



Needs, barriers and facilitators for a healthier lifestyle in haemodialysis patients: The GoodRENal project

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Abstract

Background: Malnutrition, sedentary lifestyle, cognitive dysfunction and poor psychological well-being are often reported in patients on haemodialysis (HD).

Aims: We aimed to explore needs, barriers and facilitators—as perceived by patients, their carers, and healthcare professionals (HCPs) for increasing the adherence to the diet, to physical activity and cognition and psychological well-being.

Methods: This is an observational cross-sectional study following the STROBE statement. This study is part of an ERASMUS+ project, GoodRENal—aiming to develop digital tools as an educational approach to patients on HD. For that, the GoodRENal comprises HD centers located in four Belgium, Greece, Spain and Sweden. Exploratory questionnaires were developed regarding the perceived needs, barriers and facilitators regarding the diet, physical activity, cognition and psychological well-being from the perspective of patients, their carers and HCPs.

Results: In total, 38 patients, 34 carers and 38 HCPs were included. *Nutrition:* For patients and carers, the main *needs* to adhere to the diet included learning more about nutrients and minerals. For patients, the main *barrier* was not being able to eat what they like. *Physical activity:* As *needs* it was reported information about type of appropriate physical activity, while fatigue was listed as the main *barrier*. For *Cognitive and emotional state*, it was perceived as positive for patients and carers perception but not for HCPs. The HCPs identified as *needs* working as a team, having access to specialised HCP and being able to talk to patients in private.

Conclusions: Patients and their carers listed as needs guidance regarding nutrition and physical activity but were positive with their cognitive and emotional state. The

Patricia Mesa-Gresa and Carla Maria Avesani shared authorship.

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HCPs corroborated these needs and emphasised the importance of teamwork and expert support.

KEYWORDS
cognition, haemodialysis, nutrition, physical activity, psychological well-being

1 | INTRODUCTION

Patients with advanced stages of chronic kidney disease (CKD) often suffer from comorbidities such as cardiovascular, cerebrovascular and peripheral vascular diseases, and diabetes that together with malnutrition and frailty contribute to a sedentary lifestyle, cognitive and emotional impairments (Pépin et al., 2021), increased dependency, and decreased health-related quality of life (HRQoL) (Chan, 2021; Charles & Ferris, 2020; Harnett et al., 2018; Ortega-Pérez de Villar et al., 2020; Schouten et al., 2020; Shoji et al., 2022). These problems remain despite the large societal and healthcare costs of CKD stages 4 and 5, not least for those undergoing dialysis (Kalantar-Zadeh et al., 2021; Pépin et al., 2021).

There is increased awareness of the need for more patient-centred approaches for the management of the substantial burden of physical and psychological symptoms that are not adequately addressed by usual treatment strategies (Kalantar-Zadeh et al., 2022). In addition to dialysis therapy and pharmacotherapies targeting underlying diseases and complications linked to CKD, strategies based on a holistic perspective—involving nonpharmacological interdisciplinary interventions aiming at increasing physical activity and improving the nutritional, cognitive and emotional state of the patients may provide additional benefits including enhancing the HRQoL of patients and their carers (Kalantar-Zadeh et al., 2021; Pépin et al., 2021). Before recommending general application of these types of interventions, which are currently scarce, it is important to analyse patients' own perceptions of their needs, barriers and facilitators associated with self-implementation of these promoters of health (Lunney et al., 2018; Tam-Tham et al., 2016). An important complement to the patient's own perception is that of their carers and the healthcare professionals (HCP), who care for the patient, so that all stakeholders involved are given a voice.

The aim of this study was to investigate the perceived needs, barriers and facilitators of adherence to nutritional advice, physical activity and the cognitive and psychological well-being among patients on haemodialysis (HD), as well as their carers, and the HCP involved in their care. These results will be used to guide the construction of an intervention aiming a holistic interdisciplinary non-pharmacological approach as part of an ERASMUS+ Educational multicentre Project.

What does this paper contribute to the wider global community?

- Patients on haemodialysis (HD), carers and healthcare professionals (HCPs) agree on the importance of diet, physical activity and good cognitive and psychological state.
- We describe the main needs, barriers and facilitators for patients, their carers, and HCPs for diet, physical activity and cognitive/emotional state. For that, 38 patients on HD, 34 carers and 38 HCPs responded a questionnaire.
- For patients and carers, the main *needs* are learning about nutrients and minerals. For patients, the main *barrier* was not being able to eat what they like.
- For physical activity, the *needs* were to have information about type of appropriate physical activity, while fatigue was the main *barrier*.
- For *Cognitive and emotional state*, it was perceived as positive for patients and carers, but not for HCPs.
- We conclude that a holistic approach involving patients and their carers, and HCPs is important to overcome barriers to healthier lifestyle while on HD.

2 | MATERIALS AND METHODS

2.1 | Study design and participants

This is an observational cross-sectional multicentre study with a design according to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE Statement—a checklist of items that should be included in reports of observational studies Data S1). It includes a convenience sample of 38 patients on maintenance HD, and their carers ($n=34$) and HCPs ($n=38$) involved in their care in Belgium (Katholieke Universiteit Leuven, Department of Nephrology), Greece (Renal Unit of AHEPA Hospital), Spain (Hospital of Manises, Nephrology Service) and Sweden (Skåne University Hospital, Department of Nephrology, Lund). Data collection was carried out during 2022. This study is part of the *GoodRENal* project sponsored by the European Union (ERASMUS+ Project Number: 2020-1-ES01-KA2014-083141,

<http://goodrenal.eu/>) that aims to develop a holistic educational approach for patients on HD regarding nutrition, physical activity, cognitive state and emotional well-being.

For this study, the inclusion criteria for patients were adults (older than 18 years) on maintenance HD for at least 3 months. To limit selection bias, all patients from the dialysis shift starting on a Monday were invited to participate in the study. From this group of patients, 10 were randomly invited to participate in the study. In addition, one informal carer of each patient and one of their HCPs were invited to participate. The carers comprised partners, children, parents, siblings or friends. The HCP, who cared for and knew the patients interviewed, was a member of the staff and could be a nurse, nephrologist, physiotherapist or dietitian. The questionnaires in English can be found in the Data S4.

This study complies with the criteria of the Declaration of Helsinki. The ethics committees from the entities involved approved the study (UZ/KU Leuven in Belgium, Registration number B3222021000587; Aristotle University of Thessaloniki Research Ethics and Deontology Committee in Greece Registration number EC-43/2021; Hospital Universitario y Politécnico La Fe in Spain, Registration number 2020-064-1; and Swedish Ethical Review Authority, Registration number 2021-01309). All participants received oral and written information of the objectives of the study and signed the informed consent form prior to participation.

2.2 | Exploratory questionnaires

Four exploratory questionnaires were developed by a group of experienced HCPs working with patients on HD (three nephrologists, one physiotherapist, one dietitian and two psychologists). These questionnaires were constructed to assess participants' perceptions regarding the main needs, barriers and facilitators related to following healthy habits, including nutritional and physical activity recommendations, cognitive state and emotional well-being. All questionnaires were composed of a 5-point Likert-type scale and had open exploratory questions (Data S4). The questionnaires were translated from English to the original language of each participating country (Belgium, Greece, Spain and Sweden) and were answered between January and June of 2021.

Nutrition questionnaires consisted of statements that explored aspects affecting patients' adherence to nutritional recommendations (patients: 20 statements; carers: 10 statements and HCPs: 14 statements). The answer to each statement could be rated as 1 (strongly disagree), 2 (disagree), 3 (neither agree nor disagree), 4 (agree) or 5 (strongly agree).

Physical activity questionnaires consisted of a set of questions regarding promotion of physical activity/exercise (patients: 29 statements, carers: 25 statements and HCPs: 23 statements), using a 5-point Likert scale with the same design as that used in the nutrition questionnaires.

