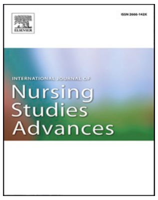
International Journal of Nursing Studies Advances 7 (2024) 100231

Contents lists available at ScienceDirect

International Journal of Nursing Studies Advances

journal homepage: www.sciencedirect.com/journal/international-journal-of-nursing-studies-advances



Feasibility and acceptability of the ShareD dEciSIon making for patients with kidney failuRE to improve end-of-life care intervention: A pilot multicentre randomised controlled trial

Louise Engelbrecht Buur[a,b,c,*], Hilary Louise Bekker[b,c,d], Henning Søndergaard[e], Michell Kannegaard[f], Jens Kristian Madsen[a], Dinah Sherzad Khatir[a,g], Jeanette Finderup[a,b,g]

[a] *Department of Renal Medicine, Aarhus University Hospital, Aarhus, Denmark*
[b] *Research Centre for Patient Involvement (ResCenPI), Aarhus University, Aarhus, Denmark*
[c] *Department of Public Health, Aarhus University, Aarhus, Denmark*
[d] *Leeds Unit of Complex Intervention Development (LUCID), Leeds Institute of Health Science, School of Medicine, University of Leeds, Leeds, UK*
[e] *The Danish Kidney Association, Taastrup, Denmark*
[f] *Profession School UCN act2learn, Aalborg, Denmark*
[g] *Department of Clinical Medicine, Aarhus University, Aarhus, Denmark*

ARTICLE INFO

Keywords:
Acceptability testing
Complex interventions
End-of-life care
Feasibility testing
Kidney failure
Kidney services
Nephrology
Palliative care
Randomised controlled trials
Shared decision making

ABSTRACT

Background: Kidney failure is associated with a high disease burden and high mortality rates. National and international guidelines recommend health professionals involve patients with kidney failure in making decisions about end-of-life care, but implementation of these conversations within kidney services varies. We developed the DESIRE (ShareD dEciSIon-making for patients with kidney failuRE to improve end-of-life care) intervention from our studies investigating multiple decision maker needs and experiences of end-of-life care in kidney services. The DESIRE intervention's three components are a training programme for health professionals, a patient decision aid, and a kidney service consultation held to facilitate shared decision-making conversations about planning end-of-life care.

Objectives: To assess the feasibility and acceptability of integrating the DESIRE intervention within kidney services.

Design: A pilot study using a multicentre randomised controlled design.

Setting: Four Danish nephrology departments.

Participants: Patients with kidney failure who were 75 years of age or above, their relatives, and health professionals.

Methods: Patients were randomised to either the intervention or usual care. Feasibility data regarding delivering the intervention, the trial design, and outcome measures were collected through questionnaires and audio recordings at four points in time: before, during, post, and 3 months after the intervention. Acceptability data were collected through semi-structured interviews with patients and relatives, as well as a focus group with health professionals post the intervention.

---

[*] Corresponding author at: Department of Renal Medicine, Aarhus University hospital, Palle Juul-Jensens Boulevard 99, 8200 Aarhus N, Denmark.
E-mail address: louikr@rm.dk (L.E. Buur).
@BekkerHilary (H.L. Bekker), @finddrup (J. Finderup)

https://doi.org/10.1016/j.ijnsa.2024.100231
Received 2 March 2024; Received in revised form 27 July 2024; Accepted 1 August 2024

Results: Twenty-seven patients out of the 32 planned were randomised either to the intervention (n= 14) or usual care (n= 13). In addition, four relatives and 12 health professionals participated. Follow-up was completed by 81 % (n= 22) of patient participants. We found that both feasibility and acceptability data suggested health professionals improved their decision support and shared decision-making skills via the training. Patient and relative participants experienced the intervention as supporting a shared decision-making process; from audio recordings, we showed health professionals were able to support proactively decision-making about end-of-life care within these consultations. All stakeholders perceived the intervention to be effective in promoting shared decision-making and relevant for supporting end-of-life care planning.

Conclusions: Participant feedback indicated that the DESIRE intervention can be integrated into practice to support patients, relatives, and health professionals in planning end-of-life care alongside the management of worsening kidney failure. Minimising exhaustion and enhancing engagement with the intervention should be a focus for subsequent refinement of the intervention.

Registration: The study has been registered at ClinicalTrials.gov with the identifier: NCT05842772. Date of first recruitment: March 20, 2023.

What is already known about the topic

- Exploring end-of-life care decisional needs in the kidney care context is an important aspect of high quality end-of-life care.
- Patients with kidney failure have rarely been provided with systematic conversations about potential options, benefits, and harms so they can make informed choices about their end-of-life care.
- Patients are often unaware that their kidney disease is worsening and may need help from relatives due to diminished capacity to make decisions about end-of-life care on their own.

What this paper adds

- The ShareD dEciSIon-making for patients with kidney failuRE to improve end-of-life care (DESIRE) intervention presents a promising way of providing shared decision-making about end-of-life care for patients with kidney failure and their relatives and of improving the fulfilment of palliative care needs among patients with kidney failure during usual kidney disease management consultations.
- The training programme for health professionals was a well-received intervention component, helping them feel prepared for having shared decision-making conversations about end-of-life care planning with patients with kidney failure and their relatives.
- After minimal adjustments, the effectiveness of the DESIRE intervention is ready to be evaluated further on a larger scale.

Data availability

Data were collected in participants' native languages. No permissions to share data have been obtained.

1. Background

The aim of this study was to assess the feasibility and acceptability of integrating the DESIRE (ShareD dEciSIon making for patients with kidney failure to improve end-of-life care) intervention within kidney services to support end-of-life care planning between patients with kidney failure who were 75 years of age or above, their relatives, and health professionals (Buur et al., al.,2022; Buur et al., 2024a).

Despite treatment advances, kidney failure is associated with a high symptom burden and high mortality rates (Murtagh et al., 2007; Combs and Davison, 2015; Davison et al., 2006). The number of elderly, frail patients with high incidence of comorbidity is increasing within this patient group (Axelsson et al., 2018; Bristowe et al., 2015). Multiple factors appear to hinder systematic end-of-life care planning in kidney services. Health professionals find it challenging to commence discussions with patients about end-of-life care preferences when patients' health is in a stable period of their illness trajectory (Lazenby et al., 2017). Initiating a conversation about preferences for end-of-life care is considered difficult from the health professional's perspective because of perceived barriers to bringing the topic up (Lazenby et al., 2017). The result may be that such conversations are initiated only sporadically and even left until a patient experiences deterioration in their health and may be too ill to engage in conversations about end-of-life care preferences (Lazenby et al., 2017; Davison, 2010; Tamura and Cohen, 2010; Aasen et al., 2012; Davison and Simpson, 2006; Eneanya et al., 2015; Mandel et al., 2017). Patients do find it important to be informed about end-of-life issues and to discuss these issues with relatives and health professionals (Davison, 2010). However, patients with kidney failure often die without having been involved in planning care and treatment in relation to the end of life and without having shared their wishes with health professionals and/or their relatives (Ladin et al., 2021). For families, barriers to talking about end of life may mean this occurs too late (Noble et al., 2013).

Patients with kidney failure may need to discuss their options for end-of-life care at an earlier stage of their disease to be able to make decisions and plan for end of life in advance based on their personal values (Axelsson et al., 2018; Bristowe et al., 2015). Timely communication about expected disease trajectory and care preferences towards end of life may afford patients and relatives opportunities to prepare for end of life and ensure care is consistent with their values and needs. There is evidence that shared decision-making methods and patient decision aids increase patients' knowledge of options, perception of risks, involvement in the decision making process, and agreement between the choices and patients' values (Stacey et al., 2024).

National and international guidelines recommend that the individual patient with kidney failure be involved in the decision making process, but researchers have found evidence that suggests this does not always happen (Lazenby et al., 2017; National Institute for Health and Care Excellence, 2014; Hemodialysis Adequacy 2006 Work group, 2006; Stiggelbout et al., 2012). The variations towards end-of-life care planning are partly due to health professionals' fear of upsetting patients and relatives, the need for patient information to support engagement with end-of-life care decision making in advance, and professional skills to initiate conversations in routine care. It is likely that a shared decision-making intervention to facilitate end-of-life care planning for patients with kidney failure in Danish kidney services will support a more systematic approach to end-of-life care discussions across services. We developed the DESIRE intervention from our findings using a mix of study designs and methods to identify multiple stakeholders' experiences and needs when making decisions about end-of-life care within kidney services (Buur et al., 2023a,b,2024b). We identified the following components as active ingredients necessary for supporting all decision makers to reason about the options and what is important to them, individually and together: a training programme for health professionals to support them in conducting shared decision-making conversations about planning end-of-life care together with patients and relatives; a patient decision aid to support the different stakeholders in end-of-life care planning; and a consultation held within kidney services to facilitate shared decision-making conversations about planning end-of-life care.

