

**"EXPERIENCE OF DIAGNOSIS AND INITIATION OF RENAL REPLACEMENT
THERAPY IN WOMEN WITH CHRONIC KIDNEY DISEASE"**

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ABSTRACT

Chronic kidney disease has considerable effects on the quality of life of female patients. Receiving the diagnosis and beginning renal replacement therapy has a great personal impact on patients. The purpose of this study was to describe the experience of female patients with chronic kidney disease at an ambulatory dialysis unit regarding diagnosis, life changes, and initiation of renal replacement therapy. A qualitative exploratory study was conducted based on a social constructivism framework. Participants were recruited using purposeful sampling. In total, 18 women who received treatment for chronic kidney disease with renal replacement therapy were included. The women were attending the Ambulatory Dialysis Unit at a hospital belonging to the public health system of Madrid (Spain). Unstructured and semi-structured in-depth interviews, researchers' field notes, and women's personal letters were used. A systematic text condensation analysis was performed. The criteria used to control trustworthiness were credibility, transferability, dependability, and confirmability. Two themes emerged from the data: a) A turning point in their lives, and b) The emotional journey of beginning renal replacement therapy. The diagnosis of chronic kidney disease and the beginning of treatment implies changing routines and adapting to a new life with chronic kidney disease. The first dialysis and puncture of the arteriovenous fistula is a major experience. Support from other chronic kidney disease patients with more experience is perceived as a necessity and a tool to share their experiences and resolve doubts among peers. The diagnosis and initiation of renal replacement therapy leads to numerous changes in the lives of women with chronic kidney disease, which may influence the acceptance of treatment.

Key words: chronic renal failure; dialysis; gender; hemodialysis; peritoneal dialysis; women.

INTRODUCTION

Background

Chronic kidney disease (CKD) is a public health problem (Glassock et al., 2017) related to highly prevalent diseases, such as arterial hypertension, diabetes, or cardiovascular disease (Llisterri et al., 2021). It is associated with a high morbimortality that increases health care costs (Song et al., 2018; Cockwell and Fisher 2020). CKD affects kidney function, causing alterations in the elimination of waste substances, control of homeostasis, regulation of blood pressure and hormone production (erythropoietin, active metabolites of vitamin D, prostaglandins) (Kalantar-Zadeh et al., 2021).

Once established, CKD progresses to more advanced stages, with renal replacement therapy (RRT) being the only effective life-sustaining treatment (Dabek et al., 2023). Within RRT there are two variants: dialysis through hemodialysis (HD) or peritoneal dialysis (PD); and kidney transplantation (Tx) (Kramer et al., 2018). The objective of RRT is the removal of low and high molecular weight molecules and excess fluid from the blood that would normally be eliminated via the kidneys, and the regulation of the intra- and extracellular milieu (Álvarez-Villarreal et al., 2019). For HD and PD, the blood is filtered through a membrane to purify the blood of metabolites and toxic products and excess fluid (Woo and Lok, 2016).

Impact of renal replacement therapy

CKD has a great emotional impact on patients and their families (Frandsen et al., 2023), together with the emergence of physical and psychological disorders (Hiramatsu et al., 2020). CKD can make people fragile, disrupt their lives and interrupt their future projects (Subramanian et al., 2017). Moreover, it is a disease that has a prolonged symptomatology requiring a great effort of adaptation on behalf of the patient (Chen et al., 2022). Both

treatments (HD and PD) require surgical vascular access and a dialysis machine (Woo and Lok, 2016). HD requires an arteriovenous fistula (AVF) or central venous catheter (CVC), and PD requires a peritoneal catheter (PC) (Woo and Lok, 2016). In the case of HD, the patient is connected for three to four hours a day, several days a week, according to medical prescription at home or at a health center; whereas PD is performed several times a day by the patients themselves, a family member, or a nurse (See et al., 2018).

Experiences when initiating treatment.