2.2.1 | Cognitive state and psychological well-being questionnaires

The questionnaires developed to assess the cognitive state of the patients were built aiming to explore the subjective perception of aspects related to patients' level of attention, memory, planning capacity and executive functions. The questionnaires related to the exploration of patients' emotional well-being aimed at assessing their perception regarding mood, anxiety, stress response, motivation, overload or sleep quality. Similar questions were included in the questionnaires for carers and HCPs. The HCPs' questionnaires also included questions addressing the main barriers and needs that they perceived were of importance in relation to the care provided to the patients. For these questionnaires a 5-point Likert scale was used to explore the presence of experiences reflecting the cognitive and emotional state of the patients during the last month, with scores from 1 (never), 2 (now and then), 3 (half of the time), 4 (more than half of the time) and 5 (almost all the time). Open questions exploring aspects related to patients' cognitive and emotional needs, barriers and facilitators were also included.

2.3 | Statistical analysis

Continuous variables are described as means and standard deviations or medians and interquartile ranges, depending on the variable's distribution. Nominal variables are described in absolute numbers and percentages. All the analyses were performed using the SPSS statistical program (version 26.0). For the nutrition and physical activity questionnaires, data were sorted in relation to the groups of needs, barriers and facilitators. For the analysis of these questionnaires, answers were grouped as 'agree' (scores 5 and 4), 'neither agree nor disagree' (score 3) and 'disagree' (scores 2 and 1). Regarding the cognition and psychological well-being questionnaires, the responses were organised into three groups as 'almost never', (scores 1 and 2), 'half of the time' (score 3) and 'almost all the time' (scores 4 and 5). In these questionnaires, the patients' responses were analysed and compared with those of the carers and the HCPs.

3 | RESULTS

In total, 10 patients from each dialysis centre ($n=40$), their respective carers ($n=40$) and HCPs ($n=40$) were randomised to participate in the study. Of these 120 subjects 110 people participated: 38 patients, 34 carers and 38 HCPs. Figure 1 shows the process of selection and reasons for exclusions or withdrawal.

Sociodemographic and clinical characteristics of the patients (age 58.0 ± 16.4 years; women 31.6%) are shown in Table 1. The carers (10 from Spain, 10 from Greece, 6 from Belgium and 8 from

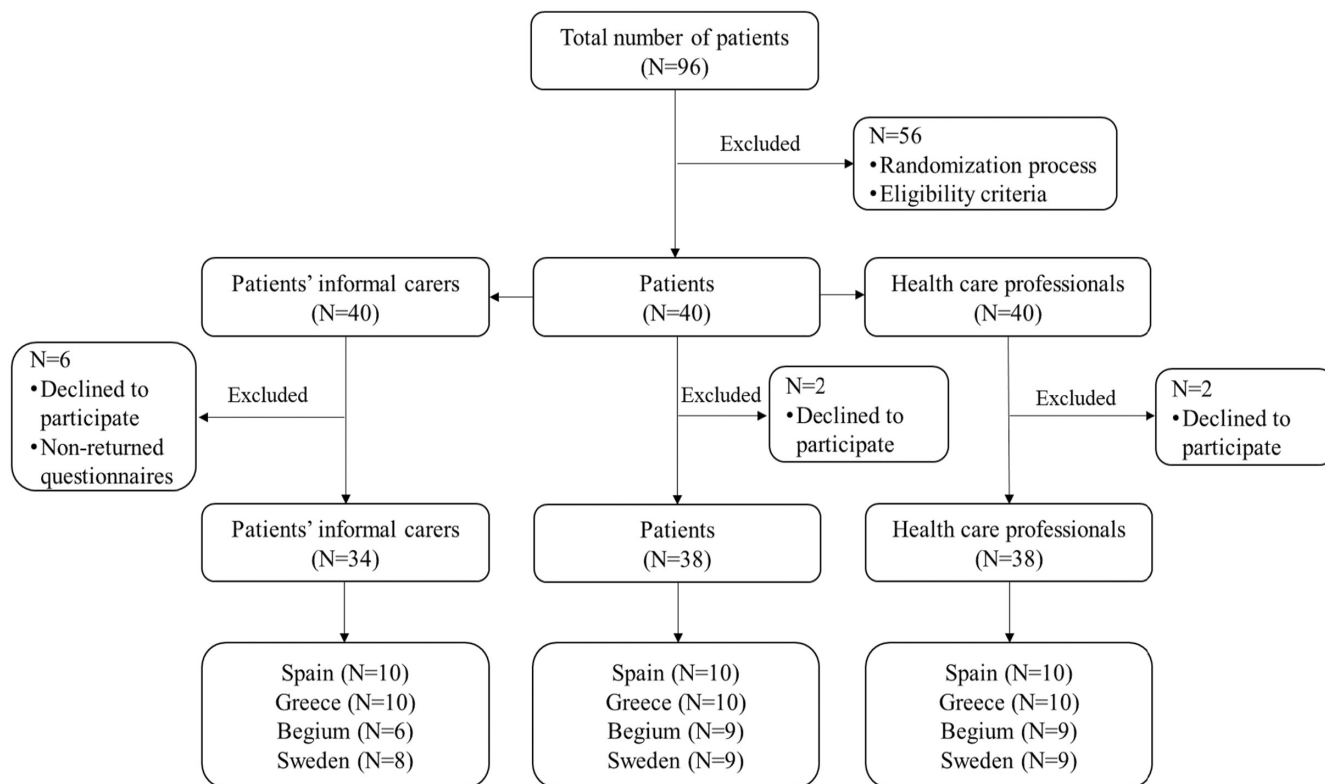


FIGURE 1 Selection of patients, carers and healthcare professionals for this study.

TABLE 1 Demographic and physical data of patients ($n=38$). Data are expressed as mean \pm SD, unless otherwise noted.

