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ARTICLE

The Connected We St@nd programme: A feasibility pilot study of an online self-management intervention for adults on in-centre haemodialysis and family caregivers

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Abstract

Objective: The 'Connected We St@nd' is an online self-management intervention programme for people receiving in-centre haemodialysis and family caregivers that combines an educational and psychosocial support component. This study aimed to evaluate its feasibility and acceptability before proceeding to a large-scale trial.

Design: This was a pre-post single-arm feasibility pilot study conducted with adults undergoing in-centre haemodialysis and family caregivers.

Methods: Feasibility was based on eligibility, consent, retention, completion and intervention adherence rates, while acceptability was assessed in post-intervention focus group interviews.

Results: Twenty-six people (16 adults on haemodialysis and 10 family caregivers) recruited through social networks completed the intervention. Consent, retention and completion rates were excellent (>90%) and eligibility (77.5%) and intervention adherence were satisfactory (69% for the psychosocial support sessions). Qualitative findings revealed that participants shared positive feelings regarding their participation in the programme. The valuable interactions with group peers and health psychologists during the support sessions, the perception of the adequacy and coherence of the programme's contents and materials and the participants' confidence in using the platform developed to deliver

the intervention were some of the aspects highlighted as facilitators of intervention acceptability. Additionally, people on haemodialysis and caregivers reported that participation in the programme brought several educational and emotional benefits (e.g., additional disease-related knowledge, improved communication and coping skills, greater confidence in managing dialysis complications or caregiving demands) that helped increase their self-management skills and psychosocial adjustment to the demands of kidney failure and renal therapies.

Conclusions: The results suggested that the 'Connected We St@nd' programme is likely to be feasible and acceptable for adults on haemodialysis and family caregivers, thus representing a promising resource for the future of interdisciplinary renal rehabilitation. Suggestions were made to fine-tune the intervention design to proceed with a large-scale trial.

KEYWORDS

caregiver, dialysis, Internet-based interventions, kidney failure, self-management

INTRODUCTION

Worldwide, thrice-weekly in-centre haemodialysis is the most common renal replacement therapy for adults with kidney failure (Himmelfarb et al., 2020). Described as one of the most burdensome ongoing treatment regimens, maintenance dialysis therapy requires a significant degree of self-management (Buemi et al., 2020). Self-management is defined as the individual's 'ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition' (Barlow et al., 2002, p. 178). For people on haemodialysis, it includes dealing with the biopsychosocial impacts of treatments (e.g., hypotension, fatigue, neurocognitive changes, psychological distress, altered family dynamics), attending dialysis sessions as prescribed and adhering to complex health behaviours (e.g., fluid and dietary restrictions, regular physical activity, vascular access care, polypharmacy intake) that are crucial to their quality of life and survival (Fotheringham et al., 2019).

Caregivers can play a central role in helping to manage these tasks and efforts; in fact, close family members are among the most important resources for disease management in kidney failure, often assisting with meal preparation, fluid control, medication supervision, transport to and from the dialysis centre, arranging medical appointments, communicating with the healthcare team and offering emotional support (Hoang et al., 2018). Nonetheless, providing this type of care and assistance can be an arduous experience likely to involve feelings of loneliness and burden and a constant need to readjust personal, family, social and work activities to meet haemodialysis caregiving demands (Gilbertson et al., 2019). In this sense, previous research has evidenced that family caregivers of adults on haemodialysis experience moderate to severe burden and poorer quality of life compared to people providing informal care to family members with other chronic conditions such as cancer (Gilbertson et al., 2019).

Despite the growing recognition of the profound changes caused by maintenance haemodialysis in the lives of the person receiving treatment and their families, self-management interventions in this context tend to focus on the education of the person with kidney failure, who receives information related to nutritional counselling, medication intake and disease pathophysiology; in turn, skills training

and psychosocial support remain scarce and the needs of family members are often neglected and under-prioritized (Hovadick et al., 2021; Narva et al., 2016).

The development and implementation of self-management interventions in renal care are even more urgent in the face of the new coronavirus. In this regard, research has shown that the COVID-19 pandemic brought several additional challenges to adults undergoing in-centre haemodialysis (e.g., electrolyte imbalances, increased difficulties in managing dietary and fluid restrictions, fear of severe complications from infection with SARS-CoV-2) and their close relatives (e.g., fear of contaminating the person with kidney failure, additional care responsibilities such as transporting the cared-for person to and from the dialysis centre), aggravating (the already elevated) levels of psychological distress, burden and social isolation (Sousa et al., 2022; Sousa, Ribeiro, Costa, et al., 2021). The global public health measures to lessen the risk of exposure to the new coronavirus, such as prophylactic isolation and physical distancing, have also amplified the need to identify and explore new approaches to ensure the accessibility of care to high-risk people and their families. In different chronic diseases such as cancer, diabetes and stroke, Internet-based interventions have increasingly become a pragmatic resource with promising results in terms of acceptability and participant satisfaction (Elhenawy & Eltonbary, 2021; Trevino et al., 2021). For people on haemodialysis and their family caregivers, the online modality can also help to minimize barriers that have been associated with low intervention adherence and retention rates in traditional face-to-face programmes, namely impediments with transportation to the intervention site (e.g., costs, geographic distance, mobility limitations) and increased burden (e.g., time constraints, work disruptions, dealing with adverse effects of dialysis) (Sousa, Ribeiro, Paúl, et al., 2021). However, the evidence regarding the effectiveness of Internet-based approaches in kidney failure is limited and uncertainties remain as to its feasibility (Chan et al., 2016; Hudson et al., 2017).

