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A qualitative evaluation of a shared decision-making intervention for dialysis choice

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A qualitative evaluation of a shared decision-making intervention for dialysis choice

Jeanette Finderup^{1,2}, Jens Dam Jensen^{1,2}, Kirsten Lomborg²

Department of Renal Medicine, Aarhus University Hospital, Denmark

² Department of Clinical Medicine, Aarhus University, Denmark

Corresponding author

Jeanette Finderup, Department of Renal Medicine

Aarhus University Hospital

Palle Juul-Jensens Boulevard 99

8200 Aarhus N

Denmark

Phone: +4578452525

Email: jeajee@rm.dk

Keywords

Shared decision-making, patient decision aid, complex intervention, qualitative evaluation

Abbreviations

HD: Haemodialysis

PD: Peritoneal dialysis

SDM: Shared decision-making

SDM-DC: Shared decision-making and dialysis choice

PDA: Patient decision aid

IPDAS: International Patient Decision Aids Standards

OPDG: Ottawa Personal Decision Guide

Abstract

Background

At Aarhus University Hospital we have developed an intervention based on shared decision-making for patients facing a choice of dialysis modality. The decision is between haemodialysis (HD) and peritoneal dialysis (PD), either performed by patients on their own or with help from a healthcare professional. The intervention is supposed to be tailored to individual patients and consists of three meetings with a dialysis coordinator who introduces a patient decision aid named 'Dialysis Choice' to the patient. The intervention, 'Shared decision-making and dialysis choice' (SDM-DC), has been implemented at four different hospitals in Denmark.

Aim

The aim of this study was to evaluate how the SDM-DC intervention influenced patients' experiences of involvement in their choice of dialysis modality and to investigate how and why the intervention works.

Methods

We conducted semi-structured individual interviews with 29 patients using systematic text condensation for data analysis.

Findings

The four main findings were: my own choice; the meetings contributed to the decision process; 'Dialysis Choice' contributed to the decision process; and the decision process was circular and iterative.

Conclusion/application for practice

The patients experienced the SDM-DC as involving them in their choice of dialysis modality. Due to the circular and iterative properties of the decision-making process, a shared decision-making intervention for dialysis choice needs to be adapted to the needs of individual patients. The active mechanisms of the meetings with the dialysis coordinator were: 1) questions to and from the patient; and 2) the dialysis coordinator's dissemination of exact knowledge about the options. The overview of options and the value clarification in the decision aid particularly contributed to the decision-making process based on informed preferences.

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Strengths and limitations of this study

- Data richness was established by interviewing 29 patients. The interviews lasted on average 50 minutes with an information load of 23 normal pages on average.
- SDM-DC seems to be the first intervention based on the ‘three-talk model’, which is a well cited SDM model.
- The whole research process has involved patients and users.
- The research only included Caucasian patients born in Denmark, and the findings are therefore limited to ethnic Danish patients.
- One of the developers of the intervention performed the interviews, but this challenge has been addressed in different ways.

Introduction

Patients with kidney failure must make a decision regarding dialysis modality, either haemodialysis (HD) or peritoneal dialysis (PD). Based on research, one modality is not uniquely better than the other (1-3). In order to offer the modality best suited to a patient's daily life, international guidelines recommend involving the individual patient in the decision-making process, thus basing the decision on the patient's preferences (3). However, patient involvement does not always happen (4-6). For example, two studies from the USA showed that only 13% of patients experienced the decision process as shared decision-making (SDM) (7) and that patients above the age of 65 years did not experience the decision as a shared one (8). More recent studies indicate improvements. A study from the UK that included routine measures of patient involvement at 27 different nephrology departments found that 69% of patients experienced SDM (9).

Based on SDM for dialysis choice, we developed and pilot tested an intervention called ‘Shared decision-making and dialysis choice’ (SDM-DC) with the purpose of involving patients and their relatives in the decision-making process (10). In this article, we document the patients’ perspective on using the SDM-DC intervention at four different hospitals in Denmark.

Background

A study regarding patient involvement and dialysis choice suggested that SDM could improve patients’ experiences of involvement (11). A Cochrane Review indicated that an intervention based on SDM and supported by a patient decision aid (PDA) increased patients’ experience of

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4 involvement (12). Another Cochrane Review regarding PDAs showed middle quality of evidence
5 that PDAs increase the proportion of people who are active in decision-making (13).
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7 The SDM-DC intervention was developed in 2015 and thereafter described and pilot tested (10). It
8 includes a PDA, named 'Dialysis Choice', and is designed for patients with kidney failure who must
9 make a decision regarding future dialysis mode: HD or PD. SDM-DC is structured according to the
10 'three-talk model' (14) and consists of three meetings between the patient and his or her relative(s)
11 and a dialysis coordinator. The dialysis coordinators need to be trained to deliver the intervention
12 based on tailoring (15) and using three different communication skills: mirroring, active listening
13 and value clarification (16-18). The PDA is designed to be utilised both at and between the
14 meetings with individual patients and relatives who may be joining them. Two videos with personal
15 stories are available to be shown and discussed at the meetings if the patient has need of a personal
16 story. Patients and healthcare professionals have been a part of the development process of the
17 intervention and the PDA (19). The decision aid is based on a systematic literature search where
18 possible. The PDA is in paper format and has been published at <https://decisionaid.ohri.ca/>. We
19 have completed an assessment according to the International Patient Decision Aids Standards
20 (IPDAS) (20). The PDA consists of a set of tools: a decision map, an overview of uremic
21 symptoms, an overview of options and the Ottawa Personal Decision Guide (OPDG) (21-22). The
22 pilot test documented that SDM-DC was useful in encounters between individual patients and a
23 dialysis coordinator at a Danish university hospital but that further research was needed to gain
24 insight into the patients' experiences of involvement and the implications for their choice of dialysis
25 mode (10).
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42 **Aim**

43 The aim of this study was to evaluate how the SDM-DC intervention influenced patients'
44 experiences of involvement in their choice of dialysis modality and to investigate how and why the
45 intervention works.
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Methods

This study is part of larger study evaluating the complex intervention SDM-DC (23-24). As recommended for complex interventions (25-27), we first conducted a qualitative evaluation. Since October 2016 the intervention has been delivered at four hospitals in Denmark by six different dialysis coordinators. The inclusion criteria for the intervention were adult patients with chronic kidney disease referred to a department of renal medicine with an eGFR below 20 ml/min measured by a 24-hour urine test. Exclusion criteria were patients who had decided on palliation, patients with a living donor and a set date for transplantation, and patients not able to participate due to cognitive impairment. The use of an interpreter was not an exclusion criterion.

Patient and user involvement

Patients and users have been involved in the whole research process (28-30) through an advisory board consisting of six dialysis coordinators and two patients. The two patients have not been part of the intervention but are part of the target group for the intervention. The first author and the advisory board have met every six months during the research process. For this study, the advisory board have especially contributed to the validation of the themes and inspiration for the discussion.

Data collection

We collected data through individual interviews with patients after they had participated in SDM-DC. We conducted interviews between 1 February 2017 and 8 August 2018. The patients were included consecutively after receiving the intervention. The interviews took place between 14 days and 42 days after the intervention. 59 patients were invited for interviews, 33 patients accepted the invitation, but 4 patients were not able to participate due to their medical condition worsening. The patients decided on their own where the interview should take place and if their relatives were to participate or not. The first author, who does not perform the intervention, conducted the interviews. The individual interviews were conducted according to Kvale and Brinkmann (31) with a semi-structured interview guide. The purpose of the individual interviews was to gain a clear insight into how the patients experienced the impact of SDM-DC on their involvement in the decision-making process. The key elements in the 'three-talk model' (14) informed the content of the interview guide, which was structured chronologically around the first talk, the second talk, the third talk and decision support, from initial preferences to informed preferences and the decision. We adapted the

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4 interview guide for each interview according to how the patient, prior to the interview, had
5 answered two questionnaires: SDM-Q9 (32) and DQM (33). During the 29 interviews, the first
6 author did some primary analysis, writing down some preliminary themes. These themes were
7 chased in interviews that followed with the next patients. During the interviews, the communication
8 skills of mirroring and active listening were used (16-17). In the first part, mirroring was used to
9 bring patients' experiences to the forefront. Active listening, like retelling the patient's story,
10 allowed patients to adjust the story if they wished. At the end of every interview, the interviewer
11 summarised the patient's story so the patient could comment on this summary. The purpose of the
12 interviews was not to question the decision the patient had made or to convey knowledge. One
13 patient was emotionally moved by the interview and was offered a new meeting with the dialysis
14 coordinator.

25 *Ethical considerations*

26 Participation in the intervention was based on consent for care and treatment. According to Danish
27 legislation, this type of research is exempted from ethical approval. The Danish Data Protection
28 Agency (jr. 1-16-02-456-16) approved data management. We obtained written consent from
29 patients before their participation in the interview.

35 *Data analysis*

36 To achieve a well-considered and well-documented analysis, we used a four-step systematic text
37 condensation (34-35). The interviews were recorded and transcribed verbatim before data analysis,
38 and the software program NVivo 11.0™ (36) was used for data management of all procedures, the
39 first naïve reading of all interviews exempted. The procedure included a naïve reading to generate
40 some preliminary themes. This step was done continuously during the period of interviewing and
41 made the huge amount of data more manageable (34-35). The other authors and the advisory board
42 discussed the preliminary themes, leading to some changes. All the interviews generated a word
43 cloud of the 50 most used words with six or more characters to identify some other preliminary
44 themes. Thereafter, we constructed meaningful units in groups of codes. A validation process then
45 reorganised the codes. Some codes with few sources and references were elaborated or merged
46 together with other codes, unless the code covered an important aspect of some patients'
47 experiences of the intervention. The NVivo 'Text search query' found meaningful units that had
48 been overlooked, and the 'Matrix coding query' stated if one code could be attributed to some
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4 characteristic within the interview situation or the interview person. The findings will only mention
5 differences in attributes between the interview situation and the interview person. The next step was
6 condensation of the meaningful units of interest for the aim of the study. This procedure was carried
7 out as 'Memos' in NVivo. All references for every source were condensed and written in the first
8 person and present tense to represent each participant's story about this specific code. The procedure
9 included a form of validation where certain meaning units were recoded because they did not fit
10 into the first chosen code. The last step consisted of a transcription of findings in accordance with
11 the final category headings and codes. All the condensed texts for each code were aggregated into
12 one text and formulated in the third person and past tense. We found a quotation to illustrate each
13 description and reworded codes into meaningful sentences. Some of the codes were subordinated
14 under a common category heading as presented in the findings below.

25 Findings

26 Table 1 shows the characteristics of the 29 patients who participated in the interviews. The variation
27 in the sample was close to the total sample for the intervention according to gender, age, hospitals,
28 dialysis coordinators and the choice of dialysis mode. The interviews lasted on average 50 minutes,
29 ranging from 26 to 73 minutes, with an information load at 670 normal pages in total, and 23
30 normal pages on average. Fifteen interviews were conducted at the hospitals and 14 in patients'
31 homes. Eight patients chose to participate in the interview together with a spouse, and 21 were on
32 their own.

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40 Table 1. Characteristics of the participants

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44 Table 2 gives an overview of the category headings, codes and chosen quotations. Number of
45 sources and references for each code are also stated in Table 2. The category headings are marked
46 with bold in the text, and the codes are marked with italics. The numbers in square brackets are the
47 identification numbers of the participants.

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52 Table 2. An overview of the findings and chosen quotations

