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Analysis of patients' experience regarding self-management capacity in dialysis treatment and the influence of the environment

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ABSTRACT

Introduction: In some cases, quality of life for dialysis patients leads to the search for home-based environments. In others, the home environment may represent a significant barrier. Analysing the environment in which dialysis treatment takes place is related to the patient's capacity for self-management of both treatment and disease. Nursing care plans should, from an early stage, assess whether an environment is appropriate and consider the patient's self-management style, encouraging an active role.

Objective: To explore the lived experience of dialysis patients in relation to personal self-management of treatment and the environment in which it occurs.

Material and Method: We conducted a descriptive phenomenological qualitative study through interviews with patients enrolled in different dialysis programmes. A non-probabilistic sampling method was used. Results were obtained through verbatim transcription, constant comparison, and field notes from the interviews. Discourse was analysed using triangulation and an iterative inductive thematic analysis.

Results: A total of 24 participants were interviewed. The categories and codes identified were: **a)** Hospital-based: a.a) Dialysis units: limited privacy, ineffective coping, social participation, passive role. **b)** Home-based: b.a) Home haemodialysis: active role, architectural barriers, family barriers. b.b) Peritoneal dialysis: daily exchanges, nocturnal cycler, space organisation, active role.

Conclusions: The environment in which dialysis treatment is carried out appears to be a key factor for patients and is linked to their capacity to enhance self-management. Nursing practice should involve early interventions aimed at understanding the impact of the environment..

Keywords: renal dialysis; haemodialysis, home; peritoneal dialysis; self-regulation; nursing; dialysis.

RESUMEN

Analisis de la experiencia de pacientes sobre la capacidad de autocontrol del tratamiento de diálisis y la influencia del entorno

Introducción: En algunos casos la calidad de vida para el paciente en diálisis conlleva a la búsqueda de entornos domiciliarios. En otros, el entorno domiciliario puede suponer una barrera importante. El análisis del entorno para el tratamien-

to de diálisis está relacionado con la capacidad de autocontrol personal de los tratamientos y la enfermedad. Los planes enfermeros deben tener en cuenta de forma temprana cuando un entorno es adecuado y también el estilo de autocontrol fomentando un rol activo.

Objetivo: Conocer la experiencia vivida por el paciente en diálisis en relación con el autocontrol personal del tratamiento y el entorno donde se produce.

Material y Método: Estudio cualitativo descriptivo fenomenológico mediante entrevista a pacientes en diferentes programas de diálisis. Muestreo no probabilístico. Los resultados se obtienen mediante trascripción textual, método de comparación constante y cuaderno de campo de las entrevistas. Se analiza el discurso mediante triangulación y análisis temático inductivo iterativo.

Resultados: Veinticuatro personas fueron entrevistadas. Las categorías y códigos resultantes son los siguientes: a) Hospitalaria; a.a) salas de diálisis: Escasa intimidad, afrontamiento ineficaz, participación social, rol pasivo. b) Domiciliaria; b.a) Hemodiálisis domiciliaria: rol activo, barreras arquitectónicas, barreras familiares, b.b) Diálisis Peritoneal: pases diarios, cicladora nocturna, organización de espacios, rol activo.

Conclusiones: Parece evidenciarse que el entorno donde se produce el tratamiento de diálisis es un elemento de relevancia para las personas en tratamiento y está relacionado con la capacidad para aumentar el autocontrol. La enfermería debería consensuar una intervención temprana dirigida a conocer el impacto del entorno.

Palabras clave: hemodiálisis; hemodiálisis domiciliaria; diálisis peritoneal; autorregulación; enfermería; diálisis.

INTRODUCTION

Chronic Kidney Disease (CKD) is a serious public health problem in which most deaths occur in older adults, and prevalence is higher in women; nevertheless, end-stage CKD and Renal Replacement Therapy (RRT) treatments occur more frequently in men[1]. Risk factors such as Diabetes Mellitus (DM), hypertension (HTN), or obesity[2] are those that produce the greatest comorbidity. Health-related quality of life is associated with survival and, in turn, with self-regulation of the disease, self-care, and personal responsibility for treatment-related care[3-5].