Therefore, the goal of the present study was to assess the feasibility and acceptability of the 'Connected We St@nd' programme, an online self-management intervention for adults undergoing in-centre haemodialysis and family caregivers. As online self-management interventions represent an innovative approach in renal rehabilitation, a feasibility pilot study is recommended to understand the potential suitability of the methods and procedures used and thereby inform the planning of a subsequent large-scale trial (Eldridge et al., 2016; Teresi et al., 2022).

METHODS

Study design and recruitment strategy

This was a pre-post single-arm feasibility pilot study conducted with adults undergoing in-centre haemodialysis and family caregivers. Participants were recruited through nationwide advertisements placed on social media platforms, newspapers and mailing lists of support associations between February and September 2021. Enrolment was made by completing a screening form on a website (https://togetherwestand.pt/) created to inform about the study objectives. To be included, people with kidney failure had to be receiving maintenance haemodialysis treatments in a national dialysis centre for at least 3 months, while family caregivers (relative and/or partner, or friend) had to be the main providers of non-paid care, support and/or assistance to a person undergoing this renal therapy under these same circumstances. All participants had to be 18 years of age or older, able to use Internet-connected devices (e.g., computer, tablet, smartphone), understand the purpose of the study and agree to voluntary participation. Compliance with the eligibility criteria was confirmed by two researchers through a telephone interview after the participants had enrolled in the study. All procedures performed followed the 1964 Helsinki Declaration and its later amendments. Electronic consent was obtained from all participants before data collection. Confidentiality was guaranteed by assigning each participant a numerical code. This study was approved by an Institutional Ethics Committee (referenced as UICISA:E 670_05/2020).

The 'Connected We St@nd' intervention programme

The development of the 'Connected We St@nd' programme was informed by four sequential steps: (i) a comprehensive review of preferences of family caregivers and people with kidney disease for online interventions; (ii) the findings from semi-structured interviews carried out with adults undergoing in-centre haemodialysis and family members to explore their self-management needs, preferences and expectations; (iii) the selection of theory-informed intervention methods and strategies; and (iv) the knowledge and collaborative work of an interdisciplinary team of researchers and healthcare professionals with relevant experience in kidney failure and/or the development and implementation of self-management programmes in various chronic diseases.

Overall, the review of the literature hinted that Internet-based approaches in chronic kidney disease should be interactive, use multimedia components (e.g., audio, video with animation and content presented by dialysis experts) and display links to resources for future reference (e.g., relevant websites, renal-friendly recipes, booklets) (Coumoundouros et al., 2023; Donald et al., 2019; Schiffer et al., 2021). Previous studies that utilized online modalities also reported that the ability to interact directly with healthcare professionals via video conferencing during the intervention was a feature appreciated by participants (Donald et al., 2019; Schiffer et al., 2021).

Additionally, the findings of the semi-structured interviews revealed that adults undergoing in-centre haemodialysis and family caregivers wish to improve disease and treatment-related knowledge (e.g., information on kidney failure aetiology, benefits and procedures of dialysis and kidney transplantation), acquire better clarification on dialysis-related health behaviours (e.g., dietary and fluid recommendations, vascular access hygiene and complications), have easier access to available community resources (e.g., monetary aids, home support services, social rights) and receive professional psychological support to facilitate coping with the impacts of renal therapies (e.g., fatigue, hypotension, altered family dynamics, uncertainty about the future, treatment-related fears, kidney transplant expectations) (Figueiredo et al., 2021, 2023a, 2023b; Sousa et al., 2023).

Based on these findings, Corbin and Strauss' Self-Management Framework (1988) was followed to guide the selection of intervention methods and strategies. This framework proposes that chronic disease self-management involves three main tasks: (1) the medical management of the health condition (e.g., dealing with dialysis complications and treatment demands), (2) behavioural management (e.g., adopting new health behaviours such as following dietary and fluid recommendations) and (3) emotional management (e.g., coping with feelings of anger, anxiety, treatment-related expectations and fears) (Corbin & Strauss, 1988). The six core skills for effective disease management discussed by Lorig and Holman (2003), namely problem-solving, decision-making, resource utilization, partnering with healthcare providers, action planning and self-efficacy, also informed the intervention design. The rationale was based on the premise that self-management employs psychoeducational and/or behavioural strategies to assist participants in developing the skills and confidence needed to address the multiple challenges caused by chronic illness (Brahim et al., 2021).

From then on, programme content and materials were co-developed by an interdisciplinary team of researchers and healthcare professionals, including nephrologists, dialysis nurses, health psychologists and specialists in health education, renal nutrition, physical therapy and social service.

Intervention content and implementation

Based on the steps outlined above, the programme followed an interdisciplinary collaborative online approach combining education and psychosocial support. The educational component was asynchronous, while psychosocial support was delivered synchronously through videoconferencing. Synchronous support sessions were in a group format to promote the sharing of experiences, mutual support and a sense of group identity and coherence among individuals facing similar challenges (Rolland, 2019).

