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Shared Decision-Making in the Choice of Peritoneal Dialysis: Patients' Perspectives on the Transition to Home Therapy

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Dedicatória

Esta tese teve, oficialmente, uma autora. Na prática, teve uma equipa que nunca assinou consentimento informado.

Aos cães da minha vida, que estiveram comigo em cada parágrafo, cada crise existencial e cada madrugada de escrita. Ao *Kuroko*, o meu menino e amor da minha vida, por ser presença constante há quase 12 anos e o meu refúgio. E ao *Schumi*, um bónus não planeado mas muito bem recebido, que surgiu quando eu mais precisava. Reviram cada versão deste documento da única forma que sabem – deitados ao meu lado ou ao meu colo, cada um segundo as limitações que a sua massa corporal impõe – e dinamizaram pausas ~~forçadas~~ surpresa que eu não sabia que precisava. Se a honestidade científica o permitisse, constariam indubitavelmente como co-autores.

À minha *mãe*, ao meu *pai* e ao meu *irmão*, por tudo aquilo que já tenho por garantido: pelo apoio incondicional, pela paciência infinita e por nunca terem deixado de acreditar, mesmo quando eu duvidei.

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Resumo

Introdução: Na ausência de possibilidade de um transplante renal preemptivo, as recomendações internacionais privilegiam uma abordagem *home-first* na terapia de substituição de função renal (TSFR). A Diálise Peritoneal (DP) é a principal modalidade domiciliária e apresenta sobrevida comparável à da hemodiálise (HD) em centro, preservando a autonomia do doente. Em Portugal, e a nível mundial, a DP continua a ser subutilizada relativamente à HD em centro.

Objetivos: Caracterizar a população em DP da Unidade Local de Saúde de Santo António (ULSSA) quanto ao perfil sociodemográfico e clínico, avaliar a qualidade percebida da decisão partilhada (SDM) durante a educação pré-diálise e analisar motivações, medos, satisfação e durabilidade da escolha terapêutica.

Métodos: Estudo transversal de 69 doentes em DP seguidos na Unidade de Diálise Peritoneal da ULSSA. Os dados foram obtidos a partir do processo clínico eletrónico (SClínico®) e de um questionário estruturado, que combinou o SDM-Q-9 e itens baseados em Finderup et al. (2020) e o Renal Treatment Satisfaction Questionnaire (Barendse et al., 2005). Recorreu-se a estatística descritiva e a testes não-paramétricos ($\alpha = 0,05$).

Resultados: A população apresentava uma mediana de idade de 55 anos (IQR 41-63), com predomínio do sexo masculino (69,6%) e uma carga significativa de comorbilidades, traduzida por uma mediana do índice de Charlson de 4 (IQR 3-6). A DP foi a primeira modalidade de TSR em 63,8% dos doentes. Na coorte global, 62,3% encontravam-se em CAPD e 37,7% em APD, gerindo a maioria (91,3%) a técnica de forma autónoma. A qualidade da decisão partilhada foi elevada, com uma pontuação média de SDM de 5,78 ± 0,49 (92,8% com média ≥ 5), à semelhança da satisfação reportada (5,85 ± 0,39); todos os respondentes (100%, n = 69) voltariam a escolher a DP. De entre todas as variáveis analisadas, a pontuação de SDM foi a única que se correlacionou com a satisfação ($\rho = 0,31$, $p = 0,010$).

Conclusão: Na ULSSA, a DP associa-se a um elevado grau de autonomia e satisfação reportada pelos doentes, apesar da elevada prevalência de comorbilidades. A qualidade da decisão partilhada durante a educação pré-diálise, e não o perfil demográfico, foi a única variável associada à satisfação com a terapia domiciliária.

Palavras-chave: Diálise Peritoneal; Insuficiência Renal Crónica; Decisão Partilhada; Educação do Doente; Preferência do Doente; Diálise Renal.

Abstract

Background: International guidelines recommend a home-first strategy for renal replacement therapy (RRT) when pre-emptive transplantation is not feasible. Peritoneal Dialysis (PD) is the main home modality and offers survival outcomes comparable to those of in-centre haemodialysis (HD), while preserving patient autonomy. Globally, as in Portugal, PD remains underused relative to in-centre HD.

Objectives: To characterise patients on PD at the Unidade Local de Saúde de Santo António (ULSSA) in terms of socio-demographic and clinical profile, to assess the perceived quality of shared decision-making (SDM) during pre-dialysis education, and to evaluate motivations, fears, satisfaction and durability of the therapeutic choice.

Methods: Cross-sectional study of 69 patients on PD followed at the ULSSA Peritoneal Dialysis Unit. Data were obtained from electronic clinical records (SClínico®) and from a structured questionnaire combining the SDM-Q-9 and items based on Finderup et al. (2020) and the Renal Treatment Satisfaction Questionnaire (Barendse et al., 2005). Descriptive statistics and non-parametric tests were applied ($\alpha = 0.05$).

Results: The cohort had a median age of 55 years (IQR 41-63), was predominantly male (69.6%) and carried a substantial comorbidity burden, reflected in a median Charlson Comorbidity Index of 4 (IQR 3-6). PD was the first RRT modality in 63.8% of patients. Across the whole cohort, 62.3% were on CAPD and 37.7% on APD, with the majority (92.8%) managing PD autonomously. The quality of shared decision-making was high, with a mean SDM score of 5.78 ± 0.49 (92.8% scoring ≥5 on average), mirrored by the reported satisfaction (5.85 ± 0.39); all respondents (100%, n=69) would choose PD again. Of all the variables analysed, the SDM score was the only one correlated with satisfaction ($\rho = 0.31$, $p = 0.010$).

Conclusion: At ULSSA, PD is associated with a high degree of patient autonomy and self-reported satisfaction, despite a substantial comorbidity score. The quality of shared decision-making during pre-dialysis education (rather than the patient's demographic profile) was the only variable associated with satisfaction with home therapy.

Keywords: Peritoneal Dialysis; Kidney Failure, Chronic; Decision Making, Shared; Patient Education as Topic; Patient Preference; Renal Dialysis.