Symptoms vary depending on CKD progression or stage and RRT modality, ranging from perceived muscle weakness, lack of mobility, poor appetite, dry mouth, or low mood, with transplant recipients showing the lowest prevalence of symptoms[6]. Furthermore, increases or decreases in the prevalence of these symptoms depend on treatment planning and healthcare resources[7]. In this regard, home-based therapies offer an alternative context to traditional therapies in large dialysis units. Assessing the most appropriate setting facilitates better adherence to home hemodialysis (HHD) or peritoneal dialysis (PD), taking into consideration architectural barriers in the home or personal/family-related barriers[4,8].

The Temporal Self-Regulation Theory (TST) describes health behaviors and helps understand how these behaviors can be beneficial. However, they may carry high costs, sometimes even becoming demotivating; in contrast, behaviors that provide greater short-term satisfaction have a lower cost yet are more harmful[9,10]. TST considers that to promote behaviors that enhance treatment self-regulation, we must address motivational aspects (connectivity beliefs). Nurses can be strong allies in this process, fostering training in self-regulation, context assessment, and management of adverse situations[11]. Based on this, the guiding question for this study was: *What is the patient's experience according to the dialysis context, and how is it related to treatment self-management?* The objective was to understand the lived experience of hemodialysis or peritoneal dialysis patients in relation to personal self-management of dialysis treatment

MATERIAL AND METHOD

Design and Ethical Considerations

We conducted a descriptive phenomenological qualitative study through semi-structured interviews with hemodialysis (HD) and PD patients. The study was carried out from February to July 2023 with patients from *Fundació Puigvert* (Barcelona, Spain). The Drug Research Ethics Committee (CEIm) of *Fundació Puigvert* granted approval in December 2022 (reference number: C2022/39). Subsequently, the admissions unit provided the list of candidate participants for selection according to research criteria. The research process was communicated to the nursing management and the staff of the Dialysis Unit at the Foundation. To maintain participant privacy, identifying information was alphanumerically coded. All information was safeguarded and protected according to protocol. Efforts were made at all times to prevent any discomfort to interviewees.

Participants

Selection was carried out through convenience sampling, a non-probabilistic method, until data saturation was reached. Inclusion criteria were: patients aged 18 years or older, diagnosis of CKD for more than 3 months, and undergoing HD or PD treatment, who had signed informed consent. Exclusion criteria were: transplant recipients not undergoing HD or PD, individuals with cognitive impairment, or mental health issues.

The interview guide included the following topics: a) onset and progression of renal replacement therapy, b) treatment context, c) course of CKD, and d) difficulties and expectations. To ensure rigor, the interview guide was reviewed by two

qualitative research experts (M.M.A. and R.B.S.). See **annex 1** for the interview guide.

Data collection and analysis

Initial contact with participants was made through the Unit's nursing staff. After accepting participation, the principal investigator (M.E.L.) provided all necessary information until full understanding was ensured. Participation was confirmed by signing the voluntary informed consent form.

Interviews were conducted outside the dialysis environment via videoconference, led by a nurse (I.M.C.) external to the patients' usual dialysis unit and accompanied by a participant observer (M.E.L.). Interviews lasted 30–45 minutes. Recruitment ended once data saturation was achieved.

Interviews were transcribed verbatim. Transcription analysis was conducted using iterative inductive thematic analysis with Atlas.ti V.24 (Atlas.ti Scientific Software Development GmbH, Berlin, Germany). Through thematic analysis, codes and code groups were generated. Throughout interviews and transcript analysis, the constant comparison method was systematically applied[12]. Categories, codes, and themes were developed through triangulation by three analysts (M.M.A., M.E.L., I.M.C.).

Quality and Rigor

This manuscript follows the COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines[13]. To avoid bias, all participants were interviewed outside the dialysis setting and by the same interviewer (I.M.C.).

The interviewer was selected for her experience in qualitative research and her lack of involvement with the patients' Dialysis Unit. Review and validation of the interview guide by the research team aimed to eliminate interpretative bias. The guide was adapted to open-ended questions to facilitate participants' responses.

To confirm reliability, a pilot interview was conducted prior to the study. After each interview, the constant comparison method was used to discuss key response patterns related to major themes, through consensus between I.M.C. and M.E.L. In parallel with the interviews, M.E.L. transcribed the recordings.

