Arancibia-Gajardo C, et al. https://doi.org/10.37551/S2254-28842024016

Nursing care of the patient with chronic kidney disease in primary health care

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Please cite this artcle in press as:
Arancibia-Gajardo C, González-Vargas A. Nursing care of the patient with chronic kidney disease in primary health care. Enferm Nefrol. 2024;27(3):128-35

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Reception: 04-11-24
Acceptance: 04-25-24
Publication: 06-30-24

ABSTRACT

Introduction: Advanced chronic kidney disease is a significant public health problem; it reduces the life expectancy and quality of life of those who suffer from it, affects many people, and represents a burden for the health system.
Nurses, in their role as educators, must carry out actions to prevent the disease. It is interesting to learn about their experiences in the care of renal patients in primary health care, as this is where the progression of the disease is prevented.

Objective: To describe the experience of nursing professionals in primary health care in the care of patients with chronic kidney disease.

Materials and Method: Qualitative study, with a sample of 10 nurses working in different primary health care centres in Copiapó (Chile). A semi-structured interview and data analysis were conducted using open coding in the Atlas Ti program.

Results: Four categories emerged: factors related to quality of care, nursing care management, multidisciplinary care, and conditioning elements for nursing care. Significant limitations for the care of the renal patient were evidenced: lack of time and specific consultations for follow-up, limited professional training in the subject, and socio-economic factors of the patient that influence care.

Conclusions: Including specific care for renal patients in primary care and training nurses are essential tools for improving the care of patients with advanced chronic kidney disease.

Keywords: nursing; nursing care; CKD; quality of life and primary health care.

RESUMEN

Cuidado de enfermería del paciente con enfermedad renal crónica en atención primaria de salud

Introducción: La enfermedad renal crónica avanzada es un importante problema de salud pública, disminuye las expectativas y calidad de vida de quienes lo padecen, afecta gran número de personas y representa una carga para el sistema sanitario.
Los enfermeros, en su rol educador, deben realizar acciones de prevención de la enfermedad, resultando interesante conocer sus experiencias en el cuidado de los pacientes renales en atención primaria de salud, siendo aquí donde se hace prevención del avance de la enfermedad.

Objetivo: Describir la experiencia vivida por los profesionales de enfermería en el cuidado de pacientes con enfermedad renal crónica en atención primaria de salud.

Material y Método: Estudio cualitativo, cuya muestra fue de 10 enfermeros que trabajaban en distintos centros de atención primaria de Copiapó (Chile). Se realizó una entrevista semiestructurada y análisis de datos mediante codificación abierta en el programa Atlas Ti.

Resultados: Surgieron 4 categorías: factores relacionados con la calidad de la atención, gestión del cuidado de enfer-

mería, cuidado multidisciplinario y elementos condicionantes para la atención de enfermería. Se evidenciaron importantes limitaciones para el cuidado del paciente renal, falta de tiempo y consultas específicas para seguimiento, formación profesional limitada en el tema y factores socio- económicos del paciente que influyen en el cuidado.

Conclusiones: La inclusión de cuidados específicos para el paciente renal en atención primaria y la capacitación del profesional de enfermería, surgen como importantes herramientas para mejorar el cuidado de los pacientes con enfermedad renal crónica avanzada.

Palabras claves: enfermería; atención de enfermería; insuficiencia renal crónica; calidad de vida, atención primaria de salud.

INTRODUCTION

Chronic kidney disease (CKD) is a public health problem that reduces life expectancy and represents a burden for the health care system.

Over the past 30 years, it has become one of the leading causes of mortality and years of healthy life lost (YHLL) in all Latin American countries. In Chile, CKD advanced from the 14th to the 4th cause of death and from the 27th to the 9th cause of YHLL between 1990 and 2019[1].

In 2022, a characterisation study of CKD patients in Chile reported that 54% of patients initiated renal replacement therapy (RRT) without prior preventive management, while those who received preventive management could delay entry into RRT by up to 10 years[2].

Nationwide, as part of a strategy for screening and early diagnosis of CKD, since 2014 Chile has included monitoring with blood tests to evaluate kidney function and damage in individuals enrolled in the Cardiovascular Health Programme (PSCV) in primary health care (PHC)[3].

Recently, there has been an increase in the number of CKD stage 5 patients requiring dialysis. The haemodialysis registry of the Chilean Society of Nephrology indicated that as of August 31st 2023, there were 25,158 patients on haemodialysis in Chile[4], including 367 patients in the Atacama region[5].

CKD in Chile is covered under the Explicit Health Guarantees (GES), which ensures care both at early stages and during dialysis. Initial diagnosis, management, and possible referral according to established clinical practice guidelines are the responsibility of PHC[6].