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56 **'My own decision'** was stated by 28 patients in different ways. Some of the patients stated that they
57 had made their decision together with their relatives; others stated that their relatives had not
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4 influenced their decision. Some patients stated that their relatives agreed with their decision. The
5 healthcare professionals had not made the decision even though the dialysis coordinator had
6 contributed to the decision process. For several patients, it had been important that the healthcare
7 professionals had confirmed their decision. One patient did not express directly that the decision
8 was his own [2]. This patient was over the age of 80, and the focus for his decision process was to
9 go on dialysis or not. Several patients stated that it was important that the decision was their own
10 because they thought it made the decision easier to accept. None of the patients experienced being
11 left alone with the decision process.
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20 *Other decisions.* Most of the patients had lived with disease for a long period. Most of them had
21 never before experienced being involved in a decision about their treatment. Most of the patients
22 felt that there had been no decision at all to previous treatments. A few patients had experienced
23 participating in a decision about treatment before, but mostly, they experienced that the healthcare
24 professionals regarded the patients' involvement as unwelcome interference. They wished that the
25 healthcare professionals had invited them to take part in the decision process and communicated
26 some knowledge to them, to enable them to participate.
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34 **The meetings contributed to the decision process.** All 29 patients reported that the meetings with
35 the dialysis coordinators had contributed to the decision process and that they would not have been
36 able to make the decision on their own without the meetings. The patients emphasised the calm at
37 the meetings as being significant. They felt they had time to go into the decision process in depth.
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42 *Questions to and from the patient* were emphasised by most patients as a significant property of the
43 meetings. There was no relation to demographic, gender, age, or the dialysis coordinator. Questions
44 to the patients addressed the impact of the decision on the patients' everyday life. The patients
45 experienced that these questions were asked in a nice and easy way. Questions from the patients
46 were concerned with practical issues. The patients felt confident to ask the same questions several
47 times.
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54 *Exact knowledge was helpful for the patient.* Some of the patients emphasised that knowledge
55 communicated by the dialysis coordinator had been helpful in the decision process. They stated that
56 the knowledge communicated should be detailed, exact, and appropriate to the patients' life and that
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4 knowledge had to be repeated. Two patients [2, 7] expressed that some of the knowledge
5 communicated by the dialysis coordinator had not been helpful; this appeared to be when the
6 dialysis coordinator communicated too much knowledge at one meeting.
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11 *Bringing a relative into the meetings contributed to the decision process.* This was emphasised by
12 most of the patients. They had chosen to bring a relative to be part of the meetings, most often a
13 wife or husband but in some cases a daughter and son-in-law or a friend. Bringing a relative to the
14 meetings was mentioned as “a habit”. These participants were used to bringing a relative for
15 important meetings at the hospital and expressed that “being two” gave them the possibility of
16 asking more and different questions. They further emphasised the benefits of there being two people
17 to listen. A few patients [6, 11, 17, 19, 29] did not bring a relative to the meetings. These patients
18 explained that they did not have a significant other in their lives or that their significant others were
19 too ill to participate in the meetings.
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28 **The decision aid contributed to the decision process.** All 29 patients expressed that they could
29 not have made their decision without help from the decision aid. The patients talked about the PDA
30 as one tool and only mentioned two of the tools within the PDA specifically: overview of options
31 and OPDG. Some of the patients mentioned the two videos, and they also mentioned other patients
32 although other patients are not an integrated part of the intervention.
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39 *'Overview of options' contributed to the decision process.* This was expressed spontaneously by
40 most of the patients. The tool had clarified or confirmed their decision. They had used the tool
41 during the conversation, but also after the conversation and in preparation for the next meeting.
42 Several patients stated that they had saved the tool and continued to use it.
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47 *'OPDG' contributed to the decision process.* Most of the patients stated spontaneously that the
48 OPDG was particularly valuable. Several patients indicated specifically that this tool had
49 contributed to the decision process and elaborated that the questions in the tool had enabled
50 reflection, in particular the part in which they write down the pros and cons. Some patients had
51 filled in the tool before the meeting, and others received help at the meeting to complete it.
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4 *The videos contributed to the decision process for some patients.* Some patients used positive words
5 in their description of the videos. One patient reported that the videos had helped him change his
6 decision [25], one reported that the videos had removed his concern about dialysis [19], and one
7 that they had given some concrete pictures of how dialysis takes place [13]. Three patients used
8 positive words about the videos but stated explicitly that the videos had not contributed to their
9 decision process [3, 4, 7]. One patient used negative words about the videos [16]. This patient had
10 made a decision before seeing the videos and would have preferred the videos to have a more
11 practical focus.
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20 *Other patients contributed sometimes with somewhat to the decision process.* In the sample, some
21 patients had met other patients on dialysis. For some of the patients, this meeting with other patients
22 on dialysis had contributed to the decision process, but several of these patients [3, 11, 22, 25, 27]
23 did not choose the same option as the patient they had met. Several of the patients did not know
24 why the patient they had met had chosen as they had. Other patients had contributed to the decision
25 process by making dialysis more concrete and presenting possibilities. For some of the patients, it
26 had been scary to meet other patients on dialysis.
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34 **The decision process was circular and iterative.** Only one patient did not mention the decision
35 process at all. This patient did only have one possible dialysis modality. Four patients stated that
36 they had made their decision before the meetings, but all four patients had their decision qualified
37 during the meetings. Nine patients experienced that their decision was made during the meetings.
38 One of these patients had made one decision before the meetings and changed his decision during
39 the meetings. Eight patients experienced that their decision was made concrete at a meeting. Two
40 patients made their decision at the first meeting, three patients made their decision at the second
41 meeting, and three patients made their decision at the third meeting. Figure 1 gives an overview of
42 when the patients experienced the decision to be made.
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51 Figure 1. Overview of when the patients experienced the decision to be made
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54 Nearly all participants experienced the decision process as circular and iterative. Although they had
55 made a decision, they still needed to confirm this decision, to ask questions, and to reconsider it.
56 There was not only one option suitable for each patient, but several patients decided one option to
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4 start with (plan A) and then they had a plan B or C.
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8 *Dialysis choice came as a shock* for half of the patients, although they have been followed in the
9 departments for renal medicine for several years. That dialysis could be an actual treatment for them
10 occurred to the patients just before the meetings or during the meetings. Some of the patients knew
11 that dialysis could be an option someday, but they had ignored this knowledge and thought it was
12 not going to happen for them. One of the patients [10] was happy not to receive this knowledge
13 previously, but two of the patients [12, 23] stated that they would have preferred to have known it
14 earlier. One patient [13] stated that he would have preferred to receive this knowledge in a nice and
15 easy way. It was harsh for the patients to receive this knowledge at this stage of their disease.
16 Surprisingly, no correlation has been found between eGFR and dialysis choice appearing as a
17 shock. Rather, it appeared to be experienced as a shock more often by patients at two of the
18 hospitals compared to those at the other two hospitals.
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28 *Received new knowledge during the interview.* Some patients received new knowledge of the
29 significance of the decision about dialysis modality during the interview. It was not the intention for
30 the interviewer to interact with the intervention, but the patients asked some questions, and the
31 interviewer tried to answer these questions briefly. The knowledge disseminated did not change
32 their decision. One patient had doubts after the interview and needed one more meeting. This extra
33 meeting did not change her decision [27].
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40 *Not sure it was the right decision* was expressed by five patients. At the same time, they said that
41 there was nothing we could do to make them more secure about the decision. They stated that they
42 thought this certainty first appeared when they started dialysis.
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47 *Preferred not to receive dialysis* was expressed by some of the patients. They preferred not to
48 receive any dialysis treatment and characterised the options as a choice between two evils
49 associated with several problems and a loss of their present life. These participants still hoped to
50 recover and no longer be in need of dialysis.
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56 *'No dialysis' was not an option* was considered by some of the patients. This code was mainly found
57 among patients over the age of 80 years. These patients over the age of 80 years had still something
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4 to live for. Some stated that if their spouse died, they would reconsider their decision and perhaps
5 choose 'no dialysis'. Most of the patients stated that they had considered these issues on their own,
6 but they had shared their consideration with the healthcare professionals.
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10 11 **Discussion**

12 In summary, the patients experienced the decision to be their own, but both the meetings and the
13 PDA had contributed to the decision-making process. They experienced the decision-making
14 process as circular and iterative. The discussion is divided into three sections. The first two sections
15 correspond to the aim and the last section focuses on limitations.
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20 21 *How the SDM-DC intervention influenced the patients' experiences of involvement*

22 The purpose of the intervention was to involve patients in the decision-making process. **'My own**
23 **decision'** was a significant finding, and this finding demonstrates that the patients experienced the
24 SDM-DC as involving them in the decision-making process. The pilot test of SDM-DC indicated
25 this finding, because some of the patients did not experience the decision as a shared decision, but
26 their own decision (10). This finding was surprising due to the age of the patient group and
27 compared to a study focusing on the involvement of the age group over 65 years old (37). A
28 decision experienced as **'my own decision'** indicates an internally motivated decision which,
29 according to the self-determination theory of Ryan and Deci is stronger than an externally
30 motivated decision because it is associated with interest/enjoyment (or in the case of dialysis less
31 discomfort) and inherent satisfaction (38). According to this self-determination theory, all human
32 beings are motivated by three basic needs: autonomy, competence, and relatedness, and the more
33 these three needs are satisfied, the better the chance of achieving intrinsic motivation (38). Applying
34 this empirical research-based assumption to the SDM-DC intervention offers an explanation for
35 how and why the intervention works. Relatedness was supported by the meetings with the dialysis
36 coordinator and the participation of patients' relatives. The competence of the patients was
37 supported by the decision aid and the exact information at the meetings. Autonomy was supported
38 by the value clarification provided by the OPDG and the feeling that the decision was based on the
39 patients' preferences. Intrinsically motivated decisions may influence how the patients cope with
40 starting dialysis and how the patients experience being on dialysis. Another study about dialysis
41 choice has shown that patients who have experienced being involved in the decision-making
42 process about dialysis choice were more satisfied with their dialysis modality (37). We found the
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4 decision process to be circular and iterative. SDM-DC is based on the ‘three-talk model’ by Elwyn
5 et al (14). The simple version of the ‘three-talk model’ presents the SDM process as linear. The
6 model suggests that patients go into the decision-making process without any decisions and finish
7 the process with a decision. In 2017, the ‘three talk model’ was updated and is no longer presented
8 as a linear model, but a circular one (39). Both models have their advantages. In clinical practice, it
9 is easier to implement an intervention based on the linear model with clear progression through the
10 process. It is, however, worth noting that the SDM-DC seems to be the first intervention to apply
11 the ‘three-talk model’ in the linear version (39). The model has been cited several times but only for
12 presentations, workshops, and training programmes. A Canadian study found five phases in the
13 decision-making process regarding dialysis choice: 1) progress toward acceptance to be dialysed; 2)
14 receive information; 3) take some time for personal reflection; 4) seek the opinion and support of
15 others; 5) re-evaluate one's choice (40). SDM-DC was not developed based on this knowledge, but
16 our evaluation showed that most of these phases have been met by the intervention.
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28 *How the SDM-DC intervention works and why*

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30 The patients stated two important elements of the meetings: 1) questions to and from the patient;
31 and 2) the dialysis coordinators’ dissemination of exact knowledge about the options. The fact that
32 daily life with dialysis needs to be described as concretely as possible has been documented
33 previously (41). The patients experienced the participation of their relatives in the meetings as an
34 advantage. This finding is in accordance with a study of the perspective of the relative, showing that
35 relatives felt involved in the decision-making process and that they had an important supportive role
36 (42). The dialysis coordinator provided decision coaching as part of the SDM process. The
37 definition of decision coaching is ‘*individualized, nondirective facilitation of patient preparation*
38 *for shared decision-making*’ (43). In spite of this, the decision was made together with the dialysis
39 coordinators at the meetings and not afterwards with the physician. Decision coaching has, in other
40 studies, been shown especially to improve knowledge and the involvement of the patient in
41 decision-making (43). The whole PDA ‘Dialysis Choice’ contributed to the decision-making
42 process, but the overview of options and the OPDG were particularly identified as helpful by the
43 patients. An Option Grid is a specific type of overview of options, and research has shown that, for
44 some health decisions, an Option Grid supports patients in the decision-making process (44). From
45 a healthcare perspective, the Option Grid has been found to be easy to use for patient involvement
46 in the decision-making process (45). In general, Option Grids have proven beneficial for sharing
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4 information but less useful for value clarification (46). In the Cochrane Review regarding PDAs,
5 value clarification is defined as an important part of a PDA and SDM (13). Some of the patients in
6 our study decided to use the overview of options as a sort of value clarification, but the OPDG is
7 intended for reflection on their own and with their relatives. The combination of the overview of
8 options and the OPDG appears to be a good one. In the development of our intervention and the
9 PDA, we tried to meet all the decision needs described for this patient population (11, 40, 47–49),
10 but this study added some more decision needs for this patient population: the decision appeared as
11 a shock for the patient; there is not only one choice but a plan A, B and C. These needs should be
12 implemented into an SDM intervention for dialysis choice. The impact of stories on patient
13 decision-making has been unknown (50). The patients in our study felt the videos were not as
14 unequivocally positive as the decision aid. Nor was knowing other patients on dialysis an
15 unequivocally positive finding. Sometimes, other patients contributed to the decision-making
16 process somewhat. The use of narratives in decision aids has been a focus in the IPDAS
17 collaboration since the beginning (20). An experimental study has shown that patients more likely
18 to choose a dialysis modality presented by a patient rather than a healthcare professional, why it
19 have been recommended caution using patient stories (48). It seems that the patients in our study
20 used the videos and other patients more as inspiration and less as direction, thus complying with the
21 purpose of SDM to establish a decision process based not on uninformed preferences but based on
22 informed preferences (14). How the intervention has contributed to this need to be investigated
23 further.
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40 *Limitations*

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42 This study has some limitations. For a qualitative evaluation, 29 patients is a relatively large
43 number of participants. This number was chosen to give the right information power (51), because
44 the intervention was performed at four different hospitals, by six different dialysis coordinators, and
45 the patients had to decide between four different options. Only Caucasian patients were included,
46 and the findings are therefore limited to ethnic Danish patients. If we had included some ethnically
47 non-Danish patients, the findings could have taken other directions. This is indicated by a study
48 showing that Japanese patients are making decisions that are more consistent with their network's
49 wishes and preferences (52). One of the developers of the intervention carried out the interviews,
50 and this is mentioned by Malterud as a point to pay attention to (34). We managed this challenge in
51 different ways: 1) the interviewer did not perform the intervention; 2) the patients did not know that
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4 the interviewer had developed the intervention; and 3) the findings were discussed with the advisory
5 board. Further, the patients expressed criticism of the intervention during the interviews. The
6 interviews were performed at least two weeks after the intervention. Thus, some memory failure
7 may have occurred since patients with an eGFR below 20ml/min may have cognitive deficit and
8 short memory (53). We assume that the patients have a better memory of the last meeting than the
9 first meeting. We do not yet know the extent to which the intervention has been performed as
10 intended. In the sample, we found two patients who had filled out the OPDG, but the dialysis
11 coordinators had not used the homework during the meetings. The dialysis coordinators, who are
12 part of the advisory group, later explained that they found the OPDG difficult to use in the
13 beginning.

23 **Conclusion**

24 The patients experienced the SDM-DC as involving them in their choice of dialysis modality. Due
25 to the circular and iterative properties of the decision-making process, a shared decision-making
26 intervention for dialysis choice needs to be adapted to the needs of individual patients. The active
27 mechanisms of the meetings with the dialysis coordinator were: 1) questions to and from the
28 patient; and 2) the dialysis coordinator's dissemination of exact knowledge about the options. The
29 overview of options and the value clarification in the decision aid particularly contributed to the
30 decision-making process based on informed preferences.

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41 provided the interventions. The authors thank the advisory board and the informants for
42 participating in this study.

