

Home care in people on hemodialysis emphasizing diet and vascular access

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ABSTRACT

Introduction: People on hemodialysis must take daily care of their vascular access, adhere to diet and fluid restrictions. However, there are few qualitative studies on this.

Objective: To analyze home care in people on hemodialysis, emphasizing diet and vascular access.

Material and Method: We conducted a qualitative, descriptive, exploratory, and interpretive study, where 12 people on hemodialysis at the Northern Kidney Center in Peru participated, with convenience sampling. The sample size was obtained by the criterion of saturation and redundancy. A semi-structured interview validated by expert judgment was used to collect the data, which were processed according to thematic content analysis.

Results: a) New eating habits to comply with dietary regimen, b) Strategies to comply with fluid regimen and thirst control, c) Care of vascular access in their daily life.

Conclusions: It has been identified that people on hemodialysis, with the support of their families, follow the recommendations of health professionals regarding dietary and fluid restrictions, meticulous care of their vascular access in terms of body hygiene and rest. However, aspects that require improvement through personalized education are identified, especially when they avoid eating at night to control weight, eating out in restaurants or at family gatherings, where the prescribed diet is not followed.

Keywords: renal dialysis; home health care; housing; caregivers; qualitative research.

RESUMEN

Cuidados en el hogar en personas sujetas a hemodiálisis enfatizando la dieta y el acceso vascular

Introducción: Las personas que reciben hemodiálisis deben cuidar diariamente su acceso vascular, cumplir con la dieta y restricción de líquidos, pero existen escasos estudios cualitativos sobre ello.

Objetivo: Analizar los cuidados en el hogar en personas sujetas a hemodiálisis enfatizando la dieta y el acceso vascular.

Material y Método: Estudio con enfoque cualitativo, descriptivo, exploratorio e interpretativo, donde participaron 12 personas que reciben tratamiento de hemodiálisis en el Centro del Riñón del Norte en Perú, con muestreo por conveniencia y el tamaño de la muestra se obtuvo por el criterio de saturación y redundancia. Para recolectar los datos se usó una entrevista semiestructurada validada por juicio de expertos. Los datos fueron procesados según el análisis de contenido temático.

Resultados: a) Nuevos hábitos alimentarios para cumplir régimen dietético, b) Estrategias para cumplir régimen hídrico y control de la sed, c) Cuidados con el acceso vascular en su vida cotidiana.

Conclusiones: Se ha identificado que las personas en hemodiálisis, con el apoyo de sus familias, siguen las recomendaciones de los profesionales de la salud en cuanto a las restricciones alimentarias, de líquidos, el cuidado meticuloso de su acceso vascular en lo que respecta a la higiene corporal y al descanso. No obstante, se identifican aspectos que requieren mejoras a través de una educación personalizada, sobre todo cuando evitan comer por la noche para controlar el peso, comer fuera de casa en restaurantes o en reuniones familiares, donde no se sigue la dieta prescrita.

Palabras clave: diálisis renal; atención domiciliaria de salud; vivienda; cuidadores; investigación cualitativa.

INTRODUCTION

Chronic kidney disease (CKD) is a progressive disease that affects more than 800 million people worldwide; its treatment is costly and impacts the economy of the State, the patient, and their family¹. When CKD progresses, these individuals require lifelong renal replacement therapy to survive, and hemodialysis (HD) is the most common modality. People receiving HD must follow a rather complex treatment regimen that includes dietary and fluid restrictions, attending HD sessions of three to four hours three times a week, caring for their vascular access (VA), and adhering to pharmacological treatment².

Despite recognizing the importance of self-care at home, they have difficulties complying with the strict fluid and food intake regimen, and they neglect themselves by indulging in "cravings" in their meals^{3,4}. Similarly, after HD treatment, vascular access care must continue at home, and in the case of the central venous catheter, the dressing must be kept clean and dry to avoid infections, since the success or failure of their treatment depends on it^{5,6}. Furthermore, non-compliance with these instructions significantly increases their hospitalization and mortality⁷. Hence, the importance of understanding how they take care of themselves at home.