The mission of the health care team is to provide patients with the tools to facilitate self-care in chronic illness. The role of PHC nurses is therefore essential in promoting and preventing CKD while managing the comorbidities that trigger it[7].

The nursing role is regulated by the Chilean Health Code, Article 113, which states that "the professional services of the nurse comprise care management in relation to the promotion, maintenance, and restoration of health; the prevention of diseases or injuries; and the execution of actions derived from medical diagnosis and treatment, with the duty to ensure the best administration of health care resources for the patient"[8].

The nursing role warrants special attention in the care of patients with kidney disease, as nurses participate in the detection of risk factors and the prevention of disease progression through promotion and prevention strategies[9-10].

In 2018, a study conducted in Atacama, Chile, among diabetic patients on haemodialysis, reported inadequate professional management during pre-dialysis stages, suggesting the need to strengthen the educational role of nurses[11]. As PHC is the setting par excellence for preventive and health promotion activities and given that no other regional studies to date have addressed nursing care of CKD patients in PHC, the present investigation aims to explore this phenomenon through the lived experiences of nurses, describing their perspectives on caring for CKD patients in primary health care.

MATERIAL AND METHOD

Design

We conducted a qualitative, descriptive, and exploratory study among nurses providing health care in different family health centres (CESFAM) within PHC in the city of Copiapó, during the period November–December 2022.

Study setting

The study was conducted in 7 CESFAM in the Atacama Region, all of which belong to the Municipal Health Department of the city of Copiapó, Atacama, Chile.

Population and sample

The population consisted of 39 nurses working in different CESFAM facilities in Copiapó. A non-probabilistic convenience sampling method was applied until data saturation was reached. The final sample included a total 10 nurses from different CESFAM who met the inclusion and exclusion criteria.

Inclusion and exclusion criteria

Two inclusion criteria were established: (1) nurses with experience in the direct care of patients with kidney disease within the Cardiovascular Programme; (2) voluntary participation confirmed by signing informed consent.

The exclusion criterion was (1) health care professionals other than nurses working in the CESFAM.

Data collection procedure

A formal request was made by the Nursing Department Universidad de Atacama to the Municipal Health Department

of Copiapó to invite nurses from CESFAM in the city to participate in the study. Subsequently, on-site visits were made to each CESFAM to meet the nurses, explain the study objectives in detail, and invite them to participate voluntarily. Those who agreed scheduled a day, time, and place for the interview.

Interviews were conducted by 5 nursing students from the Universidad de Atacama over 2 months (November–December 2022). Meetings took place within each CESFAM to provide a safe, comfortable, and confidential environment, encouraging participants to share their experiences openly. Participants were informed of the study and signed informed consent. Each interview was recorded and later transcribed.

Data collection instrument

Data were collected using a semi-structured interview consisting of 8 guiding questions designed to elicit the personal experiences of each nurse in relation to the study objective **(table 1)**.

Table 1. Semi-structured interview guide.

How do you identify a patient with possible risk of kidney disease or kidney damage?
Could you describe the care you provide to patients at risk of chronic kidney disease (CKD) and to those with CKD?
What does the education provided to patients at risk of CKD consist of?
What are the limitations of the cardiovascular program in the timely detection of patients with CKD?
What difficulties interfere with patient self-care?
How do you evaluate the follow-up of patients referred to secondary care?
Could you identify the strengths of the Ministry guidelines regarding the health care of patients with CKD?
Have you needed to provide emotional support to a patient with CKD? If so, could you describe the experience?

Data analysis

Interviews were recorded, transcribed manually, and organised into independent files, each assigned an alphanumeric code to ensure anonymity, with access restricted to the research team. A total of 4 students and 2 academics with qualitative research experience conducted individual critical readings of the transcripts. An open coding process was then applied using Atlas.ti software, followed by grouping of similar codes according to study objectives. Categories and subcategories were constructed inductively based on these groupings. Initially, 10 codes were identified, which were later consolidated into 4 categories **(table 2)**.

Ethical approval

The study was approved by *Universidad de Atacama* Ethics Committee and by the Municipal Health Department of Copiapó. Informed consent was obtained from each participating nurse. Anonymity and confidentiality of participants were ensured at all times.

RESULTS

A total of 10 nurses were interviewed, who identified important elements related to the care of renal patients. Four categories emerged: (1) factors related to quality of care; (2) nursing care management; (3) multidisciplinary care; and (4) conditioning elements influencing nursing care.

