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Analysis of vascular access self-care and health literacy of people on haemodialysis

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ABSTRACT

Objectives: To analyse the self-care of vascular access by people on haemodialysis and its relationship with the level of health literacy.

Methodology: Single-centre, cross-sectional, observational study conducted between March-April 2024. Variables: sociodemographic, vascular access-related, self-perceived knowledge and information demands. Vascular access self-care was analysed, and the level of health literacy was collected using the HLS-EU-Q16 questionnaire.

Results: A total of 39 participants were included, 64.1% men, mean age 60.76±18.33 years, mean time on haemodialysis: 5.54±7.06 years. 53.8% had arteriovenous fistula, and 33.3% of patients did not know the type of access they were carrying. 53.8% had arteriovenous fistula, and 33.3% of the patients did not see the kind of access they were carrying. A total of 36.1% reported being dependent on self-care. 18% reported a low/very low level of knowledge about vascular access self-care, and 79.5% indicated wanting more information, identifying the nurse as the primary source of information. The least followed self-care in fistula patients was “Avoid using forceps to compress when removing needles”, and in catheter wearers, “Avoid handling the catheter dressing at home”. 59% had an insufficient/problematic level of literacy. There was no relationship between vascular access self-care knowledge and health literacy level (p=0.11).self-care was analysed, and the level of health literacy was collected using the HLS-EU-Q16 questionnaire.

Conclusions: People on haemodialysis demand more information on vascular access and self-care. A significant percentage of people on haemodialysis have insufficient or problematic health literacy. No relationship has been found between vascular access self-care knowledge and health literacy.

Keywords: haemodialysis; vascular access; self-care; health literacy.

RESUMEN

Análisis de los autocuidados del acceso vascular y nivel de alfabetización en salud de las personas en hemodiálisis

Objetivos: Analizar los autocuidados del acceso vascular que realizan las personas en hemodiálisis y su relación con el nivel de alfabetización en salud.

Metodología: Estudio observacional transversal, unicéntrico, realizado entre marzo-abril del 2024.
Variables: sociodemográficas, relativas al acceso vascular, autopercepción de conocimientos y demandas informativas. Se analizaron los autocuidados del acceso vascular y se recogió el nivel de alfabetización en salud mediante el cuestionario HLS-EU-Q16.

Resultados: 39 participantes, 64,1% hombres, edad media 60,76±18,33 años, tiempo medio en hemodiálisis: 5,54±7,06 años. Un 53,8% tenían fístula arteriovenosa, el 33,3% de los pa-

cientes desconocía el tipo de acceso que portaban. Un 36,1% referían ser dependientes para el autocuidado del mismo.
El 18% manifestaron tener bajo/muy bajo nivel de conocimientos sobre autocuidados del acceso vascular, un 79,5% indicaron querer más información; identificando a la enfermera como la principal fuente de información.
El autocuidado menos seguido en los pacientes con fístula fue "Evitar utilizar las pinzas para comprimir al retirar las agujas", y en los portadores de catéter "Evitar manipular el apósito del catéter en casa". El 59% presentaba un nivel de alfabetización insuficiente/problemático.
No se encontró relación entre los conocimientos sobre autocuidados del acceso vascular y el nivel de alfabetización salud (p=0,11).

Conclusiones: Las personas en hemodiálisis demandan más información sobre los autocuidados del acceso vascular.
Existe un importante porcentaje de personas en hemodiálisis con un nivel de alfabetización en salud insuficiente/problemático.
No se ha encontrado relación entre el nivel de conocimientos para el autocuidado del acceso vascular y el nivel da alfabetización en salud.

Palabras clave: hemodiálisis; acceso vascular; autocuidado; alfabetización en salud.

INTRODUCTIÓN

Among the different dialysis modalities, haemodialysis (HD) is currently the most widely used form of renal replacement therapy[1].

Currently, vascular access (VA) remains one of the greatest challenges, due to the complications associated with its use and its major impact on the morbidity and mortality of individuals with advanced chronic kidney disease (ACKD)[2,3].