In this regard, a study in Korea⁸ revealed that people on HD take care of their fluid intake, but this restriction is the greatest stress factor they experience. In China⁹, they concluded that fluid restrictions and lack of emotional management are the aspects that most affect people on HD. In Palestine¹⁰ and Cuba², people on HD recognize that it is very complicated to comply with fluid and diet restrictions. Meanwhile, in Peru¹¹, they report that people on HD comply with vascular access cleaning, avoid lifting weight with their VA-bearing arm, and protect their catheter when showering.

The effectiveness of hemodialysis is intrinsically linked to commitment to compliance with nutritional guidelines, fluid control, and meticulous vascular access care^{12,13}. Therefore,

it is essential to explore this practice from the perspective of the experiences of people on HD, in whom the knowledge gap of qualitative studies is evident, so that health personnel, especially nurses, can offer education and follow-up tailored to each individual to prevent complications. In response, the objective was formulated to analyze home care in people undergoing HD, emphasizing diet and VA.

MATERIAL AND METHOD

Given that the topic is novel and there are few qualitative studies available, a study with a qualitative approach, descriptive, exploratory, and interpretive design¹⁴ was carried out, detailing a reality, delving into a little-researched area, to intuit the experiences of the participants about home care related to diet and VA carried out by people on HD treatment.

The population consisted of 80 people on HD at the private institution Centro del Riñón del Norte S.A.C., located in the department of Lambayeque, district, and province of Chiclayo. Adults with a minimum of 3 months on HD were included, and those who had difficulty communicating verbally and those who did not wish to participate in the study were excluded. The sample was non-probabilistic for convenience. And the sample size was reached with 12 people on HD, determined by the saturation and redundancy criterion, that is, when the interviewees' discourses became repetitive and did not provide interesting data related to the object of study.

Of the total people on HD interviewed, 9 are men and 3 women, aged between 25 and 66 years. Regarding the educational level, 4 have incomplete primary education, 4 incomplete secondary education, 3 complete secondary education, and only one patient had technological higher education. Four come from the high Andean area of the Lambayeque region, three are from the Chiclayo district, two from Cajamarca, two from Amazonas, and one from Piura.

These sociodemographic characteristics may influence the study results, since most of them have incomplete studies and therefore some difficulty in understanding the indications of health personnel about their self-care related to food and fluid intake. Similarly, most come from different Andean regions, where food customs and travel to the city for treatment cause them to fail to comply with the diet.

Data were collected through semi-structured interviews¹⁴, validated by three experts in qualitative research and the subject matter, to ensure the congruence of the questions with the object of study and improve their wording. The instrument contains general patient data and open questions related to the object of study: How do you comply with the dietary and fluid regimen at home? When you are thirsty, how do you control the fluids you drink? How do you know you are overweight (what do you feel) and how do you take care not to gain weight? How do you take care of your vascular access during the day, when you bathe, and when you sleep?

The interviews were conducted in September and October 2023. The place, date, and time of the interview were according to their preference and availability; eight interviews were conducted in the nursing topic of said institution, and four interviews were conducted in their homes, lasting approximately 20 minutes, and a voice recorder was used, with prior informed consent. It is worth mentioning that even having collected the data in two contexts (clinic and home), the interviews were conducted preserving privacy, with trust and empathy, so that, in both scenarios, the interviewees answered the questions easily and naturally.

Afterward, each interview was transcribed into a Word document and sent via WhatsApp for the interviewees to confirm the data. It should be noted that the audios will be kept for two years in case of an audit, complying with the scientific rigor criterion of credibility¹⁴.

After the interviews were conducted, data were processed and analyzed manually, through thematic content analysis¹⁵, including 3 phases: 1) pre-analysis, the collected data were transcribed and organized. Then, the information strictly related to the object of study was read and selected. Similarly, aspects not related to the research were eliminated; 2) coding, ideas and concepts were fragmented into a word or short phrase that represents the units of meaning, to favor the reduction of data, 15 codes were obtained; and 3) categorization, the codes were ordered and classified by similarity in their content, emerging three categories.