48 **Conflicts of interest**

49 The authors declared no potential conflicts of interest with respect to the research, authorship,
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5 Association, and the Danish Nurses Organisation.
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9 **Contributorship**

10 JF: Designed the project, collected and analysed data, and drafted the final manuscript.

11
12 JDJ and KL: Provided academic supervision, helped to draft the manuscript, and read and approved
13 the final manuscript.
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16 **Data sharing statement**

17 No additional data are available.
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For peer review only

Table 1. Characteristics of the participants

	The intervention Sample (n=349)		The study Sample (n=29)	
	n	%	n	%
Sex				
Female	121	35	8	28
Male	228	65	21	72
Age				
20–30	7	2	0	0
30–40	10	3	0	0
40–50	21	6	3	10
50–60	45	13	10	35
60–70	82	23	11	38
70–80	124	36	5	17
80–90	54	15	0	0
90+	6	2	0	0
eGFR ml/min				
0–5	8	2	3	10
5–10	74	21	19	66
10–15	153	44	7	24
15–20	91	26	0	0
20–25	20	6	0	0
25–30	3	1	0	0
Kidney school				
Yes	102	29	9	31
No	247	71	20	69
Decisions				
Home haemodialysis	27	8	4	14
Peritoneal dialysis	212	60	17	58
Assisted peritoneal dialysis	16	5	2	7
Dialysis at hospital	86	25	6	21
No decision	8	2	0	0
Number of meetings				
4	4	1	0	0
3	41	12	10	34
2	214	61	17	59
1	90	26	2	7
Hospitals				
Aarhus	180	52	12	41
Hilleroed	60	17	8	28
Holstebro	53	15	7	24
Soenderborg	56	16	2	7
Dialysis coordinator				
KB	60	17	8	28
AS	98	28	8	28
DK	31	9	4	14
JR	82	23	4	14
LB	22	6	3	9
RS	56	16	2	7

Table 2. An overview of the findings and chosen quotations

The quotations have been translated into English as accurately as possible. The category headings are marked with bold in the text, and the codes are marked with **italics**. The numbers in square brackets are the identification numbers of the participants.

Category headings	<i>Codes</i>
<p>My own decision (28 sources & 66 references)</p> <p>At the first meeting, my son and daughter-in-law were with me. And when we drove home, we did not talk much about it. I let a few days pass and I thought, "Let them just go and... They should also have time to think a little, and I should have some time to think what I was going to say at the next meeting and all..." Then I talked to them. Then I asked, "What would you choose after the first meeting?" They would choose dialysis at the hospital. Then I said, "Well, it's funny that you say that because that's what I've decided, that's how I want it to be." I've decided this myself, and I think it's a good thing that it's not just the hospital saying what I'm going to do. I hope, because I have decided this myself, I must make the best of it when it can't be any different. Rather than saying that we have just decided this over your head and then say, "Oh, it's so annoying that they make the decisions." There is no one to blame if I think it's a bad decision. Only myself anyway. It is already hard enough. It's my own decision. I actually think it's quite important that you make the decision yourself. I'm old enough to do that. I have not been good at saying no before, but... It's my life and it's my choice and that's how it should be. [16]</p>	<p><i>Other decisions</i> (14 sources & 28 references)</p> <p>Well, that's probably the first time I've participated in a decision about my illness and treatment. I had an operation on my throat, and I was just told how it should be and when it should be. So I just had to show up. So far, I have just been to see my doctor to get to know how my illness was developing. I get medicine, but I have not been a part of that decision. I have no background for knowing anything about it, but [in this situation] I have done so. Well, I don't know. I would not have been surprised if you had just decided what to do, because the doctors usually decide everything. And I wouldn't know I had other options. [8]</p>

<p>The meetings contributed to the decision process (29 sources & 95 references)</p> <p>If I should have done it [made a decision], without the meeting, it would have been hard. Because then I had to read about it and I would really not understand a thing. I would not be able to see myself [which decision is right for me]. Now, the dialysis coordinator like explained the different scenarios to me. And it's in light of this I said that I want P-dialysis. She [the dialysis coordinator] supported this – "I think this is right for you," she said. So no, no, it's my own decision – 100%. [10]</p>	<p><i>Questions to and from the patient</i> (21 sources & 39 references)</p> <p>She [the dialysis coordinator] actually puts the questions she has to ask in a nice way. Not like a chainsaw. In a nice way. And I also think she manages to get some answers from people. When she does it like that. I'm not an open person, I keep things to myself, and people have to lure things out of me. Her questions make me think about things. It gives me peace of mind to get rid of what I'm thinking about. I want to know what it is, and it must be reliable, what I'm told. And I always think I've received an answer. Because... that's life. Life has taught me that if I do not ask, I don't get any answers. Here, she asked her questions, because it was unfamiliar territory. I'm on shaky ground. I had the question, "Why is it HD you want, and why is it not PD?" Then we talked about the differences. Well, what happens in my everyday life if I choose HD and what happens if I choose PD. And I know that with PD, I can have some equipment I can take around with me. [13]</p> <p><i>Exact knowledge was helpful for the patient</i> (12 sources & 20 references)</p> <p>It was positive to have the meetings with XX [a dialysis coordinator]. Because she told me a lot. And she had an answer ready when I asked. And I'm sorry to say, but some of them [other healthcare professionals], I call them circus clowns. They say "Ah, well..." and "I have to look into that" and "I will be back with an answer" and stuff like that. But XX [a dialysis coordinator], she did not act in that way. I asked and then she had the answers right at hand. [12]</p> <p><i>Bringing a relative into the meetings contributed to the decision process</i> (24 sources & 75 references)</p> <p>Well, it has meant a lot to me that my wife was with me at the meetings because we were able to talk about it afterwards. She is my extra pair of ears. I have some problems with hearing. It is nice to have somebody there with you, because you get emotional sometimes. So she's not just there because of my bad hearing. The information at the meetings gets me started thinking, I get emotional, and then I don't listen that well. We are in such a vacuum at the moment, waiting to get started with a new part of our life. It is primarily me, but of course also her. It affects everybody in our household. [13]</p>
<p>The decision aid contributed to the decision process (29 sources & 70 references)</p> <p>But when you sit there starry-eyed and don't know anything, it [the decision aid] can help a lot. Also that you get more information about it [the decision]. [1]</p>	<p><i>'Overview of options' contributed to the decision process</i> (18 sources & 28 references)</p> <p>The further we went down the list with options, the more it became clear to me that I want P-dialysis. That's what I want. That's the solution that suits my life and my need for freedom best. I think the different colours will do something for me. I heard what she told me, read the chart, saw the different colours when she pointed at them, it meant something to me. [3]</p> <p><i>'OPDG' contributed to the decision process</i> (15 sources & 25 references)</p> <p>We were in a state of rebellion. We were a bit confused. Because we were not really aware of what was happening or should happen or what could happen. But then we worked with it at home and talked about it. We had a home assignment that we went through together. The assignment made us arrive at this decision. I think it made us compare the different options. It gave us an overview because we could compare pros and cons. [23]</p> <p><i>The videos contributed to the decision process for some patients</i> (14 sources & 17 references)</p> <p>The best thing about it was the short video with the man who had lived with P-dialysis for 11 years, and it's obvious that he would rather live with dialysis than not live at all. And that kind of helped. He apparently seemed to be doing well.</p>

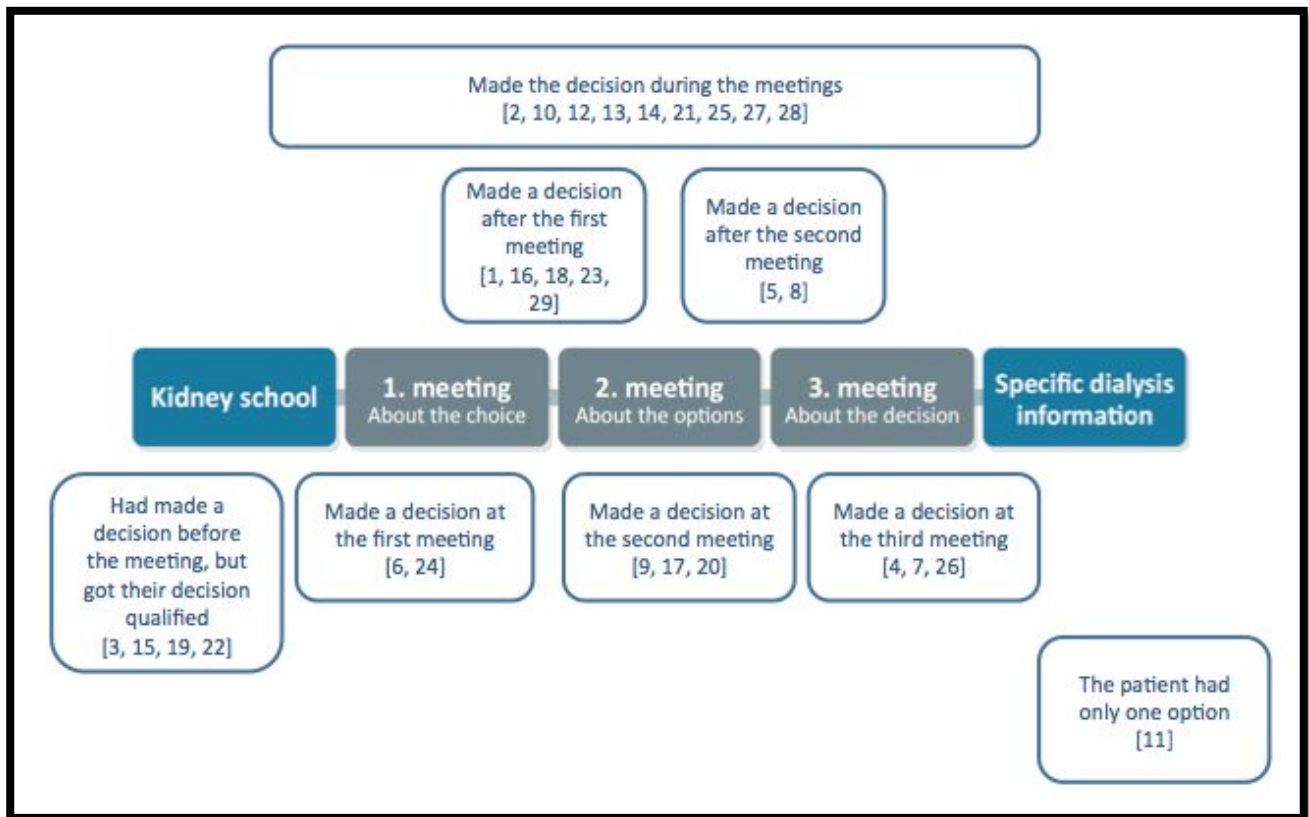
	<p>He seemed happy and satisfied. It helped me a lot, because I sometimes worry. I'm a little afraid of dialysis. It's a big deal to me and then... It was really good, because it made me less concerned about what it [dialysis] really would be, or it actually made my concern disappear. [19]</p> <p><i>Other patients contributed sometimes with somewhat to the decision process</i> (13 sources & 38 references)</p> <p>I probably had some reservations from the start. Because I was hospitalised in April last year, and I was with a guy on P-dialysis. He participated in biker meetings, and sometimes, he just had P-dialysis and then he went out [biking] again. And if he could do it, so could I with my hobby as a dog trainer. I would also do it in that way. I got an impression of freedom he had. I didn't think so much about going on dialysis myself. But I saw it as a good experience, and something was good, and the treatment was good. [8]</p>
<p>The decision process was circular and iterative (28 sources & 140 references)</p> <p>So we have had the number of meetings we think we needed. But we don't know yet. The difficult thing here is that we are talking about something we imagine. It's like a trip we're going on. Then you have some expectations, but you don't know where it really ends. It's like when we start this, we'll get to know something, and it's great, what we are told, but we don't know if there will be any questions along the way, and there will automatically be. Afterwards, we have the experience, we bought the trip or we have been on it. I have become more sure of it [my decision], after the meetings, that is. At the kidney school, they told me it should be PD, or perhaps, but without deciding, but it was the decision I was more likely to make. And then after those meetings, I realised that it should be PD. So, I made a decision, right. [5]</p>	<p><i>Dialysis choice came as a shock</i> (14 sources & 48 references)</p> <p>You have had diabetes for about 15 years; you haven't thought that it would mean that your kidneys failed at some point and that you have to have dialysis. [Interviewer] You thought then that you might lose a leg, but then I thought I haven't smoked since 1981. But I haven't thought about the kidneys. She told me that now it's time for dialysis or transplantation. It was a shock, I admit – like out of the blue. I was pretty shaken. And now, you have seen what kind of options you have and what the next step is... I decided at the third meeting because it was new to me and it was kind of a shock. It felt like the rug being pulled from under my feet. [26]</p> <p><i>Received new knowledge during the interview</i> (11 sources & 35 references)</p> <p>Really good. Well, I'm already much more informed. [17] And I should not tell you anything today, I just want to listen. It is you who should tell me something. [Interviewer]</p> <p>-----</p> <p>So, and then they say that, in the end, you can't pee. Well, now, what is that about? So, I can't imagine it, not being able to pee, and where and how does the pee accumulate? Do you at some point turn into a balloon? [27] Your urine production will slow down quietly. But then the fluid is removed by dialysis. It's the dialysis removing the urine because it draws out the fluid. [Interviewer]</p> <p><i>Not sure it was the right decision</i> (5 sources & 13 references)</p> <p>I try not to think about it in my daily life. But now and then, you think, "What is it that I'll be going through?" And then I think, "Tubes in the stomach, that was unusually uncomfortable. Could I get peritonitis?" I think. But, of course, you can also get something with the other [dialysis modality], right? Yes, and I think many, many, many times about whether it was the right decision. Just think, you get such a machine home with you and all those boxes, and they take up a lot of space. I do not know how much, and they are delivered by a truck. That sounds terrible, doesn't it? Do I have enough room? And how long is the tube that is going to reach the bathroom? And we have two cats who play around at night and have a wonderful time. They are playing with stuff. I think about how thirst will turn out. And it has to be totally clean, the room you sleep in [and use for dialysis]. [27]</p> <p><i>Preferred not to receive dialysis</i> (13 sources & 23 references)</p> <p>Well, you have to understand that I don't go around hoping for dialysis because, first of all, it doesn't look very sexy and,</p>