For the educational component, several videos of recorded interviews conducted with different nephrology and dialysis experts were gradually released. These videos promoted strategies to manage lifestyle modifications and provided information about kidney failure, renal replacement therapies, dialysis-related health behaviours (e.g., physical activity, dietary restrictions, fluid control, vascular access care) and community resources available to assist people with chronic diseases and informal caregivers (e.g., support associations, social rights, monetary aids, home support services). In turn, the psychosocial support component of the programme was intended to help participants deal with the impacts and challenges of treatments, enhance communication skills, train emotional management and problem-solving and foster a sense of personal identity and purpose in life (Sousa et al., 2023). Two health psychologists facilitated the synchronous support sessions normalizing participants' emotions, encouraging them to share experiences and reinforcing self-management efforts and group processes (e.g., cohesion, mutual support). These professionals have had prior training and experience in group (self-, couple- and family-based) interventions in chronic diseases, including kidney failure. Several active-learning methods were implemented such as group dynamic exercises (e.g., relaxation techniques), group discussions and brainstorming.

In addition, downloadable booklets were made available to supplement the educational and psychosocial support sessions, as well as provide materials for future reference. The content of these materials was largely informed by the findings of previous investigations conducted by the research team involved in designing the 'Connected We St@nd' programme (Figueiredo et al., 2021, 2023a, 2023b; Sousa et al., 2023). Efforts were made to create educational videos and/or booklets useful for both people with kidney failure and family caregivers.

The website created for enrolment in the study was used to deliver the intervention (https://togetherwestand.pt/). This website is open to the public, but only participants had access to the platform with the intervention content and materials (e.g., videos, booklets, renal-friendly recipes, audio relaxation exercises, link for synchronous sessions). This platform also allowed participants to pose anonymous questions to the different healthcare professionals involved in the synchronous and asynchronous components of this intervention programme.

Overall, the 'Connected We St@nd' programme consisted of six weekly sessions. Each session (except the first) involved an educational and a psychosocial support component. Educational videos (of approximately 20 min each) were gradually made available between synchronous support sessions to allow group discussion since the contents of both components were interconnected. Each psychosocial support session was planned to last approximately 120 min. To prevent attrition, participants were encouraged to watch the educational videos and participate in synchronous group sessions with weekly email reminders. Those who missed any of the sessions remained in the study and maintained access to the programme's educational materials.

Figure 1 presents the 'Connected We St@nd' intervention programme (per session).

Outcome measures

Feasibility was assessed based on the following indicators: (i) eligibility rate and reasons for exclusion (the number of participants who met the inclusion criteria divided by the number of participants who completed the online screening form); (ii) consent rate and reasons for not participating in the study (the number of participants who electronically consented to participate divided by the number of participants who were eligible for the study); (iii) retention rate (the number of participants who did not formally drop out divided by the number of participants who started the intervention), (iv) completion rate (the number of participants who completed the self-reported measures at baseline and post-intervention) and (v) intervention adherence rate (measured by summing the total number of sessions attended by the participants).

To estimate the completion rate, participants were emailed a web-based protocol displayed on LimeSurvey, a secure online platform for administering the questionnaires with implicit consent

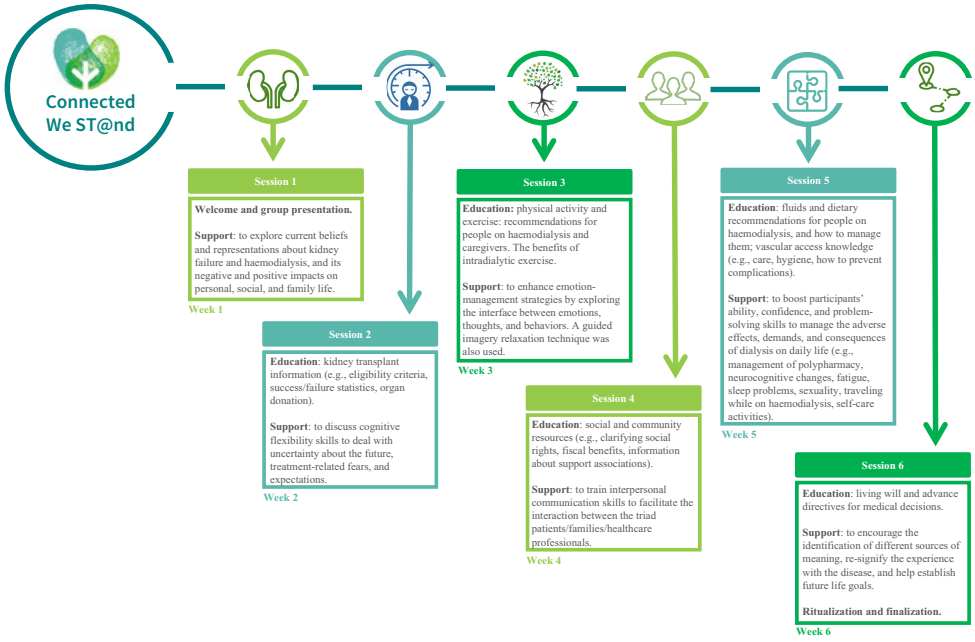

FIGURE 1 The 'Connected We St@nd' intervention programme.

