Strengthening Renal Psychology in Portuguese Dialysis Centres: The Implementation of Evidence-Informed Psychological Practices

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Abstract
Hemodialysis imposes a significant psychological burden on people receiving this kidney therapy and their families. However, the role of Renal Psychologists remains underrecognized in the majority of nephrology centres worldwide, including in Portugal. This review article presents the rationale, development, and implementation of evidence-informed psychological assessments and interventions organised in Portuguese dialysis centres. Overall, three resources – two patient-reported outcome measures that aim to facilitate the triage of psychological distress and its sources in people on hemodialysis (Hemodialysis Distress Thermometer for Patients [HD-DT]) and informal/family caregivers (Hemodialysis Distress Thermometer for Caregivers [HD-DT-C]), and an Internet-mediated psychoeducational intervention (the Connected We St@nd programme) - are presented and discussed as a means to optimise interdisciplinary collaborations and the expansion of professional psychological support services in (national and international) nephrology care settings.

Keywords: Kidney Failure, Chronic/psychology; Psychological Intervention; Psychometrics; Renal Dialysis/psychology

INTRODUCTION
Worldwide, hemodialysis is the cornerstone treatment for kidney failure, and Portugal is the European country with the highest unadjusted prevalence of people being treated with this kidney replacement therapy.[1] However, the personal, familial, societal, and economic implications of hemodialysis are extensive, leading to heightened psychological distress and a significant decline in the quality of life of the person receiving this (often long-term) treatment and their close family members.[2]

Renal Psychology is the clinical specialty that focuses on understanding and addressing the psychological (i.e., behavioural, cognitive, emotional, social, and existential) strains arising from living (or caring for a significant other dealing) with kidney diseases and treatments.[3] In the last two decades, Renal Psychology has gained increasing recognition in the international scientific literature largely due to the growing body of studies highlighting the complex interplay between the medical and psychosocial challenges faced by individuals with chronic kidney disease (CKD).[4-6] In the context of hemodialysis, cumulative research has evidenced that mental health issues negatively impact patient treatment adherence, raising the risk of dialysis-related complications, healthcare utilization and costs, and early mortality.[4-6] Conversely, psychological interventions have been shown to enhance patients/families' knowledge, confidence, and skills to effectively cope with the demands of kidney therapies over time.[7,8] In this regard, different meta-analyses have confirmed that the timely implementation of psychological interventions in nephrology centres is associated with more favourable clinical and laboratory outcomes like interdialytic weight, blood pressure, and serum levels of haemoglobin, albumin, phosphorus, and potassium.[8-11] Patient participation in these approaches also helped to alleviate adverse physical and psychological symptoms, such as pain, fatigue, insomnia, and depression, and reduce medication overuse.[6,7] Similar findings have been reported by recently

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published systematic reviews underlining the advantages of the few available psychological interventions for improving quality of life and reducing caregiver burden in people caring for a family member with kidney failure.[12,13] Despite this awareness, the presence of mental health professionals continues to be utterly insufficient in most nephrology centres worldwide,[14] including in Portugal, where the role of Renal Psychologists and the implementation of psychological interventions in dialysis units remains severely underprioritized.[15,16] This shortfall is particularly evident when compared to other European countries like Spain (Fundación Renal Española; https://fundacionrenal.com), France (France Rein, https://www.francerein.org), and the United Kingdom, which already have an active workforce of Clinical Health Psychologists in nephrology care settings. For instance, in the UK, organizations like the UK Kidney Care (https://kidneycareuk.org/) ensure free counselling services for people with CKD and their families, and several hospitals have already settled Renal Psychology Services to optimize the access of this population to professional psychological support.[14] Progressively recognized as an international reference in Renal Psychology, this country also stands out for having created the Renal Psychological Therapists Network (https://www.renalpsychologicaltherapists.org/), an official group of Renal Psychologists who contribute to strengthening the national advancement of this clinical specialty, advocating for the inclusion of mental health professionals in interdisciplinary nephrology teams.