Patients with advanced CKD acknowledge that the news of needing RRT and beginning treatment comes as a great shock (Kerr et al., 2018). Previous studies have identified how during preparation for the start of RRT they experienced fear, remorse, anger, uncertainty and emotional distress, being aware of the irreversibility of the disease and facing the different types of treatment and/or dialysis modality (HD or PD) (Thorsteinsdottir et al., 2022; Liu et al., 2023). Unmet needs for care arise during the process of initiating RRT (McKie et al., 2023) such as a lack of sufficient informational support from health professionals or not feeling involved in the decision-making process regarding their treatment (Arestedt et al., 2019), nor on the choice of vascular access (Elliott et al., 2023).

Once on dialysis, patients may feel a loss of identity and control over their lives, increasing their sense of vulnerability (Damery et al., 2019), together with loss of autonomy (Wongboonsin et al., 2021). Coping with treatment and illness involves incorporating new strategies such as seeking support from loved ones (Montalescot et al., 2023), taking refuge in faith, letting go of negative or pessimistic thoughts, and finding one's own strength (Stoye et al., 2022). RRT involves a change in patients' lives, forcing them to abandon habits and incorporate new ones depending on the treatment (Filgueiras de Assis Mello and Angelo, 2018; Sedin et al., 2023).

Gender and renal replacement therapy

Among women, there are numerous differences regarding clinical presentation, disease tolerance and response to treatment, compared to men (Cobo et al., 2016). These differences include: a) an increase in the number of hospitalizations and erythropoietin prescriptions in women compared to men (Chesnaye et al., 2024), b) increased risk of mortality due to the fact that women with RRT have a higher body mass index and greater obesity (Barrera et al., 2023), c) AVF, associated with improved survival, is used more frequently in men, whereas CVC use is more common in women (Artan et al., 2016), d) women initiate RRT later (Kovesdy, 2022), e) women are less likely than men to receive a kidney transplant (Adoli et al., 2022), and f) women have a poorer health-related quality of life, a higher percentage of depressive symptoms and a higher symptom burden (Beckwith et al., 2022; Da Silva et al., 2023). However, women with RRT have a more favorable prognosis, because more effective dialysis is achieved by reaching higher Kt/V values (Chen et al., 2023), also, they have better dietary compliance and/or adherence to phosphorus chelating drugs (Carrero et al., 2018). In addition, for young women, living with CKD is especially challenging as the treatment has effects on fertility (McLaughlin et al., 2022; Shah et al., 2023), weight gain, acne, stretch marks and hair loss that alter their appearance and can lead to decreased self-esteem (Beanlands et al., 2020).

Therefore, it is essential to know the perspective and needs related to disease diagnosis and treatment in women, to understand health-related behaviors, and to incorporate the results into clinical practice (Brar and Markell, 2019). Through the integration of gender into CKD research and management, new therapeutic targets may be identified, current treatment options may be improved, and better support could be provided during disease and decision making (Brar and Markell, 2019). The purpose of this study was to describe the experience of female

patients with CKD at an ambulatory dialysis unit regarding diagnosis, life changes, and the initiation of RRT.

METHODS

Design

A qualitative study based on an interpretive framework was conducted (Creswell and Poth 2018). Within interpretive frameworks there are different types, such as postpositivism, social constructivism, transformative frameworks, postmodernism, and pragmatism. In this study we used social constructivism, which describes how individuals seek to understand the world in which they live and work, constructing and giving meaning to their experiences. Therefore, the aim of this theoretical framework was to study and understand the participants' perspectives on events and phenomena they experience first-hand (Creswell, 2007). This study was conducted according to the Standards for Reporting Qualitative Research (O'Brien et al., 2014) and the Consolidated criteria for reporting qualitative research (Tong, Sainsbury and Craig, 2007).