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	<p>secondly, it limits me. It limits the life I would like to live, but I'm also realistic, I know it's coming. You should know that. Because I would have preferred to avoid it – who wouldn't? No, it's a choice between plague and cholera, there's no doubt about that. [10]</p>
	<p><i>'No dialysis' was not an option</i> (9 sources & 17 references)</p> <p>So, I decided that dialysis after all had to be better than just doing nothing. But we have talked about the fact that we are old, we have experienced a lot, nobody owes us anything in this life – no good and bad things. So that was a part of my considerations. [19]</p>

For peer review only

Figure 1. Overview of when the patients experienced the decision to be made



Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No	Item	Guide questions/description	Answers
Domain 1:			
Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	The first author, JF
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	RN, MHR & PhD student
3.	Occupation	What was their occupation at the time of the study?	Clinical Nurse Specialist & PhD Student
4.	Gender	Was the researcher male or female?	Female
5.	Experience and training	What experience or training did the researcher have?	Both first and last authors have performed several studies using qualitative interviews
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No relationship was established. A third person asked the patient about participation in the study.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>E.g. personal goals, reasons for doing the research</i>	A clinical nurse specialist in the area of renal medicine and a PhD student. They knew the aim of the study.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>E.g. Bias, assumptions, reasons and interests in the research topic</i>	The interviewer had developed the intervention. This was not known by the patients.
Domain 2: study design			

Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	A pragmatic approach. Kvale & Brinkmann was used for data collection, and Malterud was used for data analysis. Both have a pragmatic approach.
Participant selection			
10.	Sampling	How were participants selected? <i>E.g. purposive, convenience, consecutive, snowball</i>	Consecutive
11.	Method of approach	How were participants approached? <i>E.g. face-to-face, telephone, mail, email</i>	By a third person, the dialysis coordinator, with an information leaflet.
12.	Sample size	How many participants were in the study?	29
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	26 refused to participate. We do not know their reasons. 4 dropped out because of a deterioration in their medical condition.
Setting			
14.	Setting of data collection	Where was the data collected? <i>E.g. home, clinic, workplace</i>	Decided by the patient. Either at home or at the hospital.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Decided by the patient. 8 relatives participated.
16.	Description of sample	What are the important characteristics of the sample? <i>E.g. demographic data, date</i>	Sex, age, eGFR, decision, participation in kidney school, number of meetings
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it	An interview guide was developed based

		pilot tested?	on the 'three-talk model'. The interview guide was adapted for each interview based on two questionnaires.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	The interviews were recorded.
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made after each interview.
21.	Duration	What was the duration of the interviews or focus group?	Mean duration was 50 minutes (range 26–73)
22.	Data saturation	Was data saturation discussed?	Saturation is not the goal for Malterud but information power.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No, but a summary was made at the end of each interview for the patient to confirm.
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	One, but the coding was discussed with the two other authors and the advisory board.
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Yes
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data.
27.	Software	What software, if applicable, was used to manage the data?	NVivo 11.0
28.	Participant checking	Did participants provide feedback on the findings?	Two patients were part of the advisory board giving feedback on the

		findings.	
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>E.g. participant number</i>	Yes, presented in Table 2
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, presented in bold
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, presented in italics

Allison Tong, Peter Sainsbury, Jonathan Craig; Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care*, Volume 19, Issue 6, 1 December 2007, Pages 349–357, <https://doi.org/10.1093/intqhc/mzm042>

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An evaluation of a shared decision-making intervention for dialysis choice: a qualitative study of the patient perspective

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Keywords:	Shared decision-making, Patient decision aid, Complex intervention, Qualitative evaluation

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4 **An evaluation of a shared decision-making intervention for dialysis choice: a qualitative study**
5 **of the patient perspective**
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9 Jeanette Finderup^{1, 2}, Jens Dam Jensen^{1, 2}, Kirsten Lomborg²
10
11

12 Department of Renal Medicine, Aarhus University Hospital, Denmark

13
14 ² Department of Clinical Medicine, Aarhus University, Denmark
15
16

17 Corresponding author

18 Jeanette Finderup, Department of Renal Medicine

19 Aarhus University Hospital

20 Palle Juul-Jensens Boulevard 99

21 8200 Aarhus N

22 Denmark

23 Phone: +4578452525

24 Email: jeajee@rm.dk
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33 **Keywords**

34 Shared decision-making, patient decision aid, complex intervention, qualitative evaluation
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38 **Abbreviations**

39 SDM: Shared decision-making

40 SDM-DC: Shared decision-making and dialysis choice

41 PDA: Patient decision aid
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48 **Abstract**

49 **Objectives:** To evaluate the ‘Shared Decision-making and Dialysis Choice’ (SDM-DC)
50 intervention with regard to patients’ experience and involvement.
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52 **Design:** Semi-structured individual interviews and systematic text condensation for data analysis.

53 **Setting:** The SDM-DC intervention was implemented and evaluated at four different hospitals in
54 Denmark.
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56 **Participants:** A total of 348 patients had received the SDM-DC intervention, and of these, 29
57 patients were interviewed.
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4 **Interventions:** SDM-DC was designed for patients facing a choice of dialysis modality. The
5 available modalities were haemodialysis and peritoneal dialysis, either performed by patients on
6 their own or with help from a healthcare professional. The intervention was tailored to individual
7 patients and consisted of three meetings with a dialysis coordinator who introduced a patient
8 decision aid named 'Dialysis Choice' to the patient.
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13 **Findings:** The four main findings were: the decision was experienced as being the patient's own;
14 the meetings contributed to the decision process; 'Dialysis Choice' contributed to the decision
15 process; and the decision process was experienced as being iterative.
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18 **Conclusions:** The patients experienced SDM-DC as involving them in their choice of dialysis
19 modality. Due to the iterative properties of the decision-making process, a shared decision-making
20 (SDM) intervention for dialysis choice has to be adapted to the needs of individual patients. The
21 active mechanisms of the meetings with the dialysis coordinator were: 1) questions to and from the
22 patient; and 2) the dialysis coordinator providing accurate information about the options. The
23 overview of options and the value clarification tool in the decision aid were particularly helpful in
24 establishing a decision-making process based on informed preferences.
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31 **Strengths and limitations of this study**

- 32 • Data richness was established by interviewing 29 patients. The interviews lasted on average
33 50 minutes with an information load of 23 normal pages on average.
- 34 • SDM-DC seems to be the first intervention based on the 'three-talk model', which is a well-
35 cited SDM model.
- 36 • The whole research process has involved patients and healthcare professionals providing the
37 intervention.
- 38 • The research only included Caucasian patients born in Denmark, and the findings are
39 therefore limited to ethnic Danish patients.
- 40 • One of the developers of the intervention performed the interviews, but this challenge has
41 been addressed in several ways.
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52 **Introduction**

53 Patients with kidney failure must make a decision regarding dialysis modality, choosing either
54 haemodialysis or peritoneal dialysis. Based on research, one modality is not uniquely better than the
55 other (1-3). In order to offer the modality best suited to each patient's everyday lifestyle,
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4 international guidelines recommend involving the individual patient in the decision-making process,
5 thus basing the decision on the patient's preferences (3). However, patient involvement does not
6 always occur (4-6). For example, two studies from the USA showed that only 13% of patients
7 experienced the decision process as shared decision-making (SDM) (7) and that patients over the
8 age of 65 years did not experience the decision as a shared one (8). More recent studies indicate
9 improvements in this area. A study from the UK that included routine measures of patient
10 involvement at 27 different nephrology departments found that 69% of patients experienced SDM
11 (9).

12
13 Based on SDM for dialysis choice, we developed and pilot tested an intervention called 'Shared
14 Decision-making and Dialysis Choice' (SDM-DC) with the purpose of involving patients and their
15 relatives in the decision-making process (10). In this article, we document patients' perspectives on
16 using the SDM-DC intervention at four different hospitals in Denmark.
17

18 **Background**

19
20 A study of patient involvement in dialysis choice suggested that SDM could improve patients'
21 experiences of involvement in the decision (11). A Cochrane Review indicated that an intervention
22 based on SDM and supported by a patient decision aid (PDA) increased patients' experience of
23 involvement (12). Another Cochrane Review focusing on PDAs showed middle-quality evidence
24 that PDAs increase the proportion of people who are active in decision-making (13).
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27 The SDM-DC intervention was developed in 2015 and then described and pilot tested (10). It
28 includes a PDA, named 'Dialysis Choice', and is designed for patients with kidney failure who must
29 make a decision regarding their future dialysis mode: haemodialysis or peritoneal dialysis. Both
30 options may be performed by patients on their own or with help from a healthcare professional.
31
32 SDM-DC is structured according to the 'three-talk model' (14) and consists of three meetings
33 between the patient and his or her relative(s) and a dialysis coordinator. The dialysis coordinators
34 have been trained to deliver the intervention using tailoring (15) based on a decision needs
35 assessment and using three different communication skills: mirroring, active listening and value
36 clarification (16-18). The PDA is designed to be utilised both at and between the meetings with
37 individual patients and relatives who may be joining them. Two videos with personal stories are
38 available to be shown and discussed at the meetings if the patient needs to hear a personal story.
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40 Patients and healthcare professionals have been involved in the development of the intervention and
41 the PDA (19). The decision aid is based on a systematic literature search where possible. The PDA
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4 is in paper format and can be found in the supplementary material. It has been accepted for the A to
5 Z Inventory of Decision Aids – <https://decisionaid.ohri.ca/> – and assessed according to the
6 International Patient Decision Aids Standards (20). The PDA consists of a set of tools: a decision
7 map, an overview of uremic symptoms, an overview of options, and the Ottawa Personal Decision
8 Guide (21-22). A detailed description of the SDM-DC intervention can be found in the
9 supplementary material. The pilot test confirmed that SDM-DC was useful in encounters between
10 individual patients and a dialysis coordinator at a Danish university hospital but that further
11 research was needed to gain insight into the patients' experiences of involvement and the
12 implications for their choice of dialysis mode (10).
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21 **Aim**

22 The aim of this study was to evaluate the SDM-DC intervention with regard to patients' experience
23 and involvement.
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28 **Methods**

29 This study is part of a larger project evaluating the SDM-DC complex intervention (23-24). As
30 recommended for complex interventions (25-27), we first conducted a qualitative evaluation. Since
31 October 2016, the intervention has been delivered at four hospitals in Denmark by six different
32 dialysis coordinators. The inclusion criteria for the intervention were adult patients with chronic
33 kidney disease referred to a department of renal medicine with an eGFR below 20 ml/min measured
34 by a 24-hour urine test. Exclusion criteria were patients who had decided on palliation, patients with
35 a living donor and a set date for transplantation, and patients not able to participate due to cognitive
36 impairment. The use of an interpreter was not an exclusion criterion.
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46 *Patient and public involvement*

47 Patients and healthcare professionals have been involved in the whole research process (28-30)
48 through an advisory board consisting of six dialysis coordinators and two patients. The two patients
49 on the board have not been part of the intervention but are part of the target group for it. The first
50 author and the advisory board met every six months during the research process. For this study, the
51 advisory board has contributed particularly to the validation of the themes and inspiration for the
52 discussion.
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Data collection

We collected data through individual interviews with patients after they had participated in SDM-DC. We conducted interviews between 1 February 2017 and 8 August 2018. The patients were interviewed consecutively after receiving the intervention. The patients decided on their own where the interview would take place and whether their relatives would participate or not. The first author, who does not perform the intervention, conducted the interviews. The individual interviews were conducted according to Kvale and Brinkmann's guidelines (31) with a semi-structured interview guide. The purpose of the individual interviews was to gain a clear insight into how the patients experienced the impact of SDM-DC on their involvement in the decision-making process. The key elements in the 'three-talk model' (14) informed the content of the interview guide, which was structured chronologically around the first talk, the second talk, the third talk and decision support, from initial preferences to informed preferences and the decision. We adapted the interview guide for each interview according to how the patient, prior to the interview, had answered two questionnaires: the Shared Decision-making Questionnaire (32) and the Decision Quality Measurement (33), not changing the initial questions but making the follow-up questions more specific. During the interviews, the communication skills of mirroring and active listening were used (16-17). First, mirroring was used to bring patients' experiences to the forefront. Active listening, such as retelling the patient's story, then allowed patients to adjust their story if they wished. At the end of every interview, the interviewer summarised the patient's story so the patient could comment on this summary. The purpose of the interviews was not to question the decision the patient had made or to convey information. One patient was emotionally moved by the interview and was offered a new meeting with the dialysis coordinator.

Ethical considerations

Participation in the intervention was based on consent for care and treatment. According to Danish legislation, this type of research is exempted from ethical approval. The Danish Data Protection Agency (jr. 1-16-02-456-16) approved data management. A third person obtained written consent from patients before their participation in the interviews.

Data analysis

To achieve a well-considered and well-documented analysis, we used a four-step systematic text condensation process (34-35). Systematic text condensation is a descriptive and explorative method

for thematic cross-case analysis. During interviews, the first author performed some primary analysis and noted preliminary themes. These preliminary themes were discussed with the third author and the advisory board, which led to some changes. These themes were targeted in subsequent interviews with patients. The interviews were recorded and transcribed verbatim prior to data analysis, and the software program NVivo® 11 (36) was used for data management. Various features in NVivo® were used to support the different steps of the analysis process, and to ensure that analyses were both systematic and transparent. These features included Coding, Classification and Memos, and also Word Cloud to identify other preliminary themes, Text Search Query to find meaningful units that had been overlooked, and Matrix Coding Query to investigate whether a code could be attributed to some characteristic within the interview situation or interviewee. The first step in the systematic text condensation was naïve reading, which was performed to obtain an overview of the data. This was conducted continuously during the interview period. The second step was to identify and sort meaningful units by coding. The third step involved condensation of the meaningful units of interest in accordance with the aim of the study. All references from each source were condensed and written as narratives in the first person and present tense to represent each participant's story in relation to each specific code. The fourth and final step involved synthesizing the transcription of each finding. All condensed texts for each finding were aggregated into one text and formulated as narratives in the third person and past tense, including illustrative quotations.