Innovatively, in December 2023, the Portuguese Government approved the National Strategy for the Promotion of Kidney Health and Integrated Care in Chronic Kidney Disease 2023-2026 and created the Implementation Commission of the National Strategy for Chronic Kidney Disease (CIMEN-DRC) that includes a representative of the College of Portuguese Psychologists (OPP – Ordem dos Psicólogos Portugueses) in an attempt to establish sustainable interdisciplinary healthcare collaborations to meet the multifaceted assistance and informational needs of people diagnosed with chronic kidney disease and their families (Diário da República n.º 237/2023, Série II de 2023-12-11, pp. 102 – 107). Regardless of this much-needed and urgent initiative, little to no evidence is available to inform best practices in Renal Psychology, delimit its field of intervention, and prompt changes in national healthcare policies to include professional psychological support as a reimbursable service within state-funded dialysis units in Portugal.

The present work outlines the planning and implementation of a research project entitled Together We Stand (https://togetherwestand.pt/) that focused on developing, implementing, and testing the effectiveness of evidence-informed disease management interventions in hemodialysis with the ultimate goal of strengthening psychological assessments and interventions in Portuguese dialysis centres. Since the contributions of this research project may be transversal and applicable to other cultural contexts/countries, the global drive of this review article is to help raise awareness of the importance of reinforcing the incorporation and continuous training of Clinical Health Psychologists in renal care settings and to assist in promoting Renal Psychology as a field for research and clinical practice both nationally and internationally. The main empirical endeavours presented stemmed from the research work undertaken by an interdisciplinary team with extensive expertise at the intersection of Clinical Health Psychology and Nephrology in Portugal (https://togetherwestand.pt/team/?lang=en).

ORGANIZING RENAL PSYCHOLOGY PRACTICES IN PORTUGUESE DIALYSIS CENTRES

Fig. 1 summarizes the stepwise approach that was followed to instruct the planning of evidence-informed psychological assessments and interventions in Portugal.