The objectives of this study were to establish: 1) the feasibility of the DESIRE intervention and its components for use with patients, relatives, and health professionals; 2) the acceptability of the DESIRE intervention and its components to patients, relatives, and health professionals; and 3) the feasibility of the trial design and methods to inform an effectiveness study.

2. Methods

2.1. Intervention development and research context

The research design and methods for this intervention were informed by the Medical Research Council's guidance for complex intervention development and evaluation research (Skivington et al., 2021). We drew on a number of guidelines in reporting the methods for this feasibility phase of the project (Eldrige et al., 2016; Sepucha et al., 2018).

The theoretical approach for this intervention (O'Cathain et al., 2019) was the Making Informed Decisions Individually and Together (MIND-IT) framework for interventions supporting the reasoned decision- making of multiple decision-makers making the same healthcare decision (Breckenridge et al., 2015; Toft et al., 2022). We drew on the International Patient Decision Aid Standards (IPDAS) Collaboration to guide the development of components within this complex intervention (International Patient Decision Aid Standards (IPDAS) Collaboration, 2024; Witteman et al., 2021; Stacey and Volk, 2021), and previous shared decision-making interventions developed for the UK and Danish contexts (Winterbottom et al., 2020; Finderup et al., 2020a).

The project steering group involved researchers with experience as kidney and palliative care nurses and physicians and expertise in decision science and complex intervention development (LEB, HLB, JKM, DSK, JF) and patient and relative research partners (HS, MK). The user-centred intervention design advisory group included stakeholders with different organisational and professional roles in kidney services (n= 12), patients with kidney failure (n= 3), and relatives (n= 2). Together with the research team, they provided their views on appropriate intervention content and design during four workshops and 14 prototype iterations. A patient and a nurse tested the usability of the prototype, and the workshop participants approved a final version.

The DESIRE intervention development process is described elsewhere (Buur et al., 2024a). In brief, the intervention comprises three components:

- a training programme for health professionals on using shared decision-making in end-of-life care conversations
- a patient decision aid developed in accordance with the International Patient Decision Aid Standards Collaboration (Stacey and Volk, 2021)
- a kidney service consultation, held either at the hospital or at the patient's home according to the patient's need, to facilitate shared decision-making conversations about planning end-of-life care, including an invitation to such a consultation.

2.2. Intervention evaluation design and methods

The intervention was tested for feasibility and acceptability using a pilot multicentre randomised controlled design with two parallel groups of participants allocated to either the DESIRE intervention or usual care. The trial was part of a larger research project described in a previously published *a priori* protocol (Buur et al., 2022), and has been registered at ClinicalTrials.gov with the identifier: NCT05842772. Methods included interviews with patients with kidney failure and their relatives, a focus group with health professionals, and various questionnaires.

2.3. Participants and data collection procedures

In March 2023, health professionals associated with the nephrology departments of the four participating Danish hospitals undertook the training programme for the DESIRE intervention. From March 20, 2023 to May 31, 2023, these trained health professionals identified consecutive patients meeting the selection criteria, informed them about the research project, and obtained their consent to participate at baseline (see Fig. 1). A logbook was kept to provide an overview of the inclusion rate. Inclusion criteria were adult, Danish speaking, 75 years of age or above patients with kidney failure being treated on either haemodialysis, peritoneal dialysis, or the conservative kidney management pathway, and who were not suitable for a kidney transplant. Exclusion criteria were patients who were considered medically incompetent to make health care decisions. Adult relatives who would usually attend consultations with the patient participated in the intervention and the study if nominated by the patient. A research manager, blinded to participant identity, had prepared sealed envelopes stating whether the participant was allocated to either the intervention or the control group to generate a 1:1 balanced randomisation. All consenting participants completed demographic and baseline Integrated Palliative Care Outcome Scale-Renal (Boje et al., 2021) questionnaires and were randomised to receive the DESIRE intervention or usual care. Demographic information gathered on patient participants included sex, age, marital status, educational level, ethnicity, treatment modality, and estimated glomerular filtration rate. The participating health professionals conducted stratification by randomly picking one of the sealed envelopes. Patient, relative, and health professional participants could not be blinded. Fig. 1 shows the timeline of the data collection which occurred at baseline (T0) in both groups, during shared decision-making conversations (T1) in the intervention group, at post-shared decision-making conversations (T2) in the intervention group, and at 3-month follow-up (T3) in both groups.

2.4. Measures used to assess the feasibility of the DESIRE intervention and its components among patients, relatives, and health professionals

2.4.1. Completion rates

Data were collected on the number of eligible patient and relative participants who were approached and accepted to participate and further the number of participants who completed the intervention and the number of participants who provided data. Data were collected on the number of participating health professionals who: 1) were able to participate in the one-day training programme for the DESIRE intervention; 2) were able to complete all three sections of the training programme.

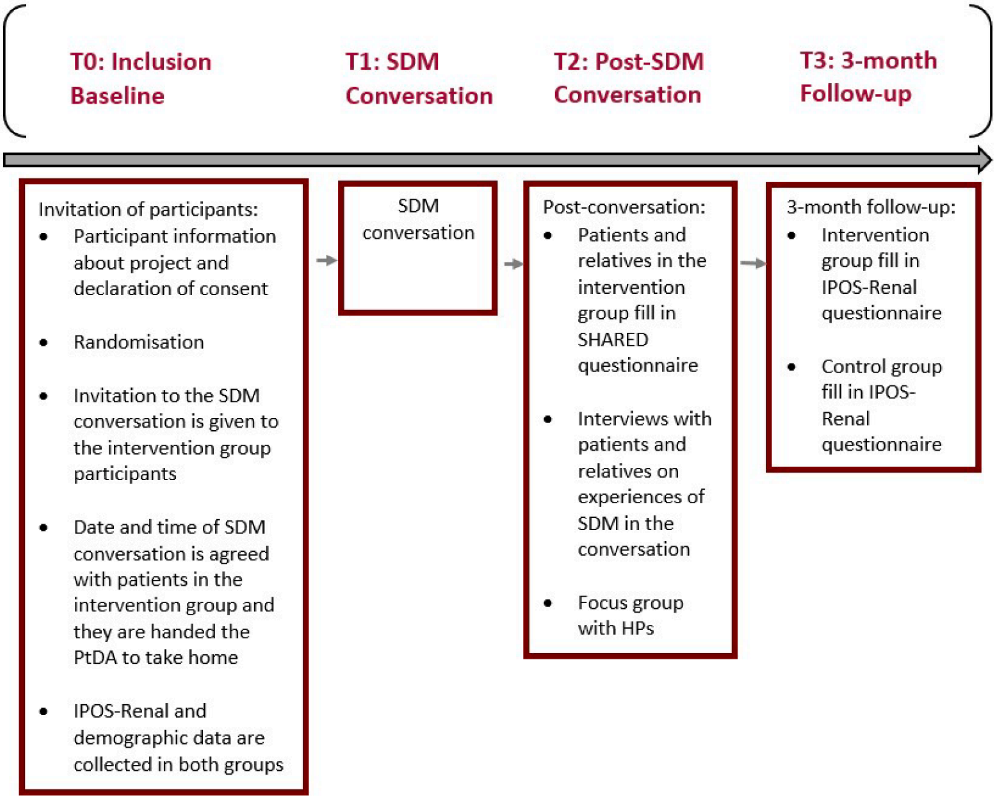


Fig. 1. Timeline of the steps for feasibility and acceptability testing DESIRE among patient and relative participants
T = Time, SDM = Shared decision-making, PtDA = Patient decision aid, IPOS-Renal = Integrated Palliative Outcome Scale-Renal questionnaire, SHARED = Patient Experience of Shared Decision Making Questionnaire, HPs = Health professionals.

2.4.2. Measures of the DESIRE components

Data were collected to measure whether the components of the DESIRE training programme were able to increase the participating health professionals' skills in implementing and practicing shared decision-making during the clinical consultations. This was measured with the questionnaire IcanSDM (Giguère et al., 2020) Danish version at the beginning and end of the training programme. The IcanSDM is an 8-item questionnaire, that begins with a definition of shared decision-making and assesses the health professional's ability to implement and practice shared decision-making. IcanSDM items were rated on an analogue scale ranging from 0 (strongly disagree) to 10 (strongly agree), and a lower total sum score indicated improved shared decision-making skills. The scale had a Cronbach's alpha of 0.74 in the current sample

Data were collected to measure whether the DESIRE components facilitated participants' experience of shared decision-making during the intervention consultation. The SHARED measure is a 10-item questionnaire (Bekker, 2020), asking for the patient's experience of a) the health professional providing details about health care options (4 items), b) discussing what was important to them about the options (3 items), and c) their agreement the decision was the best one for their situation (3 items). The items on this questionnaire can be scored either using a 5-point scale for each item (disagree strongly, disagree, neither agree/disagree, agree, agree strongly; 1–5; total 10–50) or as a presence or absence dichotomy for each item (disagree strongly, disagree, neither agree/disagree – score 0; agree, agree strongly – score 1; total 0–10). For this research project, the 5-point scoring per item was used to support psychometric analysis; the scale had a Cronbach's alpha of 0.83 in this sample.