Abbreviations

APD - Automated Peritoneal Dialysis
CAPD - Continuous Ambulatory Peritoneal Dialysis
CCI - Charlson Comorbidity Index
CKD - Chronic Kidney Disease
eGFR - Estimated Glomerular Filtration Rate
ERA - European Renal Association
ERBP - European Renal Best Practice
ESRD - End-Stage Renal Disease
HD - Haemodialysis
KDIGO - Kidney Disease: Improving Global Outcomes
PD - Peritoneal Dialysis
PDE - Pre-Dialysis Education
QoL - Quality of Life
RRF - Residual Renal Function
RRT - Renal Replacement Therapy
RTSQ - Renal Treatment Satisfaction Questionnaire
SDM - Shared Decision-Making
SDM-Q-9 - 9-item Shared Decision-Making Questionnaire
SNS - Serviço Nacional de Saúde
SPN - Sociedade Portuguesa de Nefrologia
ULSSA - Unidade Local de Saúde de Santo António

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Introduction

Chronic Kidney Disease is defined by a sustained reduction in renal function or structural kidney damage lasting more than three months, and it affects 10-12% of adults worldwide, representing a leading non-communicable cause of morbidity and mortality [1,2]. KDIGO classifies CKD by eGFR and albuminuria [1]; Stage 5, or ESRD, corresponds to an eGFR below 15 mL/min/1.73 m² or to a clinical need for RRT.

Once a patient reaches ESRD, four management options are available: kidney transplantation, HD, PD and comprehensive conservative care (non-dialytic management), the latter being an increasingly recognised choice for older or highly comorbid patients in whom dialysis may not improve survival or QoL. For patients who are candidates for renal replacement therapy, pre-emptive transplantation, ideally from a living donor, offers the best survival and QoL, thus being the first choice whenever clinically feasible [3,4]. However, transplantation is not immediately available for most patients, both due to clinical contraindications and the shortage of donor organs. As a result, most patients spend at least some time on dialysis.

Portugal currently has one of the highest dialysis prevalences in Europe. The Portuguese Society of Nephrology (SPN) reports an ESRD prevalence consistently above 1,200 patients per million population (pmp), compared to 800-1,000 pmp in most other European registries [5]. An ageing population, a high prevalence of diabetes and hypertension, and universal access through the National Health System (SNS) all contribute to these numbers, with diabetic nephropathy alone accounting for around one third of new dialysis starts [5].

Furthermore, while patients on RRT represent less than 1% of the Portuguese population, they consume around 4-5% of the national health budget [6], most of it going into in-centre HD. Similarly, at the personal level, the standard schedule of three to four-hour sessions per week, which are typically followed by hours of fatigue, constrains work, travel and daily life [7], all of which lead to major interest in home-based therapies, particularly PD.

For over a decade, KDIGO and the ERBP have promoted a shift towards home-based dialysis [8]. Under the "Home First" (or "PD First") strategy, PD is offered first to the patient, leveraging preserved RRF and the flexibility of home therapy, with transition to HD when the peritoneal membrane fails or RRF declines, thus maximising total time on RRT while preserving the patient's working life and autonomy. This approach also works in favour of the economy: as mentioned previously, in-centre HD is among the most resource-intensive hospital services, and European cost-effectiveness studies show that PD is significantly cheaper per patient-year [6]. In a universal,

tax-funded system such as the SNS, expanding PD is one of the few realistic ways to reallocate nephrology resources without compromising care and quality of services.

Despite this evidence, only 7-9% of Portuguese dialysis patients are on PD, a number that has stagnated for over a decade [5,9]. This reflects structural limitations in renal services and, above all, psychosocial barriers: fears of complications (such as peritonitis), catheter dislodgement or managing an emergency at home, the worry of becoming a burden on their support system, and practical issues such as low health literacy or inadequate housing. All these factors can push patients towards the perceived safety of an in-centre clinic [10].

Structured Pre-Dialysis Education (PDE) is the main strategy to address these barriers [4]. Modality selection should no longer be a unilateral medical decision but a Shared Decision-Making (SDM) process, in which the patient, and in some cases even the family and caregivers, weigh the benefits, risks and daily implications of each therapy before deciding. Effective PDE is multidisciplinary [4,11]: nephrologists assess eligibility and prognosis; specialised nurses familiarise patients with home therapies through visual aids, demonstrations and patient testimonies [4]; psychologists screen cognition and manage the anxiety or depression that follow advanced renal failure; and social workers evaluate the home environment, finances and community support [11,12].
The ULSSA, a university hospital in Oporto and one of the largest PD centres in Portugal, runs such a programme, aiming at balanced, modality-neutral counselling. Although clinical parameters of this cohort are routinely audited, patient-reported outcomes remain less explored, namely how patients perceive the durability of the decision to start PD, which psychological factors weigh most during education, and how satisfaction evolves over time. This study confronts that gap by surveying patients who started PD within the ULSSA programme, to improve local educational protocols and inform how SDM is applied in routine renal care.

Materials and Methods

I. Study Type, Sample, and Evaluation Period

This is a cross-sectional observational study of adult patients with ESRD enrolled in the Peritoneal Dialysis programme of the Nephrology Department at ULSSA. A convenience sample of 70 patients was considered eligible, with one being excluded from the study due to a refusal to participate. Data collection from the 69 participants took place between November 17th 2025 and March 31st 2026, combining clinical data and a structured questionnaire to assess the decision-making process and patient satisfaction.

II. Data Sources

The study protocol was approved by the Health Ethics Committee of ULSSA (reference no. 2025.250(208-CAC-202-CE)) and conducted in accordance with the Declaration of Helsinki and the GDPR (Regulation (EU) 2016/679). All participants signed an informed consent before completing the questionnaire and were informed of their right to withdraw at any time, without affecting their clinical care.

Two data sources were used: the electronic clinical record (Sclínico®), from which sociodemographic and clinical data (including comorbidities and CKD aetiology) were extracted; and a structured questionnaire combining the validated Shared Decision-Making Questionnaire (SDM-Q-9) with selected items based on Finderup et al. [13] and the Renal Treatment Satisfaction Questionnaire (RTSQ) [14], assessing satisfaction, motivations and fears. An optional Extra section, addressed to the main caregiver, assessed perceived caregiver burden; within it, item E.6 (availability of time for personal and social activities) is reverse-scored, so that higher values reflect lower burden.

All data were anonymised and stored in a password-protected Microsoft Excel® database, located on the Peritoneal Dialysis Unit workstation and accessible only to the principal investigator and the study supervisor.

III. Sample Selection

A convenience sample was used, including all prevalent patients who met the eligibility criteria. Inclusion criteria: adults with ESRD followed at the Nephrology Department of ULSSA in a regular PD programme.

Exclusion criteria: PD duration of less than one month; severe cognitive impairment without a reliable caregiver; clinical instability that prevented participation; and refusal to consent. Seventy patients were considered eligible, of whom 69 participated (one declined to take part).