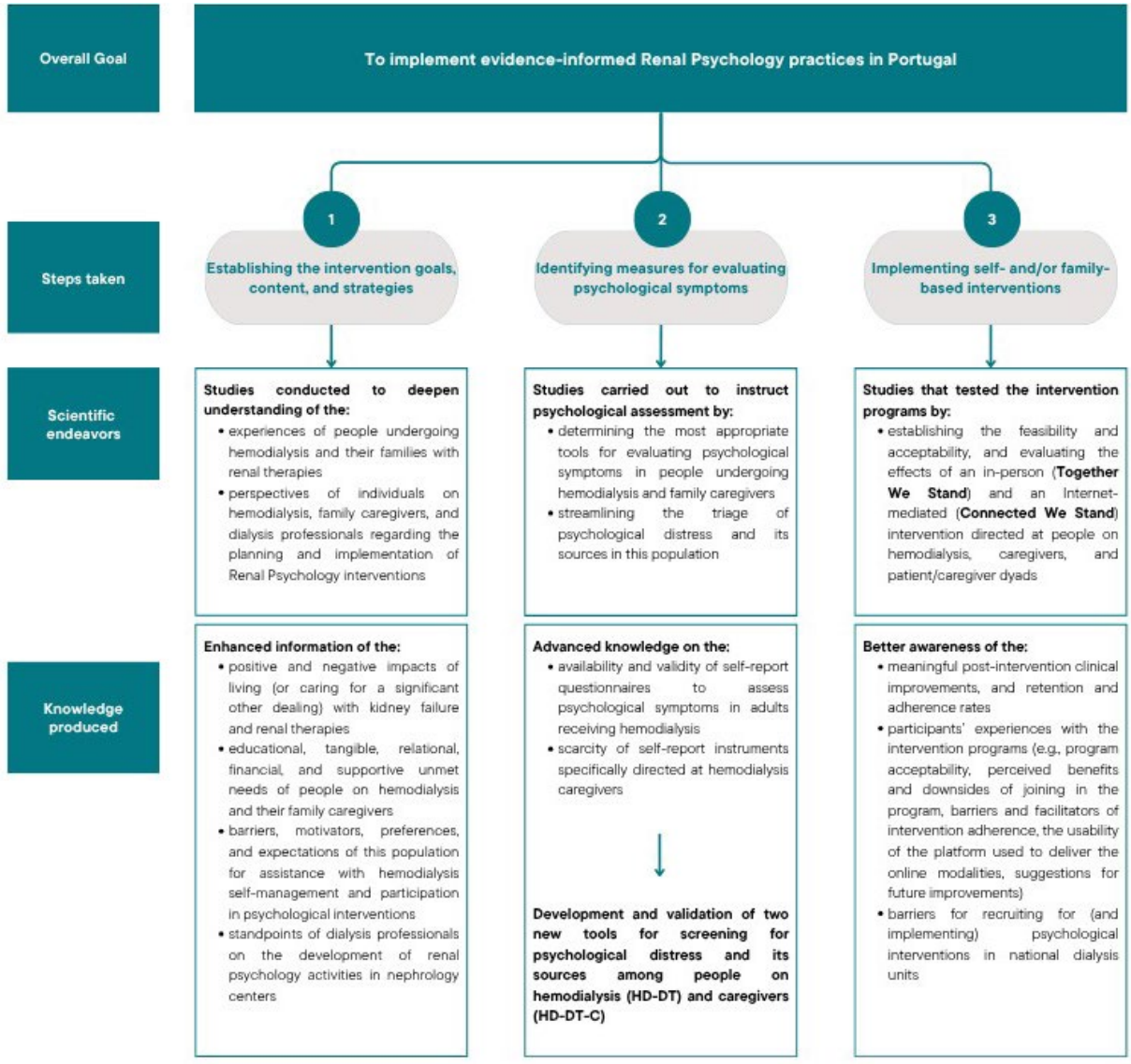

Figure 1. The stepwise approach that instructed the planning and implementation of evidence-informed Renal Psychology practices in Portuguese dialysis centres

Step 1: Designing and implementing psychological interventions in hemodialysis

The first task consisted of collecting and analysing the individual and dyadic views of people with kidney failure and their family caregivers regarding the impacts of hemodialysis in their lives, as well as the perspectives of dialysis providers about the implementation of psychological interventions in nephrology care contexts. Table 1 summarizes the research methods and scientific results of the studies that guided the design and implementation of psychological interventions in hemodialysis (cf. Step 1).

Based on these scientific efforts, the main aspects to be addressed in psychological interventions in this context were compiled.[17-22] In general, such initiatives need to consider: (i) refining patients' and caregivers' (and dialysis care professionals') communication skills and emotional management skills; (ii) increasing their psychological flexibility to cope with uncertainty about the future and treatment-related (or caregiving-specific) fears and expectations, including with kidney transplantation; (iii) and training patients/caregivers adaptive strategies to cope with the adverse effects of dialysis such as neurocognitive changes, sexual/intimacy problems, needle distress and fistula setbacks, body image and identify issues, caregiver burden, sleep impairment, and strained family relationships.[17-22]

Findings also helped to anticipate barriers that may hinder the availability and interest of patients/caregivers in joining face-to-face psychological interventions in dialysis units, particularly the geographic distance and travel costs to the intervention site, scheduling conflicts with treatment sessions or other life responsibilities, the burden of dialysis treatments,

and dealing with intra or inter dialysis adverse effects while receiving this type of assistance.[17,23] Awareness of these caveats has encouraged the planning of alternative intervention modalities, particularly Internet-mediated approaches (cf. Step 3), which may be easier to implement and more viable and practical for this typically overburdened population.[17,23-25]

Overall, the knowledge obtained in this initial step was used to delineate the intervention content, goals, and strategies, as well as its most convenient periodicity, duration, format, and mode of delivery.

Table 1. Research methods and main scientific results of the studies conducted to strengthen evidence-informed Renal Psychology practices in Portuguese dialysis units.