Among the ethical aspects, voluntary participation in the study was guaranteed through informed consent. To protect participant confidentiality, codes were assigned (OS1, OS2... OS12). Likewise, this study was carried out with the prior approval of the Ethics and Research Committee of the Faculty of Medicine of Universidad Católica Santo Toribio de Mogrovejo with resolution N° 251-2023-USAT-FMED and the authorization of Centro del Riñón del Norte S.A.C.

RESULTS

After data processing, the following categories were obtained, which are illustrated with the most significant discourses that reflected the experiences of the study subjects.

a) New eating habits to comply with the dietary regimen

People on HD have modified their eating habits to comply with a strict diet, mostly prepared by a family member. They have adopted a low-salt diet without intense flavors, even eliminating certain foods such as legumes or corn. They avoid consuming foods high in salt, sugar, dairy, coffee, and certain fruits. Some choose not to have dinner to control their weight. However, some patients face difficulties following dietary recommendations due to living alone or residing far from the hemodialysis center, which leads them to occasionally eat in restaurants or consume prohibited foods at family gatherings or social events, such as duck or pork, causing them digestive problems like diarrhea. Despite recognizing the sacrifice

involved in complying with the diet, they resign themselves and abide by it. As described below:

"My mom makes the diet they tell me, or sometimes I cook, everything is very low in salt, and we also dialyze the food, for example: if it's stew, I soak it, and throw away the water when it boils, then I add more water, and that's how it cooks... I avoid salted mackerel, for me it's poison, milk, coffee, mango, pitahaya, or plum because they give me diarrhea, it's a sacrifice to follow this diet, but I have no other choice..." OS5

"Mostly I cook, everything is low in salt... I dialyze the stews, I blend the garlic with a little salt, when I make my dressings I no longer add salt to the chicken pieces, rice, I don't add tomato to my dressings because they tell me it's harmful to me, I only eat the portion they give me, I drink chamomile or anise in sugar-free infusion..." OS11

"My daughter cooks everything low in salt... for breakfast, sugar-free oatmeal and corn, for lunch, rice scrambled eggs with lemonade soda, and sometimes at dinner, I feel heavy and don't have dinner, I just drink chamomile so I don't gain weight..." OS6

"The day I don't get dialyzed, I cook, I add very little salt to the food, I avoid eating salted fish, star fruit, and chocolate because it gives me diarrhea... but when I have birthdays, I eat pork or duck there because there is nothing else to eat..." OS4

"They eat differently here, it's not like at my house, I'm from Amazonas. Sometimes I eat at the restaurant when I leave hemodialysis, but it gives me diarrhea, so I prepare my food or my neighbor invites me... I don't have dinner anymore because I carry a lot of weight..." OS10

"I avoid salted mackerel, mango, pitahaya, or plum because they give me uncontrollable diarrhea... when I'm at home, I take care of my food, but when I go to my mom's house I mess up, she serves me a lot, and it makes me sad to disappoint her..." OS8

b) Strategies to comply with the fluid regimen and thirst control

On the other hand, people on HD use various strategies to manage the feeling of thirst they experience. When they feel thirsty, they resort to practices such as drinking warm or cold water with a little sugar-free lemon, sucking on ice cubes, gargling, or chewing ice from lemon candies. Some choose to consume juicy fruits such as pears, limes, or cucumbers to quench their thirst. Others seek to stay busy to distract themselves and avoid the temptation to drink excess water. They recognize that fluid intake control is crucial to avoid weight gain and the feeling of bloating. As they narrate below:

"I drink half a glass of very cold water... if I'm very thirsty, I put ice cubes in my mouth, and it quenches my thirst, I try to stay busy, and that way I don't think about drinking water... I avoid foods with a lot of water because my eyes, face, hands, and feet swell, my legs hurt, and I did gain weight..." OS1