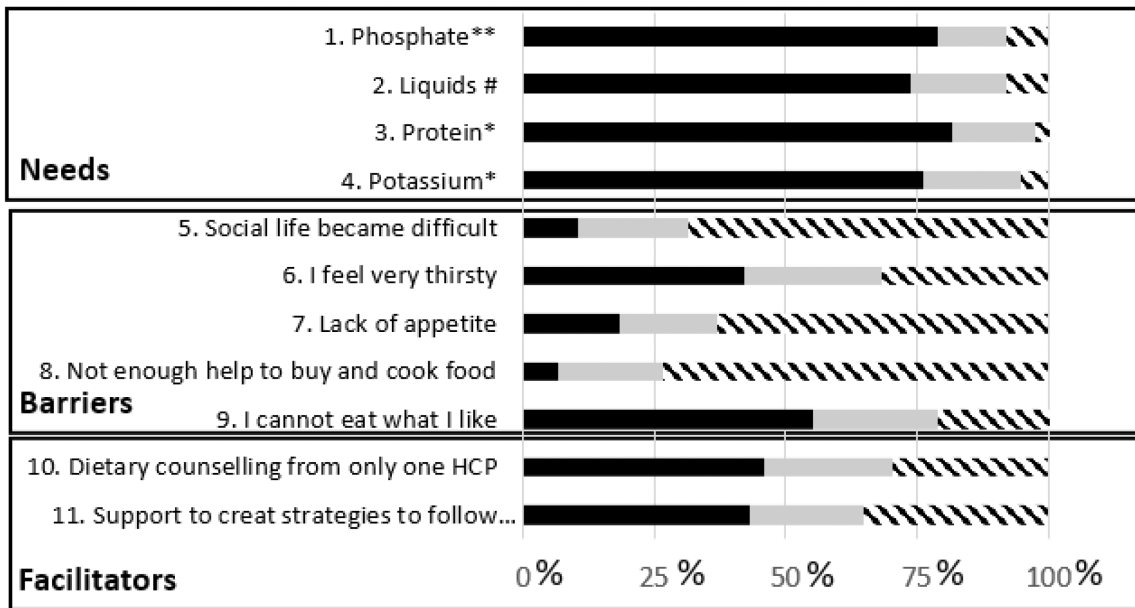
	Total ($N=38$)	Spain ($n=10$)	Greece ($n=10$)	Belgium ($n=9$)	Sweden ($n=9$)
Age (years)	58.0 \pm 16.4	66.2 \pm 17.2	56.6 \pm 6.7	65.2 \pm 18.6	43.3 \pm 11.3
Women, n (%)	12 (31.6)	6 (60.0)	2 (20.0)	2 (22.2)	9 (100)
Dialysis access					
AVF, n (%)	29 (76.3)	9 (90.0)	10 (100)	6 (66.7)	4 (44.4)
Catheter, n (%)	9 (23.7)	1 (10.0)	0	3 (33.3)	5 (55.6)
Comorbidities					
Cardiovascular disease, n (%)	16 (42.1)	5 (50.0)	2 (20.0)	5 (55.6)	4 (44.4)
HAS, n (%)	28 (73.7)	10 (100)	5 (50.0)	4 (44.4)	9 (100)
Diabetes, n (%)	11 (28.9)	4 (40.0)	3 (30.0)	1 (11.1)	3 (33.3)
Dialysis length (months)	52.5 \pm 54.9	94.7 \pm 83.5	58.4 \pm 33.0	21.2 \pm 17.1	30.1 \pm 24.9
BMI (kg/m^2)	24.5 \pm 4.0	24.2 \pm 4.1	25.9 \pm 3.1	23.4 \pm 4.1	24.5 \pm 4.8
Kt/V urea	1.6 \pm 0.3	1.8 \pm 0.4	1.5 \pm 0.1	1.7 \pm 0.2	1.3 \pm 0.2
Albumin (g/dL)	4.0 \pm 0.3	3.9 \pm 0.3	4.2 \pm 0.2	3.9 \pm 0.2	3.8 \pm 0.3
Calcium (mg/dL)	6.3 \pm 2.9	9.1 \pm 0.6	8.7 \pm 0.4	2.3 \pm 0.9	4.7 \pm 0.2
Potassium (mg/dL)	4.8 \pm 0.6	4.8 \pm 0.8	4.7 \pm 0.4	4.9 \pm 0.5	4.7 \pm 0.5
Phosphate (mg/dL)	3.9 \pm 1.8	4.6 \pm 1.5	4.6 \pm 1.1	1.6 \pm 0.7	4.9 \pm 1.8

Abbreviations: AVF, arteriovenous fistula; BMI, body mass index; HAS, hypertension; Kt/V, fractional urea clearance.

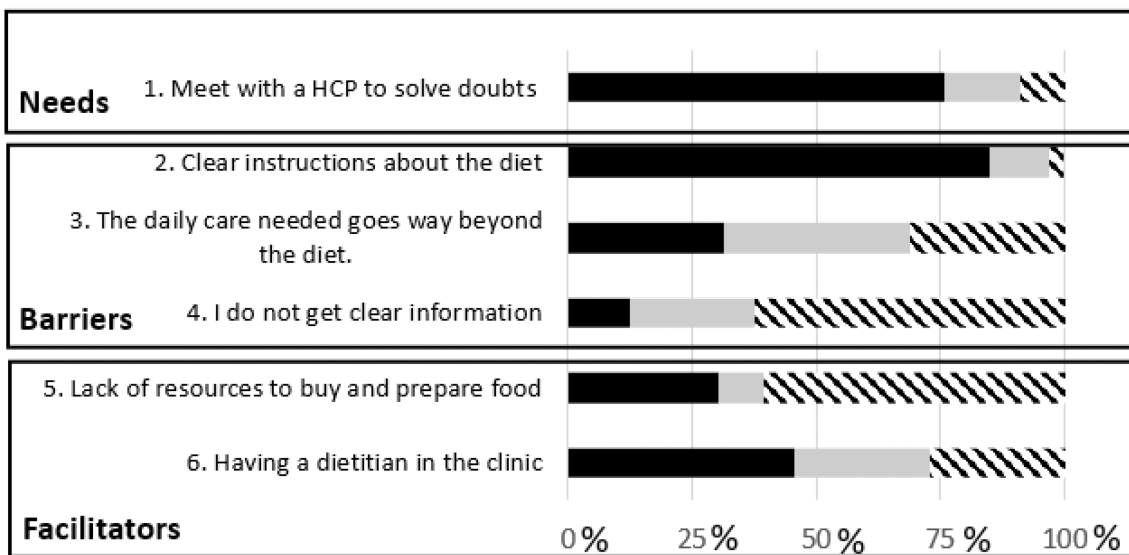
Sweden) had a mean age of 55.4 \pm 3.2 years and 79.4% were women. They were children (52.9%), parents (20.6%), partners (17.6%), friends (5.9%) or siblings (2.9%) of the patients. The HCPs (10 from Spain, 10 from Greece, 9 from Belgium and 9 from Sweden) had a

mean age of 42.6 \pm 10.6 years and 30 of them were women (78.9%). The HCPs consisted of 44.7% nurses, 42.1% nephrologists, 5.3% dietitians, 2.6% physiotherapists and 5.3% other professionals (such as clinical social workers).

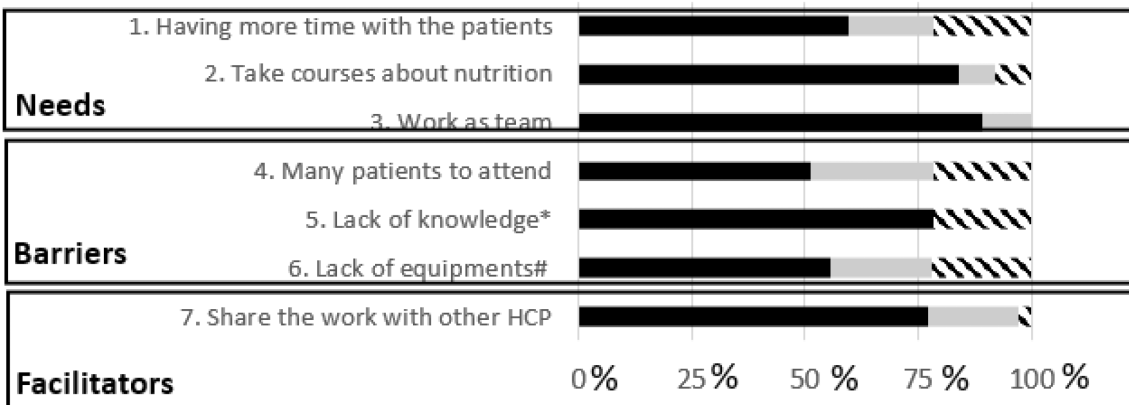
(a) Patients



(a) Carers



(c) Health care professionals



■ Agree ■ Neither agree or disagree ▨ Disagree

FIGURE 2 Perceived needs, barriers and facilitators described by patients (a), carers (b) and healthcare professionals (HCPs) (c) to adhere to dietary recommendations. (a) ** I would like to learn the dietary sources of phosphorous and the foods with phosphate additives; *I would like to learn the food sources of...; # I would like to learn how much liquids can I drink/day. (c) *about Nutrition; # to perform nutritional screening; HCP, healthcare professionals.

For the nutrition (Figure 2) and physical activity (Figure 3) results, the items from the questionnaires that showed higher level of agreement/disagreement were selected to be shown. For cognitive and emotional state (Figures 4–6), all the items are shown.