(www.limesurvey.org). Psychometric assessment comprised different self-report measures: (i) Positive Affect and Negative Affect Scale Short-Form (PANAS-SF; Galinha et al., 2014); (ii) Hospital Anxiety and Depression Scale (HADS; Pais-Ribeiro et al., 2007); (iii) Purpose in Life Test-Revised (PiL-R; Peralta & Silva, 2006); (iv) World Health Organization's Quality of Life Instruments – BREF (WHOQ-BREF; Canavarro et al., 2009); (v) End-Stage Renal Disease-Adherence Questionnaire (patient only) (ESRD-AQ; Poveda et al., 2016); and (vi) Zarit's Scale for Caregiver Burden (caregiver only) (ZBI; Sequeira, 2010). All measures were completed at baseline (pre-intervention) and one week after the intervention ended (post-intervention).

The acceptability of the programme was evaluated 2 weeks post-intervention. Based on Vaughn et al. (1996) instructions, focus group interviews were conducted via videoconference by a researcher who was not involved in the intervention. A semi-structured guide was used to explore participants' perspectives on the overall programme and its components (e.g., perceived benefits, the potential impacts of the intervention on the dyadic relationship between the person with kidney failure/caregiver, the extent to which participants considered the programme appropriate to meet their needs, difficulties experienced during participation, platform usability, comprehensibility of materials, suggestions for improvements).

Data analysis

The focus group interviews were video recorded, transcribed verbatim and analysed by two independent researchers using thematic analysis following Braun and Clark's recommendations (2006) for data categorization. Participants' perspectives regarding the intervention were examined within the context of the Theoretical Framework of Acceptability of Health Interventions (Sekhon et al., 2017). This model proposes that acceptability is a multifaceted construct, represented by seven constructs: affective attitude, burden, perceived effectiveness, ethicality, intervention coherence, opportunity costs and self-efficacy (Sekhon et al., 2017). Researcher triangulation (i.e., employing multiple raters to analyse

participant responses) and having a researcher who was not involved in the design and delivery of the intervention lead the focus groups were crucial to increasing data rigour. To ensure reflexivity, regular meetings were held to discuss study-related issues and how the researchers' personal experiences and beliefs could affect data analysis.

RESULTS

Participant characteristics and feasibility results

A total of 40 individuals completed the online screening form expressing their interest in participating in the 'Connected We St@nd' programme. Of these participants, 31 (77.5%) met the study inclusion criteria and were deemed eligible; the remaining nine individuals were excluded for not undergoing haemodialysis in a national dialysis centre ($n = 5$) and for not being family caregivers of adults receiving this renal therapy ($n = 4$ renal nurses). After being fully informed about the study objectives, format and intervention schedule, three people with kidney failure were excluded for not being able to attend the synchronous sessions. A consent rate of 90.3% was achieved as 28 individuals (out of 31) gave their electronic consent; in turn, retention through study completion was 92.9% since two participants (out of the 28) formally dropped out from the study after the first session (one person on haemodialysis for medical reasons and one spouse due to incompatibility with a new work schedule).

To this end, 26 participants (16 adults on haemodialysis and 10 family caregivers) completed the intervention. Five groups of four to eight participants were formed between March and November 2021. The groups were mixed, i.e., included both people on haemodialysis and family members receiving the same intervention at the same time. One of these groups consisted of four couples. Sample characteristics and baseline psychometric assessment results are displayed in Table 1.

Eighteen participants attended all six synchronous support sessions, while the remaining eight (five people on haemodialysis and three caregivers) missed one of the sessions due to adverse effects of treatments (e.g., fatigue, nausea, fistula complications), COVID-19 infection and consequent hospitalization, or conflict with work responsibilities, family, or social events. All adults on haemodialysis and family caregivers self-declared to have watched the five educational videos; the intervention adherence rate was 69% for the synchronous support component and 100% for the educational asynchronous videos. As per prespecified procedures, participants who missed asynchronous or synchronous sessions remained in the study and received the educational materials.

Lastly, all self-reported outcome measures showed good internal consistency with Cronbach's alphas ranging from .737 to .918 in this study's sample, which is an indicator of their psychometric suitability for the target population (Teresi et al., 2022). Additionally, the completion rate was 100% as all participants completed both assessment points and there were no missing data. Taken together, the high completion rate and satisfactory reliability are suggestive of the overall feasibility of the assessment protocol used in the present investigation, encouraging its potential use in a future large-scale trial (Teresi et al., 2022).

Figure 2 illustrates the feasibility results of the current study.

Acceptability of the intervention

All individuals who completed the programme ($n = 26$) participated in the focus group interviews with the same group of people with whom they received the intervention. The findings of the focus group interviews (Table 2) revealed that adults on haemodialysis and family caregivers shared positive feelings and experiences about their participation in the 'Connected We St@nd' programme.

TABLE 1 Participants' characteristics.