Data were collected to measure whether the components of the DESIRE training programme were able to provide the participating health professionals with the ability to give decision support during the clinical consultations. This was measured via audio recordings using the Decision Support Analysis Tool-10 (Ottawa Hospital Research Institute, 2015). The tool has been validated (Stacey et al., 2008) and was translated into Danish through a standardised forward-backward translation (Beaton et al., 2000) for the current sample. It contains five items: 1) decision-making status; 2) knowledge; 3) values/preferences; 4) others' involvement in the decision; and 5) next steps. Within these items, the health professionals' decision support must fulfil seven assessment criteria to achieve the maximum score of 10 points. The scores out of 10 points are calculated as follows: 1 point if all checkboxes in an item-box are checked; except 2 points if the importance of both benefits and harms are discussed. A higher total sum score indicates a higher quality of decision support from the health professionals. An independent research assistant trained in the use of this tool evaluated the scoring.

2.5. Measures used to assess the acceptability of the DESIRE intervention to patients, relatives, and health professionals

Patients and relatives in the intervention group were interviewed after the Time 2 questionnaire to provide a detailed understanding of the acceptability of the intervention and identify barriers and enablers for implementation of the intervention. Within a month, an independent research assistant conducted qualitative semi-structured interviews with those who had received the intervention. Post-intervention, the health professionals were offered the opportunity to participate in a focus group to contribute to a detailed understanding of the acceptability of the intervention and to identify barriers and enablers for the implementation of the intervention for this group. The interview and focus group data were transcribed by an independent research assistant and analysed by the first and last authors using Malterud's systematic text condensation (Malterud, 2012).

2.6. Measures used to assess the feasibility of the trial design and methods to inform an effectiveness study

The feasibility of the trial design was established by collecting data on outcome measures selected for potential use in a future effectiveness study. They were chosen because they were considered to be appropriate as clinical outcomes to address implementation in clinical practice.

Data were collected to determine: 1) the percentage of eligible patient participants who completed follow-up (at 3 months) and 2) the change in patients' experience of their palliative care needs from baseline to 3 months after inclusion in both groups. This was measured using the translated Danish-validated version of the Integrated Palliative Care Outcome Scale-Renal questionnaire (Boje et al., 2021). The questionnaire has shown excellent psychometric properties (Raj et al., 2018). In the current sample, the total scale had a Cronbach's alpha of 0.82 at baseline. The 11 items assess the most common symptoms patients with kidney disease experience, along with additional items on concerns beyond symptoms, such as family anxiety, information needs, and practical issues. The items for the questions on symptoms were answered on a scale from 0 for not at all to 5 for overwhelmingly. The scales for the additional questions were from 0 to 5 for items 3—9 and from 0 to 3 for items 10 and 11 because the additional questions had varying answer options. A total mean score was computed, with lower scores indicating a decrease in patients' palliative care needs. The data also determined: 3) if there was a correlation between the methods used to evaluate the feasibility of the DESIRE intervention. This was measured with statistical analysis methods using STATA® version 17 (STATA, 2017).

2.7. Analyses of questionnaire data

An independent research assistant entered data from the questionnaires into the software program Excel (Microsoft Corporation, 2018) to ensure the whole research team remained blinded. All analyses were performed using STATA® version 17 (STATA, 2017). To summarise participant characteristics, mainly descriptive analyses were conducted. For categorical data, frequency distribution was calculated and, for continuous data, medians and interquartile range (IQR) or means and standard deviations (SD). For comparison between groups with categorical data, a chi-square test or Fisher's exact test (expected value below 5) was used, and, for continuous data, the Mann–Whitney-test was used. A p-value <0.05 was considered to be the limit of significance.

2.8. Ethical approval

This study conformed to the ethical principles for medical research involving human subjects laid down in the World Medical Association Declaration of Helsinki to protect the patients' health and rights (World Medical Association, 2013). Participation in the DESIRE intervention was based on consent for care and treatment in accordance with Danish health legislation, Chapter 5, § 15 (Ministry of Health, 2018). No adverse events have been reported after a shared decision-making intervention (Stacey et al., 2024), but if something were to happen, it could be dealt with because all patients were being seen regularly in their nephrology departments and had opportunities to speak to a nephrologist or a nurse in kidney services. However, no such events were reported. Under Danish health research legislation, this kind of research is exempt from ethical approval (Ministry of Health, 2017). Written consent from patients and relatives was obtained before randomisation. The Danish Data Protection Agency approved data management for all the participating hospitals (approval: 1–16–02–85–23). All data were managed in accordance with the General Data Protection Regulation (European Parliament and Council, 2016).

3. Results

3.1. Sample

Table 1 shows the characteristics of the patient sample included at baseline (*n*= 27). A majority of patients were male, and all but three were Danish. Mean age was 80.4 years, and mean estimated glomerular filtration rate was 8.5 mL/min/1.73 m^2. More than half the patients were living alone; most had a secondary or tertiary undergraduate education level and were being treated on haemodialysis. No significant differences between groups were observed, indicating successful randomisation at baseline. A sample of 15 health professionals participated in the training programme. The mean age was 48 years (range 28—64 years); 13 were nurses and 2 were nephrology consultants. On average, they had 22 years of professional experience (range 2—40 years). A third had previous experience with shared decision-making.

Table 1

Characteristics of the patient sample in the feasibility testing of the DESIRE intervention.

	Patients			
	Total	Intervention	Control	Chi-square or Mann–Whitney-test
	n (%)	*n* (%)	*n* (%)	*p*-value
Sex (*n* = 27)				
Female	6 (22)	5 (36)	1 (8)	0.080
Male	21 (78)	9 (64)	12 (92)	
Age (*n* = 27)				
75—79	12 (44)	4 (29)	8 (62)	
80—90	15 (56)	10 (71)	5 (38)	0.304*
Over 90	0 (0)	0 (0)	0 (0)	
Marital status (*n* = 27)				
Living alone	16 (59)	9 (64)	7 (54)	0.581
Living with someone else	11 (41)	5 (36)	6 (46)	
Educational level (*n* = 27)				
Primary education	7 (26)	5 (36)	2 (15)	0.638
Secondary education	9 (33)	4 (29)	5 (38)	
Tertiary undergraduate education	8 (30)	4 (29)	4 (31)	
Tertiary graduate education	3 (11)	1 (7)	2 (15)	
Ethnicity (*n* = 27)				
Danish	24 (89)	13 (93)	11 (85)	0.496
Other	3 (11)	1 (7)	2 (15)	
Treatment modality (*n* = 27)				
HD	16 (59)	8 (57)	8 (62)	
PD	7 (26)	4 (29)	3 (23)	0.948
CKM	4 (15)	2 (14)	2 (15)	
eGFR (*n* = 26)				
3—8	15 (58)	8 (57)	7 (58)	
9—14	7 (27)	4 (29)	3 (25)	0.909
15—20	4 (15)	2 (14)	2 (17)	
IPOS-Renal baseline (*n* = 27), mean (SD)				
Total score	25.47 (12.37)	28.63 (10.66)	22.06 (13.56)	0.172

* Exact age and eGFR have been used to calculate the p-value and not age ratio and eGFR ratio; HD = Haemodialysis; PD = Peritoneal dialysis; CKM = Conservative kidney management; eGFR = Estimated glomerular filtration rate; SD = Standard deviation.

3.2. *Feasibility of the DESIRE intervention and components among patients, relatives, and health professionals*

3.2.1. *Completion rates*

Fig. 2 shows the flow of patient and relative participants throughout the study. The participating health professionals assessed 46 patients for eligibility. Of these, 30 percent declined to participate, and 16 percent of the planned sample size never entered the randomisation process. One conservative kidney management unit had not been able to recruit participants, and one peritoneal dialysis unit had failed to include one participant. Therefore, 27 patients with kidney failure were included in the study at baseline; 14 were allocated to the intervention group and 13 to the control group. Four relative participants were included, allocated to four patient participants in the intervention group. Complete demographic data were available on the 27 patients except for the estimated glomerular filtration rate of one patient, and analyses on data from the 27 patients could be carried out at baseline. Due either to deterioration in the patient's health or illness in close family, two of the 14 patients randomised to the intervention group never had the shared decision-making conversation (Time 1). The conversations had a mean duration of 53 min and a median of 57 min ranging from 23 min to 71 min. Two of the 12 patients participating in the shared decision-making conversation were unable to be interviewed at

