this study aimed to uncover the perception of older women with chronic kidney disease regarding their experiences and social support networks.

METHOD

This is a descriptive, exploratory study using a qualitative method¹² guided by the Consolidated criteria for reporting qualitative research (COREQ)¹³. It was conducted at a Nephrology outpatient clinic belonging to a public referral hospital for conservative treatment, hemodialysis, and renal transplantation, located in the city of Recife (PE), Brazil. The service is affiliated with the Unified Health System (SUS) and offers outpatient consultations, inpatient care in a Nephrology ward, and services in a dialysis unit. The multidisciplinary team consists of nephrologists, nurses, and nursing technicians, with the support of a nutritionist and a social worker, as well as residents in the areas

of physiotherapy, pharmacy, occupational therapy, and nursing. The outpatient clinic conducts an average of 30 consultations per day, Monday through Friday.

Data collection took place between January and July 2023. Initially, the researcher conducted an immersion period in the field, establishing contact with the outpatient clinic coordinator and staff in order to present the project, request support, and identify potential participants. Subsequently, a pilot test was conducted with nine older women, which facilitated familiarization with the setting, observation of the service routine, and the necessary adjustments to the data collection instrument.

The target population consisted of 21 older women with chronic kidney disease undergoing conservative treatment, seen on an outpatient basis and selected by convenience on the day of their appointment with the nephrologist. Inclusion criteria were: being a woman aged 60 years of age or older with a diagnosis of CKD undergoing conservative treatment. Older women with a documented diagnosis of dementia were excluded.

Data collection was conducted by a nurse researcher, a doctoral candidate in Nursing, with a master's degree in Gerontology and experience in CKD research. It should be noted that the researcher had no professional affiliation with the study setting.

Individual interviews took place in a private room within the outpatient clinic itself, with an average duration of 30 minutes, and were audio-recorded with participants' consent. A semi-structured guide divided into three parts was used: sociodemographic and clinical data (age, self-declared ethnicity, marital status, number of children, education level, income, length of follow-up, and CKD stage), addressed descriptively; the second part explored participants' experiences with CKD, guided by the question: what is it like to live with CKD?; and the third part investigated the support network, with the question: what is your support network like? Sample size followed saturation criteria, that is, the suspension of inclusion of new participants when responses became repetitive¹⁴.

The interviews were recorded using an MP4 voice recorder and a smartphone, and were subsequently transcribed in full by the researcher herself, manually and with double-checking of the transcribed content. The participants were identified as Older Adult, followed by the order in which the interviews were conducted (Older Adult 01, Older Adult 02, ..., Older Adult 21). In addition to the interviews, a Field Diary (FD) was used to record relevant impressions and observations, contributing to analytical contextualization and consistency¹².

The transcripts were organized into a textual corpus and processed using the IRaMuTeQ software (*Interface de R pour les Analyses Multidimensionnelles de Textes et de Questionnaires*, version 0.7 alpha 2). This program enables the coding and inference of themes present in the discourses, revealing the beliefs, concepts, and explanations mobilized by the participants¹⁵.

Two analyses were used in this study: the Descending Hierarchical Classification (DHC), also called the Reinert Method, and the Similarity Analysis. The DHC was applied to the second part of the interview guide and enabled the organization of content into lexical classes formed by semantic proximity. The software generates a dendrogram illustrating the relationships between the classes. This analysis groups text segments (TSs) according to vocabulary, using reduced forms (lemmatized words), with associations considered significant when $p < 0.05$. The pre-programmed simple classification configuration on text segments was followed, using all morphological classes of the textual corpus. The corpus was considered adequate for analysis when the retention rate was equal to or greater than 75%¹⁵.

The Similarity Analysis, applied to the third part of the guide, enabled the recognition of co-occurrences between words and the identification of the connectivity structure of the corpus, using active forms (adjectives, nouns, and verbs)¹⁵. This analysis facilitated the visualization of meaning clusters and the interrelationships between terms.

Based on the results generated by the IRaMuTeQ software, thematic content analysis of a manifest nature was conducted, focusing on the critical description of the data and the identification of patterns, recurrences, and explicit meanings in the statements¹². The categorization process occurred in two ways: in the DHC, the categories were derived from the textual classes generated automatically; in the similarity analysis, they were developed from meaning clusters and lexical connections. This methodological triangulation enabled a broader interpretation of the discourses, articulating statistical results and symbolic meanings expressed by the participants.

The study was initiated after approval by the Research Ethics Committee. Participants were protected in accordance with Resolution No. 466/2012 of the National Health Council, and were identified only by their interview sequence number.