Steps taken	Studies' design	Recruitment strategy and sample size*	Data collection/analysis procedures	Main findings
STEP 1 (*n*=6 studies)	Qualitative exploratory studies[17-21]	17 dyads (12 couples) dealing with HD for a minimum of two months[18,19] 27 people undergoing HD for a minimum of two months[17,20] 32 family caregivers (19 adult children) of people on HD for a minimum of two months[21] 23 dialysis professionals with at least 12 months of experience in dialysis settings[17]	Semi-structured interviews / thematic analysis	Dyads mentioned that HD had several negative impacts on families' leisure and daily activities, dyadic psychological health (distress and increased isolation), and couple dynamics (communication and intimacy/sexuality)[18]; Family caregivers expressed the desire to directly receive more treatment-specific information and join disease management activities in dialysis units[19]; Perceiving health benefits compared to pre-dialysis; good social support from family members, dialysis providers and dialysis peers; self-efficacy in coping with the demands of treatments; and the ability to maintain different life purposes due to HD acting as a life-sustaining treatment, were identified as facilitators of adherence to in-centre HD sessions[20]; The impacts of the inflexible HD attendance regimen on family members' emotional well-being were reported as a barrier to adherence to treatment sessions[20]; Adult children mentioned numerous caregiving-related stressors, including difficulties in managing dietary, fistula care and fluid control requirements, dealing with patients' negative reactions to treatment, and lack of support from other family members[21]; Several educational (e.g., improve disease and treatment-related knowledge; acquire better clarification on dialysis-related health behaviours) and support (unmet) needs (e.g., easier access to available community resources and professional psychological support; additional emotional and instrumental support from family members) were identified[17]; Patients/families' expressed their desire to receive more disease/treatment-specific information, but dialysis providers believe that this knowledge is easily available upon explicit request.[17]
	Descriptive-correlational study with a cross-sectional design[22]	172 family caregivers of people receiving HD for a minimum of two months	Assessment protocol comprising a set of psychometrically valid and reliable tools measuring self-reported caregiver burden, purpose in life, adaptive coping, and psychological distress / Moderated-mediation model using a regression-based approach	Maintaining life purposes, psychological acceptance, and the flexibility to reinterpret negative situations in a more positive light can help promote psychosocial adjustment (buffering caregiver distress and burden) to the HD caregiving process.

Steps taken	Studies' design	Recruitment strategy and sample size*	Data collection/analysis procedures	Main findings
STEP 2 (n=2 studies)	Stepwise mixed-methods studies, combining data from a literature search, qualitative individual and focus group interviews, and cross-sectional descriptive-correlational results[15,16]	134 people receiving HD for a minimum of two months joined the validation study of the HD-DT[15] 106 family caregivers of people receiving HD for a minimum of two months joined the validation study of the HD-DT-C[16]	Assessment protocol comprising the HD-DT and a set of psychometrically valid and reliable tools assessing the presence of symptoms of anxiety and depression, and quality of life, and caregiver burden (caregiver only) / ROC curve analysis	The European Portuguese versions of the HD-DT[15] and the HD-DT-C[16] showed good test-retest reliability and high diagnostic accuracy using a cutoff point of, respectively, ≥ 6 (people on HD) and ≥ 5 (caregivers) for total distress. High convergent validity was found with reference measures that assess psychological health, and symptoms of anxiety and depression; Both PROMs were described by feedback panels (composed of dialysis providers and members from the target population) as practical and clinically useful for rapidly screening psychological distress in dialysis centres; Feedback panels raised some concerns about the future accessibility of these PROMs in dialysis units and how/where to refer people identified as having "clinically relevant psychological distress" to appropriate psychological support services.
STEP 3 (n=3 studies)	The Together We Stand (in-person) programme: pre-post single-arm feasibility pilot study[24]	6 patient/caregiver dyads	Feasibility was calculated based on eligibility, consent, retention, completion, and intervention adherence rates Acceptability was assessed with post-intervention focus group interviews and thematic analysis/ Pre-post intervention changes were based on effect sizes measures, using the results of a psychometrically valid and reliable questionnaire that assessed the presence of symptoms of anxiety and depression; patient clinical records were consulted before and after the intervention to collect IDWG	The screening (93.5%), retention (85.7%), and completion (100%) rates of the Together We Stand programme were satisfactory, whereas eligibility (22.8%), consent (18.4%), and intervention adherence (range: 16.7%–50%) were the most critical; Participants shared positive feelings about their participation in the intervention (e.g., enhanced relationships with other dialysis peers and caregivers who joined the programme, augmented treatment-related knowledge, improved problem-solving skills); People on HD pointed out that it was difficult to attend intervention sessions, especially on treatment days due to dialysis-related side effects; Family caregivers expressed difficulties in juggling different family responsibilities and attending the intervention sessions; Medium to large effect sizes were found for reductions in participants' symptoms of anxiety and depression, and patients' IDWG;
	The Connected We St@nd (online) programme: pre-post single-arm feasibility pilot study[25] with a secondary analysis to test its preliminary effectiveness[26]	16 adults on hemodialysis 10 family caregivers (including 4 dyads/couples)	The same methods were used to evaluate feasibility and acceptability/ Pre-post intervention changes were based on effect sizes measures, using an assessment protocol comprising a set of psychometrically valid and reliable tools evaluating subjective well-being, purpose in life, quality of life, treatment adherence (patient only), and caregiver burden (caregiver only)	Consent, retention, and completion rates were excellent (>90%) and eligibility (77.5%) and intervention adherence were good and satisfactory (69%); Completing the programme enhanced participants' understanding of dialysis-related health behaviours, such as dietary restrictions and long-term consequences of non-adherence, the benefits of intradialytic exercise, and fistula puncture techniques; Several emotional benefits were pointed out by patients/families, including enhanced communication and coping skills, greater confidence in managing dialysis complications or caregiving demands, positive reframing of the disease experience, more participation in treatment decision-making, success reconciliation of caregiving and work-related demands, greater awareness and acceptance of the demands of dialysis or caregiving, and improved couple conversations about the impacts of dialysis on their lives; No obstacles related to the online modality were mentioned; Clinically meaningful pre-post intervention changes were found in the positive affect dimension of subjective well-being, purpose in life, overall quality of life, and psychological health.