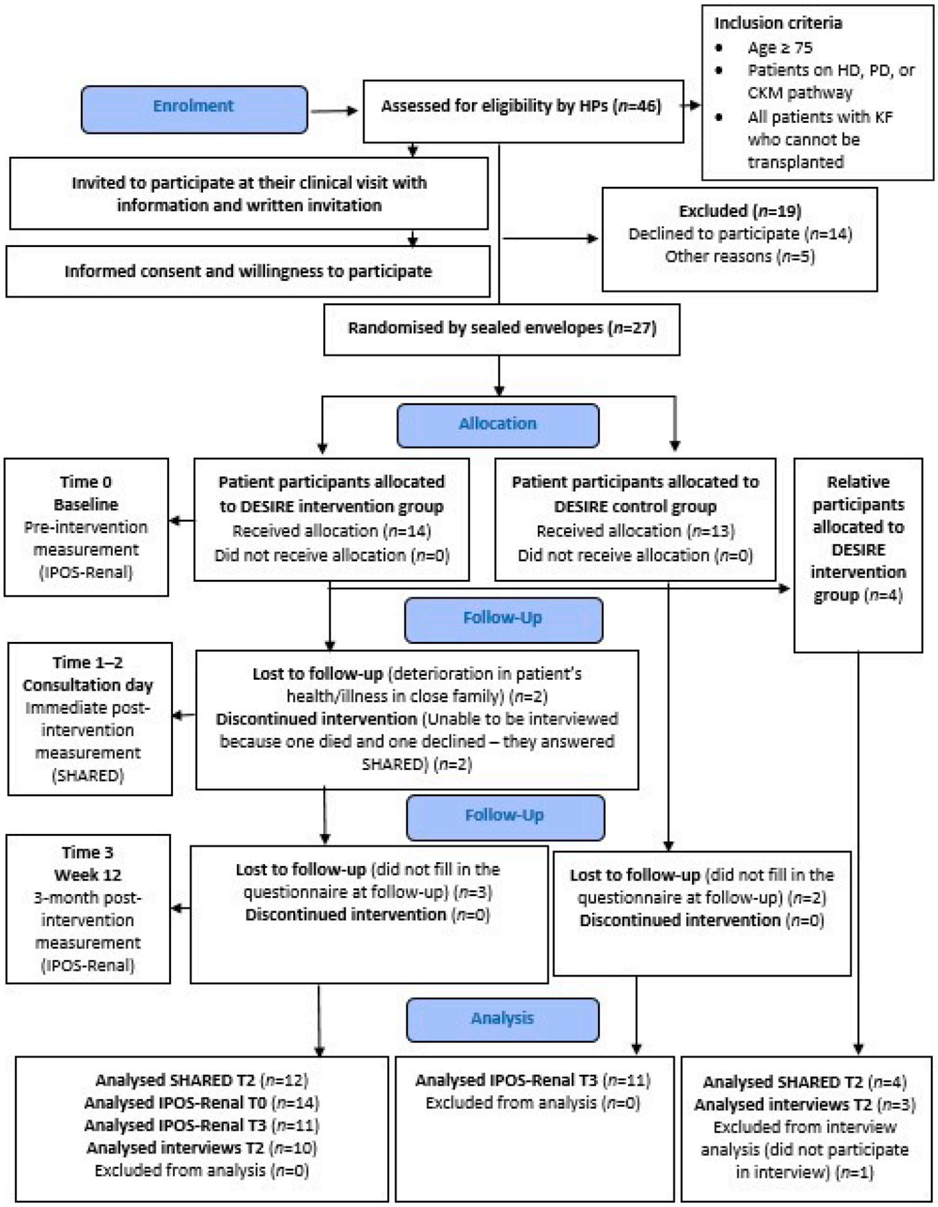


Fig. 2. Participant flow
HPs = Health professionals; HD = Haemodialysis; PD = Peritoneal dialysis; CKM = Conservative kidney management; KF = Kidney failure.

Table 2
Patients', relatives', and health professionals' perceptions of potential enablers and barriers for establishing clinical engagement in the use of DESIRE in kidney services.

		Enablers	Barriers	Quotations
DESIRE components	**Invitation letter**	• Proper introduction to SDM conversation [P, R] • Set the scene so patients and relatives know what it is about without scaring them [HP]	• Induced thoughts of a very serious conversation [P, R, HP]	*Yes, it [the invitation] informed me of (…) what I should expect (…), what you [HPs] expected of me, and what should be accomplished by it [SDM conversation] and so on (…), and overall that was fine.* [P4 – PD]
	PtDA	• Assess with the individual patient whether they should have the PtDA together with the invitation or wait till their SDM conversation [HP] • Useful as support and starting point for the conversation and to prevent it from stalling [P, R, HP] • Useful when supported by the HPs [P] • Helpful to HPs to get deeper into conversation about important EoLC topics with the patient [HP] • Not a checklist [HP] • Gives many options, it is just a matter of making the best use of it [HP] • Caused patients and relatives to reflect [P, R] • Pictograms support the conversation [P, R, HP] • OPDG makes good sense when having tried it more times; good to conclude from and feel informed about options, benefits, and harms [P, HP] • More knowledge about illness trajectory [P, R] • Helped feeling confirmed in previous EoLC choice [P, R] • Wants the conversation to be about how the patient feels now and let that be the starting point for the conversation [HP] • Whether they should have it before conversation is a matter of assessment [HP] • During conversation works particularly well [HP] • Afterwards works to discuss it with the relatives and for the patient to revisit at home [P, R, HP]	• Title may cause patients to feel they are nearing EoL and that the conversation will be overwhelming [P, R, HP] • Difficult to navigate and a large amount of text to deal with [P, R] • OPDG a little bit hard to fill out [HP] • Not remembering [P, R]	*Yes, there may actually be something there that you can recognise from yourself when you look at the pictures [pictograms] (…) yes, I think I did [use the PtDA to prepare for the conversation] it helped me see what symptoms are normal to have and what to expect in the future.* [P7 – HD] *I think the PtDA supports the patient during the conversation and it supports us [HPs] also with preventing the conversation from stalling and helps us move forward.* [HP1] *I found that the patient feared they were more ill than they first anticipated after having read the title of the PtDA.* [HP6] *No, I do not know (…) I do not remember [PtDA] (…) I think we discussed it together [patient, relative, and HP].* [P6 – PD] *I will say that I do not remember it [PtDA].* [R2] *It [PtDA] was sort of useful because I got information about the symptoms that can occur due to my illness.* [P10 – HD] *We have made the decisions together [patient and relative], and when the HP was at our house, the conversation did not change the decisions (…) nothing can change our decisions.* [R1]
	Conversation	• Helped feeling confirmed in previous EoLC choice [P, R] • Caused reflections on and acceptance of illness [P] • Valued attention and care [P] • Discussed concerns [P] • Created peace of mind [P] • Generated a great relationship between participants [P, R, HP] • Valued knowing the HP [P] • Felt secure talking about EoLC with HPs [P] • Based on what matters to the patient right now [HP] • HPs must be directive [HP] • Discussion of different topics [HP] • A conversation process can follow up on things [HP] • The more you have, the better you get at it [HP] • Open up about difficult topic [P, R, HP]	• Need support to talk about EoLC [P, R, HP] • Difficult to plan ahead [P] • Hesitancy towards talking about the future, want to take things as they come [P] • Settled beforehand and did not have any concerns or questions [P] • Not remembering [P, R] • Tiresome [P]	*She [HP] asked me about options that she knew were difficult for me to talk about (…) that made me realise that I had to accept my situation [being ill], that I am ill (…) I need to face it and she made me realise that (…) it was a fantastically great conversation with her.* [P8 – HD] *I just want to say that it [having the conversation] was an insanely good experience, I was almost completely high afterwards, so it was a really good experience and really, really good tools [PtDA] (…) the patient has mentioned several times afterwards that it was a really, really good conversation and that it had also been a really good conversation for the relatives, and I also think that we had been introduced very well before [training programme].* [HP6] *Such a discussion is interesting if there is something to decide on, but I do not think there is.* [P5 – PD]

(*continued on next page*)

Table 2 (*continued*)

		Enablers	Barriers	Quotations
	Training programme	• Prepared them for the conversation [HP] • Video recording and role-play simulation training were highlighted [HP] • The more conversations you have had, the less nervous you are [HP] • Sufficient training via programme, but more practice with more conversations [HP]	• Doubt whether conversation should be based on what is important for the patient right now or wishes for the EoL (HP) • Despite training conversation could be overwhelming for some HPs (HP)	*I think it was nice to get out in those groups [role-play], so that you had a little taste of it (…) I think it was nice that you could just put a little of that experience in your backpack before you had to go in and have the conversations yourself.* [HP3]
DESIRE outcomes	**For the patient**	• Share situation with relatives • Generate reflections/thoughts • More specific about wishes for EoLC in the conversation and made 'my last will' [P on CKM] • More concrete in the dialogue with relatives • Really good conversation • Led to changes in treatment • Decision made on future residence • Awareness on EoL • Easier to open up to relatives	• Patients on CKM pathway clearer on purpose beforehand because they have made EoL decisions • EoLC options discussed must not be too hypothetical but more concretely rooted in the current situation	*It is nice that my relatives are involved (…) that I do not have to hide anything.* [P2 – CKM]
	For the relatives	• More specific about wishes for EoLC in the conversation and made 'my last will' [R to P on CKM] • Really good conversation • Positive experience to get insight into patients' illness and treatment		*The relatives had felt that they had gained a much greater insight into what their mother [patient] was going through by having this conversation (…) and they had become aware of some issues that they were not actually aware of in relation to being a patient treated with dialysis (…) so for them it had also been very educational and very insightful.* [HP5]
	For the HPs	• Relationship enriching • Another positive and calming dimension to have the conversation in the patient's home • More experience in using intervention makes it easier	• Much to take care of in the intervention	*Some of the patients and relatives expressed that the questionnaires were difficult to fill in and the wording of the questions was complex. [HPs]*

The quotations have been translated into English as accurately as possible. Observations are followed by an abbreviation in square brackets indicating the participant's role — *P* = patient, *R* = relative or HP = health professional — and, for the quotations, the identification number of the participant, and for patient participants, their treatment. SDM = Shared decision-making; PtDA = Patient decision aid; PD = Peritoneal dialysis; OPDG = Ottawa Personal Decision Guide; HD = Haemodialysis; EoLC = End-of-life care; EoL = End of life; CKM = Conservative kidney management.