RESULTS

The 21 older women interviewed were undergoing conservative treatment for CKD and had a mean age of 69.3 years of age (SD = 4.9). The majority self-identified as non-White (71.4%), had children (95.2%), had no partner (71.4%), had an income below one minimum wage (71.4%), and had fewer than four years of schooling (66.7%). The length of follow-up at the Nephrology outpatient clinic varied, with 52.4% having been in treatment for less than five years. Regarding CKD stage, all participants were at stage IV of the disease or below.

Subsequently, an effort was made to understand the participants' experiences with CKD through the guiding question: "What is it like to live with CKD?" The interviews formed the textual corpus analyzed by Descending Hierarchical Classification (DHC), which was divided into 36 text segments (TSs), involving 379 words that occurred 1,201 times. The corpus showed an 86.11% retention rate, meeting the analytical quality criteria recommended in the literature, and yielded six content classes.

As illustrated in Figure 1, the corpus was initially divided into two sub-corpora. The left sub-corpus gave rise to Classes 1 and 6, while the right sub-corpus was subdivided, giving rise to Classes 5 and 4, as opposed to Classes 3 and 2, as shown in the figure below:

The reading and interpretation of the TSs for each class revealed strong thematic similarity between pairs (1 and 6), (5 and 4), and (3 and 2), which allowed grouping into three thematic categories:

- Feelings of resignation in the face of disease (Classes 1 and 6);
- Difficulties adapting to disease management (Classes 5 and 4);
- Emotional instability in the face of disease (Classes 3 and 2).

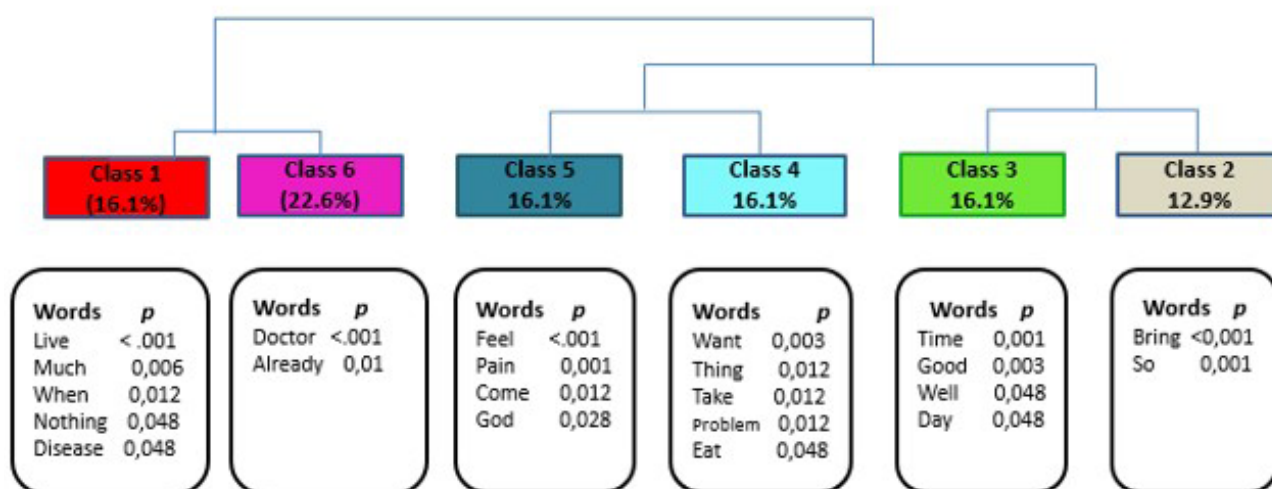


Figure 1 - Dendrogram of words distributed across six classes. Recife, Pernambuco, Brazil, 2025.

Each category expresses distinct yet interrelated dimensions of older women's experiences of living with CKD.

Category 1 – Feelings of resignation in the face of disease

This category represented 38.7% of the TSs and addresses how older women cope with the reality of living with a chronic disease, expressing processes of acceptance and adaptation. The statements reflect an attitude of resignation and conformity, in which the disease is perceived as inevitable and the focus shifts to continuing to live within the imposed limitations. The idea of “getting used to” the condition and following medical guidelines reveals a resilient approach to coping, in which acceptance replaces resistance.

living with the disease is just the way it is... (Older Adult 02)

if one could live freely it would be much better; if there's no way to live... (Older Adult 20)

you have to live; if we don't live our own lives, no one will live them for us; if you complain, nobody is going to fix anything (Older Adult 04)

I have already gotten used to it; whatever the doctor prescribes, I do... (Older Adult 16)

it's hard to do anything about it, I have gotten used to the disease, you just have to get used to it” (Older Adult 14).