AVF=arteriovenous fistula; IDGW=interdialytic weight gain; HD=hemodialysis; HD-DT=hemodialysis distress thermometer for patients; HD-DT-C=hemodialysis distress thermometer for caregiver; ROC=receiver operating characteristic.

* In all studies, participants were included based on the following criteria: i) being 18 years of age or older; ii); not suffering from any visual, auditory, or cognitive impairment that could hinder understanding the purpose of the study; and iii) agreeing to participate voluntarily. Those who joined the qualitative component of the project[17-21] were recruited from two private peripheral dialysis units in the North and Centre of Mainland Portugal; in turn, patients and caregivers who participated in the quantitative studies[15,16,22] were recruited from four private peripheral

dialysis units in the North and Centre of Mainland Portugal. For the in-person intervention – the Together We Stand programme[23] – dyads were recruited from one private peripheral dialysis unit in the North of Mainland Portugal. For the online intervention – the Connected We St@nd programme[24,25] – participants were recruited using nationwide advertisements placed on social media platforms, newspapers, and mailing lists of support associations.

Step 2: Streamlining psychological assessment in hemodialysis

Research conducted during this second step exposed the dearth of existing self-report measures specifically developed to identify psychological strains in hemodialysis.[15,16] Traditionally, in this context, a combination of non-disease-specific tools has been used to allow for a more comprehensive evaluation of the diverse symptoms and stressors faced by individuals with kidney failure and their caregivers; however, such practices can be time-consuming and unfeasible, increasing the likelihood of over- or under-identifying psychosocial issues and potentially delaying interdisciplinary efforts to help prevent adjustment struggles in this population.[15,16] Attempting to help bridge this gap, two easy-to-complete, clinically useful, valid, and reliable patient-reported outcome measures (PROMs) – the Hemodialysis Distress Thermometer for Patients (HD-DT[15]) and the Hemodialysis Distress Thermometer for Caregivers (HD-DT-C[16]) – were developed and validated to simplify the triage of psychological distress and its sources (physical, emotional social/family, and dialysis-specific) in hemodialysis. Table 1 presents the research methods and scientific results of the studies reporting the development and testing of the measurement properties of the HD-DT and HD-DT-C (cf. Step 2).