	Adults on haemodialysis ($n=16$)	Family caregivers ($n=10$)
Sociodemographic and caregiving context characteristics		
Gender, *n* (%)		
Female	10 (63%)	9 (90%)
Age (years old), $M \pm SD$ [*min–max*]	49 ± 14.2 [26–81]	50.1 ± 10.6 [34–69]
Education level, *n* (%)		
Basic education	4 (25%)	3 (30%)
Upper secondary education	5 (31%)	1 (10%)
Higher education	7 (44%)	6 (60%)
Kinship with the person on renal therapy, *n* (%)		
Spouse	–	6 (60%)
Other (adult children, sister-in-law)	–	4 (40%)
Caregiving (years), *n* (%)		
<2	–	3 (30%)
>2	–	7 (70%)
Length of time on haemodialysis (months), $M \pm SD$ [*min–max*]	128 ± 131 [6–446]	–
Baseline psychometric assessment results, $M \pm SD$ [min–max]		
PANAS-SF – Positive affect	14.81 ± 3.69 [9–22]	16.41 ± 4.77 [8–24]
PANAS-SF – Negative affect	9.50 ± 4.08 [5–20]	9.60 ± 2.91 [5–14]
HADS-Total – Psychological distress	12.69 ± 6.95 [4–26]	14.41 ± 8.81 [3–32]
PiL-R – Purpose in life	96.19 ± 20.72 [58–127]	100 ± 14.6 [79–122]
WHOQ-BREF – Overall quality of life	51.56 ± 22.76 [22.51–75]	71.25 ± 13.24 [50–87.53]
ESRD-AQ – Self-reported treatment adherence	1031.25 ± 144.48 [700–1200]	–
ZBI – Caregiver burden	–	44.61 ± 14.84 [24–71]

Abbreviations: ESRD-AQ, End-Stage Renal Disease-Adherence Questionnaire (the total score ranges from 0 to 1200; higher scores mean greater adherence); HADS, Hospital Anxiety and Depression Scale (total score ranges from 0 to 42; higher scores are indicative of greater distress); PANAS-SF, Positive Affect and Negative Affect Scale Short-Form (total score ranges from 5 to 25 on each subscale; higher scores mean increased positive/negative affect); PiL-R, Purpose in Life Test-Revised (total score ranges from 20 to 140; higher scores represent greater purpose in life); WHOQ-BREF, World Health Organization Quality of Life Instruments – BREF (total score ranges from 0 to 100; a higher score corresponds to a better perception of quality of life); ZBI, Zarit's Scale for Caregiver Burden (the total score ranges from 22 to 110; higher scores correspond to higher levels of burden).

Affective attitude and intervention effectiveness

Participants described how the programme met (or, for some, exceeded) their initial expectations, highlighting the support and bond between group peers as facilitators of their commitment to the intervention. Overall, people on haemodialysis and caregivers reported that participation in the programme brought several educational and emotional benefits that helped boost their self-management skills and facilitated psychosocial adjustment to the demands of kidney failure and renal therapies. In this sense, participants revealed that the intervention enhanced their understanding of dialysis-related health behaviours (e.g., dietary restrictions and long-term consequences of non-adherence, the benefits of intradialytic exercise, fistula puncture techniques) and improved emotional management strategies (e.g., to deal with fears, concerns about the future, frustration), psychological flexibility (e.g., greater awareness and acceptance that the demands of dialysis or caregiving can be managed and/or overcome) and communication skills (e.g., greater assertiveness, increased couple conversations about the impacts of dialysis on their lives).

FIGURE 2 Feasibility results.

TABLE 2 Acceptability of the 'Connected We St@nd' programme from the perspective of participants ($n = 26$; 16 people on haemodialysis and 10 family caregivers).

Theme [Definition[a]]	Subtheme	Representative quote(s)
Affective attitude [Feelings regarding participation in the intervention]	Expectations met (or exceeded)	*The new experiences and solutions that were exchanged in each session and the support of the psychologists along with the sharing of our* [peers] *lives and experiences exceeded my expectations in every way* [person on haemodialysis]
	Sense of commitment and bond established between participants	*The best part was the comfort of talking to someone about my life and what I went through and knowing that the people in the group were listening and accepting and trying to comfort me. This helped me* [commit to the sessions in this programme]. *I attended each support session with pleasure* [family caregiver]
Burden and opportunity costs [The perceived amount of effort required to participate in the programme or the costs associated with participation]	Efforts to attend late-night psychosocial support sessions	*Some nights were difficult because the group sessions were at night and, on those days, I had to go to bed later* [person on haemodialysis] *For me, it was difficult because I work in shifts. Like the last session… I was sleeping and had to wake up to join the group meeting* [person on haemodialysis]
	Joining synchronous sessions while dealing with treatment complications	*I had surgery on my arm* [fistula complications] *and I felt sick because of the anaesthesia. (…) I wanted to participate but it was difficult* [person on haemodialysis] *The only thing I didn't like was sitting still for an extra two hours* [during synchronous group sessions], *especially after being on dialysis for four hours* [person on haemodialysis]
Perceived effectiveness [Perception of the effects and/or benefits obtained from participating in the intervention]	Increased disease and treatment-related knowledge	*I learned to manage my fistula and the different puncture techniques. It is no longer just the nurses' choice on how to puncture my fistula, it's my choice too* [person on haemodialysis] *With the videos and booklets on what they* [patients] *can and cannot eat, I felt much more oriented. With everyone's help, now I know what information I should try to retain* [family caregiver]
	Boosted disease self-management skills	*The relaxation exercise* [trained in support sessions and then downloaded as an audio recording] *was very helpful during dialysis sessions. I used to have panic attacks (…). Breathing techniques also helped me deal with the malaise associated with hypotension at the end of treatment* [person on haemodialysis] *This programme helped me to manage my emotions as I was always irritable and nervous. I have always focused on the negative but now I do not see treatment as a sacrifice anymore* [person on haemodialysis] *I've been putting it into practice since we* [the couple] *started the sessions. Instead of reacting so aggressively, I try to be more assertive, questioning first and not being so impulsive* [person on haemodialysis] *On dialysis we are told 'Don't bring too much weight' (…) but what about potassium and phosphorus? We are often told 'Don't eat that, because it's bad', but what is bad? (…) Now, instead of talking* [to dialysis experts] *about what I can't eat, I talk more about what I can eat and how much* [person on haemodialysis]