From September to October 2023, participants received a preliminary report summarizing key themes. Some participants confirmed the identification of themes, supporting the research team's interpretations.

RESULTS

A total of 28 HD patients and 11 PD patients were informed about the study, of whom 24 were ultimately interviewed: nine women (37.5%) and fifteen men (62.5%). Seventeen were undergoing HD (70.8%), including two receiving home hemodialysis. Additionally, seven individuals were receiving PD (29.2%). See **table 1.**

Table 1. Participant characteristics.

ID	SEX	AGE	MODALITY	TIME SINCE START OF LATEST TREATMENT (HD/PD DURATION)
01	M	50	HD	11 months
02	M	52	HD	2 years and 3 months
03	M	68	HD	6 months
04	F	63	HD	18 years and 11 months
05	M	63	HD	1 year and 2 months
07	M	41	HD	13 years and 2 months
08	M	56	HD	1 year and 8 months
09	M	47	HD	1 year and 4 months
10	M	35	HD	4 months
11	F	69	HD	4 years
12	F	46	HD	11 months
13	F	50	HHD	20 years and 3 months
14	M	65	HD	18 years and 7 months
15	M	66	DP	5 years and 2 months
16	F	35	DP	1 year and 2 months
17	M	18	DP	4 months
18	F	73	HD	1 year and 8 months
19	F	71	HD	1 year
20	M	59	HD	4 years
21	M	79	DP	7 months
22	M	75	DP	5 months
23	M	73	DP	1 year and 7 months
24	F	41	HHD	4 years
25	F	57	DP	1 year and 4 months

The resulting categories, themes, and codes are as follows: **1)** Hospital-based: *a) Dialysis units:* limited privacy, ineffective coping, social participation, and passive role. **2)** *Home-based:* a) Home hemodialysis: active role, architectural barriers, and family-related barriers. *b) Peritoneal dialysis:* daily exchanges, nocturnal cycler, space organization, and active role.

■ 1) Category 1. Hospital Context: Dialysis Units

Interviewees described how the environment may act as a barrier to health behaviors, or at times, as a facilitator. Hospital-based and satellite-clinic hemodialysis share common elements that define the clinical context and its influence on patients' health behaviors. Entering the dialysis unit for the first time is a key moment and is analyzed here as a central code within this category.

1.1. From a passive role to limited patient–healthcare staff connection

Participants described the hospital environment as lacking privacy, eliciting a sense of exposure, and characterized by very large shared spaces. From the moment they enter until the moment they leave the dialysis room, patients feel that their role is minimally active. The perception that they are not taken into account and do not participate in decision-making contributes

to this passive role and intensifies their sense of illness.

"I'm fed up with hospitals and everything that comes with it. Every time you come to a hospital center it's hard to take it in. I'm like a horse (covers his eyes so as not to see sideways), and whatever is next to me, I don't want to see [...] I have one person on the right and another on the left—don't ask me who they are, I don't even talk, I'm not interested." ID03

Patients retain memories of sensory stimuli from their first entry into the dialysis room or unit. The emotion causing greatest distress is closely related to this first experience of dialysis, which is also when initial treatment guidelines are given, when they receive the most information and instructions, when they feel most overwhelmed by the impact, and when treatment acceptance is lowest.

"The smell is unlike anything else; later you get used to it, but there's a special smell in dialysis. [...] And the doctor who treated me told me I'd be there for two hours; after a week he put me on two and a half, then three, and the next week four. I wanted to kill myself." ID11

Participants reported difficulty maintaining contact with physicians in this context. Nursing assistants and nurses are the first resource for addressing health-related questions upon arrival. They perceive medical attention as infrequent and consider nursing support more accessible. In large dialysis halls, participants felt that the context makes immediate medical attention difficult, and many questions remain unresolved. Although nurses are closer, high staff turnover generates distrust toward newly assigned personnel.