Research Team

Prior to the study, the researchers' positioning was established via two briefing sessions addressing the theoretical framework for the study, their beliefs, and their motivation for the research (Carpenter and Suto, 2008). The results of these sessions were: 1) Theoretical Framework: Researchers based their approach on an interpretivist paradigm, specifically the social-constructivist theoretical framework. This paradigm was based on the assumption that human beings construct their own social reality, and that knowledge is built through increasingly nuanced reconstructions of individual experiences; 2) Beliefs: the diagnosis and treatment of CKD has a major impact on women's health; However, currently their care is equal to that received by men and gender differences are not considered; and 3) Motivation for the research: to gain insight into CKD through the first-hand experience of female patients: to

describe and understand female patients' point of view regarding aspects which they consider relevant in the diagnosis and initiation of therapy and, as a result, improve healthcare services

Six researchers (three women) participated in this study, including one clinical nurse, a physiotherapist, an occupational therapist, and a two research nurses. Three of them had experience in qualitative study designs, and in health science research. None were involved in clinical activity, nor did they have any prior relationship with the patients included. One researcher had clinical experience with chronic kidney disease.

Setting and participants

The study included CKD female patients attending the Ambulatory Dialysis Unit at a hospital belonging to the public health system of Madrid (Spain). In this unit, RRTs are applied, such as hemodialysis, kidney transplant or peritoneal dialysis. The inclusion criteria were: a) female patients; b) over the age of 18; c) diagnosed with chronic kidney disease, following the criteria of Kidney Disease Improving Global Outcomes (KDIGO) (Stevens et al.,2013) and d) women who were receiving or had received RRT. The exclusion criteria were: a) acute kidney disease requiring HD, b) serious psychiatric or cognitive disorders and c) inability to communicate in Spanish or provide informed consent.

Purposive sampling was used, based on relevance to the research question (Sebele-Mpofu, 2020). Sampling and data collection was pursued until the researchers achieved information redundancy, at which point no new information emerged from the data analysis (Moser and Korstjens, 2018; Sebele-Mpofu, 2020). In our study, this situation occurred after including 18 women.

Data collection

The first stage of data collection (participants 1-5) consisted of unstructured interviews using open questions. During the interviews, the researchers listened carefully, noted the key words and topics identified in the participants' responses, and used their answers to ask for and

clarify the content. In this manner, relevant information was collected from the perspective of the women. After the unstructured interviews, a first analysis was conducted. After this, it was necessary to deepen and understand relevant topics that appeared and required further study. This justified the need for a second stage of data collection. The second stage (participants 6-18) consisted of semi-structured interviews based on a question guide to obtain information regarding specific topics of interest (Moser and Korstjens, 2018). (Table 1). The semi-structured question guide was constructed based on the analysis of the first five interviews, thus reflecting relevant aspects to be investigated from their perspective. The time elapsed between each stage of data collection was two months. The second stage began once the first stage was completed.

The interviews were video-recorded and transcribed verbatim. The transcripts were returned to participants for comments and corrections. A total of 18 interviews with 18 researcher field notes were undertaken. One interview was collected per participant.

There was no repeat interview per participant and no participant dropout during the study. After the interviews, the participants were asked if they had any document in which they had written down their experiences since the onset of the disease, and if so, if they wished to share it to further enhance the study. No specific instructions were given for the elaboration of these written notes. Only participant 2 reported having a diary and agreed to share part of it, transcribing and copying those parts that she chose to share.

During the interviews only the researcher and the participant were present. Overall, 1,210 minutes of interviews were recorded. Of these, 450 minutes corresponded to the first stage and 760 minutes corresponded to the second stage. All interviews were conducted at the participants' homes or in a private hospital room, according to the women's preference. Researcher field notes and personal letters provided by the women were also collected.