TABLE 2 (Continued)

Theme [Definition[a]]	Subtheme	Representative quote(s)
	Amplified self-efficacy in managing caregiving activities and responsibilities	*I realized that it is important for me to keep some distance* [from the cared-for person environment]. *My parents have their house, I have mine. (…) I need to give them that space because that is how I gain mine* [family caregiver] *It* [intervention programme] *helped me look at my problems in a different way. Now I see things from a different perspective. (…) I understood how important it was to live day to day instead of anticipating problems. (…) This* [programme] *helped me to accept things as they are* [family caregiver] *It* [intervention programme] *helped me to understand that I'm mortal, I'm not made of iron and therefore I have to delegate some things* [caregiver activities and responsibilities] *to others* [family caregiver] *This* [intervention programme] *helped me to better understand how my father feels about dialysis. Now we talk more about his treatment and I can understand him better* [family caregiver]
	Enhanced couple communication	*This* [intervention programme] *increased the dialogue between my wife and I. In group sessions, we talked about the impacts of dialysis on our lives, but that conversation continued after we turned off the computer* [person on haemodialysis] *We shared our feelings for each other in front of the group and this gave us more confidence to talk about it* [the impacts of dialysis] *with each other too. After the sessions, we often rekindle the dialogue and doubts that were often seen as a ghost. The group helped us see that these ghosts are not just ours, as they are also present in other couples* [spouse]
	Improved psychosocial adjustment to illness	*This programme was a great help and had a very positive impact on me. I never imagined that my evolution in terms of accepting this disease would be so fast. Everyone's help and testimony were very important* [person on haemodialysis] *From the third week of the programme, I began to feel the benefits and to appreciate the help of psychologists. (…) I changed a lot emotionally. In the first 2 weeks of participation, I had a completely different attitude towards life* [family caregiver] *Having the opportunity to share as a couple the various topics we discussed during the sessions made us look at the disease from a different perspective, a perspective more centred on us, as a couple. (…). It further consolidated our union* [spouse]
Ethicality [Beliefs about the adequacy of the intervention to the individual's value system and potential negative impacts of programme participation]	Difficulty dealing with the negative feelings or experiences of peers	*I had some difficulty dealing with certain negative emotions because I felt helpless… I wanted to help but I didn't know how. I was sad to see some people without hope. This made me a little sad too* [person on haemodialysis] *There were moments when I felt more worried about the future of this disease because I heard the experiences of caregivers of people who became dependent and very ill. It makes me worry about what's to come* [family caregiver]

(Continues)

TABLE 2 (Continued)

Theme [Definition[a]]	Subtheme	Representative quote(s)
Intervention coherence [Opinions on the adequacy of intervention considering the programme objectives]	Videoconferencing as a facilitator of sharing	*I think it was easier for us to share online than if we were face-to-face. (…) It would not have been possible to have so many people from so many different places in the same group, from other realities, hospitals, dialysis units… If we were from the same region, we might be embarrassed and not share as much* [person on haemodialysis]
	Positive experiences with educational materials	*All materials are an asset for a good learning experience and future reference. (…) Especially due to the simplicity and clarity of the information. It has become easier to find information, less boring and more attractive. It's something we understand and can use later* [spouse] *Videos and booklets are simple but enlightening. Well-structured and easy to understand* [person on haemodialysis] *I found the videos quite interesting and objective. I liked that they were made by dialysis experts* [spouse] *I learned a lot from the information that was shared in the videos and booklets (…). They were very detailed, with easy language and lots of useful information* [person on haemodialysis]
	Flexibility of the asynchronous component	*We were able to watch the videos or read the booklets in the time we set aside and find convenient in our daily lives* [family caregiver]
	Interconnection of the contents of both components (educational and support) of the intervention	*I found the organization of the programme very interesting. It was very engaging to have homework* [educational materials] *with important information and then, at the beginning of each group session, to make a global reflection on the educational materials and then discuss psychological issues and exchange experiences related to the topics of the videos* [person on haemodialysis]
Self-efficacy [Participant's confidence that they can perform the behaviour(s) required to participate in the intervention]	Platform usability	*Even though I understand little about technology, I was able to find all the materials on the platform and it was very easy for* me to use it [person on haemodialysis] *The platform is a good tool. (…) I found it very appealing and very intuitive and it was easy to access the videos and links. There were no problems, we had no setbacks* [spouse]

TABLE 2 (Continued)

Theme [Definition[a]]	Subtheme	Representative quote(s)
Suggestions on the content, structure and organization of the programme	Expand and/or include new content	*I think sexuality was underexplored and it should be added as a main topic and have an educational video on the platform. Sexuality needs to be further addressed, regardless of our marital status* [person on haemodialysis] *There was a topic that was not covered as I wished, which was holidays and the exchange of treatments between clinics. Not only nationally but also in other countries and how this can be reimbursed by our* [national] *social security system* [person on haemodialysis] *I would like information about palliative care for people on dialysis. (…) People don't like to talk about it* [family caregiver]
	Increase the number of support sessions	*I suggest doing a few more sessions, about five or six, maybe a monthly follow-up* [family caregiver] *I would like this to be an ongoing support programme because kidney failure doesn't go away. (…) Less time per session but more sessions* [person on haemodialysis] *I think the six sessions should be just the beginning, as an introduction to the impacts of this disease on our lives. I feel like there is still more to share and learn* [person on haemodialysis]
	Include other dialysis care professionals in synchronous sessions	*If we had a dialysis expert, such as a nephrologist, present in some of the group sessions it would be enriching to clarify some of our doubts and concerns* [family caregiver]

[a]Based on the Theoretical Framework of Acceptability of Health Interventions (Sekhon et al., 2017).