"With the nurse I'm with, I'm there the whole four or five hours (dialysis unit). The doctor—you might see them every other day, for three minutes. [...]. It's impossible for the doctor to treat you and know you as well as the nurse who's with you through the whole session when the interaction is two minutes." ID07

"There are many of us, and they come in just to say hello. Dr. X used to say it: well, this is the visit—nothing, I've come to say hello. Because they don't have time for more. When they explain things, they explain them well, but rarely." ID18

Interviewees described dialysis time as very long. The last hour is considered the worst due to the anxiety caused by remaining immobile for so many hours. In some cases, time spent being transported by ambulance adds to the burden. Overall, more than 18 hours per week may be spent solely on dialysis treatment.

"The last hour is very heavy, very hard. It's four hours, and after about the first three hours, well, they go by. I've tried picking up a book but honestly, I can't [...], instead of relaxing me, it makes me nervous." ID03

However, the dialysis context can also be a facilitator. Some participants expressed that dialysis units benefit social interaction, providing an environment for conversations among peers. Most patient-to-patient discussions about illness occur in informal spaces, such as waiting rooms or during ambulance transport. They perceive positively the ability to share experiences regarding illness and treatment in settings beyond the dialysis hall itself.

"I had never heard of peritoneal dialysis in my life, and when they offered it to me, I was a bit surprised [...] I talked to a patient who showed me the catheter he had and explained how he lived. [...] And I decided on peritoneal." ID20

"In the ambulance: 'How are you?' – 'Oh, I'm not well.' [...] You start letting things out with people while you're waiting (in the waiting room)." ID12

2) Category 2. Home Context: Peritoneal Dialysis and Home Hemodialysis

The home environment allows dialysis patients to integrate treatment into a familiar setting, away from large dialysis units and with greater comfort. Bringing treatment home is not easy; it requires effort both to increase motivation toward self-regulation and to acquire technical skills necessary for safe dialysis. In relation to TST, the healthcare professional acts as an ally, guiding self-management training and helping patients identify motivational "connectivity beliefs" that foster self-control.

2.1. When the clinic comes home

The complexity of taking treatment home entails changes in the home environment and family dynamics. Although participants valued greater autonomy and motivation in managing treatment, some felt that moving the illness home imposes unnecessary suffering on the family. They believed it is better to "leave the illness at the hospital" and reduce the emotional burden that bringing a clinical context into the household entails.

"In peritoneal dialysis, you bring the illness with you—you're living it day by day and several times a day, and you never leave it; you don't even have the break that hemodialysis gives you (refers to the time away from the dialysis room) to live without illness for two days, for example, on a weekend. [...] Nobody gives you any clues about this kind of information so that you can make a proper judgment." ID14

Interviewees emphasized that home therapies require an active self-management role: meticulous hygiene, strict adherence to aseptic protocols, and readiness to manage emergencies. Family members also need education and training. Homes must be reorganized to create clean, spacious areas for treatment and storage of supplies. These requirements can become barriers—architectural or family-related—for some patients.

"New routines have entered the house; we had to change our routines and even part of the furniture in a room because it takes up so much space. [...] The reality is that a bunch of cardboard boxes arrive with all the supplies needed for dialysis [...] We had to change half the room." ID22

"I wash my hands eight times a day, for example, just for the catheter—eight times. Four masks per day, at minimum. And every time I shower, I have to do the dressing change… all the care you can imagine." ID23

Bringing treatment home requires a degree of adaptation from cohabiting family members. Some participants reported sleeping in separate rooms from their partners due to nighttime disruptions. When young children are present, explanations are necessary to minimize the emotional impact of seeing the procedures, understanding illness, and coping with its consequences.

"As for my partner, we used to sleep in the same bed, and now she sleeps in another room. With dialysis, when I got up and started moving around, I kept her awake." ID03

"This is not super easy. My son—I try to be completely transparent with him. I do dialysis in front of him. I explain that Mom doesn't have kidneys and that this is an external kidney. He worries because you're not well, you feel sick, but he's getting used to it. What I don't want is to lie to him!" ID24

Participants performing PD or HHD can travel more easily, but require significant planning to ensure materials will be delivered to the destination, that hotels or apartments can store supplies, and that a safe, aseptic space will be available. At times, planning dialysis during travel leads participants to reject the idea altogether. Even with portable machines, the volume of supplies and physical strain of treatment may make short trips unfeasible.