3.1 | Needs, barriers and facilitators to adhere to dietary recommendations

The answers obtained from the questionnaires were grouped into 11 statements from the patients, 6 from the carers and 7 from HCPs. As is shown in Figure 2a, about 60% of the patients 'agreed' that 'learning about food sources (phosphate, protein and potassium)' and 'the amount of liquids they could drink per day' (Statements 1–4), was necessary for them to adhere to dietary recommendations. Regarding barriers, about 50% of the patients 'agreed' that 'not being able to eat what they liked' (Statement 9), was a problem, while nearly 75% of the patients 'disagreed' with 'diet affecting the social life' (Statement 5), and 'lack of appetite' as a barrier (Statement 7). The statements exploring facilitators to dietary recommendations showed no consistent pattern of answers (Statements 10 and 11).

The carers 'agreed' that 'meeting with an HCP from the clinic and getting clear instructions about the diet' (Statement 1) would help patients adhere to the diet, but a majority 'disagreed' that 'not having clear information about the diet' (Statement 4) was a barrier (See Figure 2b,c). Nearly 50% of the carers, connected to the two hospitals that did not have a dietitian working at the dialysis clinic, 'agreed' that 'having a dedicated dietitian' (Statement 6) in the clinic would be a facilitator. For the HCPs 'working as a team' (Statement 3) showed the highest 'agree' rating as a need, while their own 'lack of knowledge' (Statement 5) was perceived as an important barrier.

3.2 | Needs, barriers and facilitators for promotion of physical activity

The answers from the questionnaires were grouped into 10 statements from the patients, 12 from the carers and 8 from the HCPs (Figure 3). Regarding needs, the majority of patients (71%) (Figure 3a), and carers (87.9%) (Figure 3b) 'agreed' that there was a need for further information 'on which activities and/or exercises patients can do', 'on the advantages' and the 'need for encouragement to increase the physical activity inside and outside the HD unit' (Statements 1–3). 'Fatigu' (Statement 5) was identified by 47% of both patients and carers as a barrier, while around 30%–40% in both groups 'agreed' that 'pain' (Statement 6 for patients and Statement 7 for carers), was a barrier. Fifty-three per cent of carers 'disagreed' that 'because they are sick' (Statement 5) was a

barrier. More than 54% of patients and carers 'agreed' that 'being sure that the activities are good for patients' (statement 11) and 'having fun' (Statement 12) were facilitators. Over 45% of patients and carers 'agreed' that 'exercising during the HD treatment with the support of HCPs' (Statement 8) was a facilitator.

More than 85% of the HCPs 'agreed' that 'attending special courses', 'counting on an exercise expert in the unit' and 'having all their colleagues involved' (Statements 1, 2 and 4) were necessary (Figure 3c). 47% 'agreed' that 'lack of knowledge' (Statement 5) and 39% that 'time' (Statement 6) were barriers. A majority (58%) of HCPs 'agreed' with 'exercise being good for HD patients' (Statement 8).

3.3 | Perceived cognitive state of patients

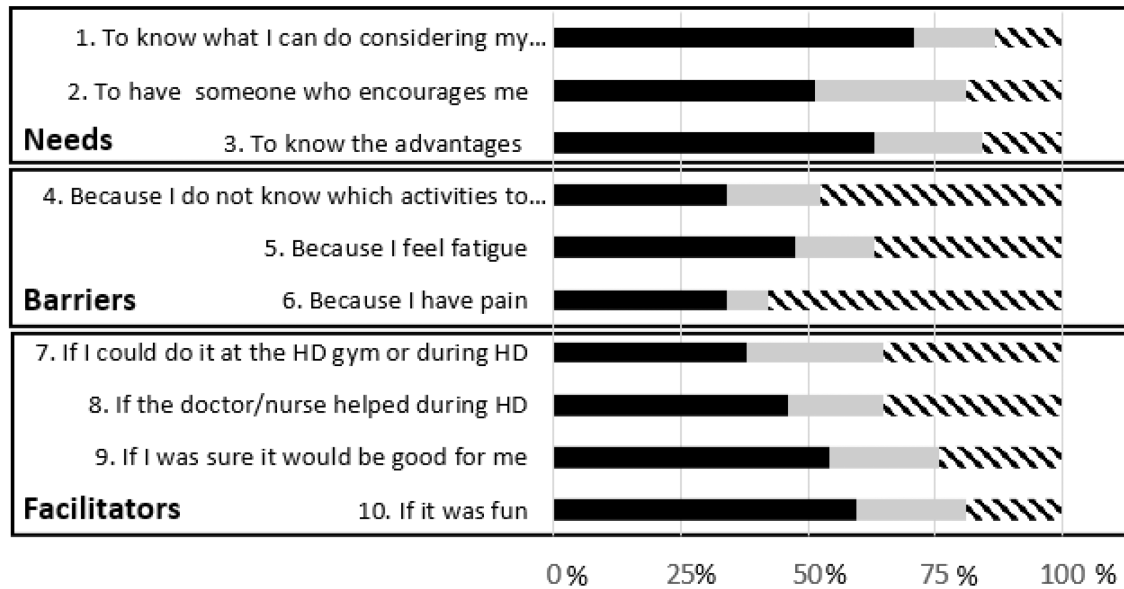
In general, patients and their carers had a positive subjective perception regarding patients cognitive functioning, as can be seen in Figure 4. Neither the patients nor their carers perceived notable difficulties in relation to attention, memory, learning, orientation and executive functions.

The HCPs differed in their perception of the patients' cognitive state compared with the patients and their carers mainly concerning items related to memory. Only 2.6% of the patients 'agreed' compared with almost 35% of the HCPs that they had difficulties in remembering procedures or the names of the professionals who usually attend to them (statement 6). These differences between the perception of patients and HCPs were also observed in relation to executive functions and mental flexibility (statements 7 and 10).

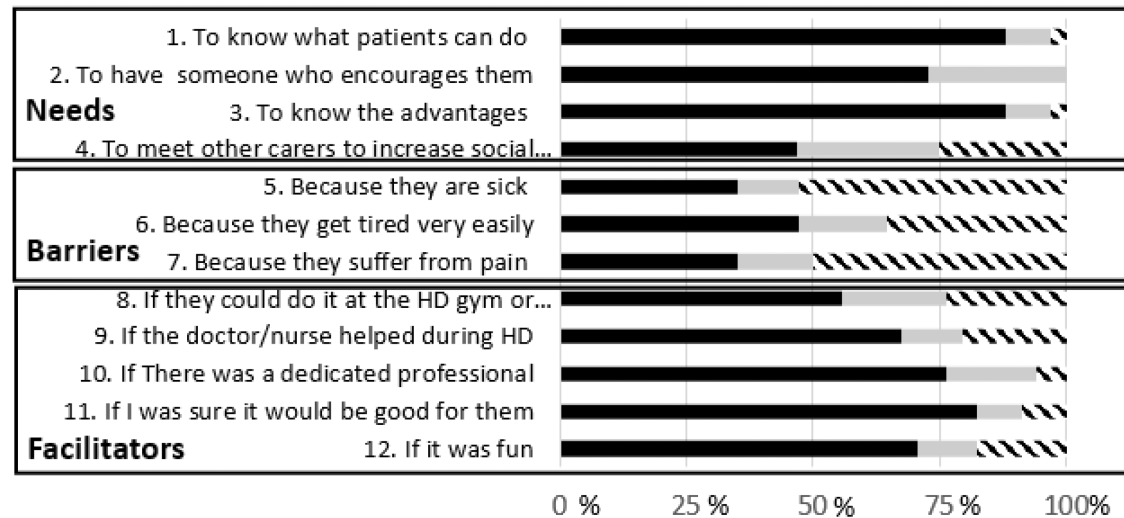
3.4 | Perceived psychological and emotional well-being of patients

In analogy to patients' perception of their cognitive state, they generally reported good emotional and psychological well-being (Figure 5). Concerning assessment of mood, anxiety, motivation, overload, restful sleep or satisfaction with life, patients' responses were indicative of a positive perception. Regarding the carers, their ratings of agreement were similar to those of the patients, although the degree of agreement was less than for the cognitive state. However, the HCPs reported pronounced differences compared with patients and carers regarding their perception of the psychological state of the patients. The HCPs described a low degree of agreement with the patients regarding positive emotions (Statements 9 and 10), motivation (Statement 5), satisfaction with life (Statement 1) or a good night's rest (Statement 2), with percentages ranging between 5.3% and 18%, compared with the patients, whose ratings of agreement were between 44.7% and 60.5%.