IV. Variables and Statistical Methods

Sociodemographic variables included age, sex, educational level, professional status and marital status. The clinical profile was assessed through the Charlson Comorbidity Index (CCI) [15,16], CKD aetiology, PD modality (CAPD or APD) and PD vintage (time on the technique).

Patient-reported variables were collected through the SDM-Q-9, which evaluates the perceived quality of the decision-making process, together with additional items on satisfaction with the therapeutic choice, motivations and fears. Logistical aspects (domestic storage, available space, family and social support) and the patient's perception of the PDE process were also recorded.

V. Statistical Analysis

Statistical analysis was carried out in IBM SPSS Statistics. Continuous variables were described as mean ± standard deviation or median (interquartile range), depending on distribution, and categorical variables as absolute and relative frequencies.

A significance level of $\alpha = 0.05$ was adopted. Group comparisons were carried out using the chi-square test for categorical variables and Student's t-test or the Mann-Whitney test for continuous variables, according to distribution. Associations between continuous variables (namely SDM-Q-9 score, satisfaction and PD vintage) were assessed using Spearman's correlation coefficient (ρ). During the writing process, Microsoft Copilot was used as a language-support tool, namely for proofreading and to reduce word repetition. All scientific content, interpretation of results and final wording remained the responsibility of the author.

Results

I. Baseline Socio-demographic and Clinical Characteristics

The study sample's baseline characteristics of the 69 participants are summarised in Table I.

The cohort was predominantly male (69.6%) with a median age of 55 years (IQR 41-63). Most patients were married or in a civil union (60.9%), and around 70% had completed at least secondary education. Almost 40% were still actively working at the time of the survey.

The most common causes of CKD were glomerulopathies (30.4%) and undetermined aetiology (23.2%). Diabetes mellitus accounted for only 7.2% of cases, in contrast with national registry data, where diabetic nephropathy is the leading cause of incident ESRD. The median PD vintage at the time of the survey was 22.1 months (IQR 10.3-38.7), and the median Charlson Comorbidity Index (CCI), calculated from secondary diagnoses, was 4 points (IQR 3-6).

II. Peritoneal Dialysis Modality and Treatment Autonomy

Most patients were on CAPD (62.3%, n=43); the remaining 37.7% (n=26) were on APD with a cycler. Treatment autonomy was high: 92.8% (n=64) of patients managed their dialysis sessions completely on their own, and a further 4.3% (n=3) performed the procedure independently but received occasional help with supplies or logistics. In only 2.9% (n=2) of cases was the treatment carried out mainly by a family member or dedicated caregiver. No patient required regular home-nursing support.

For most patients (63.8%, n=44), PD was the first RRT. The remaining 25 patients had previously used one or more other modalities: 14 (20.3%) had been on haemodialysis only, 1 (1.4%) had a prior transplant only and 1 (1.4%) had been on PD previously. Combinations of prior modalities were also seen: 3 patients (4.3%) had undergone both haemodialysis and transplantation, 3 (4.3%) had previously received haemodialysis, transplantation and PD, 2 (2.9%) had a prior transplant and PD, and 1 (1.4%) had previously been on both haemodialysis and PD.

III. Shared Decision-Making in the Choice of Peritoneal Dialysis

The eleven items derived from the SDM-Q-9 (its nine original items plus two locally added items, 2.10 and 2.11), answered on a 6-point Likert scale (1 = strongly disagree; 6 = strongly agree), showed a uniformly positive perception of the decision-making process. The overall mean SDM score was 5.78 ± 0.49, and 92.8% of patients (n=64) had a mean score of at least 5. The mean per-item score ranged from 5.56 (item 2.8, "the healthcare team and I chose the treatment together") to 5.90 (item 2.6, "the healthcare team asked me which option I preferred"). Of note, 97.1% of patients agreed or strongly agreed that home-based treatment was the most important reason for choosing PD (item 2.10), and 94.2% agreed that the structured PDE programme reinforced their confidence in this choice (item 2.11).

When asked to identify the single factor that weighed most in their choice (item 2.12), 65.2% of patients (n=45) chose the preservation of personal autonomy and daily routine. The remaining motivations were less frequent: avoiding regular visits to the dialysis centre (14.5%), the recommendation of a physician or nurse (7.2%), advice from family or other PD patients (7.2%), avoidance of needle puncture (4.3%) and preservation of residual renal function (1.4%). Regarding who had the greatest influence on the decision (item 2.13), patients identified themselves (40.6%) and the nephrologist (39.1%) in similar proportions, followed by other physicians (5.8%), nurses (5.8%), family or caregivers (4.3%) and other PD patients (4.3%); no patient identified another health professional or another source as the main influence.

IV. Fears Before Initiation and Current Difficulties with PD

Before starting PD (item 3.1), the most frequent main fear was peritonitis (43.5%, n=30), with the same proportion (43.5%, n=30) reporting no significant fear. The remaining patients feared being unable to perform the treatment without help (10.1%) or treatment-related pain (2.9%). No patient identified the absence of family or professional support as their main concern.

After initiation (item 3.2), the most common difficulty was the fear of travelling or leaving home (42.0%, n=29), followed by the time spent on exchanges or with the cycler (18.8%), dietary or fluid restrictions (17.4%), the storage of supplies at home (17.4%) and difficulty in maintaining catheter hygiene (4.3%).

V. Satisfaction with PD and Durability of the Therapeutic Choice

The three items assessing satisfaction with the therapeutic choice produced a mean satisfaction score of 5.85 ± 0.39, with 97.1% of patients (n=67) scoring at least 5 on average. Patients were satisfied with PD in general (item 4.1: mean 5.81 ± 0.69; 95.7% agreement) and felt that PD enabled them to maintain their autonomy (item 4.3: mean 5.83 ± 0.48; 94.2% agreement). The most striking result came from item 4.2 ("if I had to decide again, I would choose peritoneal dialysis"): every patient in the cohort (100%, n=69) gave a score of 5 or 6 (mean 5.91 ± 0.28).

VI. Group Comparisons and Correlations

SDM and Satisfaction scores were compared between subgroups defined by sex, PD modality (CAPD vs APD), family history of ESRD and age (≤60 vs >60 years), using the Mann-Whitney test. None of these comparisons reached statistical significance (all $p > 0.05$). The same was observed when patients were compared by educational level (basic, secondary, higher) using the Kruskal-Wallis test (SDM: $H=1.51$, $p=0.470$; Satisfaction: $H=0.22$, $p=0.897$). The high perception of shared decision-making and the high satisfaction reported in this cohort, therefore, appear to be independent of

these clinical and demographic characteristics.