"It's portable (the nocturnal cycler), like a slightly bigger computer. […] The bags of fluid, disinfectants… all of that takes up space. Every 15 days they send me 14 boxes of bags. It's a lot. […] And if I travel, they have to send it there." ID21

DISCUSSION

This qualitative study aimed to understand the lived experience of hemodialysis and peritoneal dialysis patients regarding strategies needed to promote self-control behaviors and the relationship between these behaviors and the setting in which treatment occurs. The two principal categories obtained were: a) hospital-based (dialysis units), and b) home-based (home hemodialysis and peritoneal dialysis). The resulting themes were: **1)** *from a passive role to limited patient–healthcare staff connection*, with codes including limited privacy, ineffective coping, social participation, and passive role; and **2)** *when the clinic comes home*, with codes including active role, architectural and family barriers, daily exchanges, nocturnal cycler, and space organization.

Former studies on HD patient experiences confirm the broad view of barriers and facilitators inherent to the dialysis context[14-17]. Meeting the needs of dialysis patients is challenging given current conditions in hospital-based or satellite dialysis units. TST helps us understand the behaviors described by patients and to identify the codes within each category, as well as motivational reinforcers ("connectivity beliefs") that may enhance self-control[9-11].

CKD and RRT, with their temporal, dietary, social, and economic constraints, strain patients, and nurses play a key role as allies—supporting self-regulation skills, enhancing abilities, and teaching complication management[4,5]. Exploring alternatives that allow treatment flexibility seems to reduce the "cost" of health behaviors. Increased self-responsibility may help RRT patients better understand their limitations and the degree of flexibility possible in their treatment; this cannot occur in individuals who remain passive in their treatment and do not acquire self-regulation skills.

RRT patients tend to be middle-aged or older[1]. Developing individualized care plans values patients' abilities and reduces age-related bias. While some older adults experience the hemodialysis unit as a social environment with minimal time cost, middle-aged individuals may find the space less private and more disruptive to family and social activities[18]. According to our findings, the HD context may serve as either facilitator or barrier, requiring attention to human factors, unit characteristics, and available resources[19].

Recommendations highlighting the positive impact of home-based therapies and the need to increase PD availability[20,21] align with our findings. This shift requires significant changes in treatment models and substantial investment in the development of dedicated units and specialized training for nursing staff, nephrologists, and family caregivers[22]. Understanding the patient's home context also requires awareness of cultural factors that may act as barriers[14,15,21,23].

Communication styles influence the therapeutic relationship and the connection established with dialysis patients[24]. Patient information must be clear long before RRT initiation. Personalized information can better align expectations regarding RRT modalities, CKD management, or transplantation. Rapid access to unspecialized web-based information also shapes patient perspectives. Fostering appropriate use and oversight of online health information should be a topic for professional scientific forums[25].

This study presents methodological limitations. Participant heterogeneity must be considered when interpreting codes, and the number of home-based dialysis participants was limited. Generalizability may be restricted by the fact that all participants were treated at the same hospital. As for strengths, our phenomenological approach enabled us to capture lived experience and identify nuances unlikely to emerge from quantitative methodologies.

Based on our findings, the treatment setting appears highly relevant to patients and is linked to their capacity to enhance self-control. Nurses are well-positioned to coordinate early interventions aimed at understanding the motivational impact of the dialysis environment and supporting patients' ability to increase treatment self-regulation.

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Conflicts of interest

None declared.

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ANNEX 1. Semi-structured interview guide

Start, dialysis treatment (HD or PD), and expectations

– What has your experience with dialysis been like?

– How did you feel at the beginning of the treatment?

– What do you think about the information you have received throughout the treatment?

– Did you receive information about choosing between HD or PD?

– How do you feel during the session and after the session?

Care process, complications, and HD context

– How would you describe the care you receive at the hospital?

– What do you think about the nursing/medical staff who care for you?

– How do you perceive the information you receive?

– How do you feel during the session and after the session?

To conclude

– Is there any topic you would like to emphasize or any aspect you would like to comment on that we haven't discussed?

Supporting questions

– What do you perceive as support or a facilitator?

– What do you perceive as a barrier, something negative, or something that makes you uncomfortable?

– Could you give an example?

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