As in other chronic diseases, patient involvement in self-care has a positive impact on quality of life and reduces complications and hospital admissions, thereby improving healthcare system costs[4,5],

In recent decades, the profile of patients undergoing HD has changed, with an increasingly elderly, dependent and frail population, with significant comorbidity—factors that may be directly related to patients' capacity for self-care[1,6].

Health literacy (HL) is a fundamental process that enables individuals to understand and use information related to their health and different aspects of their disease. In the context of patients with ACKD, health literacy becomes even more important, as this is a chronic condition in which patients and their families must understand the necessary care, recognise the signs and symptoms of potential complications, and know how to act in such situations[7].

The sources from which patients receive information about their disease and treatment are multiple, and situations may arise in which they follow incorrect practices due to lack of knowledge, potentially generating complications with a major impact on health outcomes[8,9].

Health education therefore constitutes a key component in this population[10-12], To design effective health education strategies, it is necessary to assess the knowledge held by the individuals we care for, as well as their needs, to identify the main topics to be addressed.

For all these reasons, it is necessary to determine patients' level of knowledge regarding VA self-care, as well as their level of HL, which is particularly relevant for promoting disease-specific knowledge and improving behaviours that enhance treatment adherence[13,14],

The general objective of this study was to analyse VA self-care practices among people undergoing HD and their relationship with HL level.

The specific objectives were to:

- Identify the main sources of information used by these patients to carry out VA self-care, as well as their preferences.
- Analyse adherence to recommendations for VA self-care in HD, both for arteriovenous fistulae (AVF) and central venous catheters (CVC).
- Evaluate the level of HL among people on haemodialysis.
- Analyse the relationship between HL and knowledge regarding VA self-care.

MATERIALS AND METHODS

Study design, setting and period

We conducted an observational cross-sectional study among patients on HD at *Hospital Universitario de Jaén* (Jaén, Spain) from April through May 2024.

Population and sample

All individuals on HD were included after applying the following criteria:

Inclusion criteria: adults aged ≥18 years, undergoing HD for at least 3 months, and carrying a VA for HD, either an AVF or a CVC.

Exclusion criteria: individuals with cognitive impairment, sensory deficits or clinical conditions that prevented completion of the questionnaire, as well as refusal to participate after receiving appropriate information.

Variables

Data were collected using an ad hoc questionnaire designed for this study, divided into three sections.

The first section collected sociodemographic variables (age and sex), variables related to HD treatment and VA (time on HD, number and types of previous VAs, type of current VA, and duration of current VA). It also recorded whether assistance was required for VA self-care, self-perceived level of knowledge for self-care, desire to receive additional information, sources of information, preferences regarding information (source, format, and intended recipient), and hygiene practices (showering, bathing or washing by parts).

The second section recorded variables related to adherence to VA self-care recommendations among patients on HD. Two separate documents were created: one for patients with AVF and one for those with CVC.

The third section assessed HL level.

Measurement instruments

To assess VA self-care practices, a document was developed based on the most recent recommendations for people with chronic kidney disease published by the Spanish Multidisciplinary Vascular Access Group (GEMAV)[15].

The questionnaire items were agreed upon by HD unit nurses with >10 years of experience. Two documents were developed, each containing 12 items: one for AVF patients and one for CVC carriers. These documents were piloted in 10 individuals to ensure comprehensibility. Participants carrying both types of VA (e.g., patients temporarily using a CVC while awaiting repair of a dysfunctional AVF) completed both questionnaires. Response options were "No", "Sometimes" or "Yes". Correct responses were those consistent with guideline recommendations; "Yes" or "No" was considered correct depending on the item, while "Sometimes" was always considered incorrect.

HL was assessed using the HLS-EU-Q16 questionnaire in its validated Spanish version[16]. This 16-item instrument has high reliability (intraclass correlation coefficient 0.923; kappa 0.814) and high internal consistency (Cronbach's alpha 0.982). Each item is scored on a 4-point Likert scale (very difficult/difficult/easy/very easy). Responses "very difficult" and "difficult" were scored as 0; "easy" and "very easy" as 1. Total scores ranged from 0 to 16, classifying HL as inadequate (0–8), problematic (9–12) or sufficient (13–16).