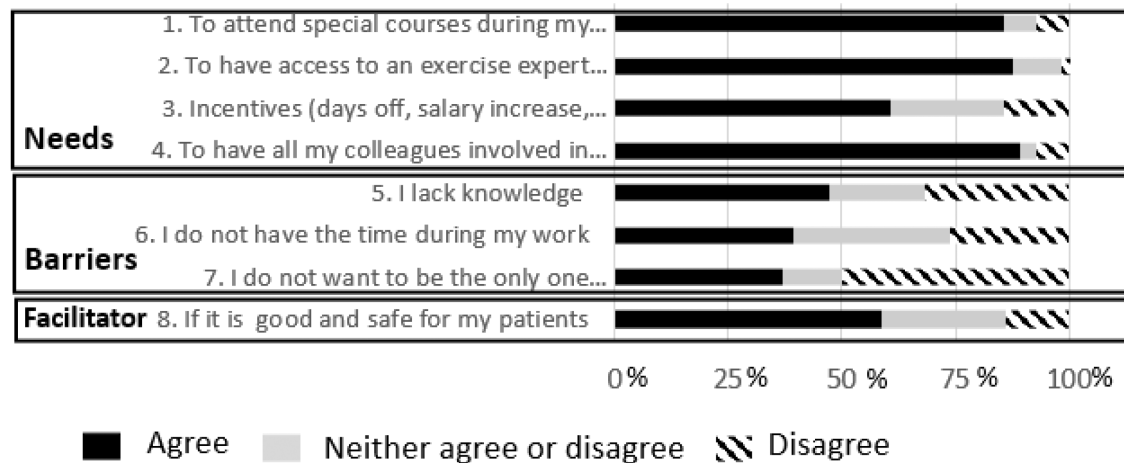
(a) Patients



(b) Carers



(c) Health care professionals



■ Agree ■ Neither agree or disagree ▨ Disagree

FIGURE 3 Perceived needs, barriers and facilitators described by patients (a), carers (b) and healthcare professionals (HCPs) (c) for physical promotion and active lifestyle. HD, haemodialysis.

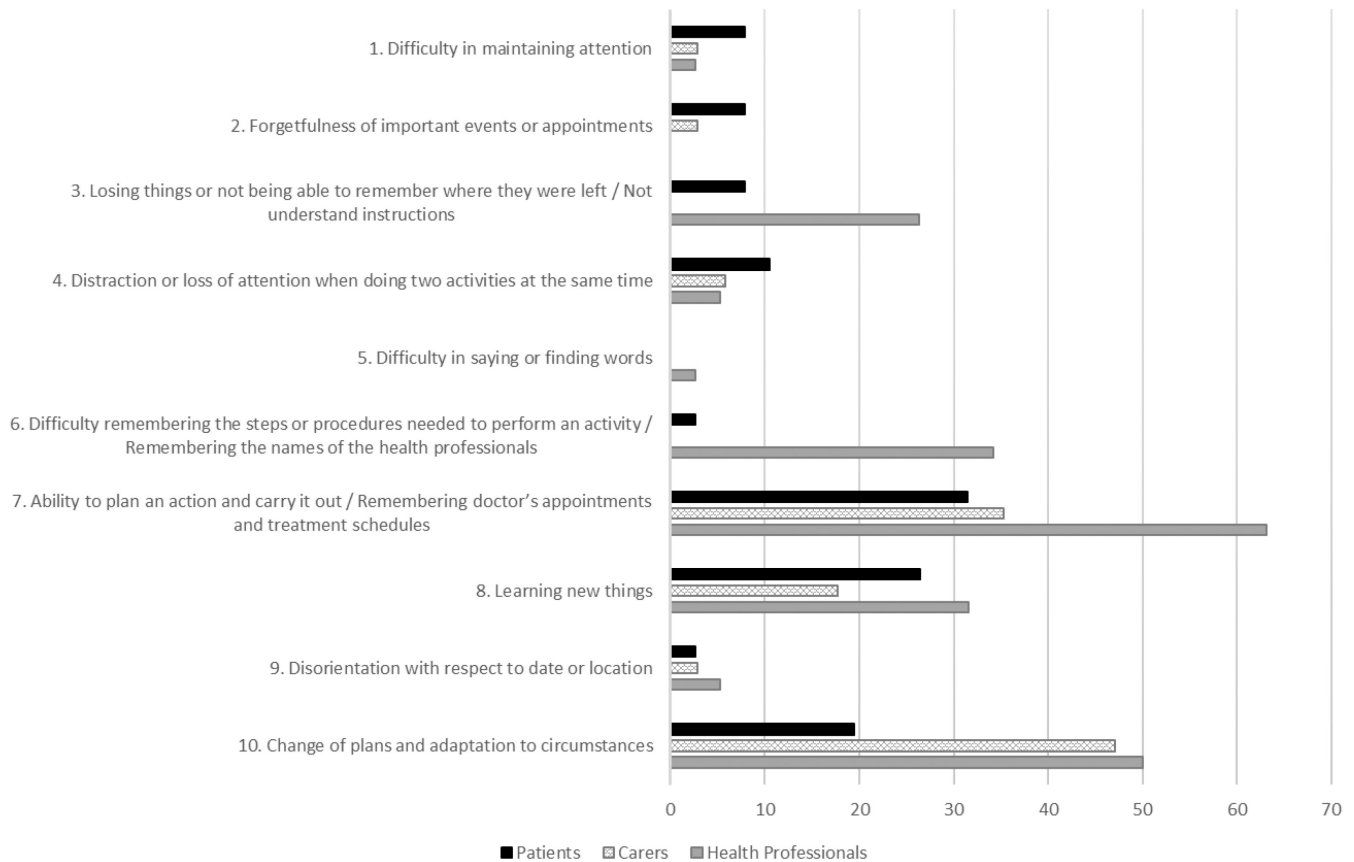


FIGURE 4 Comparison of the subjective perception of patients' cognitive state versus the point of view of their carers and healthcare professionals.

3.5 | Needs and barriers perceived by HCPs regarding mental and cognitive state of patients

HCPs reported the highest levels of agreement in relation to patients' lack of access to mental health professionals (psychologists or psychiatrists), the lack of time and privacy available to attend to patients' cognitive and psychological issues. Finally, HCPs had a 94.7% level of agreement with the patients concerning the importance of psychological and cognitive treatment for nephrological patients (Statement 1) (See Figure 6).

3.6 | Differences between countries in the responses obtained from the patients regarding cognition and emotional state

In order to show the main differences obtained by patients from the different countries involved in the study, a comparison was made on the basis of the percentages of agreement in the cognition and emotional state questionnaires (Figure 7).

If we look at the perception of their cognitive and emotional state, the main differences are observed in the following aspects. At the cognitive level, the most notable differences are observed in the ability to plan activities, with a higher degree of agreement

among patients in Spain (60%) and Sweden (50%), compared to Greece (10%) and Belgium (12.5%). In addition, certain differences are also observed in the perception of cognitive status related to the attentional level and learning ability, with a worse perception being observed in Spanish and Swedish patients, compared to Greek and Belgian patients.

Finally, and in relation to the patients' perception of their mood, it is observed that, in general, patients belonging to Greece and Belgium show a higher degree of agreement than patients from Spain and Sweden with items related to positive mood (60% and 77.7% vs. 40% and 33.3%, respectively), motivation towards the performance of new activities (60% of patients from Greece vs. 11.1% of patients from Sweden) or the achievement of restful sleep (80% and 88.8% vs. 20% and 33.3%, respectively). On the other hand, when asked to analyse the degree of overload perceived by the patients in their daily life activities, the patients from Greece showed the highest degree of agreement with this statement (40%).