Spearman correlation showed a single significant association: the SDM score correlated positively, although moderately, with the Satisfaction score ($\rho = 0.31$, $p = 0.010$). Patients who perceived greater involvement in the decision-making process tended to report higher satisfaction with PD. Neither score correlated significantly with age (SDM: $\rho = 0.15$, $p = 0.205$; Satisfaction: $\rho = 0.13$, $p = 0.272$) or with PD vintage (SDM: $\rho = -0.01$, $p = 0.959$; Satisfaction: $\rho = -0.13$, $p = 0.281$).

VII. Caregivers' Perspective

The Extra section of the questionnaire, addressed to the principal caregiver, was completed in three cases (4.3% of the cohort): two patients whose PD was performed mainly by a family caregiver (a 27-year-old man on APD and an 80-year-old woman on APD) and one patient who reported occasional caregiver support (a 70-year-old woman on CAPD). Despite the small subsample, the responses were consistent.

All three caregivers agreed that PD was the best option for the person they cared for (item E.1, all responses returned with 6). Perceived training adequacy (E.2) and the integration of PD into the family routine (E.3) were also rated highly, with a median of 6 in both cases (E.2 range 5-6; E.3 range 4-6).

The items addressing caregiver burden, however, were less uniform. Caregivers reported only partial agreement that the care routine had affected their health (E.4, median 4, range 4-6) and that they felt overloaded or fatigued (E.5, all responses = 4). On the reverse-scored item, inquiring about the existence of free time, they likewise only partially agreed that they retained enough time for their own personal and social activities (E.6, all responses = 4), pointing to a moderate intrusion on free time.

The only maximum-burden response came from the carer of the oldest, most dependent patient, an 80-year-old woman, fully caregiver-dependent, with the longest PD vintage in the subsample at 60 months.

Although the subsample is too small to support inferential analysis, the pattern is internally coherent: caregivers endorse PD as the right modality and feel adequately prepared, while still acknowledging a moderate, non-trivial impact on their own well-being and free time. These results should be interpreted alongside the high autonomy rate of the overall cohort (92.8% of patients self-managed PD without caregiver or nursing support), which limits the reach of the caregiver questionnaire in this setting.

Discussion

This study set out to characterise patients on PD at ULSSA in terms of their socio-demographic and clinical profile, to assess the perceived quality of the SDM process during pre-dialysis education, and to evaluate motivations, fears, satisfaction and the durability of the therapeutic choice. Mapping the results back onto these objectives yields five principal findings, each discussed in turn against the published literature.

First, the cohort combines a high degree of therapeutic autonomy (92.8% self-managed) with a substantial comorbidity burden (median CCI of 4), which translates as an unusual pairing in the assisted-PD literature [17,18,19]. Second, PD was the first RRT modality in nearly two-thirds of patients (63.8%), but the remainder reached PD via prior HD or a failed transplant, showing that PD operates as one stage of an integrated renal-replacement trajectory, rather than as a stand-alone treatment [7,8]. Third, the SDM process was rated very highly (mean SDM score 5.78 ± 0.49; 92.8% scoring ≥ 5), with patient and nephrologist sharing authorship of the decision in roughly equal proportions [11,20]. Fourth, the dominant pre-initiation fear (peritonitis) was displaced post-initiation by lifestyle-restriction concerns (travel and leaving home), pointing to distinct educational needs before and during PD [3,12]. Fifth, satisfaction was uniformly high (mean 5.85 ± 0.39) and 100% of patients said they would choose PD again; SDM quality was the only variable significantly associated with that satisfaction, in opposition to age, sex, modality or dialysis vintage [11,14].

Demographic Patterns and Psychosocial Considerations

The median age of our cohort (55 years) is lower than that of the overall European dialysis population, which is typically in the seventh decade of life. This probably reflects a selection effect, as younger and more functional patients are more often proposed for, or choose, home therapies [3,21]. The male predominance (69.6%) is in line with registry data, which consistently report faster CKD progression and higher RRT incidence in men [2,9].

A relevant proportion of the cohort remained in active employment (39.1%) or was studying (2.9%). This is clinically meaningful because in-centre HD interferes more directly with working schedules than PD, and continued employment has been associated with better health-related quality of life and lower rates of depression in ESRD [22].

Autonomy, Modality Choice and the Role of Caregivers

PD was the first RRT modality in nearly two-thirds of patients (63.8%), in line with the PD-first strategy supported by the ERA [8]. This approach preserves the vascular anatomy for future HD access and helps to maintain RRF, which is associated with survival [7,23]. The remaining patients had reached PD via prior HD (30.4%, counting both HD-only and combination histories), a failed renal transplant (13.0% across all transplant-containing histories), or a combination of these, showing that PD is not used in isolation but rather as one stage within a longer renal replacement pathway.

Most patients in this cohort were on CAPD (62.3%), with only 37.7% on APD. In several northern European centres, APD is currently the predominant modality, mainly because it allows more daytime freedom [3,21]. The higher proportion of CAPD at ULSSA reflects the unit's CAPD-first protocol, whereby all patients begin treatment on CAPD and transition to APD only when there is either a clinical indication or at the patient's express request.

Despite the high comorbidity index, 92.8% of patients managed PD on their own, without external nursing or caregiver support. In published series, high CCI values are often associated with a shift to assisted PD, either by family members or community nurses [17,18]. The high self-management rate observed at ULSSA suggests that the local pre-dialysis education and nursing training programme effectively prepares patients for autonomous treatment, supported by the available social and family network, which is itself associated with better quality of life in dialysis patients [24]. Self-administered PD has also been associated with lower peritonitis rates than family-assisted PD, possibly because of stricter adherence to aseptic technique and the smaller number of individuals interacting with the procedure, which reduces opportunities for contamination [19].