Data collection

Participants were informed of the study objectives, voluntary participation and full anonymity. Questionnaires were self-administered; assistance from a family member was permitted when necessary, provided responses reflected the patient's own views. To ensure anonymity, a collection box was provided in the unit.

Statistical analysis

Data were entered into a database and analysed using IBM SPSS Statistics 20.

Descriptive analysis used absolute frequencies and percentages for categorical variables and measures of central tendency and dispersion for quantitative variables. Normality was assessed using the Shapiro–Wilk test.

Inferential analysis employed chi-square or Fisher's exact test for categorical variables, Mann–Whitney U and Kruskal–Wallis tests for comparisons involving numerical and categorical variables with two or more categories, and Spearman's correlation to assess relationships between age, time on HD, and number of correct VA self-care responses.

To analyse the relationship between HL and the remaining variables studied, health literacy was categorised as a dichotomous variable, with the categories inadequate/problematic and sufficient.

An alpha error of 5% was accepted.

Ethical considerations

The study complied with ethical research principles and Spanish Organic Law 3/2018 on Personal Data Protection and Digital Rights. Written informed consent was obtained from all participants. The study followed Law 14/2007 on Biomedical Research and the principles of the Belmont Report and the Declaration of Helsinki (2013 revision) on biomedical research.

RESULTS

Of the 41 individuals who met the eligibility criteria for participation, a final sample of 39 was obtained (response rate 95.1%).

The mean age of participants was 60.76±18.33 years (min: 22–max: 92); 64.1% (n=25) were men, and mean time on HD was 5.54±7.06 years (min: 0.25–max: 31) (see **table 1**). Two patients had both an AVF and a CVC as VA.

A total of 33.3% of individuals on HD (n=13) did not know or answered incorrectly when asked to indicate the type of fistula or catheter they had; that is, they were unable to identify whether their fistula was autologous or prosthetic, or whether their catheter was tunnelled or non-tunnelled. One patient with an AVF and one with a CVC incorrectly identified the type of VA, and 5 patients with an AVF and 6 with a CVC stated that they did not know. The two individuals who had both an AVF and a CVC correctly identified the types of VA they had.

When participants were asked whether they needed help to care for their VA, 59% (n=23) reported being fully autonomous in its self-care, whereas 36.1% reported requiring help from another person. A total of 18% (n=7) reported having low or very low knowledge to carry out adequate VA self-care (see **figure 1**). Overall, 79.5% (n=31) stated that they would like more information about VA self-care.

A total of 64.1% (n=25) stated that they would like this information to be provided to the patient, and 66.6% (n=26) that it should be given to a family member/carer. Six patients indicated that this information should only be provided to the family member/carer and not to the patient.

Table 1. Characteristics of the participants.

Variable	Category	Frequency	Percentage
Sex	Male	25	64.1%
	Female	11	28.2%
	Other	3	7.7%
Age	Young (18–40 years)	5	12.8%
	Adult (40–65 years)	16	41%
	Older (>65 years)	18	46.2%
Time on HD	≤1 year	6	15.4%
	1–5 years	19	48.7%
	>5 years	13	33.3%
	Missing values	1	2.6
Type of VA*	Native AVF	23	58.97%
	Prosthetic AVF	0	0%
	Tunnelled CVC	17	43.5
	Non-tunnelled CVC	1	2.5%

VA: vascular access; **CVC:** central venous catheter; **AVF:** arteriovenous fistula; **HD:** haemodialysis.

* 2 participants had both an arteriovenous fistula and a central venous catheter as vascular access.

Regarding the preferred timing and format, 48.7% (n=19) wanted this information to be provided during the HD session, whereas 30.7% (n=12) preferred it to be provided outside the HD session; 41.1% (n=16) requested some form of paper-based material, and 10.2% (n=4) requested informational resources via the internet (websites, apps, videos, etc.).

When asked about the source from which they had obtained information on VA self-care, the most frequent source was the nurse; however, when asked who they would like to provide further information on these aspects, a higher proportion of participants indicated the nephrologist **(figure 2)**.

On analysing responses to the AVF self-care knowledge questionnaire, the mean number of correct answers was 8.78±2.15 out of 12; the least followed recommendation was "Avoid using clamps to apply pressure when removing the needles" (see **table 2**). Regarding CVC self-care, the mean number of correct answers was 8.83±2.17; the least followed recommendation was "Avoid manipulating the catheter dressing at home" **(table 3)**.