Time 2 because one died and one declined. All patients and relatives in the intervention group who participated in the shared decision-making conversation completed the SHARED questionnaire. In total, three out of 12 patients received the intervention in their homes, and all participants had only one conversation.

All the health professionals approached (n= 15) were able and agreed to participate in the one-day training programme for the DESIRE intervention and were able to complete the three sections of the training programme.

3.2.2. *Measures of the DESIRE components*

3.2.2.1. To measure if the components of the DESIRE training programme increased the health professionals' decision support and shared decision making skills. Fourteen of the 15 health professionals had filled in both IcanSDM questionnaires at the one-day training programme. The questionnaire's post- scores showed an improvement on items 1 (median $= -0.63$, $p = 0.281$), 2 (median $= -0.40$, $p = 0.318$), 4 (median $= -0.00$, $p = 0.532$), 6 (median $= -0.15$, $p = 0.248$), and 8 (median $= -0.22$, $p = 0.852$) in comparison to the pre-scores, indicating that the training programme may have improved their ability to implement and practice shared decision-making. However, none of these showed a statistically significant improvement, and item 5 (median $= 1.62$, $p = 0.004$) showed a statistically significant decrease.

3.2.2.2. To measure if the DESIRE components were able to provide the patient and relative participants with an experience of shared decision making. Findings for the patients (n= 12) showed a median total on the SHARED questionnaire score of 41 (IQR = 38–46) out of 50, reflecting that the patient participants mainly agreed or strongly agreed that the intervention was based on shared decision-making. The median total SHARED score for the relative participants (n= 4) was 46 (IQR = 45–47) out of 50, reflecting that the relative participants strongly agreed that the intervention was based on shared decision-making. Exploring the by-item responses suggests that most participants perceived they were supported to deliberate about which option best met their personal situation (e.g., talked about other options from the one I chose, what was important to me about the decision, the decision made was the best one for me).

3.2.2.3. To measure if the components of the DESIRE training programme were able to provide the health professionals with the ability to use decision support. The mean overall Decision Support Analysis Tool-10 score was 9.58 (SD = 0.7) out of 10, indicating high quality for the health professionals' (n= 12) use of decision support. Item 5 (provide information on options, benefits, and harms), and item 8 (Intervene to handle pressure or support needs from others) did not obtain a full score. Item 5 obtained 0.67 (SD = 0.49) out of 1.00, and item 8 obtained 0.92 (SD = 0.29) out of 1.00.

3.3. *Acceptability of the DESIRE intervention to patients, relatives, and health professionals*

Overall, patients, relatives, and health professionals experienced the DESIRE intervention as challenging but also rewarding. They expressed that the conversations enabled elaborations on important topics. Qualitative evaluation results are discussed below, on themes of enablers and barriers for implementation, and refinement of the intervention content and study design. Table 2 presents the qualitative evaluation results with illustrative quotes from the interviews or focus group.

3.3.1. *Enablers and barriers*

Seven of the patient participants specifically emphasised that they had experienced the intervention positively and felt well taken care of. The intervention enabled them to be more specific about their wishes for end-of-life care and open up about difficult topics. This was further emphasised by two of the relatives. Patients, relatives, and health professionals highlighted that the intervention enhanced their understanding of each other and was a benefit to their relationship. Most of the patients had felt well-informed about what the conversation was about after having read the invitation. In a few cases, the invitation had induced thoughts of a very serious conversation, which had caused them to feel hesitant about participating. However, after the purpose had been explained by the health professional at the beginning of the conversation, they had felt positive about participating. Some experienced challenges with reading and understanding the patient decision aid. The pictograms, however, were positively received by all stakeholders as a helpful starting point for the conversation. Patients being treated on a conservative kidney management pathway were clearer on the purpose beforehand because they had already made decisions about end-of-life care. Health professionals highlighted the rarity of consultations

Table 3
Change in palliative care needs in each group between exit and baseline measurements.

Mean (SD)						
	Baseline		Exit		Change	
IPOS-Renal	Control (n = 11)	Intervention (n = 11)	Control (n = 11)	Intervention (n = 11)	Control (Exit—Baseline) (n = 11)	Intervention (Exit—Baseline) (n = 11)
Total score	17.98 (10.08)	28.79 (12.09)	18.36 (9.74)	27.83 (12.92)	0.38 (5.16)	−0.97 (7.24)

IPOS-Renal = Integrated Palliative Outcome Scale-Renal questionnaire; SD = standard deviation.

with this patient group as a barrier. Moreover, the patients' wishes for the conversations to take place at their home could be a barrier for some of the kidney units. All the health professionals confirmed that they felt well-trained to have the shared decision-making conversations with patients about their wishes and needs in relation to end-of-life care and treatment. Accordingly, the patient decision aid was seen as a great resource to support the conversation and a starting point for the discussion. There were challenges in relation to getting the patients to read the material and understand the purpose of the conversation. Despite these challenges, the conversation was experienced as enriching and opened up important topics. The patients' wishes and needs were not always about the end of life, but about other things that filled their lives at the time in question. To focus on what is important in life just now helps the patient to realise what may be important in the future. The health professionals expressed the need to conduct more conversations to build on their skills in having such conversations in the future.

3.3.2. *Refinements of the DESIRE intervention components*

Overall, the participants were grateful for and satisfied with the components of the DESIRE intervention. However, the health professionals pointed out several logistical aspects important for conducting the intervention in kidney services. First, it was important to ensure a calm and quiet environment for the conversation, ideally in the patient's home. Second, the one-hour duration of the conversation was regarded as suitable to ensure it did not exhaust patients and relatives. The title of the patient decision aid was overwhelming to some patients and relatives and may be changed to a title more specifically aligned to the intent of the intervention. They also highlighted the amount of text in the patient decision aid. This was seen as a lot to read, and some refinement may be beneficial for future use of the patient decision aid.

3.3.3. *Refinement of study design and methods*

The health professionals emphasised that they had experienced challenges in obtaining an overview of all the different aspects of the study design and methods (for example, randomisation of participants and the data collection via different questionnaires), along with planning shared decision-making conversations, having the conversations, and using the patient decision aid. This was also challenging to some of the participating units as some of the health professionals needed help at an organisational level to be able to deal with all the different aspects of the study design. The health professionals stated that some patients and relatives found the various questionnaires difficult to fill in because the wording of the questions was complex, and they had needed to help some of the patients and relatives understand the questions. Moreover, in future evaluations of the DESIRE intervention, there should not be too much time between the shared decision-making conversation and the interview, as this poses a risk that the patient and relative might forget the conversation.

3.4. *Feasibility of the trial design and methods to inform an effectiveness study*

3.4.1. *Completion rate of three-month follow-up*

Eighty-one percent (n= 22/27) of the total sample who were randomised completed the three-month follow-up.

3.4.2. *To measure if there was a change in patients' experience of their palliative care needs from baseline to three-month follow-up*

Table 1 shows a baseline total Integrated Palliative Care Outcome Scale-Renal mean score of 25.5, with scores of 28.6 in the intervention group and 22.1 in the control group; at this point, there was no statistically significant difference between the groups. Some participants were lost to follow-up at three months; they had to be excluded from the analysis of change in the Integrated Palliative Care Outcome Scale-Renal score. This changed the distribution at baseline, so the intervention group had a statistically significant higher Integrated Palliative Care Outcome Scale-Renal score at baseline ($p = 0.034$) (see Table 3). The overall Integrated Palliative Care Outcome Scale-Renal scores decreased for participants in the intervention group, whereas scores increased for the control group participants (however, these differences were not statistically significant ($p = 0.620$).