The three caregivers who completed the Extra section of the questionnaire, although too few for an inferential analysis, all endorsed PD as the right modality and felt adequately prepared, while reporting only moderate impact on their own health and free time. The single maximum-burden response came from the carer of the oldest, most dependent patient, consistent with the literature describing higher carer strain in elderly, fully assisted PD [17,18]. The very low rate of caregiver questionnaires (3/69) is itself a finding: at ULSSA, assisted PD is the exception rather than the rule, which contrasts with French and other European registries where assisted PD accounts for a substantial share of older patients [18,19]. This low rate, however, should be interpreted with caution. In Portugal, assisted PD relies almost exclusively on family members and informal caregivers, as no programme of professional assisted PD or nurse-delivered models, like the ones available in France, is currently in place. The scarcity of assisted PD may therefore reflect the absence of alternatives, rather than a genuine lack of need, since patients who cannot self-manage and who have no available carer have limited options. Furthermore, in the cases where informal caregivers take on this role, the burden can be considerable. This is visible in this study, where the single maximum-burden response came from the carer of the oldest and most dependent patient, illustrating the strain that fully assisted home dialysis can place on elderly or isolated families. The development of professional assisted-PD pathways could relieve this burden and widen access to home therapy for patients who would otherwise be unable to undertake it.

The Patient's Voice: Decision Quality, Motivations, Fears and Durability of Choice

Beyond clinical metrics, this study also captures how patients perceived their entry into PD. The mean SDM score was 5.78 ± 0.49, with 92.8% of patients scoring ≥5 on average, which is in line with, or above, values reported in European chronic-disease cohorts using the SDM-Q-9 [11,20].

Scores were consistent across all items, with the lowest-scoring item (2.8, "the healthcare team and I chose the treatment together") still above 5 out of 6. Combined with the high rating of item 2.11 (regarding the impact of the PDE programme), these results suggest that pre-dialysis education at ULSSA functions as a true deliberative process rather than as a one-way transfer of information. The motivation profile is consistent with this interpretation. The single most important factor in the choice of PD was the preservation of autonomy and daily routine (65.2%), which alone outweighed all other clinical and logistical reasons combined. Patients identified themselves (40.6%) and the nephrologist (39.1%) in similar proportions as the main driver of the decision, while family, nurses and peer patients each accounted for less than 7%. This pattern, in which patient and clinician share authorship of the decision, corresponds to current models of shared decision-making [11,12,25] and contrasts with the more paternalistic approach historically used in dialysis modality choice.

Pre-initiation fears and post-initiation difficulties showed a clinically relevant shift. Before starting PD, the most frequent fear was peritonitis (43.5%), with an equal proportion of patients (43.5%) reporting no significant fear. After initiation, the main concern was no longer infection, but restrictions on travel and leaving home (42.0%), followed by exchange time, dietary restrictions and storage of supplies. This shift from fear of a catastrophic clinical event to discomfort with lifestyle restrictions [10] suggests that the educational and psychosocial support needed before starting PD differs from that needed during follow-up. Initial counselling should keep focusing on infection prevention, while follow-up should prioritise travel-enabling strategies (portable cyclers, holiday-supply logistics, telemedicine) and dietary self-management.

Satisfaction with PD was uniformly high (mean 5.85 ± 0.39; 97.1% of patients with a mean score ≥5). The most remarkable finding was that every patient in the cohort (100%, n=69) said they would choose PD again if they had to decide today (item 4.2). This level of unanimity is unusual in patient-reported outcome research and, together with the absence of significant differences between subgroups (sex, age, modality, education, family history), suggests that the home-therapy pathway at ULSSA is not dependent on a specific demographic profile. The only variable that correlated significantly with satisfaction was the SDM score itself ($\rho = 0.31$, $p = 0.010$), supporting the idea that the quality of the decision-making process, rather than the patient's demographic profile or how long they have been on PD, is what predicts later satisfaction with the therapy.

Study Limitations and Strengths

This study has several limitations. First, being a single-centre study, the local protocols and the population's socio-demographic characteristics may limit generalisability to other Portuguese regions or to international cohorts. Second, the questionnaire was, in some cases, administered by clinical staff known to the patients, which may have introduced a social desirability bias towards more favourable ratings of the decision-making process. Third, the sample size (n=69) limits the

statistical power to detect subgroup differences and small-effect correlations.

The main strength of this study is the detailed characterisation of a real-world PD cohort, combining clinical, socio-demographic and patient-reported outcomes in the same population. The combination of high autonomy and substantial comorbidity score is information specific to this centre, which can be used by the nephrology team at ULSSA to improve pre-dialysis education, home-therapy training protocols and multidisciplinary care pathways.

Conclusion

The PD cohort at ULSSA combines a high degree of therapeutic autonomy (92.8%) with a substantial comorbidity score (median CCI of 4). The predominance of CAPD over APD reflects the local protocol, under which all patients begin on CAPD and transition to APD only for clinical reasons or by patient choice. Furthermore, the proportion of patients still in active employment illustrates how home dialysis at this centre supports the continuation of working life. Patients reported a uniformly positive perception of the shared decision-making process and very high satisfaction, with 100% saying they would choose PD again.

The quality of the decision-making process, rather than the patient's demographic profile, was the only variable significantly associated with satisfaction. This finding gives the ULS Santo António nephrology team a concrete baseline for further work: targeted reinforcement of the lowest-scoring SDM items, structured travel-enabling support during follow-up, and longitudinal monitoring of technique survival and patient-reported outcomes in this cohort.

Appendix

Table I. Baseline sociodemographic and clinical characteristics of the study cohort (n = 69).

Variable	n (%) or median [IQR]
Age, years - median [IQR]	55 [41-63]
≤60 years	45 (65.2)
>60 years	24 (34.8)
Sex	
Male	48 (69.6)
Female	21 (30.4)
Marital status	
Married / civil union	42 (60.9)
Divorced / widowed / separated	15 (21.7)
Single	12 (17.4)
Education level	
Basic	19 (27.5)
Secondary	29 (42.0)
Higher	21 (30.4)
Employment status	
Student	2 (2.9)
Employed	27 (39.1)
Homemaker	1 (1.4)
Unemployed	11 (15.9)
Retired	28 (40.6)
CKD aetiology	
Glomerulopathies	21 (30.4)
Indeterminate	16 (23.2)
Autosomal-dominant polycystic kidney disease	6 (8.7)
Diabetes mellitus	5 (7.2)
Tubulointerstitial / chronic pyelonephritis	5 (7.2)
Autoimmune / lupus / vasculitis	5 (7.2)
Hypertension	4 (5.8)
Rare hereditary	4 (5.8)
Vascular / ischaemic / cardiorenal	2 (2.9)
Other	1 (1.4)
PD modality	
CAPD	43 (62.3)
APD	26 (37.7)
PD vintage, months - median [IQR]	22.1 [10.3-38.7]
Mean ± SD	27.5 ± 22.7
Range	1.1-83.5
Prior RRT modality	
None (PD as first RRT)	44 (63.8)
Prior haemodialysis only	14 (20.3)
Prior transplant only	1 (1.4)
Prior PD only	1 (1.4)
Prior haemodialysis + transplant	3 (4.3)
Prior haemodialysis + transplant + PD	3 (4.3)
Prior transplant + PD	2 (2.9)
Prior haemodialysis + PD	1 (1.4)
Family history of ESRD	
Yes	17 (24.6)
No	52 (75.4)

References

1. Kidney Disease: Improving Global Outcomes (KDIGO) CKD Work Group. KDIGO 2024 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease. Kidney Int. 2024;105(4S):S117–S314.