For people with kidney failure, the programme also encouraged positive reframing of the disease experience ('I do not see treatment as a sacrifice anymore') and expanded their confidence in dealing with treatment requirements and/or complications (e.g., more participation in treatment decision-making regarding fistula and nutritional care; perceived self-efficacy in managing episodes of hypotension and anxiety during dialysis sessions). Likewise, for family caregivers, the intervention improved their ability to deal with conflicting responsibilities and tasks (e.g., successfully reconciling caregiving and work-related demands), as well as developing and maintaining self-care activities.

Burden, opportunity costs and ethicality

No obstacles related to the online modality that could potentially interfere with adherence to the asynchronous and/or synchronous components of the programme were mentioned by participants; nonetheless, some barriers to attendance were identified. Impediments were mainly related to interference from work responsibilities, adverse effects of dialysis treatments (e.g., fistula complications, nausea, fatigue) and/or efforts to attend late-night psychosocial support sessions. Some participants also mentioned difficulties in coping with the negative feelings or experiences reported by their peers during group meetings.

Intervention coherence

Encouraging opinions about the appropriateness of the intervention procedures and materials given the programme objectives were conveyed during the focus group interviews. In this regard, the use of videoconferencing in support sessions was positively appraised, as it brought the opportunity to share experiences with other family members and people with kidney failure from different renal care settings without having to 'leave the comfort of my home' [person on haemodialysis]. Positive feedback was also given to the educational videos and booklets, described as 'enlightening', with adequate and comprehensive language and an 'important asset for a good learning experience and future reference' [spouse]. According to participants, the asynchrony of the educational component was another positive aspect, as it allowed greater flexibility to watch the educational videos and read the booklets at their best convenience. Lastly, the programme was deemed well structured, given the interconnection of the contents (and materials) of both components which gave participants the impression of a 'path to follow between the videos [educational component] and the sessions [support component]' [family caregiver].

Self-efficacy during participation

People on haemodialysis and caregivers reported feeling confident in their ability to use the platform developed to carry out the intervention; this resource was considered easy to navigate, well designed and visually pleasing.

Suggestions about the content, structure and organization of the programme

Participants also made some fundamental suggestions for the development of future interventions. Most agreed that it was essential to increase information on the impacts of dialysis on sexuality, going on vacation while on dialysis and palliative care in nephrology, indicating that these contents need to be discussed in more detail in synchronous support sessions and/or integrated into educational videos.

Finally, people with kidney failure and their families recommended carrying out monthly reinforcement sessions as six synchronous support sessions were seen as an 'introduction to the impacts of this

disease on our lives' [person on haemodialysis]. The presence of a nephrologist in the synchronous component to clarify doubts about treatment complications (e.g., cardiovascular disease, anaemia, dual-organ transplantation) was also advised by the participants for future interventions.

DISCUSSION

The 'Connected We St@nd' programme is an online self-management group intervention for adults undergoing in-centre haemodialysis and family caregivers that follows an interdisciplinary approach combining synchronous psychosocial support with an asynchronous educational component. Overall, the results of this feasibility pilot study suggested that this intervention programme is likely to be feasible and acceptable for this population although some aspects need to be carefully considered before proceeding to a large-scale trial.

In the present research, retention and completion rates were excellent (>90%) and intervention adherence was also high (69% for the synchronous support group sessions) which is an indicator of the overall feasibility of the 'Connected We St@nd' programme. Moreover, these rates were greater than those found in other online or face-to-face interventions with people with kidney failure, with retention rates ranging from 50% to 80% (Hernandez et al., 2018; Hudson et al., 2017; Jakubowski et al., 2020). Although studies on the viability of online approaches for this population are still scarce, to date and to the best of our knowledge, this investigation is pioneering for family caregivers of people receiving renal therapy. According to two recent systematic reviews, there are only eight face-to-face group psychosocial interventions targeting caregivers of adults on dialysis with sustained effectiveness (Bártolo et al., 2022; Hovadick et al., 2021) but the feasibility of these initiatives remains unexplored.

Several aspects may have contributed to the satisfactory rates found in the present feasibility pilot study, including the valuable interactions with group peers and health psychologists described by participants, the adequacy and coherence of programme contents and materials and their confidence in using the platform developed to deliver the intervention, as pointed out during the focus group interviews conducted after the programme. Furthermore, different educational and emotional benefits were also perceived, such as improvements in coping skills (e.g., greater psychological flexibility and emotional management and communication strategies) and increased self-efficacy in managing dialysis demands (e.g., better awareness of the needs of the person being cared for; more participation in treatment decision-making regarding nutritional and vascular access care) and complications (e.g., hypotension episodes). Taken together, these positive experiences may have increased the acceptability of the programme and participants' commitment to the intervention.