The HD-DT and the HD-DT-C can be used as a starting point to encourage communication between dialysis providers and patients/families about the challenges of kidney therapies, identify the most prevalent difficulties and/concerns of this population, and determine their need/desire for referral to the most suitable (and available) support services.[6,7] Both PROMs are available in European-Portuguese (original version), American-English[15,16] and Turkish.[26] The translation, cultural adaptation, and validation to Brazilian-Portuguese, Australian-English, and Chinese are currently in progress.

Fig. summarizes the structure of the HD-DT[15] and the HD-DT-C.[16]

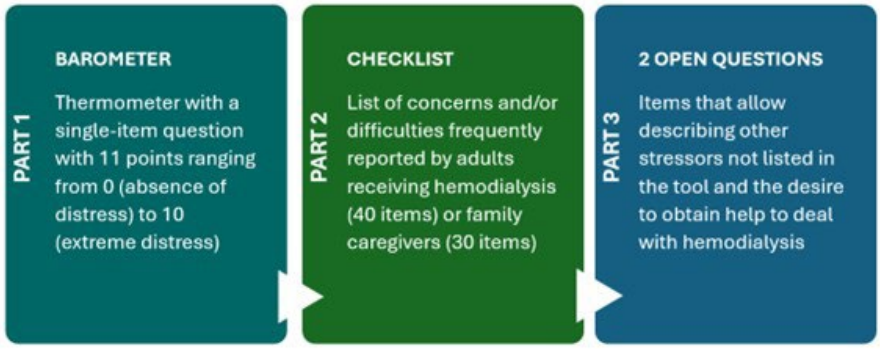

Figure 2. The tripartite structure of the HD-DT[15] and the HD-DT-C.[16]

Step 3: Testing and implementing psychological interventions in hemodialysis

Table 1 gathers the research methods and scientific results of the studies that focused on designing, evaluating, and implementing two evidence-informed interventions that aimed to boost successful disease management among individuals on hemodialysis and their caregivers (cf. Step 3). More specifically, two psychoeducational interventions were organized, executed, and tested, namely the Together We Stand programme,[23] a face-to-face family-based approach carried out in a dialysis unit in the North of Mainland Portugal; and the Connected We St@nd programme, an Internet-mediated intervention nationally implemented that, innovatively, can be offered as a patient-, caregiver-, or dyadic-based group initiative (e.g., couple-oriented), depending on participants' preferences and needs.[24,25] Table 2 compares the key components of the Together We Stand and the Connected We St@nd intervention programmes.

Fig.3 presents the Connected We St@nd programme, session by session.[24,25] Currently, efforts are being made to proceed with a large-scale trial of this technology-assisted intervention to, in due course, encourage its dissemination and integration into routine nephrology practices.

Table 2. Side-by-side comparison of the main features of the Together We Stand[23] and of the Connected We St@nd[24,25] intervention programmes.

	Together We Stand[23]	Connected We St@nd[24,25]
Mode of delivery	In-person	Online
Format	Multifamily group	Patient-, caregiver-, or dyadic-based group
Duration	6 weeks	6 weeks
Structure	Weekly sessions (~120 minutes each)	Weekly asynchronous educational videos + synchronous psychological support
Facilitators	2 Clinical Health Psychologists	Educational videos: different healthcare professionals with experience in dialysis (e.g., Fistula Nurse Specialist, Renal Nutritionist, Nephrologist, Social Worker) Psychological support: 2 Clinical Health Psychologists
Target Population	Patient–caregiver dyads	Patients, caregivers, or dyads
Intervention Focus	Health education + psychosocial support	Health education + psychosocial support
Topics Covered	Dialysis health-related behaviours, emotional regulation, assertive communication, symptom management, problem-solving, purpose in life	Similar core topics adapted for online delivery (see Fig. 3 for a detailed summary of the programme's sessions)
Feasibility & Acceptability	Feasible and acceptable, but critical (<50%) intervention adherence	Feasible and acceptable with satisfactory (>70%) intervention adherence
Preliminary Outcomes	Reduced anxiety and depression symptoms, and interdialytic weight gain	Improved psychological health, well-being, quality of life, and purpose in life
Attendance Challenges	Dialysis fatigue; caregiver time constraints	Online format may reduce intervention adherence barriers; poor digital health literacy in hemodialysis may difficult national implementation of this initiative
Important caveats	Small sample size; participants belonged to only one dialysis unit; lack of control group	Participants had a particularly high level of education (50% of the sample has a university degree) which could increase sampling bias; lack of control group
Future Directions	Needs adjustments to improve intervention adherence	Plans for large-scale trial