2. Chen TK, Knicely DH, Grams ME. Chronic kidney disease diagnosis and management: a review. JAMA. 2019;322(13):1294–1304.

3. Cho Y, Bello AK, Levin A, et al. Peritoneal dialysis use and practice patterns: an international survey study. Am J Kidney Dis. 2021;77(3):315–325.

4. Brown EA, Blake PG, Boudville N, et al. International Society for Peritoneal Dialysis practice recommendations: prescribing high-quality goal-directed peritoneal dialysis. Perit Dial Int. 2020;40(3):244–253.

5. Sociedade Portuguesa de Nefrologia. Relatório Anual do Gabinete de Registo da Doença Renal Crónica em Portugal. Lisboa: SPN; 2024.

6. Karopadi AN, Mason G, Rettore E, Ronco C. Cost of peritoneal dialysis and haemodialysis across the world. Nephrol Dial Transplant. 2013;28(10):2553–2569.

7. Mehrotra R, Devuyst O, Davies SJ, Johnson DW. The current state of peritoneal dialysis. J Am Soc Nephrol. 2016;27(11):3238–3252.

8. European Renal Association. Home dialysis – a call to action: the Home First initiative. Nephrol Dial Transplant. 2022;37(11):2007–2010.

9. Kramer A, Boenink R, Mercedes Mas Fontao C, et al. The ERA Registry Annual Report 2021: a summary. Clin Kidney J. 2024;17(2):sfae032.

10. Ziolkowski SL, Liebman SE. A qualitative assessment of mismatch between dialysis modality selection and initiation. Perit Dial Int. 2016;36(4):463–466.

11. Hill S, Pereira-Salgado A, Slewa-Younan S. Shared decision making interventions for people with end-stage kidney disease: a systematic review. BMC Nephrol. 2021;22(1):402.

12. Morton RL, Tong A, Howard K, Snelling P, Webster AC. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. BMJ. 2010;340:c112.

13. Finderup J, Lomborg K, Jensen JD, Stacey D. Choice of dialysis modality: patients' experiences and quality of decision after shared decision-making. BMC Nephrol. 2020;21(1):330.

14. Barendse SM, Speight J, Bradley C. The Renal Treatment Satisfaction Questionnaire (RTSQ): a measure of satisfaction with treatment for chronic renal failure in haemodialysis patients. Diabet Med. 2005;22(9):1226–1233.

15. Davies SJ, Phillips L, Naish PF, Russell GI. Quantifying comorbidity in peritoneal dialysis patients and its relationship to other predictors of survival. Nephrol Dial Transplant. 2002;17(6):1085–1092.

16. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis. 1987;40(5):373–

383.
17. Oliver MJ, Salenger P, Boudville N. Assisted peritoneal dialysis: practical considerations and clinical outcomes. Adv Chronic Kidney Dis. 2017;24(6):437–444.
18. Boyer A, Solis-Trapala I, Tabinor M, Davies SJ, Lambie M. Impact of the implementation of an assisted peritoneal dialysis service on technique and patient survival: results of a French prospective registry. Nephrol Dial Transplant. 2020;35(9):1595–1601.
19. Bechade C, Lobbedez T, Ivarsen P, et al. Assisted peritoneal dialysis for older people with end-stage renal disease: the French and Danish experience. Perit Dial Int. 2015;35(6):663–666.
20. Kriston L, Scholl I, Hölzel L, Simon D, Loh A, Härter M. The 9-item Shared Decision Making Questionnaire (SDM-Q-9): development and psychometric properties in a primary care sample. Patient Educ Couns. 2010;80(1):94–99.
21. Li PK-T, Chow KM, Van de Luijtgaarden MWM, et al. Changes in the worldwide epidemiology of peritoneal dialysis. Nat Rev Nephrol. 2017;13(2):90–103.
22. Brown EA, Zhao J, McCullough K, et al; PDOPPS Patient Support Working Group. Burden of kidney disease, health-related quality of life, and employment among patients receiving peritoneal dialysis and in-centre haemodialysis: findings from the DOPPS program. Am J Kidney Dis. 2021;78(4):489–500.e1.
23. Wong B, Ravani P, Oliver MJ, et al. Comparison of patient survival between haemodialysis and peritoneal dialysis among patients eligible for both modalities. Am J Kidney Dis. 2018;71(3):344–351.
24. Zamanzadeh V, Heidarzadeh M, Oshvandi K, Lakdizaji S. Relationship between quality of life and social support in hemodialysis patients in Imam Khomeini and Sina educational hospitals of Tabriz University of Medical Sciences. Med J Tabriz Univ Med Sci. 2007;29(1):49–54.
25. Kröncke S, et al. The German Society of Nephrology shared decision-making initiative in dialysis modality selection. Clin Kidney J. 2022;15(7):1284–1293.

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Conflict of Interest

The author declares no conflicts of interest in relation to this work.

Annexes

Annex I - Questionnaire

Questionário nº __

QUESTIONÁRIO ESTRUTURADO PARA DOENTES EM DIÁLISE PERITONEAL (DP)

Instruções: Por favor, selecione a opção que melhor reflete a sua situação e opinião. Todas as suas respostas são confidenciais e destinam-se a melhorar a qualidade dos cuidados renais.