Findings

The interviews took place between 14 days and 42 days after the intervention. Out of 59 patients invited for interviews, 33 accepted the invitation, but four of these patients were not able to participate due to their medical condition worsening. Table 1 shows the characteristics of the 29 patients who participated in the interviews side by side with the characteristics of the whole sample. The variation in the sample was close to the total sample for the intervention according to gender, age, hospitals, dialysis coordinators and the choice of dialysis mode.

Table 1. Participant characteristics*

	Intervention sample (n=349)	Interview I study sample (n=29)
	n (%)	n (%)
Sex		

Female	123 (35)	8 (28)
Male	226 (65)	21 (72)
Age (years)		
age < 50	38 (11)	3 (10)
50 ≤ age < 60	45 (13)	9 (31)
60 ≤ age < 70	94 (27)	12 (42)
70 ≤ age < 80	112 (32)	5 (17)
age ≥ 80	59 (17)	0 (0)
eGFR** (ml/min)		
eGFR < 10	82 (23)	3 (10)
10 ≤ eGFR < 20	244 (70)	26 (90)
eGFR ≥ 20	23 (7)	0 (0)
Chosen option		
Peritoneal dialysis	228 (65)	20 (69)
Home haemodialysis	26 (8)	4 (14)
Hospital haemodialysis	87 (25)	5 (17)
No decision	8 (2)	0 (0)
Number of meetings		
1	90 (26)	2 (7)
2	215 (62)	17 (59)
3	40 (11)	10 (34)
4	4 (1)	0 (0)
Hospitals***		
I	180 (52)	12 (41)
II	53 (15)	7 (24)
III	60 (17)	8 (28)
IV	56 (16)	2 (7)

*Data used in this table have been registered by the dialysis coordinators and are consistent with the documentation in the patients' electronic health records.

**eGFR is the abbreviation for estimated glomerular filtration rate.

***The roman numerals indicate each of the participating hospitals.

The interviews lasted on average 50 minutes, ranging from 26 to 73 minutes, with an information load of 670 normal pages in total, and 23 normal pages on average. Fifteen interviews were conducted at the hospitals and 14 in patients' homes. Eight patients chose to participate in the interview together with a spouse, and 21 were on their own. Table 2 gives an overview of the category headings, codes and chosen quotations.

Table 2. An overview of the findings and chosen quotations[†]

Category headings ^{††}	Codes ^{†††}
<p>The decision was experienced as being their own (28 sources & 66 references)</p> <p>At the first meeting, my son and daughter-in-law were with me. And when we drove home, we did not talk much about it. I let a few days pass and I thought, "Let them just go and... They should also have time to think a little, and I should have some</p>	<p><i>Other decisions</i> (14 sources & 28 references)</p> <p>Well, that's probably the first time I've participated in a decision about my illness and treatment. I had an operation on my throat, and I was just told how it should be and when it should be. So I just had to show up. So far, I have just been to see my doctor to get to know how my illness was developing. I get medicine, but I have not been a part of that decision. I have no background to know anything about it, but [in this situation] I have done so. Well, I don't know. I would not have been surprised if you had just decided what to do, because the doctors usually decide everything. And I wouldn't know I had other options. [8]</p>

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<p>time to think what I was going to say at the next meeting and all..." Then I talked to them. Then I asked, "What would you choose after the first meeting?" They would choose dialysis at the hospital. Then I said, "Well, it's funny that you say that because that's what I've decided, that's how I want it to be." I've decided this myself, and I think it's a good thing that it's not just the hospital saying what I'm going to do. I hope, because I have decided this myself, I must make the best of it when it can't be any different. Rather than saying that we have just decided this over your head and then say, "Oh, it's so annoying that they make the decisions." There is no one to blame if I think it's a bad decision. Only myself anyway. It is already hard enough. It's my own decision. I actually think it's quite important that you make the decision yourself. I'm old enough to do that. I have not been good at saying no before, but... It's my life and it's my choice and that's how it should be. [16] ††††</p>	
<p>The meetings contributed to the decision process (29 sources & 95 references)</p> <p>If I should have done it [made a decision] without the meeting, it would have been hard. Because then I would have to read about it and I would really not understand a thing. I would not be able to see myself [which decision was right for me]. Now, the dialysis coordinator like explained the different scenarios to me. And it's in light of this I said that I want peritoneal dialysis. She [the dialysis coordinator] supported this – "I think this is right for you," she said. So no, no, it's my own decision – 100%. [10]</p>	<p><i>Questions to and from the patient</i> (21 sources & 39 references)</p> <p>She [the dialysis coordinator] actually puts the questions she has to ask in a nice way. Not like a chainsaw. In a nice way. And I also think she manages to get some answers from people when she does it like that. I'm not an open person, I keep things to myself, and people have to lure things out of me. Her questions make me think about things. It gives me peace of mind to get rid of what I'm thinking about. I want to know what it is, and it must be reliable, what I'm told. And I always think I've received an answer. Because... that's life. Life has taught me that if I do not ask, I don't get any answers. Here, she asked her questions, because it was unfamiliar territory. I'm on shaky ground. I had the question, "Why is it haemodialysis you want, and why is it not peritoneal dialysis?" Then we talked about the differences. Well, what happens in my everyday life if I choose haemodialysis and what happens if I choose peritoneal dialysis? And I know that with peritoneal dialysis, I can have some equipment I can take around with me. [13]</p> <p><i>Accurate information was helpful for the patient</i> (12 sources & 20 references)</p> <p>It was positive to have the meetings with XX [a dialysis coordinator]. Because she told me a lot. And she had an answer ready when I asked. And I'm sorry to say, but some of them [other healthcare professionals], I call them circus clowns. They say "Ah, well..." and "I have to look into that" and "I will be back with an answer" and stuff like that. But XX [a dialysis coordinator], she did not act in that way. I asked and then she had the answers right at hand. [12]</p> <p><i>Bringing a relative into the meetings contributed to the decision process</i> (24 sources</p>

	<p>& 75 references)</p> <p>Well, it has meant a lot to me that my wife was with me at the meetings because we were able to talk about it afterwards. She is my extra pair of ears. I have some problems with hearing. It is nice to have somebody there with you, because you get emotional sometimes. So she's not just there because of my bad hearing. The information at the meetings gets me started thinking, I get emotional, and then I don't listen that well. We are in such a vacuum at the moment, waiting to get started with a new part of our life. It is primarily me, but of course also her. It affects everybody in our household. [13]</p>
<p>The decision aid contributed to the decision process (29 sources & 70 references)</p> <p>But when you sit there starry-eyed and don't know anything, it [the decision aid] can help a lot. Also that you get more information about it [the decision]. [1]</p>	<p><i>The overview of options contributed to the decision process</i> (18 sources & 28 references)</p> <p>The further we went down the list of options, the more it became clear to me that I want P-dialysis. That's what I want. That's the solution that suits my life and my need for freedom best. I think the different colours will do something for me. I heard what she told me, read the chart, saw the different colours when she pointed at them, it meant something to me. [3]</p> <p><i>The value clarification tool contributed to the decision process</i> (15 sources & 25 references)</p> <p>We were in a state of rebellion. We were a bit confused. Because we were not really aware of what was happening or should happen or what could happen. But then we worked with it at home and talked about it. We had an assignment to do at home that we went through together. The assignment made us arrive at this decision. I think it made us compare the different options. It gave us an overview because we could compare pros and cons. [23]</p> <p><i>The videos contributed to the decision process for some patients</i> (14 sources & 17 references)</p> <p>The best thing about it was the short video with the man who had lived with P-dialysis for 11 years, and it's obvious that he would rather live with dialysis than not live at all. And that kind of helped. He apparently seemed to be doing well. He seemed happy and satisfied. It helped me a lot, because I sometimes worry. I'm a little afraid of dialysis. It's a big deal to me and then... It was really good, because it made me less concerned about what it [dialysis] really would be, or it actually made my concern disappear. [19]</p> <p><i>Other patients contributed to the decision process sometimes</i> (13 sources & 38 references)</p> <p>I probably had some reservations from the start. Because I was hospitalised in April last year, and I was with a guy on peritoneal dialysis. He participated in biker meetings, and sometimes, he just had peritoneal dialysis and then he went out [biking] again. And if he could do it, so could I with my hobby as a dog trainer. I would also do it in that way. I got an impression of freedom he had. I didn't think so much about going on dialysis myself. But I saw it as a good experience, and something that was good, and the treatment was good. [8]</p>
<p>The decision process was experienced as being iterative (28 sources & 140 references)</p> <p>So we have had the number of meetings we think we needed. But we don't know yet. The difficult thing here is that we are talking about something we imagine. It's like a trip we're</p>	<p><i>Dialysis choice came as a shock</i> (14 sources & 48 references)</p> <p>You have had diabetes for about 15 years; you haven't thought that it would mean that your kidneys failed at some point and that you have to have dialysis. [Interviewer] You thought then that you might lose a leg, but then I thought I haven't smoked since 1981. But I haven't thought about the kidneys. She told me that it's now time for dialysis or transplantation. It was a shock, I admit – like out of the blue. I was pretty shaken. And now, you have seen what kind of options you have and what the next step is... I decided at the third meeting because it was new to me and it was kind of a shock. It felt like the rug being pulled from under my feet. [26]</p>

<p>going on. Then you have some expectations, but you don't know where it really ends. It's like when we start this, we'll get to know something, and it's great, what we are told, but we don't know if there will be any questions along the way, and there automatically will be. Afterwards, we had the experience, we bought the trip or we have been on it. I have become more sure of it [my decision], after the meetings, that is. At the kidney school [a 2-day Kidney school, each day with a four hour information session on chronic kidney disease] they told me it should be peritoneal dialysis, or perhaps, but without deciding, but it was the decision I was more likely to make. And then after those meetings, I realised that it should be peritoneal dialysis. So, I made a decision, right. [5]</p>	<p><i>Received new information during the interview</i> (11 sources & 35 references)</p> <p>Really good. Well, I'm already much more informed. [17] And I shouldn't tell you anything today, I just want to listen. It's you who should tell me something. [Interviewer]</p> <p>-----</p> <p>So, and then they say that, in the end, you can't pee. Well, now, what is that about? So, I can't imagine it, not being able to pee, and where and how does the pee accumulate? Do you at some point turn into a balloon? [27] Your urine production will slow down gradually. But then the fluid is removed by dialysis. It's the dialysis removing the urine because it draws out the fluid. [Interviewer]</p> <p><i>Not sure it was the right decision</i> (5 sources & 13 references)</p> <p>I try not to think about it from day to day. But now and then, you think, "What is it that I'll be going through?" And then I think, "Tubes in the stomach, that was unusually uncomfortable. Could I get peritonitis?" I think. But, of course, you can also get something with the other [dialysis modality], right? Yes, and I think many, many, many times about whether it was the right decision. Just think, you get this machine home with you and all those boxes, and they take up a lot of space. I don't know how much, but they are delivered by a truck. That sounds terrible, doesn't it? Do I have enough room? And how long is the tube that is going to reach the bathroom? And we have two cats who play around at night and have a wonderful time. They play with stuff. I think about how thirst will turn out. And it has to be totally clean, the room you sleep in [and use for dialysis]. [27]</p> <p><i>Preferred not to receive dialysis</i> (13 sources & 23 references)</p> <p>Well, you have to understand that I don't go around hoping for dialysis because, first of all, it doesn't look very sexy and, secondly, it limits me. It limits the life I would like to live, but I'm also realistic, I know it's coming. You should know that. Because I would have preferred to avoid it – who wouldn't? No, it's a choice between plague and cholera, there's no doubt about that. [10]</p> <p><i>'No dialysis' was not an option</i> (9 sources & 17 references)</p> <p>So, I decided after all that dialysis had to be better than just doing nothing. But we have talked about the fact that we are old, we have experienced a lot, nobody owes us anything in this life – no good and bad things. So that was part of my considerations. [19]</p>
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†The quotations have been translated into English as accurately as possible.

††The category headings are in **bold** in the text.

†††The codes are in *italics* in the text.

††††The numbers in square brackets are the identification numbers of the participants.

‘The decision was experienced as being their own’ was stated by 28 patients in different ways.