Analysis

Complete verbatim transcripts were produced for each of the interviews, researcher field notes and letters. The texts were collated to enable qualitative analysis (Moser and Korstjens, 2018). A systematic text condensation (STC) analysis was performed (Malterud, 2012). This descriptive approach presents the experience of the participants as expressed by themselves, thus STC represents an explorative proposal to present vital examples from peoples' life worlds (Malterud, 2012). STC includes four steps of analysis: 1) Total impression; reading all the material and an overview of the data. 2) Identifying and sorting meaning units and codes; systematically reviewing the transcript line by line to identify meaning units. A meaning unit is a text fragment containing some information about the research question. Subsequently, decontextualization begins, which includes identifying, classifying, and sorting meaning units and marking these with a code—a label that connects related meaning units into a code group. 3) Condensation—from code to meaning; involving the systematic abstraction of meaning units within each of the code groups established in the second step of analysis. Empirical data are reduced to a decontextualized selection of meaning units sorted as thematic code groups across individual participants. 4) Synthesizing – from condensation to descriptions and concepts; data are reconceptualized, putting the pieces together again. By synthesizing the contents of the condensates, descriptions and concepts are developed, providing stories that reflect the participants' experiences (Malterud, 2012). Each of the interviews were analyzed separately, without performing any comparison between one and the other. After analyzing each interview, each researcher listed their themes. Finally, in the case of different opinions, theme identification was decided by consensus. No qualitative software was used on the data.

Rigor criteria

The Guba & Lincoln criteria for guaranteeing trustworthiness were followed (Korstjens and Moser, 2018). The techniques performed are described in Table 2 (O'Brien et al. 2014; Korstjens and Moser, 2018).

Ethics/IRB statement.

The study was approved by the Local Ethical Committee at **Rey Juan Carlos University** (code: **2806201711017**), and the Clinical Research Ethics Committee of Hospital Universitario **Puerta de Hierro Majadahonda** (code: **1117**). The participants were informed of the objective of the study and the reasons for doing the research. All **participants** gave their informed consent before inclusion.

RESULTS

The sample consisted of 18 women. The mean age was 54.11 (SD 14.30). The mean number of years since disease diagnosis was 12.5 (SD 11.8) and the mean number of years on RRT was 6.27 (SD 9.57) (Table 3). Two themes emerged from the data: a) A turning point in their lives, and b) **The emotional journey of beginning RRT**. We included some of the women's narratives taken directly from the interviews in relation to the emerging themes (Table 4).

A turning point in their lives.

The CKD diagnosis marked a turning point, provoking an abrupt change in the lives of the women interviewed. All participants related that the diagnosis resulted in a break from their former lifestyle, resulting in numerous physical and psychological changes, forcing them to adapt to a situation that imposed new rules on them. The women's narratives highlighted the progression of the disease, which caused a direct impact in the physical and functional dimension. They described loss of strength, muscle decline, fatigue, loss of energy and vitality, leading to significant limitations. After the diagnosis, the women felt that their life was torn apart. In the narratives, the emotional impact of receiving the CKD diagnosis was described. The chronic nature of the disease was experienced with a **sense** of "permanence", "for life",

which caused a drastic change in their world. This forced them to modify their life projects and to adapt to losses derived from the disease. The women who had previous contact with the disease and/or with people or loved ones with CKD responded more quickly. Upon the diagnosis, after the shock of the news, they began to organize their lives to cope with the disease. In addition, having had previous contact with the disease at the time of diagnosis can influence the choice of treatment modality. Thus, participant 17 described how living with a relative with AVF and daily in-center dialysis made her decide on another treatment modality.

For the women, one of the key aspects influencing their coping with the disease was the relationship with the healthcare professionals at the dialysis unit, the information and preparation provided, together with the support received during the disease. Faced with a lack of information from professionals, participants decided to seek information from the Internet, books, or other patients, instead of asking for clarification.