Secção 1: Dados Sociodemográficos e Clínicos

Idade (Anos): _____ **Sexo:** ☐ **Feminino** ☐ **Masculino**

Estado civil:

☐ Solteiro ☐ Casado ☐ Divorciado ☐ Viúvo ☐ Separado ☐ Em união de facto

Nível de Escolaridade:

☐ Ensino Básico ☐ Ensino Secundário ☐ Ensino Superior

Situação Profissional:

☐ Estudante ☐ Trabalhador ☐ Doméstico ☐ Em situação de desemprego ☐ Reformado

Comorbilidades:

☐ **EAM**	☐ **IC**	☐ **Doença Vascular Periférica**
☐ **Doença Cerebrovascular**	☐ **Demência**	☐ **DPC**
☐ **Doença reumática**	☐ **Doença Péptica Ulcerosa**	☐ **Hepatopatia Ligeira**
☐ **Diabetes**	☐ **Episódio de Hemiplegia**	☐ **D. Renal Moderada-Severa**
☐ **DM c/ complicações crónicas**	☐ **Neoplasia sem metástases**	☐ **Leucemia**
☐ **Linfoma**	☐ **Hepatopatia Moderada-Severa**	☐ **Tumor Sólido Metastático**
☐ **HIV/SIDA**		

Etiologia da DRC:

☐ **DM** ☐ **HTA** ☐ **Glomerulonefrite Crónica** ☐ **Doença Renal Poliquística**

☐ **Outra:** _____

Data da 1ª Consulta de Nefrologia: ____ /____ /_____

História Familiar de DRCT: ☐ **Sim** ☐ **Não**

Caso a resposta seja sim, qual(ais) o(s) grau(s) de parentesco?

_____

Questionário nº __

Tipo de DP Atual:

☐ DPCA (Manual) ☐DPA (Automática/Cicladora)

Duração da DP (Meses): _____

1. O tratamento de Diálise Peritoneal é realizado por si de forma autónoma ou conta com a ajuda de um cuidador/familiar?

☐ Realizo o tratamento totalmente sozinho(a)

☐ Realizo o tratamento, mas recebo apoio ocasional (p. ex., logística de material)

☐ O tratamento é realizado principalmente por um cuidador/familiar

☐ Recebo apoio de enfermagem ao domicílio para a realização da DP

2. Alguma vez realizou outras formas de Terapia de Substituição Renal (TSR)?

☐ Não, A Diálise Peritoneal é a minha primeira TSR

☐ Sim, fiz Hemodiálise em centro ou domicílio

☐ Sim, tive um Transplante Renal prévio

☐ Sim, fiz Diálise Peritoneal anteriormente

Caso a resposta seja sim, data de início da 1ª TSFR: ____ /____ /_____

Secção 2: O Processo de Escolha e a Motivação

1. A equipa de saúde informou-me explicitamente que seria necessário tomar uma decisão.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

2. A equipa de saúde quis saber exatamente como é que eu tencionava participar nessa decisão.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

Questionário nº __

3. A equipa de saúde informou-me que existiam diferentes opções de tratamento para as minhas queixas.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

4. A equipa de saúde explicou-me exatamente as vantagens e as desvantagens das diferentes opções de tratamento.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

5. A equipa de saúde ajudou-me a compreender todas as informações.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

6. A equipa de saúde perguntou-me qual a opção de tratamento que eu preferia.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

7. A equipa de saúde e eu ponderámos cuidadosamente as diferentes opções de tratamento.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

8. A equipa de saúde e eu escolhemos conjuntamente uma opção de tratamento.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

9. A equipa de saúde e eu chegámos a um acordo sobre como proceder de seguida.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

Questionário nº __

10. A possibilidade de realizar o tratamento em casa foi o fator mais importante para a minha escolha da DP.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

11. O processo de Educação Pré-Diálise (EPD) deu-me confiança para realizar o tratamento em casa.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

12. Qual dos seguintes fatores pesou MAIS na sua decisão de escolher a DP? (Escolha apenas uma opção)

☐ Queria manter a minha autonomia e rotina (trabalho, escola, etc.)

☐ O meu médico/enfermeiro de Nefrologia sugeriu a DP

☐ Recomendação de amigos/familiares já submetidos a DP

☐ Queria evitar as idas frequentes ao centro de diálise

☐ Impossibilidade de realizar as deslocações frequentes ao centro de diálise

☐ Queria evitar a punção com agulhas

☐ Para preservar a função renal residual

13. Quem teve a maior influência na sua decisão final de optar pela DP? (Escolha apenas uma opção)

☐ Médico nefrologista
☐ Outro médico (ex. Médico de família)
☐ Equipa de enfermagem
☐ Família/Cuidador Principal
☐ Outro(s) doente(s) em DP
☐ Fui eu próprio(a)
☐ Outro profissional de saúde (ex. Nutricionista, psicólogo, auxiliar da ação médica)
☐ Outro: _____

Questionário nº __

Secção 3: Receios e Barreiras Percebidas

1. **Qual dos seguintes foi o seu MAIOR receio antes de iniciar a DP?**

☐ Medo de ter complicações/infeção (Peritonite)

☐ Medo de não conseguir fazer o tratamento sozinho(a)

☐ Medo de não ter apoio suficiente da família/profissionais de saúde

☐ Medo de o tratamento ser doloroso

☐ Nenhum receio significativo

2. **Qual dos seguintes fatores representa a MAIOR dificuldade na sua vida atual com a DP?**

☐ O tempo gasto com as trocas/cicladora

☐ A necessidade de espaço para armazenar o material em casa

☐ A restrição na ingestão de fluidos/dieta

☐ O medo de viajar ou sair de casa

☐ A dificuldade em manter o cateter limpo

Secção 4: Satisfação e Reafirmação da Escolha

1. **No geral, atualmente estou satisfeito com a Diálise Peritoneal (DP).**

   ☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

   ☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

2. **Se pudesse voltar atrás no tempo, escolheria novamente a Diálise Peritoneal (DP).**

   ☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

   ☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

3. **A DP permite-me manter a minha autonomia e um estilo de vida mais próximo do normal.**

   ☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

   ☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

Questionário nº __

Secção Extra: Perspetiva do Cuidador (A ser preenchida pelo cuidador principal)

Instruções: Por favor, assinale o seu nível de concordância, onde **1 = Discordo Totalmente** e **6 = Concordo Totalmente**.

1. A Diálise Peritoneal é a melhor opção para a pessoa que cuido.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

2. Fui devidamente treinado(a) para a minha função de apoio ao tratamento.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

3. A DP integra-se bem na minha rotina e na rotina familiar.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

4. A minha saúde ou bem-estar foi negativamente afetada(o) pela rotina de cuidados.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

5. Sinto-me sobrecarregado(a) ou com cansaço extremo (físico e/ou emocional) devido aos cuidados.

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

6. Sinto que tenho tempo suficiente para as minhas atividades pessoais e sociais (lazer, trabalho, etc.).

☐ 1 - Discordo totalmente ☐ 2 - Discordo maioritariamente ☐ 3 - Discordo parcialmente

☐ 4 - Concordo parcialmente ☐ 5 - Concordo maioritariamente ☐ 6 - Concordo totalmente

Annex II - Informed Consent Form

CONSENTIMENTO INFORMADO PARA PARTICIPAÇÃO EM ESTUDO DE INVESTIGAÇÃO

Título do Projeto:

Shared Decision-Making in the Choice of Peritoneal Dialysis: Patients' Perspectives on the Transition to Home Therapy

Investigador Responsável:

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1. Convite e Objetivo do Estudo

Está a ser convidado/a a participar, de forma voluntária, num estudo de investigação. O objetivo é compreender o que o/a motivou a escolher a **Diálise Peritoneal** em detrimento de outras opções, como a hemodiálise, e como tem sido a sua experiência de vida com este tratamento em casa. Pretendemos usar esta informação para melhorar a forma como outras pessoas são informadas e apoiadas na sua decisão.