The statements reveal that resignation can emerge both as an adaptive coping mechanism and as a reflection of helplessness in the face of chronicity and the absence of emotional support. Although functional, this posture may indicate submission to the limitations imposed by the disease, requiring attention from nursing professionals to foster autonomy and empowerment in care.

Category 2 – Difficulties adapting to disease management

This category corresponds to 32.2% of the TSs and describes the dietary restrictions and physical pain associated with treatment, which affect the well-being and quality of life of older women. The statements reflect frustration and emotional distress in response to the loss of dietary freedom and physical discomfort, aggravated by associated conditions such as diabetes.

it is difficult, because sometimes you want to eat something better and you cannot... (Older Adult 18)

it is very hard; I want to eat something and cannot; I want to drink beer and cannot... (Older Adult 09)

there is so much pain in my body; I do not know where it comes from, whether it is from diabetes or what it is (Older Adult 13)

These difficulties go beyond the biological aspects of CKD and reveal significant psychosocial implications that need to be recognized by healthcare providers. Sensitive listening and a receptive response to subjective demands can contribute to the development of educational strategies that strengthen coping and treatment adherence.

Category 3 – Emotional instability in the face of disease

Accounting for 29% of the TSs, this category highlights mood fluctuations and feelings of insecurity regarding CKD progression. The statements demonstrate that living with the disease involves a complex subjective experience marked by emotional distress, affective needs, and the need for support.

I get by... there are times when I feel more cheerful, there are times when I feel sadder, and so it goes... (Older Adult 16)

Support network and relational experiences


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Family support and dependence

The statements highlight the central role of the family as the primary source of support, particularly in medical follow-up and activities of daily living. The older women express gratitude and recognition for the assistance received, associating it with the maintenance of well-being and quality of life.

my daughter is good to me, even though she has her own child too, but when I go for a test or go to a doctor, she has to come with me...” (Older Adult 03)

they support me in everything; my son, he works, but he traded shifts with his friend to bring me here today (Older Adult 05)

My family helps me so much; they go up and down with me, everywhere; they help me so much... (Older Adult 11)

My daughter cooks for me; she does not let me do things around the house; I do what I can (Older Adult 14)

I have 3 children who are blessings; what would become of me without my children; they bring me to appointments, and at home they work for my benefit (Older Adult 08)

Feelings of loneliness and lack of support

On the other hand, some of the interviewees reported isolation and the absence of family support, attributed to geographic distance or relatives' work obligations. The statements reveal social and emotional vulnerability, reinforcing the importance of public policies and interprofessional practices that broaden support for these women.

My son lives far away; I am alone; I have family, I have a lot of family, but they say they cannot help (Older Adult 13)

the doctor said that I should already have someone to take care of me, that I was not supposed to do anything, but I have to do things myself; my daughters-in-law all work, they cannot manage it, and neither can my daughter (Older Adult 12)

my family's support is each person in their own place; they know I have a kidney problem, that I have only one kidney.... I even have a son who is hospitalized, and the other one lives in São Paulo. (Older Adult 07)

DISCUSSION

The study participants, characterized by low levels of education and income, experience CKD marked by feelings of resignation, emotional instability, and difficulties adapting to the restrictions imposed by the condition. Their statements reveal a strong dependence on family support, which at times contrasts with experiences of loneliness and helplessness. This ambivalence suggests that a negative perception of the disease can directly compromise the capacity to live with well-being and quality of life.

Low levels of education and income are common characteristics in the older population with CKD and are considered factors that predispose individuals to developing the disease, reflecting precarious and less accessible educational and health conditions¹⁶. This context limits the lives of people with CKD, since difficulty understanding health information, restricted access to prevention services, and barriers to adopting self-care practices make it even more challenging to manage the demands of treatment in daily life.

Although older women express resignation in the face of the disease, they recognize the importance of treatment, revealing a dichotomy in their perception of CKD: treatment is perceived as uncomfortable and unpleasant, yet necessary to sustain life. Research on the experiences of people with CKD indicates that, in response to physical, social, and emotional losses, many patients develop a posture of resignation. Although such resignation may function as an adaptive mechanism, it is frequently associated with low mood, apathy, and reduced motivation for self-care, compromising treatment adherence. Moreover, a negative perception of the disease contributes to depressive symptoms and a limited perspective on the future, reinforcing the need for interventions that encourage the reinterpretation of the illness experience and promote the development of more adaptive cognitive strategies. These strategies can transform resignation into critical acceptance, resulting in improved quality of life. Despite the challenges, patients may be able to reframe the process over time, learning new ways to live^{17,18}.