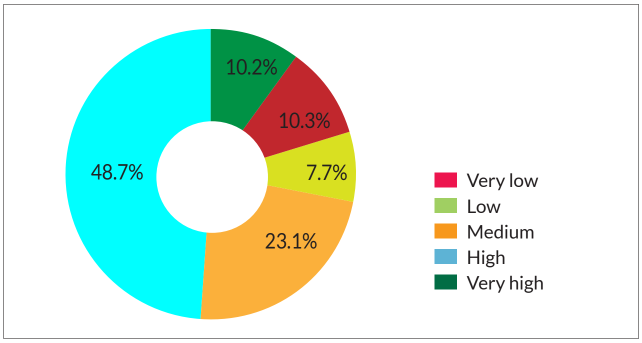

Figure 1. Self-perceived level of knowledge for VA care.

When patients were asked about their usual hygiene practice, 61.5% (n=24) used the shower, 7.7% (n=3) took an immersion bath, 23.1% (n=9) performed strip washing, and 7.7% (n=3) alternated between showering and strip washing. None of the patients with a catheter took immersion baths. Among those who performed strip washing, two had an AVF and the remainder had a CVC.

HL analysis showed that 17.9% (n=7) had an inadequate level, 41% (n=16) a problematic level, and 38.5% (n=15) a sufficient level; one patient left this section of the questionnaire incomplete.

No differences were found in the number of correct answers regarding VA self-care according to participants' age (p=0.20), sex (p=0.60), time on HD (p=0.22) or the type of VA carried (p=0.96).

No differences were found when comparing HL level with age (p=0.90), sex (p=0.21) or time on HD (p=0.31), nor with the number of correct answers regarding VA self-care (p=0.11).

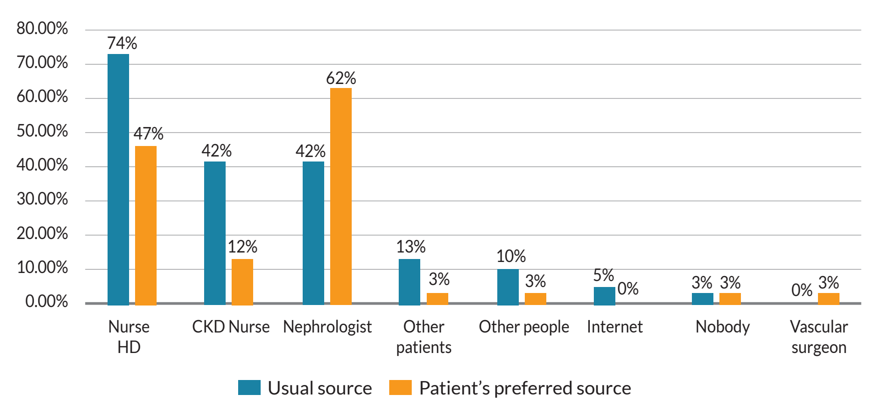

Figure 2. Usual *vs* preferred sources of information reported by patients regarding VA self-care.*

*A single patient could select more than one response option for each question.

DISCUSSION

In this study, we sought to analyse VA self-care practices among people undergoing HD, based on the recommendations of the GEMAV Vascular Access Manual for People with Kidney Disease, and their potential relationship with participants' HL level.

The SEDEN Manual of Procedures and Protocols with Specific Competencies for Nephrology Nursing highlights the importance of VA care performed by the patient and/or carer, which is directly related to the occurrence of complications and the evolution of VA[17].

Therefore, one of the first striking findings is that one third of participants reported not knowing the type of VA they had or identified it incorrectly. Although the use of more or less technical terms can sometimes be difficult for some individuals, the questionnaire text specified that an autologous fistula is created using the person's own veins. For catheters, the term "permanent catheter" was also used to refer to a tunnelled catheter, and "temporary" or "transient catheter" to refer to a non-tunnelled catheter.