The emotional journey of beginning RRT

Once the diagnosis was given, RRT began. The beginning of treatment was a crucial moment of great impact. The experience was different when it was a scheduled treatment (there was **time to prepare**) compared to whether it was implemented suddenly. Thus, participant 13 recounted how she experienced the abrupt start of her dialysis treatment. The women who abruptly began treatment described it as a horrible experience. They recounted how from one day to the next, they found themselves connected "to a machine" without knowing what it did, and with a high-flow vascular access, without enough time to assimilate it. In the case of scheduled RRT, although patients have more time to prepare, the moment **patients are told that they will begin RRT, they still find it challenging** and difficult to accept. Many women, despite knowing that it will come one day, hoped that it would not materialize. Conversely, participant 1 described how the time required by the professionals to construct and prepare her arteriovenous fistula in her arm to administer dialysis helped her to prepare mentally and

emotionally. Regardless of the type of treatment, the women described a series of sensations, emotions, and feelings that they experienced during the first dialysis sessions, including fear, sadness, anger, pain, surprise, uncertainty, frustration, the feeling of being trapped, the awkwardness of the catheter, of being connected to the machine, the unfamiliarity of the treatment and "blood purification", reported as "traumatic" experiences. The narratives of two of the women (P8 and P10) highlight their feelings of unease regarding the treatment and the "machine". Moreover, women with CKD with HD, recalled their experience with the first AVF punctures in detail. They narrated how it was painful, accompanied by a sense of estrangement at the sight of the fistula, along with fear. Over time, despite the continuous need to administer RRT, many women reported that they continued to have difficulties and had not yet gotten used to the fistula punctures. The women described the importance of receiving support throughout the treatment, emphasizing the support received from other patients who had experienced or were still undergoing RRT, enabling them to share their experiences, fears and insecurities. The women described their desire to become counselors or "mentors" to other patients, highlighting two essential messages for future patients: a) the disease must be accepted as part of life, b) encouragement to continue with treatment, and c) an opportunity to continue living despite the seriousness of the disease.

DISCUSSION

Our results show that the diagnosis of CKD marked a turning point in the lives of our participants. Previous studies on the meaning of RRT have described this change as a "*life metamorphosis*" (Gullick et al., 2017). This term refers to the transformation that appears in the daily life of people and in their physical and emotional dimensions, when they are diagnosed with CKD (Filgueiras de Assis Mello and Angelo, 2018). After diagnosis, patients are faced with a new reality (Stavropoulou et al., 2020). New habits and routines are incorporated, lifestyles are changed, and they begin to adapt to a new life conditioned by the

disease (Stavropoulou et al., 2020). These changes include dietary requirements, frequent contact with the hospital environment and interruption of daily activities that affect work or studies (Stavropoulou et al., 2020). Learning to cope with the disease and the new challenges that arise is a long process that requires patients to be patient and persevere in the face of difficulties (Ghaffari et al., 2019). This is not something that can be achieved overnight (Ghaffari et al., 2019). When these changes occur suddenly, in relation to diagnosis and urgent treatment, patients feel that their whole world is shaken (Ghaffari et al., 2019; Lin and Chu, 2022).

Previous qualitative studies on the impact of CKD in women describe how the disease influences the experience of motherhood, becoming pregnant, and childcare, triggering changes in the self-perception of their body and sexuality (Álvarez-Villarreal et al., 2019). Álvarez-Villarreal et al. (2019) described how the catheter and the fistula caused alterations in the body image and sexuality of women with CKD. Thus, patients perceived their bodies as swollen or deformed. In addition, women changed the way they dressed, in an attempt to hide the catheter and/or fistula and reported how the presence of catheters and/or AVF was uncomfortable during sexual relations.

The initiation of RRT is an important change in the life of the CKD patient, therefore an adequate adaptation is necessary to achieve a good health-related quality of life (Fuertes et al., 2017; Sousa et al., 2023). Our participants recounted the difficulties faced to adapt to the treatment. They were not used to this new routine in their life. Previous studies (Stavropoulou et al., 2020; Schrauben et al., 2021) highlight contradictions in the self-care of patients with CKD, due to erratic and irregular compliance with professional recommendations, because it was difficult for patients to change their previous habits and routines.