4 | DISCUSSION

Patient reported outcomes and interventions aimed at improving mental and physical aspects of HRQoL are receiving increased attention (Kalantar-Zadeh et al., 2022). In many studies, patients with

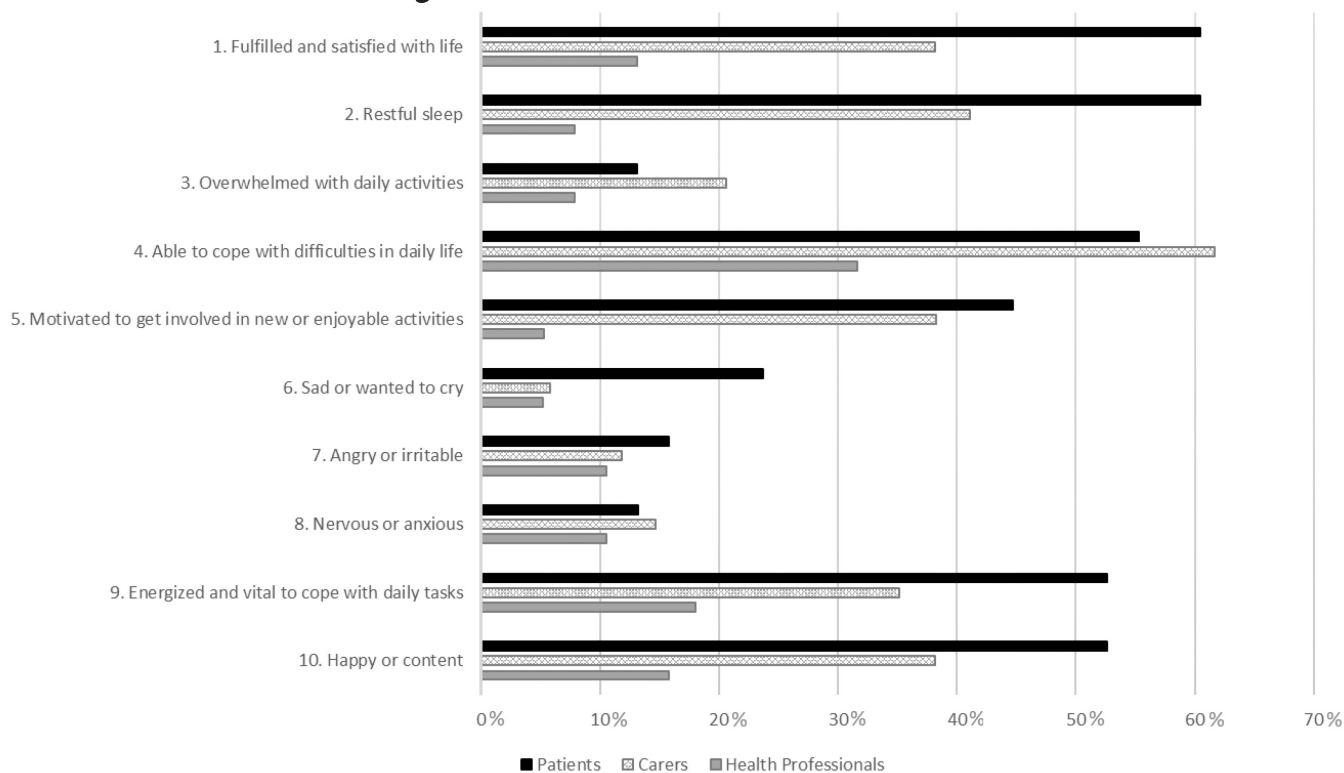


FIGURE 5 Comparison of the subjective perception of patients' psychological well-being and emotional state versus the point of view of their carers and healthcare professionals.

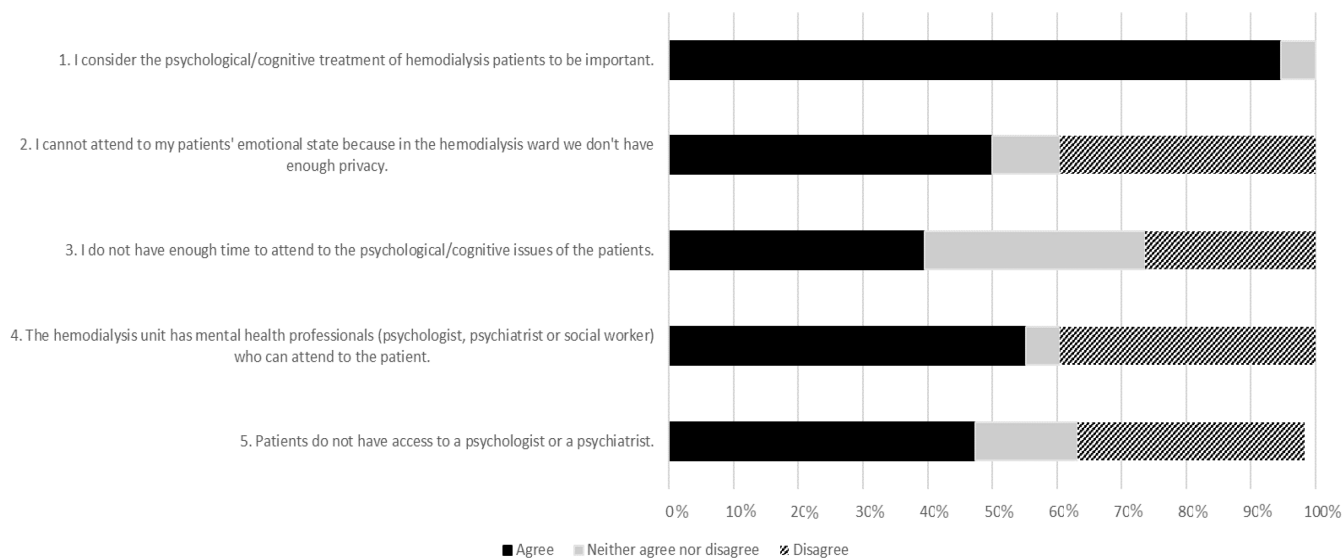


FIGURE 6 Perceived needs and barriers described by healthcare professionals (HCPs) related to patients' cognitive state and emotional well-being.

CKD report low HRQoL and poor emotional well-being (Gerogianni et al., 2019; Schouten et al., 2020; Viana et al., 2019) and the Standardised Outcomes in Nephrology Initiative (SONG, 2022) ranks these outcomes as core and middle tier outcomes in patients with CKD including those on dialysis. In this European study, which is part of an ERASMUS+ Educational Project aimed to develop holistic digital tools to increase education regarding nutrition, physical

activity and emotional well-being to three stakeholders (patients, HCP and carers), we explored how patients on HD, their carers and HCPs perceived needs, barriers and facilitators regarding interventions targeting nutrition, physical activity, cognition and psychological well-being that taken together would enable patients to adhere to a healthier lifestyle. The assessment of nutritional status and frailty were not aimed when developing and applying the questionnaires,