"I have cold water in my jug, I gargle up to three times, and I play with the water in my mouth until the water gets warm and I spit it out, then I take a sip of water, and it goes away... or I keep myself busy so I don't think about thirst..." OS10

"I put a lemon candy in a glass of water, then I put it in the refrigerator to freeze, I suck on that ice, and I keep it like playing in my mouth until my thirst goes away... when I work or get distracted, I forget I'm thirsty..." OS12

"When I'm thirsty, I drink warm water with half a lemon cap, and I take small sips with a spoon... or I eat a pear, a lime, or a cucumber, and it calms my thirst... I try to maintain my weight, when I carried too much weight, I felt agitated, my feet swelled, and my head was bursting with pain..." OS9

"I try to maintain my weight and drink little water, because when I swell, the headache is unbearable..." OS5

c) Vascular access care in their daily life

All people on HD diligently care for their VA, avoid forced exercises on the carrier arm, or use gloves or long-sleeved clothing when leaving home. During sleep, they adopt supine, right, or left lateral positions, being careful not to compress or damage the fistula. In addition, they monitor the normal functioning of their VA, recognizing it by a sound similar to a vibrator, calling it a "motor." To prevent hematomas or scars, some apply creams like Ubresan®. And they are cautious during bathing, covering their VA with cloths, plastic bags, adhesive bandages, or a family member assists them in their hygiene to prevent the dressings from getting wet.

As they describe:

"I wear a shirt up to my elbow so it doesn't show that I have a fistula, I always touch the little motor of my fistula, which should be very electric... I don't do hard work, I don't lift weight... when I sleep, I lie down straight so I don't crush it" OS10

"I limit doing force with the arm where my fistula is, and I sell it so I don't hit it... I also apply Ubresan so it doesn't leave a scar... at night I sleep with my hand crossed on my chest" OS1

"I keep my arm nice, I apply Ubresan so it doesn't leave a scar... To sleep, at first I had difficulty, the little motor of my arm moved by itself due to the vibration, and I try to sleep on my back and not let my bed hit the fistula" OS9

"When I have pain in my fistula, I put aloe vera leaf on it, I previously remove the iodine, leave it in water for a few hours, and apply it to my fistula. I lie on my right side to sleep and not touch my fistula..." OS3

"During the day I work in my workshop and avoid doing force with my arm that has the catheter... I cover my catheter with a bag, and I bathe by pouring water with a jug or I ask my family member to help me. Sometimes I wipe a damp cloth on my neck, shoulders, down to my waist to avoid wetting my catheter" OS6

"With a clean cloth and packing tape I stick to the contour of my catheter, first I wash my head with running water, then I call my daughter to rub my back with soap and I rinse myself, but even if the gauze of my catheter gets wet, I change it, first I put alcohol on my hands and place dry gauze and fix it with adhesive bandage..." OS4

"I bathe with a jug, first I wash my head, I wrap my head with a towel, and I continue with my body without wetting my catheter..." OS12

DISCUSSION

In this study, people on HD highlight the difficulty of incorporating new habits to address the recommended diet, but they recognize the importance for their well-being. The family plays a fundamental role in the preparation of this diet, promoting the reduction of salt use, dialysis of certain foods, consumption of cooked egg whites, soy drinks, or sugar-free infusions. However, there are also inappropriate behaviors, such as skipping dinner to avoid gaining weight, not following the diet at family gatherings, or eating out in places where there is no specific option for them. When feeling hungry, many do not consider the potential risk to their health. Therefore, it is recommended that nursing and nutrition personnel continuously monitor dietary compliance, to raise awareness among patients and their families.