One of the experiences reported by the participants in this study was difficulty adapting to treatment, which is consistent with earlier research¹⁹ pointing to similar challenges from the outset of therapy. Among the main challenges, the burden of daily symptoms resulting from compromised renal function stands out, including pain, fatigue, loss of appetite, constant worry, and depressive symptoms. Despite these hardships, the participants recognized that adherence to dietary restrictions and limits on fluid intake was essential for controlling the disease, representing an important step toward adopting more effective coping strategies¹⁹.

Emotional instability also stood out in the participants' statements, presenting emotional distress permeated by mood fluctuations that interfere with physical, psychological, and social well-being. The emotional instability of the participants reveals how CKD affects not only psychological functioning but also physical and social well-being. Mood swings, anguish, and anxiety compromise therapeutic adherence and quality of life, confirming the need for comprehensive and interdisciplinary care. Recognition of this distress highlights the importance of mental health promotion strategies that strengthen the resilience and support network of older women undergoing conservative treatment²⁰.

The discovery of a CKD diagnosis is a moment pervaded by representations grounded in experiences of loss and uncertainty about the future. Negative feelings and an image of suffering typically surround this disease, shaped by despair, fear, and the prospect of death; the uncertainty about the future, fear, and panic intensify, causing the person to perceive CKD as a barrier to the process of living²¹. In this context, the discovery of the diagnosis not only triggers feelings of fear and uncertainty but also underscores the relevance of the emotional dimension, whose sharing and monitoring remain poorly explored in clinical practice. Patients' emotions and sense of well-being may vary over time, with anxiety and depression being common. It is therefore essential that healthcare providers monitor and interpret these emotional instabilities together with family members^{18,22}.

Reports about the support network reveal diverse experiences, highlighting the importance of family support for the quality of life of older women. Women who receive frequent assistance demonstrate gratitude and better adaptation to their health conditions, while those who face the absence of support reveal the need for public policies and support networks that ensure a dignified and safe life. The analysis of these reports points to the need for close attention to the living conditions of older women, considering both the support received and its absence, promoting autonomy and well-being through an integrated approach involving family and community.

Support networks assist in meeting basic needs such as food preparation, medication management, and transportation to appointments, as well as providing emotional support, which is essential given the mental burden associated with CKD. As the disease progresses, the intensity of required care increases. Studies indicate that older adults with CKD perceive less family support than their healthy counterparts, exhibiting higher levels of depression and anxiety. Although family support

may reduce fears and feelings of guilt, it can also intensify negative experiences, demonstrating that support is not uniformly beneficial. Strategies that balance receptiveness and encouragement of autonomy are essential to ensure that family assistance does not become a source of distress^{11,23}.

Given the ambiguities of family support, the role of healthcare providers becomes even more relevant, as they offer qualified care and guidance that balance support with the preservation of patient autonomy. During conservative treatment, nurses play a fundamental role in this care by acting as a balancing point in decision-making, providing information about the disease, and guiding patients on the possibility of initiating renal replacement therapy²⁴. Follow-up enables pre-dialysis education, which demystifies the disease and provides information on available treatments, allowing patients to make the best choice of method in line with their lifestyle, provided there are no clinical or social contraindications^{9,25}.

Data collection, conducted through interviews, may have been influenced by memory limitations or by participants' discomfort in reporting aspects related to their experiences with the disease. Despite these potential limitations, the study provides significant contributions to the understanding of the experiences and support networks of older women with CKD. Furthermore, the depth of the findings can be applied to other individuals facing similar situations of chronic illness, offering relevant insights into care practices and support strategies.

CONCLUSION

The study found that, for older women, living with CKD is challenging and gives rise to feelings of resignation, emotional instability, and difficulties adapting to the disease. Regarding the support network, it revealed feelings of dependence, lack of support, and loneliness.

By uncovering the experiences and support networks of older women with CKD undergoing conservative treatment, this study contributes to improving healthcare for these individuals, providing input for the reassessment of health education strategies.

The need for further studies on the experiences and support networks of older women with CKD is emphasized, as the problem requires interventions, particularly because many patients remain in treatment for many years. A holistic and individualized view of this population, along with specialized multidisciplinary follow-up based on attentive and qualified listening, is therefore considered essential.

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NOTES

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CONFLICT OF INTEREST

The authors declare there are no conflicts of interest.

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Research data is available upon request to the corresponding author.

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