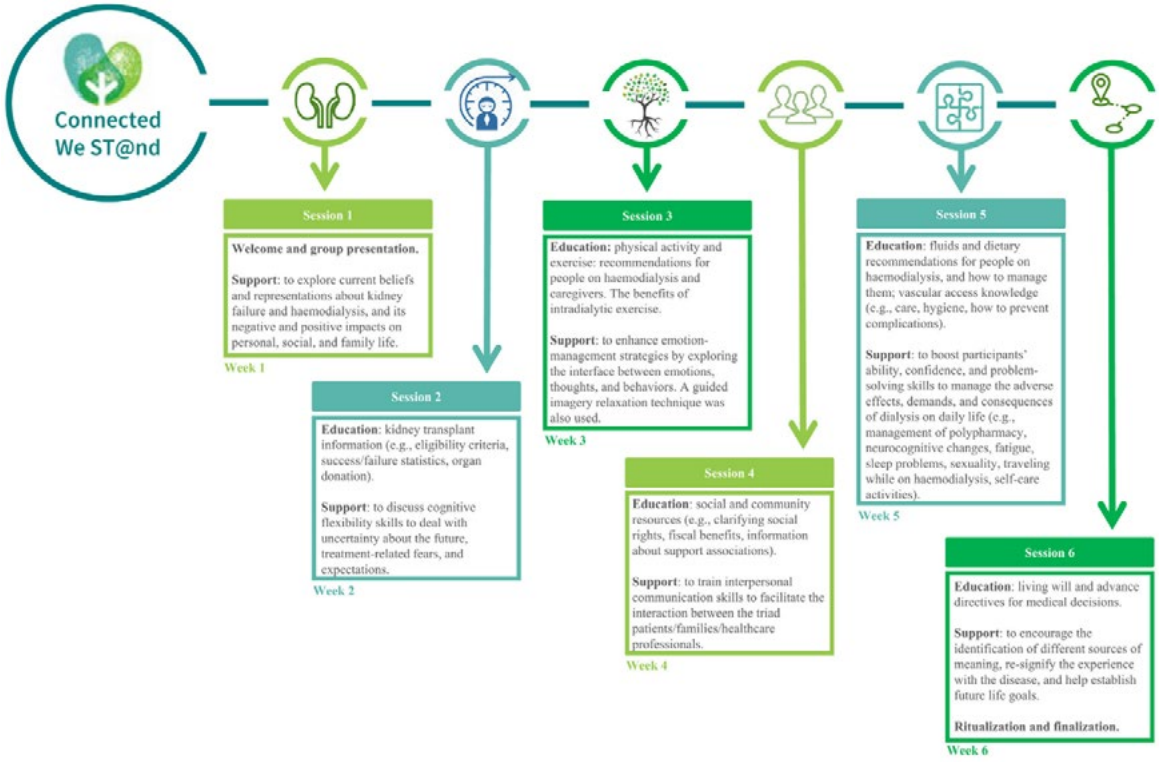

Figure 3. The Connected We St@nd intervention programme.[24,25]

DISCUSSION AND CONCLUSION

This review article provides important information about psychological assessments and interventions in hemodialysis, recommending three nationally developed evidence-informed resources that can be easily integrated and regularly implemented in dialysis centres: the HD-DT,[15] the HD-DT-C,[16] and the Connected We St@nd programme.[24,25] Notably, the Connected We St@nd programme is, to date and as far as known, the first evidence-informed, Internet-mediated, interdisciplinary, disease management intervention with evidenced feasibility and acceptability among people on hemodialysis and their caregivers, with the possibility of being available as a dyadic-oriented practice.