Category 1: Factors related to quality of care

Nurses identified factors associated with the quality of care provided to renal patients. Among these was the absence of established guidelines and protocols in PHC for the management of patients with kidney damage, since this condition is regarded as a consequence of diabetes mellitus and hypertension. Other factors mentioned included poor connectivity, shortage of professionals, and limited training specific to CKD management.

a) Subcategory: Limitations in health care provision

One of the greatest limitations highlighted was the short time allocated for cardiovascular check-ups.

"The limitation is the consultation times they give us; I think this is very important because they are reduced too much, so you only do something quickly and cannot do it with quality. It's as if they prefer quantity over quality." (E9)

Participants also reported coverage problems and connection issues with the CESFAM computer servers, staff shortages, limited access to medicines, restricted slots for laboratory tests, and insufficient appointment availability. These factors directly affected continuity of care.

"The lack of staff, the lack of consultation rooms, this system. You are seeing a patient and suddenly the system crashes, everything stops because RAYÉN went down." (E4)

"There aren't enough slots for lab tests, or for sample collection; there aren't enough appointments for nurses, nutritionists, or doctors." (E5)

Another limitation mentioned was the shortage of nephrologists in Copiapó, meaning patients were seen late even when referred. A further concern was inadequate training for foreign doctors working in PHC regarding Chilean Ministry of Health guidelines.

"There's a shortage of nephrologists. They receive patients very late because even if you refer them, there are so many patients that they can't keep up…" (E9)

Table 2. Study categories, definitions, and subcategories.

Category	Definition	Subcategories
Factors related to quality of care	Health services that enable positive outcomes in relation to gaps identified by health professionals, recognising new tools and/or improvements that help meet and optimise the demand for care.	Limitations in health services
		Improvements in health care
		Professional satisfaction
Nursing care management	Actions that provide care according to individuals' needs to improve health not only physically but also biopsychosocially and emotionally, promoting self-care and fostering user autonomy.	Emotional support
		Nursing care
		Influence of regulations on care
Multidisciplinary care	Care and activities provided by health professionals throughout the life course, aimed at promoting health and prevention, maintaining continuity through a care plan with a multidisciplinary approach.	Multidisciplinary team
		Continuity of care
Conditioning elements for nursing care	Interpersonal or environmental elements that influence the user's biopsychosocial state, which may facilitate or hinder understanding and improvement of health status.	User self-care
		Intrinsic and extrinsic factors influencing user care

"When doctors are trained in Chile, they are familiar with ministry guidelines, how the GES works, and so on. But with foreign doctors it's an issue—they are not familiar with the guidelines, the flowcharts, or even how the GES system itself works." (E6)

b) Subcategory: Improvements in health care provision

Nurses recognised the need to strengthen knowledge about CKD among both health care professionals and patients, noting that training opportunities are scarce.

"Continuous training, perhaps forming a team focused on chronic kidney disease, maybe having a protocol for when to refer with abnormal lab results. At present we don't have anything fixed for that. And it's not only for doctors—nurses, nutritionists, and nursing assistants in the cardiovascular programme should also know when to refer or when to alert for early referral." (E2)

Other improvements suggested included reorganising human resources to better address CKD through specialised programmes or teams providing a biopsychosocial approach.

"In primary care we could form an accompaniment team, maintaining a database of patients with chronic kidney disease." (E5)

"I think there could be a programme in primary care for renal patients; I would design a programme for those in stage 1 or 2." (E2)

"Group workshops where patients meet, share their experiences, discuss how they manage their treatment and adherence." (E1)

c) Subcategory: Professional satisfaction

Some nurses expressed a sense of undervaluation of their professional role and insecurity due to insufficient training in CKD care.

"We don't really have tools or updates on chronic kidney disease. I think it has been very neglected, yet it's increasing. It would be important to update us and perhaps provide another approach for these patients." (E2)

Conversely, participants reported positive feelings of professional satisfaction derived from strong patient–provider relationships, which foster trust and facilitate health education.

"In general, patients react positively because they are long-term patients, we've built a lot of trust. They are seen by the same professionals, so there's already a bond and that helps us a lot in patient education." (E8)

Category 2: Nursing care management

This category highlighted the influence of health regulations and the biopsychosocial model of care in CKD management.
a) Subcategory: Emotional support

Nurses described providing emotional support through active listening and effective communication.

"No one had sat with him to explain why all that had happened. I took the time because I had a free slot, so I stayed with him to explain everything. The gentleman actually cried out of gratitude—no one had ever explained anything to him before." (E5)

They also emphasised the importance of support from psychologists and social workers to deliver holistic care.