The experience of the participants in the present study is marked by the first dialysis sessions and the first AVF punctures. In previous studies (Kopple et al., 2017; Griva et al., 2019), patients described their first dialysis session as a process that was hard, long, and insidious. The beginning of dialysis treatment brings an end to their dreams, and their professional, social, and personal activity.

In the presence of fear, uncertainty and the emotional impact of the treatment and the changes derived from it, previous studies show that it is necessary to establish educational programs for patients and family members, where they can reflect on the perceived difficulties (Díaz-Medina and Guerreiro-Vieira-da-Silva, 2020). It is key to provide comprehensive, concise education on a regular basis, encouraging patient motivation and participation in their self-care (López-Vargas et al., 2016; Al Rahbi and Al Salmi, 2020). This education should lead patients to modify their behaviors and help them to adopt new life habits that will enable them to control their thoughts, feelings, motivations and actions (Al Rahbi and Al Salmi, 2020).

Furthermore, to incorporate a comprehensive perspective of CKD care, it is necessary to incorporate the patients themselves as agents of change and with a voice within the collective spaces of care and health promotion (López-Vargas et al., 2016). Haldar et al. (2017) showed that the strategy of "learning from the experience of others" with people who share a similar life situation is effective for behavioral changes and educational processes. Our participants demand the help of other patients with whom to share experiences and clarify the uncertainties that arise as CKD patients. Patient-led hospital mentoring programs help to incorporate the community into healthcare strategies and provide emotional support in long-term illnesses (Ghahramani et al., 2021).

The experience of peer support in CKD, as an educational tool in hospital teams, covers patient needs that are not usually addressed, such as the emotional dimension (García-Llana et al., 2019; Ghahramani et al., 2021). In addition, it offers an opportunity for patients to share

their difficulties and concerns with others regarding the challenges of CKD (Enriquez and Conn, 2016; Ghahramani et al., 2021). There are other initiatives regarding peer-to-peer support and mentoring that are effective for promoting adherence to pharmacological treatment, through social support networks, the use of Internet discussion groups and peer-led interventions (Enriquez and Conn, 2016).

The involvement of chronic patients in the exchange of information and support for patients with chronic diseases has a positive influence on coping strategies, helping patients to feel more hopeful by sharing their real-life experiences (Enriquez and Conn, 2016). In CKD, the use of peer mentors leads to improved quality of life for patients, resulting in patient-centered care, anxiety relief, reduced feelings of isolation, and improved adherence to self-care (Ghahramani et al., 2021).

The limitation of the present study is that it only includes women and therefore we cannot determine whether the experiences described in the paper are unique to them or whether men have similar experiences. Future research should incorporate both perspectives or address the experience of male patients. Also, gender roles should be taken into account when considering concealment of disease, as underlying differences due to gender may influence the disease experience and how it affects daily life (Tong et al., 2015). Indeed, our results cannot be extrapolated to the whole population with CKD, however, they can most likely be applied to other contexts with similar characteristics (Creswell and Poth, 2018).

CONCLUSIONS

The diagnosis of CKD and the initiation of treatment marks a profound change in the lives of women with CKD. It involves a change of routines and habits and an adaptation to their new life with CKD. The first dialysis and the use of AVF puncture is an experience that marks the lives of women with CKD. The presence of support from other patients in similar situations, and/or who have more experience is perceived positively as a necessity, and a way

to share their experiences and resolve their doubts and treatment uncertainty treatment among peers. Women with CKD should receive more information and education on aspects such as the AVF and the RRT application process.

RELEVANCE FOR CLINICAL PRACTICE

The results this study could be applied to establish peer mentoring programs among CKD patients in dialysis units and would enable the establishment of collaborations between healthcare centers and CKD patient associations. Care programs should take gender into account by providing care that is specifically focused on women, given the impact of CKD diagnosis and treatment.