Particularly during/after the COVID-19 pandemic, digital health services have exponentially grown and become a convenient and pragmatic way to deliver care to high-risk populations, such as people with kidney failure on hemodialysis and their families, with promising results in terms of recipient/facilitator satisfaction in different clinical settings.[27-29] In hemodialysis care contexts, technology-assisted practices offer the prospect of smoothing patient/family access to psychological assessments and/or interventions by minimizing restrictions related to the logistical, financial, and time burden of traveling to the intervention site, interferences with work-related impediments, scheduling conflicts with dialysis sessions and/or other medical appointments, and difficulties in managing (or caring for someone experiencing) treatment-related adverse effects, including (but not restricted to) fatigue, pain, dizziness, and reduced functional independence.[17,23-25,29]

Despite the potential benefits of implementing online or in-person psychological practices in renal care settings, hemodialysis is one of the costliest treatments for healthcare systems globally.[30] In Portugal, kidney failure represents a heavy burden on the National Health Service (SNS), with recent reports stating that expenses with hemodialysis are estimated to have reached around 300 million euros of the 2022 Portuguese State Budget,[31,32] which can make it difficult to allocate resources to integrate Renal Psychologists as part of interdisciplinary nephrology care teams. In this sense, it is worth stressing that psychological interventions are effective in improving adherence to complex therapeutic regimens, which is the case of hemodialysis adherence requirements.[33,34] Improved adherence in this kidney therapy may, in turn, reduce the use or intensification of dialysis-related polypharmacy, like phosphate binders, potassium-lowering agents, or antihypertensives,[17-18] typically ensured by dialysis units within the comprehensive and integrated care payment model funded by the Portuguese National Health Service.[31,32] Still, to date, the cost-effectiveness of implementing professional psychological interventions in this context remains undetermined, and more research is needed to assess how equipped and inclined nephrology centres are, both nationally and internationally, to advance Renal Psychology.[29] Having this knowledge may be useful to stimulate the development of human-rights-based approaches on public health grounded on scientific evidence and professional practice that would be crucial to enhancing the quality of life of people receiving hemodialysis and their family caregivers.[29]

Future Challenges for Renal Psychology in Portugal

Research carried out in Portugal shows that patients and caregivers are willing to participate in routine psychological assessments and flexible disease management intervention programmes, indicating that there is great acceptability and potentially high clinical utility in implementing such initiatives in national dialysis centres.[15,16,24,25] Altogether, the scientific endeavours outlined in this review article confirm the importance of channelling future investments towards the organization and/or strengthening of psychological support services and investigations in Portuguese renal care settings.

To advance Renal Psychology practices in Portugal, it is urgent to: (a) enhance the interdisciplinarity of nephrological care by facilitating patient and family access to specialized mental health professionals in dialysis centres; (b) invest in the ongoing training of Clinical Health Psychologists interested in working at the intersection with Nephrology to ensure the provision of disease/treatment-specific interventions and better respond to the unique assistance needs of this population; (c) build on the evidence of the most (cost)effective, feasible, clinically useful, and acceptable psychological evaluation/support resources in hemodialysis; and (d) expand the use, availability, accessibility, and testing of digital health technologies, such as telepsychology, video-conferencing, and mental health applications, to adapt the structure, scheduling, and duration of psychological assessments and interventions, ensuring that such help is offered at times when those in need are most willing/open to accept them.

Renal Psychology is a growing field that presents numerous opportunities and challenges for research, clinical practice, and training in Clinical Health Psychology and Nephrology. The future requires a persistent commitment to design, fund, and disseminate all scientific endeavours and establish fruitful collaborations between researchers and clinicians that will continue to develop and refine evidence-informed Renal Psychology practices both nationally and internationally.

Ethical Disclosures

Conflicts of Interest: The authors have no conflicts of interest to declare.
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HS: Conceptualization; data curation; writing – original draft; investigation; methodology; formal analysis; data curation; resources; visualization.
OR: Conceptualization; methodology; supervision; validation; writing – review and editing.
DF: Conceptualization; methodology; funding acquisition; project administration; formal analysis; data curation; supervision; resources; validation; writing – review and editing.
All authors approved the final version to be published.

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