"I've provided emotional support and fortunately we have a good psychology team. They supported me in how to approach the patient, how to help them accept that this is a therapeutic process that will help them." (E2)

"At that moment we give the patient the time they need to express their problem or emotion, but there's also support from other professionals who intervene." (E7)

b) Subcategory: Nursing care

The importance of a comprehensive assessment was highlighted as the foundation for personalised nursing care.

"You need to cover all the patient's needs to provide appropriate care. Considering their needs allows me to deliver much more effective education." (E2)

c) Subcategory: Influence of regulations on care

Nurses acknowledged that ministerial guidelines for cardiovascular patients are used for CKD management in PHC, since CKD is seen as a complication of cardiovascular disease.

"CKD is not directly addressed in PHC; it feels like an add-on to the cardiovascular programme. It's not even listed in our forms as a cardiovascular programme disease. It's a neglected issue—we are too focused on other chronic diseases, and I think this one needs reinforcing, but with the whole team, not just doctors." (E1)

This led to limited specific nursing care for CKD patients, often restricted to referrals for tests.

"I think the strengths lie in the fact that the guidelines are mostly in place in primary care; it is quite well outlined what you need to apply and what is done. The required tests are available—for example, the ACR test, which is very expensive and, in practice, almost never carried out because of its high cost. Nevertheless, there are good screening tests that allow you to detect problems in time." (E9)

Category 3: Multidisciplinary care

This category underscored the benefits of multidisciplinary care, which enables more comprehensive and specialised management according to patients' needs.

a) Subcategory: Multidisciplinary team

Care delivered by a team of health professionals according to identified needs was strongly linked to optimal and high-quality care.

"If there are risk factors like malnutrition, then the nutritionist is included; if there are pharmacological problems, the pharmacist is included; if there are mental health issues, the psychologist is involved. It depends on the needs, but basically, it's doctor and nurse." (E2)

b) Subcategory: Continuity of care

Participants emphasised the need for continuous care across different levels of the health system. Although continuity was seen in the cardiovascular programme at the primary level, this was often lost when patients were referred to secondary care.

"In the cardiovascular programme we have continuity of care—the patients know they will be seen regularly by different professionals throughout the year." (E2)

"We don't really have counter-referrals; I don't know of any mechanism that ensures feedback from secondary care." (E2)

The lack of communication between primary and secondary care was perceived as a barrier, making it difficult to reinforce or complement specialist recommendations.

"There's no feedback, so sometimes you don't know. You ask patients to bring the notes from the nephrologist about medications, fluid restrictions, all those things—but often they don't." (E9)

Category 4: Conditioning elements influencing nursing care

Nurses recognised several factors influencing how patients receive care, with socioeconomic conditions being especially relevant. They also highlighted the role of patient self-care as key to improved health and quality of life.

a) Subcategory: Patient self-care

Patients who assumed responsibility for their own care and actively participated in it were able to prevent health deterioration, as perceived through follow-up.

"Some patients are very compliant, very disciplined, and it shows in their exams and blood pressure." (E9)

"There are patients who maintain their adherence, their treatment, their attendance to check-ups, although others are in denial—most of them, actually." (E7)

Conversely, patients with poor self-care showed resistance to change and a negative attitude toward professional recommendations, accelerating disease progression.

"Some patients or their families say, 'We know we need to change,' but they won't do it because they don't want to. We explain and encourage, but sometimes they simply don't accept it." (E9)

b) Subcategory: Intrinsic and extrinsic factors influencing care

Several factors were identified as influencing the care of patients with CKD, among which economic hardship was the most frequently cited, being associated with poor nutrition due to the limited access patients have to foods considered healthy.

"We are dealing with a population facing severe economic precariousness, so it is complex to tell them, 'you should eat fish several times a week'. The first step is to understand the patient's needs and, based on that, provide education." (E2)

Another element mentioned as conditioning health was the educational level of users, since low literacy prevents adequate health education of the population.

"We need to assess whether patients are illiterate. We have encountered many people who cannot read, and if they cannot read, how are they supposed to take their medications?" (E2)

Age was also highlighted by professionals, who emphasised the importance of support networks for older adults during treatment.

"The patient's age, their physical condition, their psychological condition. And another very important factor is the support network available to the patient, whether family or otherwise." (E8)

At the same time, it was noted that working-age adults also experience difficulties related to their employment, which contributes to non-adherence to recommendations and missed health appointments.