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AUTHOR CONTRIBUTIONS

MA-N: Investigation, Methodology, Formal Analysis, Writing—Original Draft Preparation; EV-C: Conceptualization, Formal Analysis, Writing—Review and Editing; AS-C: Conceptualization, Formal Analysis, Writing—Review and Editing; MG-S and AG-C: Conceptualization, Resources, Writing—Review and Editing; DP-C: Conceptualization, Investigation, Formal Analysis, Funding Acquisition, Writing—Original Draft Preparation.

DECLARATION OF CONFLICTING INTEREST

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Table 1. Unstructured and semi-structured interview guide.

Interview type	Questions
Unstructured interview	<p>What is your experience with CKD?</p> <p>What is the most relevant for you?</p>
Semi-structured interview	<p>Do you consider that CKD has changed your life? How?</p> <p>How was it when you were diagnosed with CKD, what was the most relevant issue for you?</p> <p>What do you consider to be the most relevant aspect of the renal replacement therapy that you have been prescribed?</p> <p>What challenges have you faced as a woman with CKD?</p>
<p>During all the interviews (if needed) to enhance the depth of the discussion of a specific topic, researchers used prompts or probes: (a) to encourage the patients to provide more detail, (b) to encourage the participant to keep talking, (c) to resolve confusion (paraphrasing something that the patient had said) and (d) to show that they had the researcher’s full attention.</p> <p>Please, can you tell me a bit more about that?</p> <p>Have you experienced the same thing since?</p> <p>That’s really interesting, please tell me more.</p>	

Table 2. Trustworthiness criteria.

Criteria	Application procedures
Credibility	<p>Investigator triangulation: each data source was analyzed. Thereafter, team meetings were performed during which the analyses were compared and themes were identified.</p> <p>Triangulation of data collection methods: including unstructured interviews, semi-structured interviews, and researcher field notes.</p> <p>Participant validation: this consisted of asking the women to confirm the data obtained during data collection.</p>
Transferability	<p>In-depth descriptions of the study performed, providing details of the characteristics of researchers, participants, contexts, sampling strategies, and the data collection and analysis procedures.</p>
Dependability	<p>Audit by an external researcher: an external researcher assessed the study research protocol, focusing on aspects concerning the methods applied and the study design.</p>
Confirmability	<p>Investigator triangulation, data collection triangulation.</p> <p>Researcher reflexivity was encouraged via previous positioning, performance of reflexive reports and by describing the rationale behind the study.</p>

Table 3. Demographic and clinical features of the women with chronic kidney disease

Age	Mean age: 54.11 (SD 14.30) Minimum age: 28 years old Maximum age: 78 years
Age at diagnosis (years)	Mean age since diagnosis of disease, 12.5 (SD 11.8)
Years on renal replacement therapy	Mean number of years on renal replacement therapy, 6.27 (SD 9.57).
Treatment type	Hemodialysis, n= 13 Peritoneal dialysis, n=5
Vascular access device	Arteriovenous fistula, n=9 Catheter peritoneal dialysis, n=5 Permanent venous catheter, n=4