In recent decades, HD patients have become older. According to the latest Spanish Renal Patients Registry data (2023), the incidence of patients aged over 65 years was 59%[1]. Moreover, these patients may, a priori, have greater knowledge deficits and a poorer disposition towards learning, which could partly explain some of our findings[18,19]. For instance, some patients wanted the information to be provided only to their family member/carer and not to themselves.

We found that most participants wanted more information about VA self-care. Although almost half wanted this information to be delivered during the HD session, a substantial number preferred it outside the session. These findings prompt reflection on the need to establish different strategies for delivering health education to people on HD (individual and group education programs, including expert patient programs) as effective multimodal approaches[17].

Despite living in a highly digitalised society—and although some authors emphasise patients' interest in new technologies[20,21]—only a small proportion of participants in our study requested information via the internet (websites, apps, videos, etc.), with paper-based formats being the preferred option.

Table 2. Responses to the AVF self-care questionnaire.

Items assessed (valid responses)	No n (%)	Sometimes n (%)	Yes n (%)
1. I usually wear tight clothing, bracelets, a watch or a tight bandage on the arm with the fistula.	**22 (95.7%)**	1 (4.3%)	0 (0%)
2. I usually lift heavy weights, perform strenuous exercise or impact sports with the arm that has the fistula.	**21 (91.3%)**	2 (8.7%)	0 (0%)
3. I allow the fistula to be used for blood tests or for insertion of an intravenous line.	**19 (82.6%)**	0 (0%)	4 (17.4%)
4. I wash the arm with the fistula before entering the haemodialysis session.	5 (21.7%)	2 (8.7%)	**16 (69.6%)**
5. During dialysis, I cover the area where the needles have been inserted with a sheet or blanket so that it is not visible to the staff.	**16 (76.2%)**	4 (19%)	1 (4.8%)
6. When the haemodialysis needles are removed, I use clamps to apply pressure over the puncture sites.	**7 (31.8%)**	4 (18.2%)	11 (50%)
7. I usually touch and/or pick at the scabs from previous puncture sites.	**17 (73.9%)**	2 (8.7%)	4 (17.3%)
8. If I bleed from the puncture sites after dialysis, I apply pressure with a clean gauze and slightly elevate the limb.	5 (25%)	3 (15%)	**12 (60%)**
9. If I bleed from the puncture sites after dialysis, I apply a tight bandage that wraps around the arm.	**16 (69.5%)**	4 (17.4%)	3 (13%)
10. Every day I palpate (touch with my fingers) the fistula to check for vibration or bruit (to ensure the fistula is functioning).	2 (8.7%)	2 (8.7%)	**19 (82.6%)**
11. I observe the appearance of the fistula daily.	4 (17.4%)	0 (0%)	**19 (82.6%)**
12. If I notice any change in the fistula, either in appearance or vibration, I inform the dialysis staff before taking any action myself.	3 (13%)	1 (4.3%)	**19 (82.6%)**

HD: Haemodialysis.
Correct responses according to the Vascular Access Manual for People with Kidney Disease are shown in bold.

Tabla 3. Responses to the CVC self-care questionnaire.

Items assessed (valid responses)	No n (%)	Sometimes n (%)	Yes n (%)
1. I maintain daily personal hygiene (n=18).	0 (0%)	5 (27.8%)	**13 (72.2%)**
2. I check daily that the dressing covering the catheter is clean and dry (n=18).	2 (11.1%)	2 (11.1%)	**14 (77.8%)**
3. I change and/or care for the dressing covering the catheter myself at home (n=18).	**8 (44.4%)**	2 (11.1%)	8 (44.4%)
4. I allow the haemodialysis catheter to be used in other areas of the hospital (outside the dialysis unit) for blood tests or medication if I am admitted (n=18).	**15 (83.3%)**	0 (0%)	3 (16.7%)
5. I wear clothing that presses on the catheter and is very tight (n=17).	**16 (94.1%)**	1 (5.9%)	0 (0%)
6. When I shower, I protect the catheter with a waterproof dressing so that it does not get wet (n=17).	5 (29.4%)	0 (0%)	**12 (70.6%)**
7. When I shower, I usually direct the water stream towards the catheter dressing area (n=17).	**15 (88.2%)**	0 (0%)	2 (11.8%)
8. I can swim in a pool or in the sea and submerge the catheter in water (n=17).	**17 (100%)**	0 (0%)	0
9. I am careful and avoid pulling on the catheter (n=18).	2 (11.1%)	1 (5.6%)	**15 (83.3%)**
10. If I develop a high fever with shivering, I know this is a warning sign of a possible catheter infection, and in that case I go to the emergency department (n=18).	5 (27.8%)	0 (0%)	**13 (72.2%)**
11. I follow the precaution: "Avoid using sharp objects (scissors) around the catheter area, and in males, take special care when shaving" (n=18).	3 (23.1%)	1 (7.7%)	**9 (69.2%)**
12. If I have any problem with the catheter, I contact the dialysis unit and consult them before acting on my own (n=12).	1 (8.3%)	0 (0%)	**11 (91.7%)**