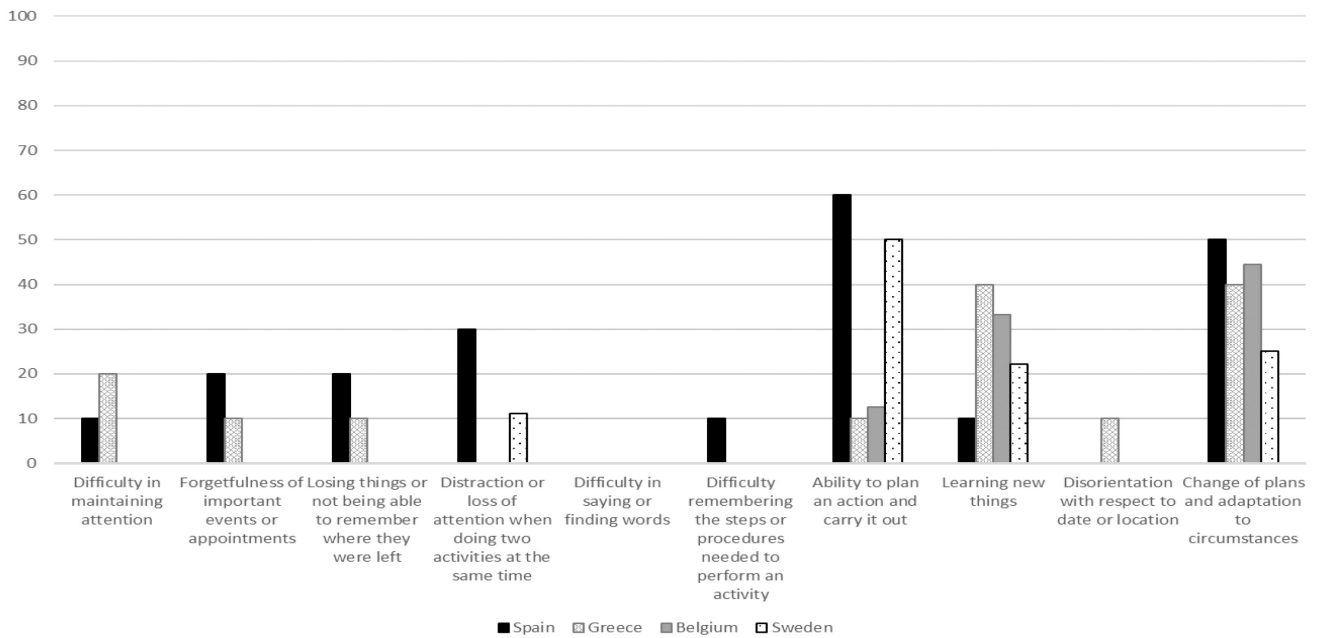
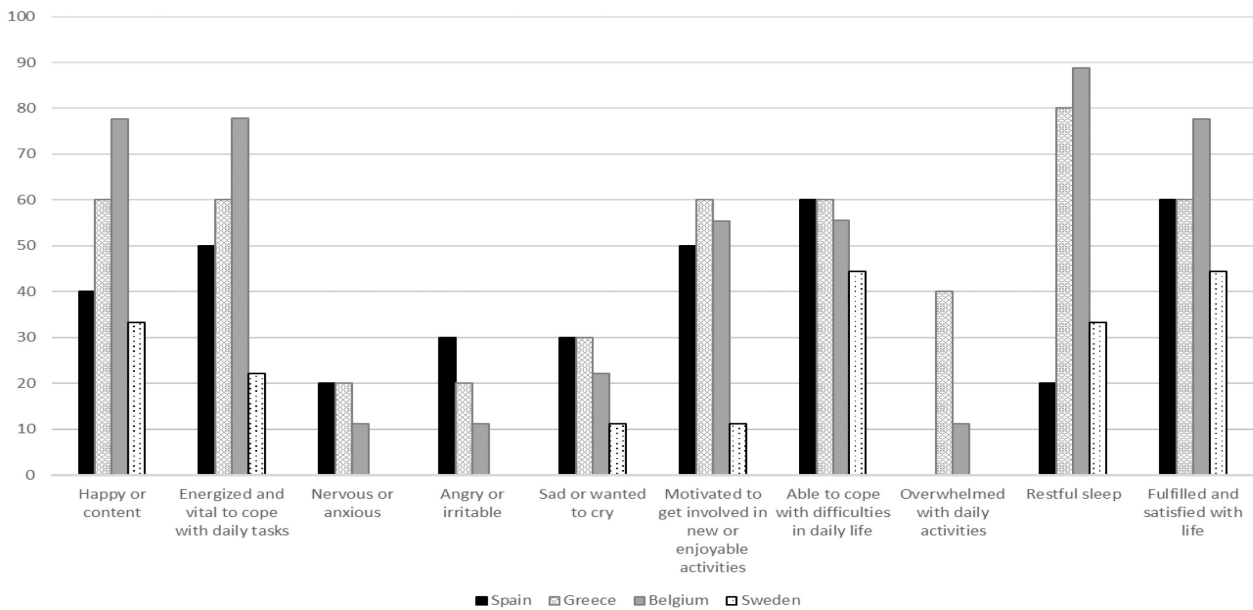
(a) Cognitive state**(b) Emotional well-being**

FIGURE 7 Comparison of the subjective perception of patients of cognitive (a) and emotional status (b) according to country of origin (Spain, Greece, Belgium and Sweden).

but rather exploring factors enabling the adherence to healthier lifestyle among this group of patients.

This study showed that both patients and their carers required more knowledge and information to enable them to adhere to dietary recommendations and participate in physical activity. They indicated a need to learn more about food sources of nutrients and minerals

and what type of physical activity would be appropriate. Regarding physical activity they perceived fatigue, followed by pain to be the main barriers for the pursuit of an active lifestyle. Concerning emotional and cognitive state, patients' and their carers' subjective perception was generally positive in contrast to the HCPs, who identified certain cognitive and emotional difficulties in patients.

4.1 | Nutrition

Our findings indicate that patients feel the need to better understand the food sources of potassium, phosphate, sodium and liquids. This agrees with the results from an earlier study in which patients reported that they struggle to learn about food sources of different electrolytes and minerals (Lambert et al., 2018). The need for more information about food, diet and liquid intake expressed by patients and carers in this study is interesting in view of the results from previous studies in which patients felt overwhelmed by dietary recommendations (Lambert et al., 2018). Although, it is not surprising that patients perceive nutritional recommendations to be complex and challenging (Lambert et al., 2018). Earlier studies have reported low adherence to dietary recommendation by patients with CKD, ranging from 32% to 60% (Lambert et al., 2017; Paes-Barreto et al., 2013). Our results indicate that not being able to eat what they like is perceived to be a barrier for dietary adherence by patients. In a previous study, this feeling was described as a sense of loss and that not being able to eat favourite meals was experienced as a limitation to social life, resulting in social isolation (Lambert et al., 2018). As facilitators, carers reported that it would be useful to receive clearer information about diet. Moreover, they also felt overwhelmed by the numerous aspects of treatment including diet, medication and exercise. To date, there are few studies in the field of CKD addressing these perspectives. In the clinics lacking a dedicated dietitian, the present study shows that patients, carers and HCPs all felt that a dietitian on the team would be an important facilitator. This opinion is corroborated by previous studies which reported that dietitians normally are the first person from whom patients learn about diet (Beto et al., 2016; Lambert et al., 2019).

4.2 | Physical activity

To increase physical activity, both patients and carers require more information and more encouragement from HCPs. The lack of guidance from HCPs regarding physical activity has also been highlighted in patients with CKD stages 3–4, as well as in patients on dialysis (Fiaccadori et al., 2014; Kendrick et al., 2019). Even though HCPs believed physical activity to be good for their patients, they perceived lack of knowledge as a barrier for them to promote physical activity in patients, which is in accordance with earlier studies (Fiaccadori et al., 2014). Strategies to enable physical activity in patients with CKD including those on HD are necessary, especially having access to dedicated physiotherapists. In this study, about 47% of both patients and carers perceived fatigue as a barrier to increase physical activity, which is in line with previous studies (Delgado & Johansen, 2012; Hannan & Bronas, 2017; Jayaseelan et al., 2018; Parsons et al., 2018; Zhang & Bennett, 2019). Plans for implementation of exercise should take into account that fatigue is perceived as a main barrier both for patients and their carers. Thus, exercise programmes should have a slow progression of intensity and duration

and allow for situational adaptation to symptoms. A recent study in patients with CKD stages 3–5 showed that the Borg scale of Rating of Perceived Exertion is both safe and effective when prescribing and monitoring individualised exercise training, especially in older and multimorbid patients (Svensson et al., 2022). Pain was also perceived as a barrier to physical activity in around 40% of the patients in the present study. A previous study reported pain as a drawback to activity in around 20% of those asked (Parsons et al., 2018). Thus, pain is a common symptom in a substantial proportion of patients on HD and exercise should be prescribed taking this into consideration. Safety was a major concern for carers, they wanted to be sure exercise would not harm the patients. Previous studies confirm this concern, patients worry about the risk of injury, needle dislodgement and hypotension (Zhang & Bennett, 2019), so creating a safe and supportive environment is a major prerequisite for promoting an active lifestyle. For both patients and carers, other facilitators included exercising during HD with fun activities, in line with several studies, that reported that adherence to exercise programs was higher during HD compared with home-based programs (Ortega-Pérez de Villar et al., 2020).