For people on haemodialysis, perceived self-efficacy is a fundamental component of effective disease self-management, referring to the individual's confidence in their abilities to overcome treatment-related barriers and achieve the desired health outcomes (Bandura, 2001; Lin et al., 2012). In this population, self-efficacy has been associated with increased treatment adherence, lower levels of psychological distress, open communication with caregivers and better interactions with dialysis care professionals (Curtin et al., 2008). In turn, for family members, self-efficacy (i.e., the caregiver's belief in their ability to perform various caregiving tasks and/or contribute to the well-being of the person being cared for) can have a protective effect on their health due to its associations with reduced burden and depression (Ritter et al., 2022; Tan et al., 2021). In this sense, the Social Cognitive Theory (Bandura, 2001) recognizes that the positive impacts of self-efficacy can be extended to the social/family system, which is particularly relevant for adults receiving renal therapy and spouses who participated in the 'Connected We St@nd' programme as a dyad. In focus group interviews, these four couples congruently expressed improvements in dyadic communication regarding treatment-related issues (e.g., sexuality). This finding is also in line with previous research on theoretical models of family systems (Rolland, 2019) that have already highlighted the importance of developing interventions that promote the perception of chronic disease as a 'we' challenge rather than a problem of the person with the disease.

Finally, it is important to make some considerations about the enrolment of caregivers and adults on haemodialysis in the current study. Although recruitment through social networks allowed reaching participants from different renal care settings, research has shown that people are more likely to enrol in online interventions when they have already interacted with the healthcare professionals who will be involved (Johansson & Andersson, 2012; Schiffer et al., 2021), which was not the case in the present study. Despite this, the sample size of previous investigations exploring the feasibility of Internet-based programmes with videoconferencing that recruited directly from dialysis centres is relatively similar to the sample size of the current research ($n = 26$, i.e., 16 people on renal therapy and 10 family members), ranging from 6 to 25 participants (Hudson et al., 2017; Jakubowski et al., 2020). One possible explanation for the low enrolment and/or participation rates may be related to the sociodemographic characteristics of adults with kidney failure and their family caregivers such as poor socioeconomic status, advanced age and low levels of education and digital literacy (Jain & Green, 2016). Consequently, a large proportion of individuals may be excluded from online interventions, as they lack the skills and means to participate (Schrauben et al., 2021). Nevertheless, some barriers to the use of Internet-connected devices will inevitably decrease and therefore advances in digital health are extremely valuable for the future of interdisciplinary comprehensive renal care.

Limitations

Participants had a particularly high level of education (50% of the sample has a university degree, i.e., 44% of adults on dialysis and 60% of caregivers) which could increase sampling bias. Before proceeding to a large-scale trial, it may be important to explore barriers perceived by people on haemodialysis and their families who are less likely to engage in digital health interventions and focus on alternatives to improve their accessibility to these new modalities (e.g., including a digitally qualified family member within a dyadic approach, enhance the involvement of dialysis centres in the implementation of technology-mediated initiatives).

As for the organization of the programme, the platform used for the educational component did not allow a reliable analysis of the visualization and/or download of the materials (videos and booklets); consequently, adherence to the asynchronous sessions is based on participants' self-declaration, which raises the question of whether the intervention was consistently received by all participants in the same way (intervention fidelity). In an attempt to minimize this limitation, the initial part of each synchronous support session was dedicated to reviewing the content of the video interviews (e.g., group reflection on the content of the interviews and participants' learning experiences, clarification of doubts).

It is also important to mention that the acceptability of the programme was only explored from the participants' perspective and the views of healthcare professionals involved in delivering the intervention were not explored. Having this information would have been crucial to understanding the potential accessibility and appropriateness of implementing the 'Connected We St@nd' programme in nephrology centres (e.g., cost-effectiveness and economic implications; whether health psychologists can be recruited, trained and retained and/or deliver the intervention as intended) (Teresi et al., 2022).

Lastly, this study did not directly involve people on haemodialysis and families as 'co-designers' of the programme, which could have been important in increasing the clinical utility of the intervention and further facilitating its dissemination and implementation at a national level (Tong et al., 2022).

CONCLUSIONS

The current feasibility pilot study suggested that the 'Connected We St@nd' programme is likely to be feasible and acceptable in improving the psychosocial adjustment of adults on haemodialysis and family caregivers to the challenges inherent in living with kidney failure. This investigation represents an important contribution to the future landscape of renal rehabilitation programmes as it provides

the necessary support to justify and fine-tune the development of a large-scale trial that examines the effectiveness of an online self-management intervention combining psychosocial support with an educational component. Future studies should consider recruiting participants from social networks and directly from dialysis centres to reach as many people as possible.

AUTHOR CONTRIBUTIONS

Helena Sousa: Conceptualization; data curation; writing – original draft; funding acquisition; investigation; methodology; formal analysis; visualization. **Oscar Ribeiro:** Conceptualization; methodology; project administration; supervision; writing – review and editing; validation. **Ana Bártolo:** Conceptualization; investigation; methodology. **Elísio Costa:** Conceptualization; supervision. **Fernando Ribeiro:** Conceptualization; supervision. **Mário Rodrigues:** Software; conceptualization. **Constança Paúl:** Conceptualization; supervision. **Daniela Figueiredo:** Conceptualization; funding acquisition; writing – review and editing; methodology; formal analysis; project administration; data curation; supervision; resources; validation.

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CONFLICT OF INTEREST STATEMENT

The authors declare there are no competing interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author, [DF], upon reasonable request.

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