3.4.3. *To measure if there was a correlation between the methods used to evaluate the feasibility of the DESIRE intervention*

To further establish the suitability of DESIRE and its outcome measures, correlation analyses of the Integrated Palliative Care Outcome Scale-Renal, the SHARED questionnaire, and the Decision Support Analysis Tool-10 instruments showed a simple pairwise correlation coefficient between Integrated Palliative Care Outcome Scale-Renal score and Decision Support Analysis Tool-10 score at -0.4204, between Integrated Palliative Care Outcome Scale-Renal score and the SHARED score at -0.5118, and between Decision Support Analysis Tool-10 score and the SHARED score at 0.4359, indicating close to similar correlation between all three instruments. Correlation coefficients below 0.50 are considered to be a moderate correlation, and a correlation coefficient above 0.50 represents a strong correlation.

4. Discussion

We carried out this study to assess the feasibility and acceptability of the DESIRE intervention and its components to patients with kidney failure, their relatives, and health professionals in kidney services. In addition, we assessed the feasibility of the trial design and methods to inform a future effectiveness study. We found that integrating a shared decision-making intervention within kidney services is feasible and acceptable to all stakeholders. The training programme helped the health professionals to deliver decision support in a way that proactively supported conversations about future end-of-life care. The patient decision aid was useful in structuring the shared decision-making consultation and in supporting patients and relatives in discussing what was important to them about their kidney disease and future end-of-life care options. We identified how the intervention needed to be adapted for sustainable integration within kidney practice. In addition, we identified the next steps for evaluating implementation and the impact of the DESIRE intervention on patients, relatives, health professionals, and service outcomes. These are described in more detail below.

4.1. Feasibility of the DESIRE intervention and its components among patients, relatives, and health professionals

In assessing the feasibility of the DESIRE training programme, we suggest that the health professionals found it adequate in supporting their ability to implement and practice shared decision-making and that they understood how to use the intervention. However, we found a significant decrease for the item 'shared decision-making takes up too many resources', indicating that the training had led to more concerns among some of the health professionals that shared decision-making conversations about end-of-life care planning would require more resources in daily clinical practice. This could suggest that the training programme had made the health professionals aware of what shared decision-making entails and that conducting these conversations would require changes in their daily clinical practice. These findings highlight the need for support from high-level leadership staff in implementing the DESIRE intervention in kidney services and providing health professionals with the time necessary to adopt the intervention. Other researchers have shown that when health professionals are new to using shared decision-making, consultations are longer in the beginning, leading to an increase in time commitment (Veenendaal et al., 2023; Geiger et al., 2017). It is likely that when these new skills are assimilated into health professionals established clinical reasoning and consultation patterns, the time commitment is likely to decrease and return to normal. The implementation of evidence-based interventions may be challenged by contextual factors (Damschroder et al., 2022). An example of contextual factors could be the one conservative kidney management unit being occupied with other tasks. This emphasises the need for a more organisational implementation strategy; for example, use of the Consolidated Framework for Implementation Research (Damschroder et al., 2022). The findings based on the IcanSDM data from this study should be interpreted with attention to the small participant sample size of 14 health professionals. This does not make it possible to demonstrate a linear relationship between the suitability of the training programme for the health professionals and the improvement in their skills in providing shared decision-making conversations to patients and relatives. However, the views expressed by the health professionals in the focus group showed that they felt well-trained to have shared decision-making conversations with patients about their wishes and needs in relation to end-of-life care and treatment. Therefore, there is good reason to believe the training programme influenced the improvement that was observed in their shared decision-making skills.

Furthermore, according to the findings from the assessment of the feasibility of the DESIRE components, the patients and their relatives indicated that they had perceived that the intervention was based on shared decision-making, facilitated by structuring conversations using the patient decision aid. In addition, the findings from evaluating whether the components of the DESIRE intervention training programme provided the health professionals with the ability to give decision support indicated a high quality performance through the conversations. Whether this outcome was a result of the extra attention the patients and relatives in the intervention group received from the health professionals during conversations and while using the patient decision aid is unclear. A conceptual review has shown that it is feasible to integrate patient decision aids into kidney services to enable patients and relatives to make informed, value-based decisions together with health professionals (Bekker et al., 2023). To the best of our knowledge, the DESIRE intervention is the first to support multiple stakeholders in end-of-life care planning in Danish kidney services. Seven interventions have been identified internationally, targeting both patients, relatives and health professional, but none of those includes a shared decision-making component (Buur et al., 2023a).

4.2. Acceptability of the DESIRE intervention

Data on the acceptability of the DESIRE intervention for all stakeholder groups showed that it was challenging to have this conversation but also rewarding and beneficial to end-of-life care planning. Overall, participants were grateful for and satisfied with the different components of the DESIRE intervention. Data on enablers and barriers showed that participants from across stakeholder groups highlighted the pictograms as being helpful prompts from which to start the conversation. Two of the pictogram overviews were used in two other Danish patient decision aids for patients with chronic kidney disease (Finderup et al. 2020a,b; Finderup et al., 2018; Finderup et al. 2019). In this study, the health professionals found pictograms helpful when talking with patients with kidney disease about their kidney disease management (Finderup et al., 2019). As part of our study, it was emphasised by the people involved as patient and public involvement in research partners that a pictogram overview with examples of how kidney failure can affect people mentally, socially, and practically needed to be developed and included in the patient decision aid for the DESIRE intervention (Buur et al., 2024a). The design and content of the overview was inspired by the items in the Integrated Palliative Care Outcome Scale-Renal questionnaire (Boje et al., 2021). The rationale behind the pictogram overviews could be explained by the concept of health literacy (Santana et al., 2021). This suggests that when patients need to have the capacity to obtain, process, and understand information, to be able to engage in shared decision-making conversations and potentially accomplish value-based decision making, they may benefit from recognising themselves in the tools used. The reason why the pictograms were included in the patient decision aid in the first place was to engage patients and relatives in conversations about their care. The qualitative findings demonstrate a need for repetition to allow the health professionals to feel more experienced in using the components of the DESIRE intervention. Goff et al. (2019) studied an intervention for advance care planning shared decision-making for patients on haemodialysis and found that one of the barriers to implementing the intervention was the complexity of the intervention causing a need for the health professionals to be trained in using it (Goff et al., 2019). In our study, the training was considered appropriate. However, health professionals hypothesised that the more they used the DESIRE intervention with patients and their relatives, the more confident they would become with it.

4.3. Feasibility of the trial design and methods to inform an effectiveness study

The baseline characteristics and Integrated Palliative Care Outcome Scale-Renal measurements presented in Table 1 show that the randomisation of patient participants was successful. However, during the 2-month inclusion period, we succeeded in including only 27 of the anticipated 32 patients. Furthermore, the dropout of the patient participants included from baseline to follow-up was 18.5 %: three from the intervention group and two from the control group. The dropout from the intervention group was due to patient health issues, and, in the control group, it was due to issues among the participating health professionals. We found a statistically, significant higher need for palliative care in the intervention group at baseline compared to the control group. The reason for this observed difference is unknown and could simply be due to chance or the small sample size. Moreover, looking at the change in palliative care needs between baseline and exit measurements in each group indicated a decrease in palliative care needs in the intervention group compared to an increase in the control group, although this was not statistically significant. Researchers have concluded that a change of about five points in Integrated Palliative Care Outcome Scale-Renal scores represents a moderate effect size (Murtagh et al., 2019), which is why we presumed that our study could show similar findings. This presumption cannot be rejected while the change between groups showed a 95 % confidence interval above five points. Given the small sample size, furthermore, it is possible that the observed small changes in measured outcomes were due to random effects rather than to the DESIRE intervention. The purpose of feasibility testing a complex intervention is to find out if it is feasible to test the intervention in a larger evaluation and implementation study (Skivington et al., 2021; Craig et al., 2008, 2013). This study was however, not powered to detect differences between groups after the intervention, but based on a change in Integrated Palliative Care Outcome Scale-Renal scores of five points, and, considering the dropout of 18.5 %, a future effectiveness study would benefit from including 31 participants in each treatment group (haemodialysis, peritoneal dialysis, and conservative kidney management). Accordingly, including 93 participants in each group in a randomised controlled study should be able to achieve a power of 80 %. Twenty-seven patients from four different hospitals were included during the 2 months of this study. This means that in a future effectiveness study, either more hospitals or a longer inclusion period will be necessary to be able to include 186 participants.

It is also necessary to question whether the Integrated Palliative Care Outcome Scale-Renal measurement is a useful outcome measure to evaluate the DESIRE intervention. In the definition of advance care planning, it is stated that advance care planning '*addresses individuals' concerns across the physical, psychological, social, and spiritual domains*' (Rietjens et al., 2017), and these are the exact domains measured in Integrated Palliative Care Outcome Scale-Renal. The Integrated Palliative Care Outcome Scale-Renal consists of items measuring physical, psychological, spiritual problems, communication needs including with family, and practical support (Murtagh et al., 2019). The DESIRE intervention may be directed more towards emotional and communicational items than towards symptoms. A sub-analysis of the differences in change scores between the two groups where the data on physical symptoms were excluded showed a larger decrease in the patients' experience of their palliative care needs in the intervention group (mean = −2.7, SD = 5.5) compared to the control group (mean = −0.11, SD = 3.36); however, this was not statistically significant ($p = 0.20$). Based on the findings from the previous study (Murtagh et al., 2019), a relevant change would in this case be about 1.3 points, and the intervention group in this sub-analysis shows a change score of more than twice that size. This may indicate that in a future effectiveness study, the training programme may benefit from including more training of health professionals in intervening when addressing physical symptoms in the shared decision-making conversations or consider to use a subscale only including the items measuring psychological and spiritual problems, communication needs including with family, and practical support.