"Patients of working age are often not given permission [by employers], so they miss appointments or show poor adherence to treatment." (E10)

DISCUSSION

A study conducted in Spain in 2021 described the patient with CKD on haemodialysis as "a being who experiences fear, sadness, hopelessness, moments of anger, pain and suffering due to the loss of autonomy, and insecurity from living in constant anguish at the proximity of death." Individuals with CKD undergo various changes throughout the course of the disease[12]. For this reason, nurses accompany and provide emotional support to patients during this process[13]. This was also evident in the present study, in which nurses described care actions delivered as part of the emotional support provided to users, citing active listening and effective communication as facilitators of care and acceptance of the disease. Regarding other aspects of care delivery in PHC, multidisciplinary work with users emerged as a positive element, with the involvement of other professionals—such as psychologists and social workers—considered a strong complement to comprehensive care.

A second study, based on Merle Mishel's theory and entitled "Uncertainty in the face of chronic kidney disease," reported that renal patients often lack sufficient knowledge about the disease and how it may change their lives, generating fear and distress. Consequently, nurses are the primary agents in guiding patients so they can manage the condition as effectively as possible[14], once again underscoring the importance of nursing staff, who accompany patients as they first come to terms with their new health status[15]. Another study from Peru noted that "the nursing intervention on the patient's level of knowledge produced significant changes, with greater understanding of how to characterise CKD, recognition of signs and symptoms, complications, treatment, and self-care measures,"[16] highlighting the impact of nursing interventions on self-care and quality of life[17,18]. In the present study, although emotional support is mentioned as an important component of CKD care in PHC and as intrinsic to a comprehensive nursing approach, a gap remains regarding education that could be provided to patients about their disease and self-care[19]. This is explained in part by lack of time for CKD-specific consultations—since CKD is not a stand-alone service—resource shortages (including staffing), and limited CKD-specific training for professionals[20]. Participants reported lacking specific training that would allow them to feel confident about the care delivered. Moreover, their role in CKD care tended to be limited to referrals for monitoring tests which, while useful for tracking disease progression, leaves a gap in the essential nursing role of patient education. Related to this, a 2020 study from Chile sought to understand how health care professionals in a dialysis unit perceived educational processes. Among its findings were patient-related factors that hinder teaching, including age, health status, educational level, and lack of family support[21]. Similar findings emerged in the present study, in which professionals identified user-related factors—particularly socioeconomic and educational level—directly associated with favourable adherence to recommendations. The same Chilean study also identified system-related barriers to patient education, such as lack of time, insufficient physical space, and limited state support[21]. Likewise, the present study found constraints on nursing care delivery: CKD was addressed as a complication of cardiovascular disease rather than as renal care per se, which professionals viewed as a limitation because they lacked sufficient time for CKD-focused consultations—again reflecting insufficient institutional support.

In Chile in 2018, a study entitled "Characterisation of diabetic patients on haemodialysis in the Atacama region" reported inadequate professional management during pre-dialysis stages, including failure to refer patients to a nephrologist in a timely manner, thereby contributing to progressive harm[11]. The same study suggested strengthening the educational role of nurses, linking this to poor treatment adherence[11]. Comparable results were found in a study from Spain, which emphasised the importance of early identification of renal damage in primary care[22]. The present investigation complements those findings by describing how nursing care is delivered to renal patients prior to renal replacement therapy; however, the results indicate it is imperative to enhance patient education, with emphasis on preventing disease progression.

Study limitations include the sample size and the specificity of the population selected, given their particular experience with the phenomenon of interest. Consequently, the largely descriptive results do not allow for generalisation.

Based on insights from nurses' experiences caring for CKD patients in PHC, it is urgent to strengthen health promotion and prevention, as well as early detection and follow-up, as key measures to avoid deterioration in patients' health, reductions in quality of life, and increased expenditure on disease-related resources and treatments. In light of these findings, although guarantees for the care of renal patients exist, gaps remain in PHC. It is therefore suggested to establish a CKD-specific health check, which would improve follow-up and reinforce nursing's educational role in prevention and health promotion. Another important measure would be the allocation of resources for professional staffing, infrastructure, and professional training—actions aimed at improving quality of life and preventing complications associated with disease progression.

To date, there is limited evidence on nursing care for people with early-stage CKD, as most published studies focus on patients receiving haemodialysis. This invites further investigation and the implementation of action-research studies to generate strategies that improve the care of these patients in PHC.

Acknowledgements
We express our sincere gratitude to the nursing students who participated in this study and contributed significantly to data collection and analysis. Their dedication and tireless effort were fundamental to the success of this work. We thank: Joan Rojas Durán, Katherine Villarroel Cortés, Gisella Aróstica Zárate, Francisca Cortés Villegas, and Loredana Guaita Olave.

Acknowledgements

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Conflicts of interest

None declared.

Funding

None declared.

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