4.3 | Cognition and psychological well-being

It is interesting to note the positive perception that patients and their carers had of their cognitive and psychological state in this study. In contrast, several previous studies reported that CKD is a predictor of cognitive dysfunction and associated with an increased risk of developing dementia. (Bronas et al., 2017; Drew et al., 2019; McAdams-DeMarco et al., 2020; Shoji et al., 2022; Viana et al., 2019; Zhao et al., 2019). Cognitive function has been reported to show a gradual decline as kidney function decreases and has been identified as an independent predictor of mortality, hospitalisation and decreased HRQoL (Drew et al., 2019; Tian et al., 2019; Zhao et al., 2019). Earlier studies have indicated that interventions in patients with CKD with cognitive impairment could have a positive impact on their HRQoL; however, further studies are warranted (Drew et al., 2019; Tian et al., 2019). Studies in patients with CKD have found an increased risk of mood disturbances and emotional problems, such as depression and anxiety (Drew et al., 2019; Schouten et al., 2020; Tanaka & Okusa, 2020; Tian et al., 2019; Viana et al., 2019), which in turn can also be related to cognitive impairment in affected patients (Bronas et al., 2017; Drew & Weiner, 2014; Viana et al., 2019). In fact, despite the high incidence of these cognitive and emotional disorders reported in earlier studies, these conditions are most likely underdiagnosed in patients with CKD (Gerogianni et al., 2019; Zegarow et al., 2020). Thus, the positive perception of cognitive health and emotional well-being reported by patients and carers in this study is not in line with the literature. On the contrary, the literature is congruent with the less positive perception shown by the HCPs in the present study, *most of them being nurses*. It should be recalled that these HCPs knew and cared for patients on a regular basis

and showed a diverse opinion on the cognitive and emotional status of patients. A possible explanation for this discrepancy might be related to social desirability, distorted subjective perception, minimization or normalisation of symptoms. The findings of the present study underscore the necessity of employing objective assessments through standardised questionnaires (for depression, anxiety, quality of life, attention or memory) and using objective psychophysiological measures to provide adequate support as needed. A comparison between the perception of patients from the different countries participating in the study shows that patients from Spain and Sweden consider that they have worse attentional or learning capacity, but better functioning of executive functions than patients from Greece and Belgium. While the results obtained pertain to a small sample of patients and may not be entirely representative, we can infer, based on previous literature, that potential differences could be associated with the age of the participants enrolled in the study (despite the Spanish are the older and the Swedish the younger ones), cultural and socioeconomic aspects, the healthcare system and the existing coverage in each country, as well as the available mental health specialists' assistance (De Godoi Rezende Costa Molino et al., 2022).

Patients, their carers and HCPs were in agreement about the value of nutritional treatment, an active lifestyle and cognitive and psychological support. In general, the HCPs were positive to the concept of participating in interdisciplinary support, their main barriers were lack of time, lack of knowledge and not having access to adequate equipment. They highlighted the need for interdisciplinary teamwork involving experts within nutrition, physical activity and psychology and cognition. An earlier study on strategies to improve management within CKD care reported similar findings, emphasising the importance of creating an adequate organisational framework facilitating interdisciplinary care (Pellegrino & Schmidt, 2011). Another study discusses that building a culture within the dialysis unit acknowledging the importance of healthy behaviour for patients creates a positive environment that facilitates the implementation of health strategies (Jhamb et al., 2016). One strategy that could enhance the promotion of healthy habits among patients on dialysis could be having dedicated interdisciplinary HCPs to support changes in attitudes and to overcome other barriers (Regolisti et al., 2018). However, future studies should clarify the cost-effectiveness of this interdisciplinary approach.

Key strengths of our study are first including both patients, their carers and HCPs and second a broad European perspective with four countries from northern, central and southern Europe represented. This comprehensive perspective is innovative as most previous studies did not consider the perspectives from various stakeholders. Another novel approach is the interconnectivity of four nonpharmacological treatment modalities comprising nutrition, physical activity and emotional and cognitive state. We believe that this approach may be helpful when planning nonpharmacological intervention strategies for patients on HD, but also for other groups of patients. Another interesting aspect is the exploration of the HCPs perspective and the issues they consider relevant both regarding their

patients and to their own work. The results from this study offer perspectives on which changes or improvements in the work teams that could facilitate the provision of healthy habits. A weakness of this study is the small sample size in each centre, and, possibly, the lack of ability from the questionnaire to capture socioeconomic and cultural differences from each country that could have influenced the outcome. Finally, the lack of validation of the questionnaires is a limitation. The exploratory questionnaires used in the present study are not a standardised tool, and this could limit the generalisation of the results to other groups of patients.

In summary, we developed and tested questionnaires to explore patient-reported outcomes and unmet needs, barriers and facilitators of interest for facilitating interventions aiming at improving nutrition, physical function, cognitive function and emotional well-being among HD patients. The responses of patients, their carers and the HCPs involved in the patients' care are of value when constructing an individualised interdisciplinary strategy that is responsive to changes in the health status of patients on dialysis. Finally, the findings from these exploratory questionnaires were used to build an educational platform using a digital tool, in this case, games that adopt a multitask approach for the patient to play during the dialysis session. Furthermore, we were able to build educative sessions for patients, carers and HCP as peer-to-peer training addressing what were to them their main needs, barriers and facilitators for adhering to dietary recommendations, improving physical activity and ameliorating their emotional well-being.

AUTHOR CONTRIBUTIONS

Patricia Mesa-Gresa, Carla Maria Avesani were involved in Conception and design of the work; analysis and interpretation of data for the work; drafting the work; final approval of the version to be published; agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Naomi Clyne, Alicia García-testal, Evangelia Kouidi, Amaryllis H. Van Craenenbroeck and Eva Segura-Ortí were involved in Conception and design of the work; acquisition, analysis, and interpretation of data for the work; revising it critically for important intellectual content; final approval of the version to be published; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Bengt Lindholm, Jose Antonio Lozano-Quilis and Alexandra-Elena Marin were involved in Substantial contributions to the conception or design of the work; revising it critically for important intellectual content; final approval of the version to be published; agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. Rafael García-Maset, Kevin Yang were involved in substantial contributions to the acquisition of data for the work; revising it critically for important intellectual content; final approval of the version to be published; agreement to be accountable for all aspects of the work in ensuring that questions related to the

accuracy or integrity of any part of the work are appropriately investigated and resolved.

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CONFLICT OF INTEREST STATEMENT

Patricia Mesa-Gresa, Carla Maria Avesani, Naomi Clyne, Alicia García-Testal, Evangelina Kouidi, Amayllis H. Van Craenenbroeck, Jose Antonio Lozano-Quilis, Alexandra-Elena Marin, Rafael García-Maset, Kevin Yang, and Eva Segura-Ortí have no conflicts of interest. Bengt Lindholm BL is employed by Baxter healthcare.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

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