Results similar to the study by Fuentes et al.¹⁶, where people on HD treatment modify their lifestyles, especially restricting the consumption of fish, dairy, sausages, and dialyzing food, a technique that consists of soaking legumes and tubers for 24 hours to reduce mineral content. However, other participants tend to eat everything and do not control themselves. In contrast, Kim and Lee¹⁷, express that some people on HD use a small plate and chopsticks instead of a spoon to reduce their food intake, and exclude prohibited foods. And Hwang et al.¹⁸ showed that participants with normal blood results reported restricted food intake, avoided eating out, processed foods, raw fish, and did not skip meals.

To regulate fluid intake, they adopted certain habits such as drinking half a cup of cold or hot water with sugar-free lemon, sucking on ice cubes or frozen lemon candies. Some participants preferred to consume pears, limes, or cucumbers to quench their thirst, and they strive to stay busy to distract themselves from the feeling of thirst. They recognized that lack of control in fluid intake could trigger symptoms such as tachycardia and swelling in eyelids, face, hands, and feet, resulting in weight gain.

These results are similar to the study by Kim and Lee¹⁷, highlighting that hemodialysis patients drank water only when they wanted it gradually, very slowly, and used a straw. When the water was in their mouth, they held it before spitting it out. Then they repeated this process, never swallowing the water. They also did outdoor activities to distract themselves and suppress thirst. In addition, Vijay and Kaur¹⁹ concluded

that non-compliance with fluid restrictions is highly prevalent among HD patients, causing them fluid overload in the interdialytic phase and the accumulation of metabolic waste that limits the benefits of HD²⁰.

Of note, the study participants' families are aware and monitor compliance with the indicated intake of food, fluids, weight control, and reduced salt consumption. As can be seen in the aforementioned studies, in different parts of the world people receiving hemodialysis have the same indications, but according to their customs, habits, and available foods, they adapt to the recommendations of health personnel, acquiring some particular strategies to comply with the imposed restrictions, it is necessary that they comply because the success of this treatment depends on it. In this regard, Özkan and Taylan¹³, recommend that there be individualized counseling on diet and fluid restriction, considering the cultural environment, barriers, or difficulties of each person on HD.

This study shows that people on HD are very careful with their VA, for which they follow some routines for their daily protection, avoid activities that cause them to use force, use bandages or an elbow pad for fear of hitting the arm where they have the VA, they check the vibration of the VA. They also adapt some sleeping positions and do not compress their VA. Sometimes they receive family support to perform their body hygiene and are very careful when handling it. This is because the personnel who hemodialyze them indicate the daily routine of self-care practices so that they maintain a clean and protected access²¹. Fernández et al.²², reports that learning to shower with the VA awakened restlessness and impotence in people on HD who were used to exercising self-care, which increased the feeling of loss of control over their body.

In view of the above, it is suggested that nursing personnel continuously supervise people on HD on compliance with the diet, fluid regimen, vascular access care, and even pharmacological treatment, resorting to telenursing, to prevent intra- and post-dialytic complications, which can be detected through the results of monthly laboratory tests of each patient. Likewise, it is proposed to provide information through brochures or exclusive guides for home care, encouraging the participation of both the person on HD and their family caregiver.

We should also mention that it would be valuable to explore in future research the opinion of the family caregiver and nursing staff to triangulate the information.

In conclusion, the family caregiver is a fundamental pillar for home care and compliance with health recommendations for people on HD. Changes in eating habits were observed, where most receive help from their families to prepare the diet, low in salt and without intense flavors, and modifying certain foods. However, some people on HD skip dinner to control their weight or have difficulty following dietary indications when eating out, or when they come from other cities because

they eat in restaurants and do not follow the diet, which can compromise their health.

Regarding fluid control, they resort to methods such as drinking water with sugar-free lemon or consuming juicy fruits, but they recognize that lack of control can trigger symptoms such as tachycardia and fluid retention.

In addition, meticulous vascular access care is evident, implementing protection measures during sleep and personal hygiene, avoiding activities that require effort and using bandages or elbow pads to prevent arm injuries.

Conflicts of interest

The authors declare no conflicts of interest related to the research, authorship, and/or publication of this manuscript.

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