Some of the patients stated that they had made their decision together with their relatives; others stated that their relatives had not influenced their decision. Some patients stated that their relatives agreed with their decision. They stated that the healthcare professionals had not made the decision, even though the dialysis coordinator had contributed to the decision process. For several patients, it had been important that the healthcare professionals had confirmed their decision. One patient did not directly express that the decision was his own [2]. This patient was over the age of 80, and the focus for his decision process was whether to go on dialysis or not. Several patients stated that it

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4 was important that the decision was their own because they thought it made the decision easier to
5 accept. None of the patients experienced being left alone with the decision process.
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9 *Other decisions.* Most of the patients had lived with disease for a long period. Most of them had
10 never before experienced being involved in a decision about their treatment. Most of the patients
11 felt that no decision had been involved in previous treatments at all. A few patients had experienced
12 participating in a decision about treatment before, but mostly, their experience was that the
13 healthcare professionals regarded patient involvement as an unwelcome interference. Such patients
14 wished that these healthcare professionals had invited them to take part in the decision process and
15 communicated some information to them, to enable them to participate.
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23 **The meetings contributed to the decision process.** All 29 patients reported that the meetings with
24 the dialysis coordinators had contributed to the decision process and that they would not have been
25 able to make the decision on their own without the meetings. The patients emphasised the relaxed
26 nature of the meetings as being significant. They felt they had time to go into the decision process
27 in depth.
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33 *Questions to and from the patient* were emphasised by most patients as a significant property of the
34 meetings. There was no relation to demographic, gender, age, or the dialysis coordinator. Questions
35 to the patients addressed the impact of the decision on their everyday life. The patients experienced
36 these questions as being asked in a nice, easy way. Questions from the patients were concerned with
37 practical issues. The patients felt confident they could ask the same questions several times.
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44 *Accurate information was helpful for the patient.* Some of the patients emphasised that information
45 communicated by the dialysis coordinator had been helpful in the decision process. These patients
46 stated that the information communicated should be detailed, accurate, and appropriate to their life,
47 and that information should be repeated. Two patients [2, 7] expressed that some of the information
48 communicated by the dialysis coordinator had not been helpful; this appeared to be when the
49 dialysis coordinator gave too much information at a single meeting.
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56 *Bringing a relative into the meetings contributed to the decision process.* This was emphasised by
57 most of the patients. They had chosen to bring a relative to be part of the meetings, most often a
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4 wife or husband but in some cases a daughter and son-in-law or a friend. Bringing a relative to the
5 meetings was mentioned as “a habit”. These patients were used to bringing a relative to important
6 meetings at the hospital and expressed that “being two” made it possible for them to ask more and
7 different questions. They further emphasised the benefits of there being two people to listen. A few
8 patients [6, 11, 17, 19, 29] did not bring a relative to the meetings. These patients explained that
9 they did not have a significant other in their lives or that their significant others were too ill to
10 participate in the meetings.
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18 **The decision aid contributed to the decision process.** All 29 patients expressed that they could
19 not have made their decision without help from the decision aid. The patients talked about the PDA
20 as one tool and only mentioned two of the tools within the PDA specifically: the overview of
21 options and the value clarification tool. Some of the patients mentioned the two videos, and they
22 also mentioned other patients, although other patients are not an integrated part of the intervention.
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28 *The overview of options contributed to the decision process.* This was expressed spontaneously by
29 most of the patients. The tool had clarified or confirmed their decision. They had used the tool
30 during the meeting, but also after the meeting and in preparation for the next meeting. Several
31 patients stated that they had saved the tool and continued to use it.
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37 *The value clarification tool contributed to the decision process.* Most of the patients stated
38 spontaneously that the value clarification tool was particularly valuable. Several patients indicated
39 specifically that this tool had contributed to the decision process and elaborated that the questions in
40 the tool had enabled them to reflect, in particular the part where they write down pros and cons.
41 Some patients had filled in the tool before the meeting using the value clarification tool, and others
42 received help at the meeting to complete it.
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49 *The videos contributed to the decision process for some patients.* Some patients used positive words
50 in their descriptions of the videos. One patient reported that the videos had helped him change his
51 decision [25], one reported that the videos had removed his concern about dialysis [19], and one
52 that they had provided some concrete visuals of how dialysis takes place [13]. Three patients used
53 positive words about the videos but stated explicitly that the videos had not contributed to their
54 decision process [3, 4, 7]. One patient used negative words about the videos [16]. This patient had
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4 made a decision before seeing the videos and would have preferred them to have a more practical
5 focus.
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9 *Other patients contributed to the decision process sometimes.* A number of patients in the sample
10 met other patients on dialysis. For some of this group, meeting other patients on dialysis contributed
11 to the decision process, but several of these patients [3, 11, 22, 25, 27] did not choose the same
12 option as the patient they had met. A few of the patients did not know why the patient they met had
13 chosen as they had. Other patients contributed to the decision process by making dialysis more
14 concrete and presenting possibilities. For some of the patients, it was scary to meet other patients on
15 dialysis.
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23 **The decision process was experienced as being iterative.** Only one patient did not mention the
24 decision process at all. This patient had only one possible dialysis modality. Four patients stated
25 that they had made their decision before the meetings, but all four had their decision confirmed
26 during the meetings. Nine patients experienced that their decision was made during the meetings.
27 One of these patients had made a decision beforehand but changed this during the meetings. Eight
28 patients experienced that their decision was made concrete at a meeting. Two patients made their
29 decision at the first meeting, three patients made their decision at the second meeting, and three
30 patients made their decision at the third meeting. Figure 1 gives an overview of when patients felt
31 their decision was made.
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40 **Figure 1. Overview of when the patients experienced the decision to be made**

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44 Nearly all participants experienced the decision process as iterative. Although they had made a
45 decision, they still needed to confirm this decision, to ask questions, and to reconsider it. There was
46 not only a single option suitable for each patient, but several patients decided on one option to start
47 with (plan A) and then had a plan B and C.
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52 *Dialysis choice came as a shock* for half of the patients, although they had been known to the
53 departments of renal medicine for several years. That dialysis could actually be a treatment for them
54 occurred to the patients just before the meetings or during the meetings. Some of the patients knew
55 that dialysis might be an option someday, but they had ignored this knowledge and thought it was
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4 not going to happen to them. One of the patients [10] was happy not to have received this
5 knowledge previously, but two of the patients [12, 23] stated that they would have preferred to have
6 known earlier. One patient [13] stated that he would have preferred to receive this knowledge in a
7 nice, easy way. Surprisingly, no correlation has been found between eGFR and dialysis choice
8 coming as a shock. Rather, it appeared to be experienced as a shock more often by patients at two of
9 the hospitals compared to those at the other two.
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16 *Received new information during the interview.* Some patients received new information about the
17 significance of the decision regarding dialysis modality during the interview. It was not the
18 intention for the interviewer to interact with the intervention, but the patients asked some questions,
19 and the interviewer tried to answer these questions briefly. The information given did not change
20 their decision. One patient had doubts after the interview and needed one extra meeting. This
21 meeting did not change her decision [27].
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28 *Not sure it was the right decision* was expressed by five patients. At the same time, they said that
29 there was nothing we could do to make them more certain about the decision. They stated that they
30 thought they would feel certainty when they first started dialysis.
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35 *Preferred not to receive dialysis* was expressed by some of the patients. They preferred not to
36 receive any dialysis treatment and characterised the options as a choice between two evils
37 associated with various problems and a loss of their present lifestyle. These participants still hoped
38 to recover and no longer be in need of dialysis.
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44 *'No dialysis' was not an option* was considered by some of the patients. This code was mainly found
45 among patients over the age of 80 years. The patients aged over 80 felt they still had something to
46 live for. Some stated that if their spouse died, they would reconsider their decision and perhaps
47 choose 'no dialysis'. Most of the patients stated that they had considered these issues on their own,
48 but they had shared their consideration with the healthcare professionals.
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53 54 **Discussion**

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56 In summary, the patients experienced the decision as being their own, but both the meetings and the
57 PDA had contributed to the decision-making process. They experienced the decision-making
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4 process as iterative. The discussion is divided into three sections. The first two sections correspond
5 to the aim, and the last section focuses on limitations of the study.
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9 *How did the patients experience the SDM-DC intervention in terms of their involvement?*

10 The purpose of the intervention was to involve patients in the decision-making process. **The**
11 **decision was experienced as being their own** was a significant finding, which demonstrates that
12 the patients experienced SDM-DC as involving them in the decision-making process. The SDM-DC
13 pilot test predicted this finding, because some of the patients did not experience the decision as a
14 shared decision, but their own decision (10). Due to the age of the patient group, this finding was
15 surprising when compared to a study focusing on the involvement of the over-65 age group. That
16 study showed that patients who were involved in the decision-making process about dialysis choice
17 were more satisfied with their dialysis modality (37). We found the patients experienced the
18 decision process as iterative. SDM-DC is based on the 'three-talk model' by Elwyn et al (14). The
19 simple version of the 'three-talk model' presents the SDM process as linear, suggesting that patients
20 go into the decision-making process without any decisions and complete the process with a
21 decision. In 2017, the 'three-talk model' was updated and is no longer presented as a linear model,
22 but a circular one (38). Both models have their advantages. In clinical practice, it is easier to
23 implement an intervention based on the linear model with clear progression through the process.
24 Nonetheless, it is worth noting that SDM-DC seems to be the first intervention to apply the linear
25 version of the 'three-talk model' (38). The model has been cited a number of times elsewhere but
26 only for presentations, workshops and training programmes. A Canadian study found five phases in
27 the decision-making process regarding dialysis choice: 1) progress toward acceptance to be
28 dialysed; 2) receive information; 3) take some time for personal reflection; 4) seek the opinion and
29 support of others; 5) re-evaluate one's choice (39). The development of SDM-DC was not based on
30 this framework, but our evaluation showed that most of these phases have been met by the
31 intervention.
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50 *How did the patients experience the SDM-DC intervention?*

51 The patients highlighted two important elements of the meetings: 1) questions to and from the
52 patient; and 2) the dialysis coordinator providing accurate information about the options. The fact
53 that daily life with dialysis needs to be described as concretely as possible has been documented
54 elsewhere (40). The patients experienced the participation of their relatives in the meetings as an
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4 advantage. This finding is in accordance with a study of the perspective of the relative, showing that
5 relatives felt involved in the decision-making process and that they had an important supportive role
6 (41). The dialysis coordinator provided decision coaching as part of the SDM process. The
7 definition of decision coaching is '*individualized, nondirective facilitation of patient preparation*
8 *for shared decision-making*' (42). In spite of this, the decision was made together with the dialysis
9 coordinators at the meetings and not afterwards with the physician. Decision coaching has, in other
10 studies, been shown especially to improve the patient's knowledge and involvement in decision-
11 making (42). The whole of the 'Dialysis Choice' PDA contributed to the decision-making process,
12 but the patients identified the overview of options and the value clarification tool as being
13 particularly helpful. An Option Grid is a specific type of overview of options, and research has
14 shown that, for some health decisions, an Option Grid supports patients in the decision-making
15 process (43). From a healthcare perspective, the Option Grid has been found to be easy to use to
16 facilitate patient involvement in the decision-making process (44). In general, Option Grids have
17 proven beneficial for sharing information but less useful for value clarification (45). In the
18 Cochrane Review of PDAs, value clarification is defined as an important part of a PDA and SDM
19 (13). The combination of the overview of options and the value clarification tool appears to be a
20 good one. In the development of our intervention and the PDA, we tried to meet all the decision
21 needs described for this patient population (11, 39, 46-48), but this study added some more decision
22 needs for this patient population: the decision came as a shock to the patient; there is not only one
23 choice but a plan A, B and C. These needs should be implemented into an SDM intervention for
24 dialysis choice. The impact of stories on patient decision-making has been unclear (49). The
25 patients in our study felt the videos were not as unequivocally positive as the decision aid. Nor was
26 meeting other patients on dialysis an unequivocally positive finding. Sometimes, other patients
27 contributed to the decision-making process to a certain extent. The use of narratives in decision aids
28 has been a focus in the International PDA Standards collaboration since the beginning (20). An
29 experimental study has shown that patients are more likely to choose a dialysis modality presented
30 by a patient rather than a healthcare professional, which is why caution has been recommended in
31 the use of patient stories (47). It seems that the patients in our study used the videos and other
32 patients more as inspiration and less as direction, thus complying with the purpose of SDM to
33 establish a decision process based not on uninformed preferences but on informed preferences (14).
34 How the intervention has contributed to this needs to be investigated further.
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Limitations

This study has some limitations. For a qualitative evaluation, 29 patients is a relatively large number of participants. This number was chosen to give the right level of information power (50), because the intervention was performed at four different hospitals, by six different dialysis coordinators, and the patients had to decide between different options. Only Caucasian patients were included, and the findings are therefore limited to ethnic Danish patients. If we had included some ethnically non-Danish patients, the findings could have taken other directions. This is indicated by a study showing that Japanese patients make decisions that are more consistent with their network's wishes and preferences (51). One of the developers of the intervention carried out the interviews in our study, and this is mentioned by Malterud as a point to pay attention to (34). We managed this challenge in various ways: 1) the interviewer did not perform the intervention; 2) the patients did not know that the interviewer had developed the intervention; and 3) the interview findings were discussed with the advisory board. Furthermore, the patients expressed criticism of the intervention during the interviews. The interviews were performed at least two weeks after the intervention. Thus, some memory failure may have occurred since patients with an eGFR below 20ml/min may have cognitive deficit and short memory (52). We assume that the patients have a better memory of the last meeting than the first meeting. We do not yet know the extent to which the intervention has been performed as intended. In the sample, we found two patients who had filled out the value clarification tool, but the dialysis coordinators had not used the homework during the meetings. The dialysis coordinators, who are part of the advisory group, later explained that they found the value clarification tool difficult to use in the beginning.

Conclusion

The patients experienced SDM-DC as involving them in their choice of dialysis modality. Due to the iterative properties of the decision-making process, an SDM intervention for dialysis choice needs to be adapted to the needs of individual patients. The active mechanisms of the meetings with the dialysis coordinator were: 1) questions to and from the patient; and 2) the dialysis coordinator providing accurate information about the options. The overview of options and the value clarification tool in the decision aid particularly contributed to the decision-making process based on informed preferences.