4.4. Limitations

This pilot study did not aim to achieve statistical significance between outcome measures because of the small sample size. However, a study strength is that it was conducted across four different Danish hospitals, representing two university hospitals and two regional hospitals in two different regions, suggesting findings will be relevant to different hospital and patient contexts.

In general, participants were positive towards the DESIRE intervention, reporting more enablers than barriers to using the intervention components, and evaluating the intervention as personally relevant and experiencing beneficial effects. Some implementation challenges were identified, as well as the health professionals need to repeat delivery to feel more experienced. This can be accomplished in a future effectiveness study.

A limitation caused by the design of the study is related to the health professionals' data collection. The participating health professionals had experienced the administrative and logistical part of the data collection as something of a challenge. They stated that it could be difficult to obtain an overview of all the data that had to be collected at the same time as randomisation, conducting the shared decision-making conversations, using the patient decision aid, and reporting the decisions in the patients' health records. This also affected the participating departments. In a future study, the researchers should probably manage the randomisation and questionnaire data collection, and similar tasks so that the participating health professionals only have to conduct the conversations, use the patient decision aid, and report in patients' health records. Nevertheless, the health professionals managed to collect data very thoroughly throughout the period of the study.

Furthermore, there was a potential for response bias in the study from the fact that the health professionals collected the study questionnaires, and patients may have responded in favour of their role in supporting decision making. However, the Integrated Palliative Care Outcome Scale-Renal only measures how the patients experience their situation, although two questions relate to health service delivery (information and time wasted).

5. Conclusions

To our knowledge, this shared decision-making intervention is the first to address end-of-life care planning for patients with kidney failure, their relatives, and health professionals. We have added to the building evidence about how to involve all parties in effective advance care planning for long-term conditions. We have shown promising results. Participants who completed the intervention indicated that the DESIRE intervention was valid and could be integrated into practice to support multiple stakeholders in end-of-life care planning alongside the management of worsening kidney failure. The innovative approach of delegating end-of-life care information provision to trained health professionals using shared decision-making and an evidence-based patient decision aid has the potential to facilitate informed decision making in patients with kidney failure and their relatives. Furthermore, it has the potential to support health professionals in Danish kidney services. Minimising exhaustion and enhancing engagement with the intervention should be a focus for subsequent refinement of the intervention.

CRediT authorship contribution statement

Louise Engelbrecht Buur: Writing – review & editing, Writing – original draft, Visualization, Validation, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Hilary Louise Bekker:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Henning Søndergaard:** Writing – review & editing, Validation, Investigation. **Michell Kannegaard:** Writing – review & editing, Validation, Investigation. **Jens Kristian Madsen:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Dinah Sherzad Khatir:** Writing – review & editing, Supervision, Resources, Project administration, Methodology, Investigation, Formal analysis, Conceptualization. **Jeanette Finderup:** Writing – review & editing, Writing – original draft, Supervision, Resources, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

None.

Data availability

Data were collected in participants' native languages. No permissions to share data have been obtained.

Acknowledgments

Thank you to all the people who participated in this study. Thank you to Christopher Stanners who provided language support and Morten Overgaard who provided statistical support.

Funding

This study has received funding from the Augustinus Foundation, Copenhagen, Denmark; the Department of Public Health, Aarhus University, Aarhus, Denmark; and the Danish Kidney Association, Taastrup, Denmark. These funding sources had no role in study design, data collection, analysis, or publication.

References

Aasen, E.M., Kvangarsnes, M., Heggen, K., 2012. Perceptions of patient participation amongst elderly patients with end-stage renal disease in a dialysis unit. Scand. J. Caring. Sci. 26 (1), 61–69.

Axelsson, L., Alvariza, A., Lindberg, J., Öhlén, J., Håkanson, C., Reimertz, H., et al., 2018. Unmet palliative care needs among patients with end-stage kidney disease: a national registry study about the last week of life. J. Pain. Symptom. Manage. 55 (2), 236–244.

Beaton, D.E., Bombardier, C., Guillemin, F., Ferraz, M.B., 2000. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine 25 (24), 3186–3191.

Bekker, H., 2020. Psychometric Testing of SHARED - a Patient Reported Outcome Measure of Shared Decision Making [cited 22/04/2024]. Available from: http://eprints.whiterose.ac.uk/158425/1/SHARED_Questionnaire_2020.pdf.

Bekker, H.L., Winterbottom, A.E., Gavaruzzi, T., Finderup, J., Mooney, A., 2023. Decision aids to assist patients and professionals in choosing the right treatment for kidney failure. Clin. Kidn. J. 16 (Suppl 1), i20–i38.

Boje, J., Madsen, J.K., Finderup, J., 2021. Palliative care needs experienced by Danish patients with end-stage kidney disease. J. Ren. Care 47 (3), 169–183.

Breckenridge, K., Bekker, H.L., Gibbons, E., van der Veer, S.N., Abbott, D., Briançon, S., et al., 2015. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. Nephrol. Dialy. Transplant.: Offi. Publicat. Eur. Dialy. Transpl. Assoc. - Eur. Renal. Assoc. 30 (10), 1605–1614.

Bristowe, K., Horsley, H.L., Shepherd, K., Brown, H., Carey, I., Matthews, B., et al., 2015. Thinking ahead – the need for early advance care planning for people on haemodialysis: a qualitative interview study. Palliat. Med. 29 (5), 443–450.

Buur, L.E., Bekker, H.L., Madsen, J.K., Søndergaard, H., Kannegaard, M., Khatir, D.S., et al., 2023a. Patient involvement interventions for patients with kidney failure making end-of-life care decisions: a scoping review. JBI Evid. Synthes. 21 (8), 1582–1623.

Buur, L.E., Bekker, H.L., Mathiesen, C.L., Holm, L.T., Riise, I., Finderup, J., et al., 2023b. Decision coaching for people with kidney failure: a case study. J. Ren. Care 49 (4), 220–228.

Buur, L.E., Bekker, H.L., Søndergaard, H., Kannegaard, M., Madsen, J.K., Khatir, D.S., et al., 2024a. ShareD dEciSIon making for patients with kidney failuRE to improve end-of-life care: development of the DESIRE intervention. J. Clin. Nurs. https://doi.org/10.1111/jocn.17209.

Buur, L.E., Bekker, H.L., Rodkjaer, L., Kvist, A., Kristensen, J.B., Søndergaard, H., et al., 2024b. Decisional needs in people with kidney failure, their relatives and health professionals about end-of-life care options: a qualitative interview study. J. Adv. Nurs.

Buur, L.E., Finderup, J., Søndergaard, H., Kannegaard, M., Madsen, J.K., Bekker, H.L., 2022. Shared decision-making and planning end-of-life care for patients with end-stage kidney disease: a protocol for developing and testing a complex intervention. Pilot. Feasibil. Stud. 8 (1), 226.

Combs, S.A., Davison, S.N., 2015. Palliative and end-of-life care issues in chronic kidney disease. Curr. Opin. Supp. Palliat. Care 9 (1), 14–19.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., 2008. Developing and evaluating complex interventions: the new Medical Research Council guidance. BMJ 337, a1655.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M., 2013. Developing and evaluating complex interventions: the new Medical Research Council guidance. Int. J. Nurs. Stud. 50 (5), 587–592.

Damschroder, L.J., Reardon, C.M., Widerquist, M.A.O., Lowery, J., 2022. The updated consolidated framework for implementation research based on user feedback. Implement. Sci. 17 (1), 75.

Davison, S.N., Simpson, C., 2006. Hope and advance care planning in patients with end stage renal disease: qualitative interview study. BMJ 333 (7574), 886.

Davison, S.N., Jhangri, G.S., Johnson, J.A., 2006. Cross-sectional validity of a modified Edmonton symptom assessment system in dialysis patients: a simple assessment of symptom burden. Kidn. Int. 69 (9), 16215.

Davison, S.N., 2010. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. Clin. J. Am. Soc. Nephrol. 5 (2), 195–204.

Eldridge, S.M., Chan, C.L., Campbell, M.J., Bond, C.M., Hopewell, S., Thabane, L., et al., 2016. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. BMJ 355, i5239.

Eneanya, N.D., Goff, S.L., Martinez, T., Gutierrez, N., Klingensmith, J., Griffith, J.L., et al., 2015. Shared decision-making in end-stage renal disease: a protocol for a multi-center study of a communication intervention to improve end-of-life care for dialysis patients. BMC Palliat. Care 14 (30).