2. Procedimentos da Participação

A sua participação neste estudo envolverá o preenchimento de um questionário curto de respostas curtas e ou/abertas. Ser-lhe-á pedido para responder a um questionário simples sobre a sua satisfação, motivações, e os seus receios em relação à Diálise Peritoneal. Este questionário demorará cerca de 10 minutos a preencher.
Para além disso, serão ainda recolhidos dados demográficos e clínicos do seu processo clínico, que incluem:

- Idade
- Sexo
- Nível de escolaridade
- Situação profissional
- Comorbilidades
- Data da 1ª consulta de Nefrologia
- Etiologia da DRC

- TSFR previamente realizadas
- Data de início de TSFR
- Tipo de DP
- Data de início de DP

3. Confidencialidade e Anonimato

- A sua participação é **totalmente confidencial e anónima**.
- O seu nome não será associado a nenhuma das suas respostas.
- Os dados recolhidos serão codificados (ser-lhe-á atribuído um número) e armazenados de forma segura (num ficheiro encriptado com *password*), de acordo com o Regulamento Geral sobre a Proteção de Dados (RGPD). Apenas a equipa de investigação terá acesso a estes dados.
- Os questionários serão eliminadas após a transcrição e análise.
- Os dados transcritos serão conservados por um prazo máximo de 5 anos, e posteriormente eliminados da base de dados.

4. Riscos e Benefícios

- **Riscos:** Não se prevêem riscos físicos, clínicos ou financeiros. O único risco é um desconforto ou cansaço mínimo ao responder às perguntas ou ao falar sobre aspetos sensíveis. Pode recusar-se a responder a qualquer questão a qualquer momento.
- **Benefícios:** Embora não haja um benefício direto para si, a informação que nos fornecer será fundamental para melhorar a qualidade do Serviço de Nefrologia da ULSSA e o processo de Educação Pré-Diálise para futuros doentes.

5. Voluntariedade e Direito de Retirada

- A sua participação neste estudo é **inteiramente voluntária**.
- Tem o direito de **recusar** participar ou de **retirar o seu consentimento** a qualquer momento, sem ter de dar qualquer justificação.
- A sua recusa ou desistência **não afetará de modo algum** os cuidados clínicos que recebe atualmente ou que venha a receber no Serviço de Nefrologia da ULSSA ou em qualquer outra unidade de saúde.

DECLARAÇÃO DE CONSENTIMENTO

Eu, _____,
declaro que:

1. Fui informado(a) de forma clara e acessível sobre o objetivo, os procedimentos e a natureza da minha participação neste estudo.
2. Tive a oportunidade de colocar questões e todas elas foram devidamente esclarecidas pelo(a) investigador(a).
3. Compreendo que a minha participação é voluntária e que posso desistir em qualquer momento, sem que isso afete os meus cuidados médicos.
4. Compreendo o tratamento que será dado aos meus dados (confidencialidade e anonimato).

Adicionalmente, concordo em participar no **Questionário** sobre a minha experiência em Diálise Peritoneal.

_____

(Assinatura do Participante)

Data: ____ / ____ / _____

Declaração do Investigador(a):

Eu, Maria Francisca Simões Pinhão da Silva Damas, confirmo que expliquei o propósito e a natureza deste estudo ao participante e obtive o seu consentimento informado e voluntário.

_____

(Assinatura do/a Investigador/a)

Annex III - Ethics Committee Approval

Ø15

REPÚBLICA PORTUGUESA SAÚDE | SNS SERVIÇO NACIONAL DE SAÚDE | UNIDADE LOCAL DE SAÚDE SANTO ANTÓNIO | santo antónio CENTRO HOSPITALAR UNIVERSITÁRIO DE SANTO ANTÓNIO | U.PORTO ICBAS INSTITUTO DE CIÊNCIAS BIOMÉDICAS ABEL SALAZAR SCHOOL OF MEDICINE AND BIOMEDICAL SCIENCES

COMISSÃO DE ÉTICA Santo António / ICBAS

APRECIAÇÃO E VOTAÇÃO DO PARECER

Deliberação	Data: 15 ABR. 2026	Órgão: Reunião Plenária

Título: **"Shared Decision-Making in the Choice of Peritoneal Dialysis: Patients' Perspectives on the Transition to Home Therapy"**		Ref.ª: **2025.250(208-CAC-208-CE)**
Protocolo/Versão: **TA-MIM**	Promotor: **o(a) próprio(a)**	Investigador / Local: **Maria Francisca Damas Serviço de Nefrologia - CHUdSA**

A Comissão de Ética *Santo António* / ICBAS, ao abrigo do disposto no Decreto-Lei n.º 80/2018, de 15 de outubro, em reunião realizada nesta data, apreciou a fundamentação do relator sobre o pedido de parecer para a realização do **TA-MIM** acima referenciado:

Ouvido o Relator, o processo foi votado pelos Membros da Comissão de Ética *Santo António* / ICBAS presentes:

Presidente: Prof. Doutor João Nuno Melo Beirão
Vice-Presidente: Dr.ª Paulina Aguiar

Dr. Aníbal Albuquerque, Prof.ª ~~Doutora Carla Teixeira~~, Prof.ª Doutora Cármen de Carvalho, Dr.ª Fernanda Manuela Costa, Prof. Doutor José António Pinho, Prof.ª ~~Doutora Margarida Araújo~~, Prof.ª Doutora Maria Strecht, Prof.ª ~~Doutora Susana Magalhães~~, Mestre Virgínio Costa Ribeiro.

Resultado da votação:

PARECER FAVORÁVEL

A deliberação foi aprovada por unanimidade.

Pelo que se submete à consideração superior.

Data 15 ABR. 2026

O Presidente da Comissão de Ética *Santo António* / ICBAS

Prof. Doutor João Nuno Melo Beirão

Imp.10/2025