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7 in this study.
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13 **Conflicts of interest**

14 The authors declare no potential conflicts of interest with respect to the research, authorship and/or
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27 **Contributorship**

28 JF: Designed the project, collected and analysed data, and drafted the final manuscript.

29 JDJ and KL: Provided academic supervision, helped to draft the manuscript, and read and approved
30 the final manuscript.
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35 **Data sharing statement**

36 No additional data are available.
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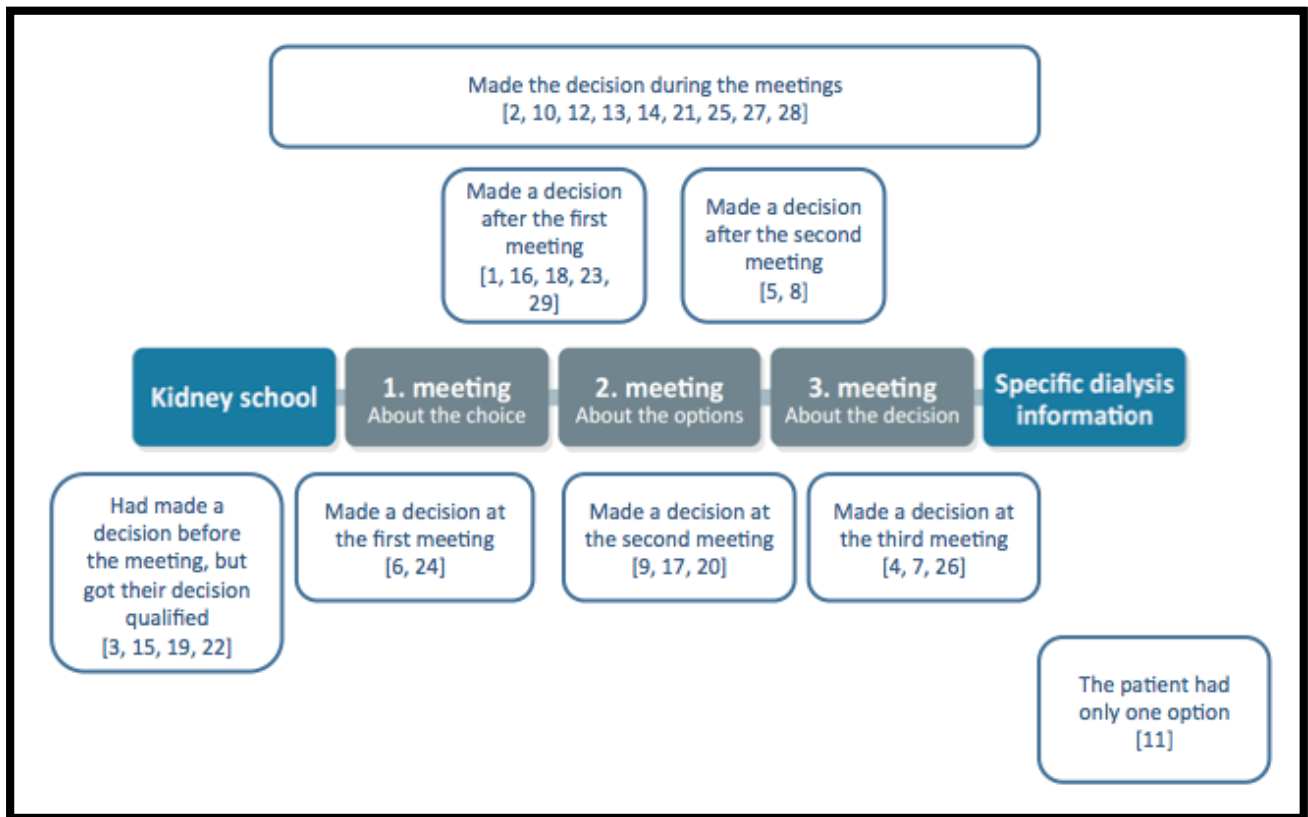
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For peer review only

Figure 1. Overview of when the patients experienced the decision to be made



Kidney school: A 2-day school, each day with a four hour information session on chronic kidney disease

Dialysis choice



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Content

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- **Home haemodialysis –page 7**
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- 3. meeting about the decision – page 14
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 - Explore your decision
 - Which option do you prefer?
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Introduction

This leaflet is made for you, who have kidney failure and have to make a decision regarding your future mode of dialysis.

The purpose of the leaflet is to involve you and your relatives in the decision-making regarding mode of dialysis to ensure you make the choice that fits you and your life best.

In this leaflet we perhaps use some words you do not know. In the end of the leaflet you find a short glossary explaining some of the technical words uses.

Meetings regarding choice of dialysis mode

Your contact doctor and your contact nurse have found out that you soon need to make a decision regarding your future mode of dialysis.

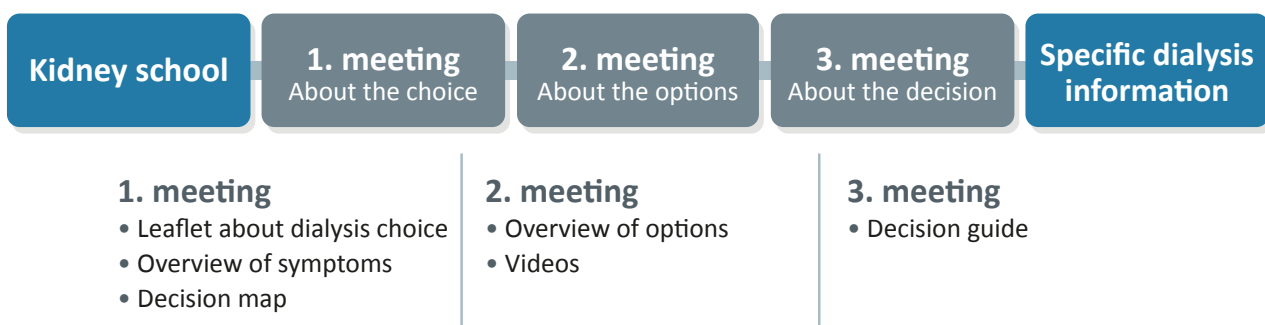
The outpatient clinic will invite you and your relatives to some individual meetings with a nurse. The purpose of these meetings is that you, your relatives and the nurse together make a decision on which dialysis mode fits your everyday life best.

There are three meetings:

1. meetings – about the choice
2. meetings – about the options
3. meetings – about the decision

The meetings will be organised individually according to your needs. Figure 1 shows how the meeting could be organised, but the meeting will always be scheduled to fit your individual needs and not necessarily as three separate meetings. Most patients are offered to join the kidney school before the meetings. The kidney school is an education programme together with other patients in the same situation as you. Here you get information about kidney failure and the treatment opportunities you have. The teaching is carried out by healthcare professionals and patients together.

Figure 1: Overview of the meetings



1. meeting – about the choice

The purpose with this first meeting is to create an understanding of why a choice about dialysis mode has to be made and which options there are to choose between.

Why do I need to make a decision?

You need to make a decision because you have kidney failure.

Kidney failure is when your kidneys are no longer able to sufficiently cleanse the blood and remove extra fluid from your body and you therefore need to cleanse your body in another way.

The outpatient clinic measures your kidneys ability to cleanse the blood in your body in eGFR. An eGFR below 10 ml/min is often the limit where you will need dialysis and most patients have symptoms of kidney failure.

It differs from person to person when you reach this limit; maybe it will take weeks, months, but also years. Most often there is a slow deterioration over months, but the deterioration will be faster if you for example get an infection.

Together with you the staff will work to delay the time of dialysis and slow down the progression of your kidney failure.

We know it is important to start dialysis as planned. This means that you as soon as possible need to make a decision and to get a dialysis access.

The symptoms of kidney failure are not necessarily symptoms that you associate with kidney failure. The symptoms usually come quietly over a period of time, and you may not notice them because you have gotten used to them. But try to think back a year and how it was at that time.

Figure 2 shows the most common symptoms of kidney failure. Try to discuss these symptoms with someone who knows you very well. Maybe that person is more able to see these symptoms in you.

Figure 2: Symptoms of kidney failure



What is the choice?

In order to replace the kidneys with reduced function there are two options; kidney transplant or dialysis. Many patients choose transplantation. Nevertheless, most patients are required to consider the choice of dialysis mode because not all are suitable candidates for kidney transplantation and because there is a waiting list for kidney transplantation.

There are two modes of dialysis:

P-dialysis, which is dialysis where the peritoneal is used as a filter to clean your blood.

Haemodialysis where the blood is cleansed by a filter on a machine.

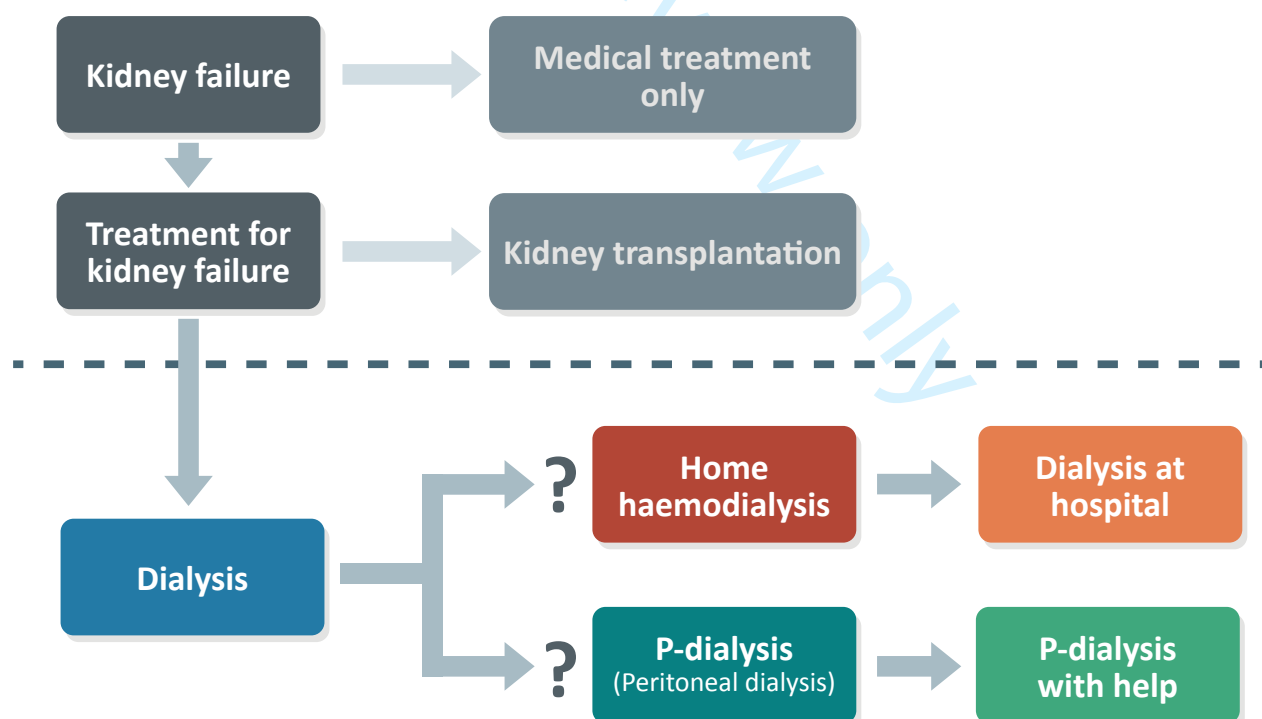
Both dialysis modes are able to take place in your home.

Most patients can choose freely between the two dialysis modes, and we cannot say that one dialysis mode is better than the other. However, it is recommended that you as a patient is involved in the decision-making on which dialysis mode to choose.

There are many decisions in your life when you have kidney failure. Figure 3 shows some of the decisions you have to make. The figure is divided by a dotted line. Decisions over the dotted line - marked with a grey colour - are decisions that are ahead of the decision you have to make now. The decision you are facing now is shown below the dotted line.

The decision is between home haemodialysis and P-dialysis. If you are unable to manage the treatment yourself, you may be able to get help. In P-dialysis you can get the help at home. In haemodialysis your treatment will take place at the hospital where you will get the necessary help.

Figure 3: Decision map



2. meeting – about options

The purpose of the second meeting is to provide insight into which options you have for dialysis as well as discussing the advantages and disadvantages of each dialysis mode.

Which possibilities do I have?

Dialysis means cleansing and is a treatment where your body is cleansed for excess liquid and waste products.

There are two forms of dialysis, but both forms can be obtained with or without help, which involves four forms of dialysis:

- Home haemodialysis
- P-dialysis
- P-dialysis with help
- Dialysis at the hospital

The four dialysis modes are described in brief below.

Home haemodialysis

In haemodialysis, you cleanse your blood through a filter on a dialysis machine. The blood is led through a needle from your body to the filter on the dialysis machine and back into your body through another needle.

Most often a fistula is made in your arm. There are two blood vessels, a vein and an artery that have been sewn together. The needles used for dialysis which lead the blood to the machine are placed in the fistulaarm. If it is not possible to make a fistula, a haemodialysis catheter is used. It is a plastic tube placed through a hole in the skin into one of the large blood vessels on the chest.

You plan yourself in collaboration with the healthcare professionals, when, how long and how often you go through dialysis. At least you should have 15 hours of dialysis each week divided into 4-6 treatment sessions. The more dialysis you choose, the fewer symptoms of kidney failure you will experience.

Usually, it takes three months (three to five days a week in four to six hours) to be trained for home haemodialysis. Specially trained nurses teach you and the training takes place while receiving dialysis treatment.



Equipment for the treatment will be delivered to your home. You must store equipment for 14 days of treatment at a time, which corresponds to the size of a 2-winged wardrobe. In addition, you must store the dialysis machine and a water system.

Every second or third month, you will meet for a control visit at the hospital, but you will be able to contact the hospital around the clock if problems arise related to your treatment.

The most frequent complications of home haemodialysis are:

- Difficulty placing the needles in the fistula
- Fistula or catheter infection. Infections are treated with antibiotics.

P-dialysis

A sugary fluid is placed into the peritoneal during P-dialysis. The fluid drags liquid and waste from the blood into the peritoneal.

The dialysis fluid is led into the abdominal cavity through a thin plastic tube called a P-dialysis catheter. The catheter is operated into the stomach. It is approximately ½ cm in diameter, and about 30-50 cm is visible outside the stomach.

The fluids can be manually routed, for example, four times a day or with a machine at night when you sleep.

It usually takes three to five days (of six hours) to be trained in P-dialysis treatment. Specially trained nurses will teach you.

Equipment for the treatment will be delivered to your home. You must store equipment for 14 days of treatment at a time, which corresponds to the size of a 2-winged wardrobe and the dialysis machine itself.