Microsoft Corporation, 2018. Microsoft Excel. Available at: https://office.microsoft.com/excel [cited 22/04/2024].

Finderup, J., Jensen, J.D., Lomborg, K., 2018. Developing and pilot testing a shared decision-making intervention for dialysis choice. J. Ren. Care 44 (3), 152–161.

Finderup, J., Jensen, J.D., Lomborg, K., 2019. Evaluation of a shared decision-making intervention for dialysis choice at four Danish hospitals: a qualitative study of patient perspective. BMJ Open 9 (10), e029090.

Finderup, J., Jensen, J.D., Lomborg, K., 2020a. Dialysis Choice [cited 22/04/2024]. Available from: https://e-dok.rm.dk/edok/editor/AAUHNY.nsf/vLookupUpload/ATTACH-RMAP-BT4EF6/$FILE/Dialysis%20Choice%2027082020.pdf.

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

Geiger, F., Liethmann, K., Reitz, D., Galalae, R., Kasper, J., 2017. Efficacy of the doktormitSDM training module in supporting shared decision making - results from a multicenter double-blind randomized controlled trial. Patient Educ. Counsel. 100 (12), 2331–2338.

Giguère, A., Bogza, L.-M., Coudert, L., Carmichael, P.-H., Renaud, J.-S., Légaré, F., et al., 2020. Development of the IcanSDM Scale to Assess Primary Care Clinicians' Ability to Adopt Shared Decision-Making.

Goff, S.L., Unruh, M.L., Klingensmith, J., Eneanya, N.D., Garvey, C., Germain, M.J., et al., 2019. Advance care planning with patients on hemodialysis: an implementation study. BMC. Palliat. Care. 18 (1), 64.

Hemodialysis Adequacy 2006 Work Group, 2006. Clinical practice guidelines for hemodialysis adequacy, update 2006. Am. J. Kidn. Dis.: Off. J. Nat. Kid. Found. 48 (Suppl 1), S2–90.

International Patient Decision Aid Standards (IPDAS) Collaboration [cited 22/04/2024]. Available from: http://ipdas.ohri.ca/.

Ladin, K., Neckermann, I., D'Arcangelo, N., Koch-Weser, S., Wong, J.B., Gordon, E.J., et al., 2021. Advance care planning in older adults with CKD: patient, care partner, and clinician perspectives. J. Am. Soc. Nephrol. 32 (6), 1527–1535.

Lazenby, S., Edwards, A., Samuriwo, R., Riley, S., Murray, M.A., Carson-Stevens, A, 2017. End-of-life care decisions for haemodialysis patients – 'We only tend to have that discussion with them when they start deteriorating'. Health. Expect. 20 (2), 260–273.

Malterud, K., 2012. Systematic text condensation: a strategy for qualitative analysis. Scand. J. Public. Health. 40 (8), 795–805.

Mandel, E.I., Bernacki, R.E., Block, S.D., 2017. Serious illness conversations in ESRD. Clin. J. Am. Soc. Nephrol. 12 (5), 854–863.

Murtagh, F.E., Addington-Hall, J., Higginson, I.J., 2007. The prevalence of symptoms in end-stage renal disease: a systematic review. Adv. Chronic. Kidn. Dis. 14 (1), 82–99.

Murtagh, F.E., Ramsenthaler, C., Firth, A., Groeneveld, E.I., Lovell, N., Simon, S.T., et al., 2019. A brief, patient- and proxy-reported outcome measure in advanced illness: validity, reliability and responsiveness of the integrated palliative care outcome scale (IPOS). Palliat. Med. 33 (8), 1045–1057.

National Institute for Health and Care Excellence, 2014. National Clinical Guideline C. National Institute For Health and Care Excellence: Clinical guidelines. Chronic kidney Disease (partial update): Early Identification and Management of Chronic Kidney Disease in Adults in Primary and Secondary Care. National Institute for Health and Care Excellence, LondonUK).

Noble, H., Kelly, D., Hudson, P., 2013. Experiences of carers supporting dying renal patients managed without dialysis. J. Adv. Nurs. 69 (8), 1829–1839.

O'Cathain, A., Croot, L., Duncan, E., Rousseau, N., Sworn, K., Turner, K.M., et al., 2019. Guidance on how to develop complex interventions to improve health and healthcare. BMJ Open 9 (8), e029954.

Ottawa Hospital Research Institute. Decision support analysis tool (DSAT-10), 2015. Ottawa: the Ottawa Hospital Research Institute [cited 22/04/2024]. Available from: https://decisionaid.ohri.ca/eval_dsat.html.

Raj, R., Ahuja, K., Frandsen, M., Murtagh, F.E.M., Jose, M., 2018. Validation of the IPOS-Renal symptom survey in advanced kidney disease: a cross-sectional study. J. Pain. Symptom. Manage. 56 (2), 281–287.

Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation) [cited 22/04/2024]. Available from: https://eur-lex.europa.eu/eli/reg/2016/679/oj.

Rietjens, J.A.C., Sudore, R.L., Connolly, M., van Delden, J.J., Drickamer, M.A., Droger, M., van der Heide, A., Heyland, D.K., Houttekier, D., Janssen, D.J.A., Orsi, L., Payne, S., Seymour, J., Jox, R.J., Korfage, I.J., 2017. European Association for Palliative Care. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol. 18 (9), e543–e551.

Santana, S., Brach, C., Harris, L., Ochiai, E., Blakey, C., Bevington, F., et al., 2021. Updating health literacy for healthy people 2030: defining its importance for a new decade in public health. J. Public Health Manag. Pract. 27 (Suppl 6), S258–S264.

Sepucha, K.R., Abhyankar, P., Hoffman, A.S., Bekker, H.L., LeBlanc, A., Levin, C.A., et al., 2018. Standards for UNiversal reporting of patient Decision Aid Evaluation studies: the development of SUNDAE Checklist. BMJ Qual. Saf. 27 (5), 380–388.

Skivington, K., Matthews, L., Simpson, S.A., Craig, P., Baird, J., Blazeby, J.M., et al., 2021. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. BMJ 374, n2061.

Stacey, D., Lewis, K.B., Smith, M., Carley, M., Volk, R., Douglas, E.E., et al., 2024. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst. Rev. 1, Cd001431.

Stacey, D., Taljaard, M., Drake, E.R., O'Connor, A.M, 2008. Audit and feedback using the brief decision support analysis Tool (DSAT-10) to evaluate nurse-standardized patient encounters. Patient. Educ. Couns. 73 (3), 519–525.

Stacey, D., Volk, R.J., 2021. The International Patient Decision Aid Standards (IPDAS) collaboration: evidence update 2.0. Med. Decisi. Mak.: Int. J. Soc. Med. Decisi. Mak. 41 (7), 729–733.

Stiggelbout, A.M., Van der Weijden, T., De Wit, M.P., Frosch, D., Légaré, F., Montori, V.M., et al., 2012. Shared decision making: really putting patients at the centre of healthcare. BMJ 344, e256.

STATA version 17 [cited 22/04/2024] (2017). Available from: https://www.stata.com/new-in-stata/.

Sundheds- og ældreministeriet. [Ministry of Health] Bekendtgørelse af lov om videnskabsetisk behandling af sundhedsvidenskabelige forskningsprojekter 2017 [cited 22/04/2024]. Available from: https://www.retsinformation.dk/Forms/R0710.aspx?id=192671.

Sundheds- og ældreministeriet [Ministry of Health]. Sundhedsloven. LBK nr 191 af 28/02/2018 [cited 22/04/2024]. Available from: https://www.retsinformation.dk/forms/R0710.aspx?id=199871.

Tamura, M.K., Cohen, L.M., 2010. Should there be an expanded role for palliative care in end-stage renal disease? Curr. Opin. Nephrol. Hypertens. 19 (6), 556–560.

Toft, B.S., Rodkjaer, L., Andersen, A.B., de Thurah, A., Nielsen, B., Nielsen, C.P., et al., 2022. Measures used to assess interventions for increasing patient involvement in Danish healthcare setting: a rapid review. BMJ Open 12 (12), e064067.

Veenendaal, H.V., Chernova, G., Bouman, C.M., Etten-Jamaludin, F.S.V., Dieren, S.V., Ubbink, D.T., 2023. Shared decision-making and the duration of medical consultations: a systematic review and meta-analysis. Patient Educ. Couns. 107, 107561.

Winterbottom, A., Bekker, H.L., Mooney, A., Russon, L., Hipkiss, V., Williams, R., et al., 2020. A Dialysis and Conservative Care Decision aid: Living With Kidney disease. (the YoDCA Study Booklet). University of Leeds, Leeds.

Witteman, H.O., Maki, K.G., Vaisson, G., Finderup, J., Lewis, K.B., Dahl Steffensen, K., et al., 2021. Systematic development of patient decision aids: an update from the IPDAS Collaboration. Med. Decisi. Mak.: Int. J. Soc. Med. Decisi. Mak. 41 (7), 736–754.

World Medical Association, 2013. Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA 310 (20), 2191–2194.