HD: Haemodialysis.
Correct responses according to the Vascular Access Manual for People with Kidney Disease are shown in bold.

VA clinical practice guidelines highlight the importance of establishing multidisciplinary VA teams within dialysis units[22], integrating nephrologists, radiologists, vascular surgeons and nephrology nursing staff; some authors report favourable outcomes[23,24]. In such units, multidisciplinary team contact is established even before VA creation[22], conveying to the patient a message of teamwork and that the information provided is endorsed by all members of the team.

Most patients identified the nurse as the most common source of information on VA self-care, as the professional responsible for patient health education and for promoting self-care behaviours[25]. However, patients also indicated that they would like other professionals to be involved in these aspects.

Although the number of correct responses was high among both AVF and CVC patients, we must consider that the future of VA depends largely on the quality of such care[17]. Therefore, the goal should be for patients to achieve the highest possible level of knowledge.

Among AVF patients, the least followed recommendation was "Avoid using clamps for haemostasis over the puncture sites." In healthcare settings, the performance of clinical practices not aligned with scientific evidence has been described for years[26,27]. The reasons may be multiple; however, staff shortages and time constraints (tightly scheduled shifts), among other factors, may mean professionals do not remain with the patient to perform haemostasis for the full necessary time and instead place these devices. This tends to occur more frequently in frail patients who, due to reduced physical capacity or cognitive impairment, cannot perform haemostasis themselves. Other patients observing this practice may, often for convenience, also request the use of such clamps, despite being able to apply pressure independently. This may lead patients to regard it as correct, despite guideline recommendations indicating otherwise.

For CVC patients, the least followed recommendation was "Avoid manipulating the catheter at home." Although GEMAV recommends never removing the dressing applied in the dialysis unit and never manipulating the catheter independently[15], it should be noted that HD is a chronic therapy and many patients carry this type of VA for years. As a result, they observe daily how professionals manage it. In addition, many patients live far from the dialysis centre and may prefer to place a new dressing over the previous one if it becomes detached, or change it if it becomes wet. They generally attend the dialysis unit or emergency department only when they consider the situation more serious, such as the presence of exudate and/or bleeding on the dressing.

The main limitation of this study is that it was single-centre, resulting in a limited sample size. Nevertheless, willingness to participate was high, reflected in a high response rate. Notably, some patients with physical difficulties completing the questionnaire expressed interest in participating and requested assistance from a family member/professional. The results reflect the reality of patients in this unit, and although caution is required when extrapolating to other units, we believe they highlight important aspects regarding the role of health education in VA self-care among people on HD.

The HL results may be concerning: approximately 59% of individuals on HD had inadequate/problematic HL. Although more optimistic than those reported by Pelayo-Alonso et al.[7], who also studied an HD population and found approximately 83% with inadequate/insufficient HL, it should be noted they used a different validated questionnaire. Our findings are closer to those from an international study in the general population across eight European countries[28], where approximately 47% showed this situation. Based on our results, individuals on HD request more information about VA self-care, and multimodal strategies addressing different needs may be useful.

There are areas for improvement in VA self-care among people on HD, for both AVF and CVC, although overall knowledge levels appear high.

No relationship was found between VA self-care practices among people on HD and HL level; however, it should be emphasised that a substantial proportion of individuals on HD have insufficient/problematic HL.

Conflicts of interest

None declared.

Funding

None declared.

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