Table 4. Narratives from female participants with chronic kidney disease

<p>A turning point in their lives.</p> <ul style="list-style-type: none">• The diagnosis changes everything: <i>“...My life was totally changed when I was diagnosed with this problem. It affected me psychologically, and physically.”</i> (P2).• Functional limitations: <i>“...before this disease, I was strong, I did a lot of things, I was agile, but now I can't even walk. I am no longer the same.”</i> (P5), <i>“Before, I had more strength, I liked to go out a lot. The disease has forced me to stay at home.”</i> (P10).• Aggressive disruption of the disease: <i>“... it felt like I was split in half. It affected me because I had other things to do in my life, and I experienced it as being very aggressive. I didn't want to be sick. It was a terrible downfall for me ...”</i> (P8), <i>“When the disease begins, everything falls apart, and within a year I couldn't see people, I couldn't even set foot on the street.”</i> (P16).• Preparing for change and coping with the disease: <i>“My disease runs in my family, I have been seeing it for a long time because it started with my grandfather, my uncles, my mother, my cousins. I knew what it was about, I was prepared.”</i> (P9).• Reasons for choosing a treatment modality: <i>“I had seen the vein thing in my family, and I didn't like it. The fistula in the arm swelled and the vein got fat, I couldn't cope with it. Being at hospital all day, with an ambulance to go there and come back... it's a long time, I resented it and decided to go on peritoneal dialysis at home.”</i> (P17)• Searching for information on the internet, books or other patients: <i>“I think that many people on dialysis would like to have it explained to them better. When you</i>
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don't know something, you figure it out among the other patients, that's when you find out, not from the professionals. Sometimes they give you a little piece of paper and that's it. I have made an effort to buy books, to find out which diets have more potassium" (P1).

The emotional journey of beginning RRT

- **The abrupt** start of dialysis treatment: *"I was fine and the next day I was on dialysis, plugged into a machine. It scared me and I cried and cried. The first few days, I wasn't even able to think about what had happened." (P13)*
- **Seeing the catheter and the machine:** *"I didn't know what was going on, and I started crying like a baby. I wasn't well, I was sad, I was heartbroken. Seeing myself with a catheter and on dialysis, needing the machine. I couldn't sleep, I was crying because my heart was broken. It wasn't easy" (P16). "They sent me to the intensive care unit. The worst thing was when the doctor came and told me that I had to have the catheter dialyzed in the emergency room, it was a horrible experience." (P3).*
- **The beginning of treatment:** *"I already knew it, and I knew that sooner or later it was going to be like this, but when they tell you for sure, the day and the hour... the truth... you get a shock: I remember it was a very hard day." (P9).*
- Prepare mentally and emotionally: *"I came out with the fistula; I didn't have any dialysis that day. Even though everything was ready, and my fistula was prepared, I needed to be alone and to be able to think about myself. To prepare myself emotionally for what was to come. It was hard work." (P1)*
- Discomfort with the treatment and the "machine": *"Well, very strange. I had seen the process, how they drew the blood. However, one thing is seeing it, and another is feeling it, it's very different. Very ugly, very bad, it felt strange." (P8), "I felt very bad, I cried for two days. Of course, I remember it. It felt strange, I thought, oh my*

God, I must live off a machine. It's disgusting, they take your blood, they put your blood in." (P10).

- Painful, estrangement and fear at the sight of the fistula: *"The first time they puncture you in the fistula is quite painful and traumatic. They have to find the vein and remove the needle inside your arm and you're afraid the fistula will rupture."* (P1), *"... the jabs... I have those jabs in my mind, I can still remember them. It was a very strange feeling, partly pain, partly fear. It showed you what your life was going to be from that moment on... Pain and fear."* (P2).
- Difficulties and not getting used to fistula punctures: *"You should become used to it, because you have no choice. The thing is I don't get used to being needed. I don't think I'll ever get used to being needed."* (P13).
- **Peer support is considered as essential by patients:** *"I think it's good that people who are about to go on dialysis get together with people who have been and are on dialysis and tell them that nothing is wrong, that life goes on. It's a great support to see another person who has gone through the same thing as you and is still there."* (P12). *"It can always come in handy for you, because I could have asked, how did you cope, what did it feel like the first time, how did you cope afterwards. I'm sure it would have made me feel better."* (P17).
- Being counsellors or "mentors" to other patients: ***"The truth is that it is necessary. Your help is like a guide, to understand everything, share what they are feeling, make some sense of it. Only those of us who have lived through it understand it and can help other dialysis patients."*** (P2).