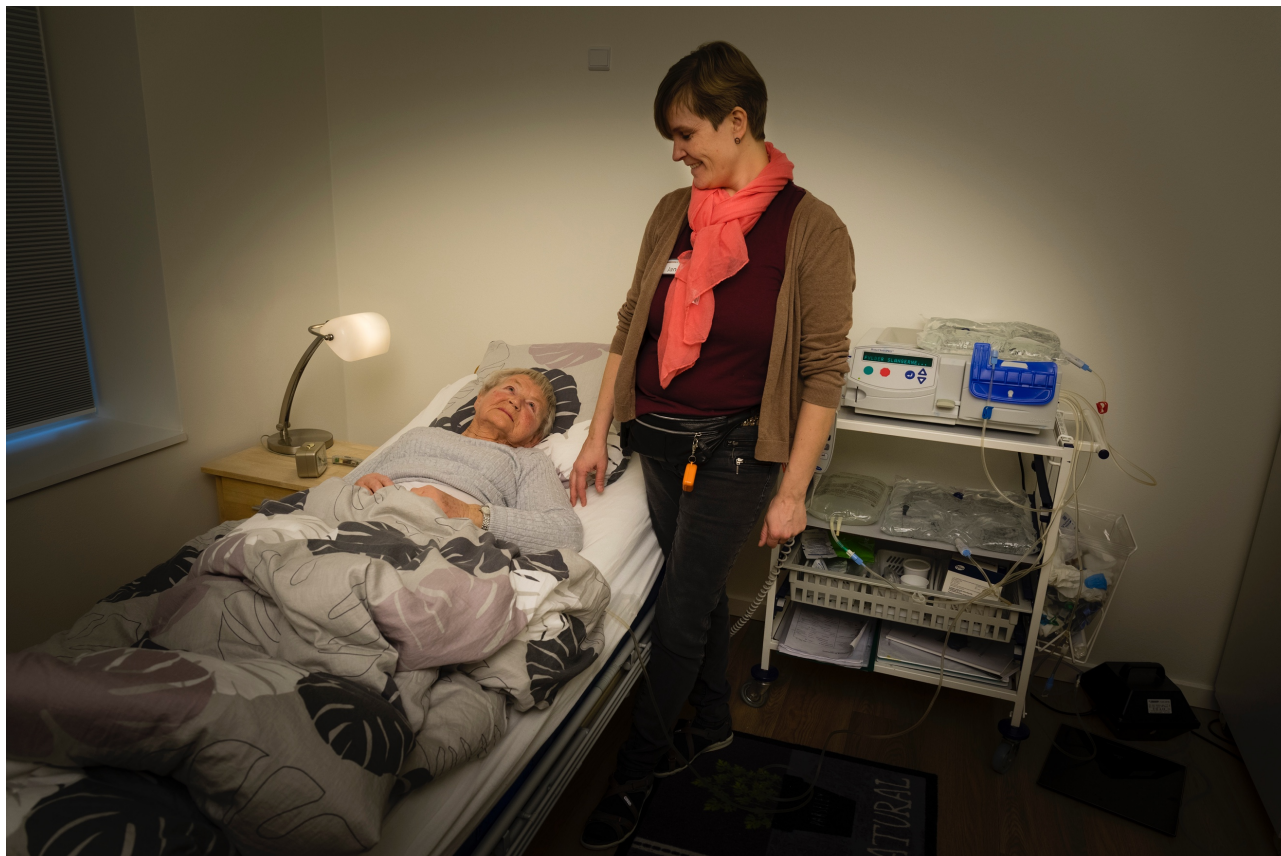
Every 6th to 8th week you meet for a control visit at the hospital, but you will be able to contact the hospital around the clock if problems arise related to your treatment.

The most frequent complications of P- dialysis are infection at the catheter exit site or in the peritoneal. Infections are treated with antibiotics.



P-dialysis with help

P-dialysis with help largely corresponds to P- dialysis. But instead of taking care of the treatment yourself, primary care staff will be taught. They help you with the treatment to the extent needed. For some, it means a visit to your home every morning and evening. For others, it means a visit in the middle of the day.



Dialysis at hospital

If you are not able to manage haemodialysis treatment yourself at home or do not want to take care of your treatment at home, you can get haemodialysis treatment at the hospital.

This treatment is technically equivalent to home haemodialysis.

You are offered dialysis treatment three times a week for four hours. Overall, you will have to spend about five hours in the hospital three times a week, and you will also have to consider time for transport to and from the hospital. Your fixed dialysis appointments are organised according to your wishes and the appointments available at the dialysis unit. It will primarily be nurses who take care of your treatment, but it is expected that you participate as much as possible.



If you are not able to transport yourself to and from dialysis, transportation will be arranged for you to and from the hospital

The most frequent complications of dialysis at the hospital are the same as in home haemodialysis, but you may also experience headaches, tiredness, dizziness, cramps and drops in blood pressure. These additional complications are due to fewer dialysis sessions compared to home haemodialysis.

What are the advantages and disadvantages of each option?

In Figure 4, you will find an overview of the most frequently asked questions by other patients who have had to decide on dialysis mode. The answers to the questions depend on which dialysis mode you choose.

If you have any other questions, please ask the nurse or your contact doctor. You are also welcome to ask additional questions to the answers given in the overview.

Keep in mind that P- dialysis with help does not have its own column, as it largely corresponds P-dialysis. The answers that specifically apply to P- dialysis with assistance are marked with a light green colour.

Figure 4: Frequently asked questions, an overview of options

Dialysis choice	Home haemodialysis	P-dialysis	Dialysis at hospital
		P-dialysis with help	
How often will I need the treatment?	As often you want. A minimum of 15 hours a week divided into 4-6 treatment sessions.	Every day. Either 7 – 9 hours a night and 15 minutes for mounting and dismantling, or 4 daily bag changes each lasting 30 minutes.	3 times a week. Every treatment session lasts 3 – 5 hours, and transport is added.
Do I need an operation?	Yes. If it is possible an operation in your arm, where two vessels are sewn together. It is called a fistula. If this is not possible, a dialysis catheter will be placed in one of the big vessel at your chest.	Yes. A P-dialysis catheter will be operated into your stomach.	Yes. If it is possible an operation in your arm, where two vessels are sewn together. It is called a fistula. If this is not possible, a dialysis catheter will be placed in one of the big vessel at your chest.
Who will take care of my treatment?	You do it yourself. There will be meetings at the hospital if needed. If you have problems or questions you will be able to contact the hospital.	You do it yourself. There will be meetings at the hospital if needed. If you have problems or questions you will be able to contact the hospital. If you are not able to take care of the treatment yourself, you are able to get help at your home.	A nurse will take care of your treatment at the hospital in collaboration with you. We expect you to participate as much as possible.
Do I need to storage equipment at home?	Yes. The dialysis machine, a water system (size of a kitchen cabinet) and some materials for the dialysis (size of a 2-winged wardrobe closet).	Yes. The dialysis machine and material for the dialysis (size of a 2-winged wardrobe closet).	No.
Which complications may arise in relation to my treatment?	Infection and other problems with the fistula or the dialysis catheter.	Infection and other problems with the fistula or the P-dialysis catheter.	Infection and other problems with the fistula or the dialysis catheter, as well as headache, tiredness, muscle cramps and lowered blood pressure.
How does the treatment influence my residual kidney function?	Your residual kidney function will diminish – probably faster than if you are on P-dialysis.	Your residual kidney function will diminish.	Your residual kidney function will diminish – probably faster than if you are on P-dialysis.
For how long will the treatment be effective?	This is a permanent treatment to go on as long as you or a relative is able to take care of it.	This is a time-limited treatment.	This is a permanent treatment.

Dialysis choice	Home haemodialysis	P-dialysis P-dialysis with help	Dialysis at hospital
What am I allowed to eat and drink?	There will be a few things you should not eat and drink. The more dialysis sessions you choose, the more freely you can choose to eat and drink among the few things you should not eat and drink.	There will be a few things you should not eat and drink. Maybe you will need to be careful concerning the amount of fluids you drink.	There will be several things you should not eat and drink. At the same time there will often be limitations to the amount of fluids you are allowed to drink.
What does this mean for my medicine consumption?	If you do dialysis every day, many can avoid or reduce medicine intake	Some will need extra medicine due to lack of kidney function.	Most people need extra medicine due to lack of kidney function.
How will it influence my life?	You can customize the time and duration of your dialysis according to work and leisure activities yourself.	You will be able to continue working and do what you used to do.	You will have regular appointments for dialysis and need to adjust your life accordingly.
What does it mean for my physical activities?	If you have a fistula you can go use swimming pools and swim in the ocean and lakes. You should avoid blows to the fistula. If you have a dialysis catheter you cannot use a swimming pool.	When using a swimming pool, swim in the ocean or lakes you have to put on a special dressing on your P-dialysis catheter. You should avoid heavy lifting.	If you have a fistula you can use swimming pools and swim in the ocean and lakes. You should avoid blows to the fistula. If you have a dialysis catheter you cannot use a swimming pool.
Can I still travel?	Yes It is possible to borrow a travel dialysis machine. You can also book a dialysis at a dialysis centre at the location you are travelling to. Planning is needed.	Yes It is possible to have liquids delivered to the destination of your holiday. Planning is needed when travelling abroad. Planning is needed. It requires that you have someone to help you at the destination of your holiday.	Yes You can book a dialysis at a dialysis centre in the country/at the location you are travelling to.
Will I experience changes in my appearance?	The fistula is placed in one arm. The fistula will develop and blood vessels will be more pronounced and maybe there will be a pouch on the vessel. You can feel a constant buzzing in the fistula. The dialysis catheter is placed at the chest.	The P-dialysis catheter is placed on your stomach. You may experience that your stomach gets a little larger than usual because of fluid in the abdominal cavity. You may experience a slight weight increase.	The fistula is placed in one arm. The fistula will develop and blood vessels will be more pronounced and maybe there will be a pouch on the vessel. You can feel a constant buzzing in the fistula. The dialysis catheter is placed at the chest.
What does these changes mean to my sex life?	No direct changes.	No direct changes.	No direct changes.

3. meeting – about the decision

The purpose of the third meeting is that you and your relatives will make a decision on future dialysis together with the nurse.

You are encouraged to prepare for the meeting with your relatives using the decision support template on the next two pages. Figure 5.

Figure 5: Decision guide, for you, who have to make decision regarding dialysis choice

1. Clarify your decision

What decision do you face?

What are your reasons for making this decision?

When do you need to make a choice?

How far along are you with making a choice? Not thought about it Thinking about it Close to choosing Made a choice

2. Explore your decision

Knowledge
List the options and benefits and risks you know.

Values
Rate each benefit and risk using stars (*) to show how much each one matters to you.

Certainty
Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option (Benefits/Advantages/Pros)	How much it matters to you: 0 * not at all 5 * a great deal	Reasons to Avoid this Option (Risks/Disadvantages/Cons)	How much it matters to you: 0 * not at all 5 * a great deal
Home haemodialysis				
P-dialysis				
P-dialysis with help				
Dialyse at hospital				

Which option do you prefer?

Home haemodialysis

P-dialysis
(Peritoneal dialysis)

P-dialysis with help

Dialysis at hospital

Unsure

Who supports your decision?

Who else is involved?	Who:	Who:	Who:
Which option do they prefer?			
Is this person pressuring you?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
How can they support you?			
What role do you prefer in making the choice?	<input type="checkbox"/> Share the decision with... <input type="checkbox"/> Decide myself after hearing views of...		<input type="checkbox"/> Someone else decides...

3. Identify your decision making needs

Knowledge	Do you know the benefits and risks of each options?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Values	Are you clear about which benefits and risks matter most to you?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Support	Do you have enough support and advice to make a choice?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Certainty	Do you feel sure about the best choice for you?	<input type="checkbox"/> Yes <input type="checkbox"/> No

The decision on dialysis choice is important for your life, both in terms of physical, mental and social conditions. Please note that a decision regarding dialysis choice can be changed. The decision can be changed before you start dialysis, but also when you have started dialysis. If your dialysis choice does not match your expectations, talk to your contact nurse or contact doctor.

Perhaps you should start dialysis in a month, maybe in a year. If it delayed, reconsider the decision at least every six months, to see if the decision you made still fits you and discuss it with your relatives, your contact doctor and contact nurse. When the time comes for starting dialysis, believe in the decision you have spent a lot of energy making.

"It is and will be a mess. I would prefer to be free of dialysis. But when it can not be different, I would like some options, so I can find the dialysis mode I prefer. I have gained so much knowledge about this, so I'm ready. It's entirely my own decision and I'm convinced that's the right one."




Bjarne Brøchner, a patient

Glossary

Dialysis:	Artificial cleansing of the blood for wastes and excess liquid. It is a replacement for lost kidney function.
Haemodialysis:	Cleanses the blood and removes excess liquid through a filter.
P-dialysis:	Cleanses the blood and removes excess liquid through the peritoneal.
Kidney transplantation:	May either occur with a kidney from the deceased donor or a kidney from a living donor. Requires lifelong treatment to avoid that the body rejects the transplanted kidney.
Fistula:	The fistula is made surgically by sewing together an artery and a vein in the arm to be used for cannulation?
Haemodialysis catheter:	Plastic tube surgically inserted into one of the big blood vessels through a small hole in the skin on the chest or the neck.
P-dialysis catheter:	Soft silicone tube surgically placed in the abdominal cavity.
Dialysis access:	An overall term for accesses which can be used for dialysis, i.e. fistula, haemodialysis catheter and P-dialysis catheter.

Further information regarding dialysis choice

- The homepage of the National Kidney Association: <http://nyre.dk>
- The APP from the National Kidney Association: 
- Sundhed.dk: <https://www.sundhed.dk/borger/patienthaandbogen/nyrer-og-urinveje/sygdomme/diverse/dialyse/>

This leaflet has been developed by patients and healthcare professionals in collaboration as a part of the project; Shared Decision-making and Dialysis Choice. Information about the project; contact clinical nurse specialist and PhD student, Jeanette Finderup jeajee@rm.dk. The project has not received any industrial funding. Last updated the 7th of November 2017.

A description of shared decision-making and dialysis choice (SDM-DC)¹

Item	Description
1. BRIEF NAME	Shared decision-making and dialysis choice (SDM-DC).
2. WHY	The intervention is an SDM intervention and achieving the ideal and essential elements of SDM stated by Makoul and Clayman [1]. The intervention is based on the first version of the three-talk model [2] consisting of three meetings, but also inspired by the Ottawa Decision Support Framework [3].
3. WHAT – MATERIALS	A PDA, called 'Dialysis choice', has been developed based on the method suggested by Coulter et al. [4], trying to meet the IPDAS criteria. The PDA consists of several tools: an overview of symptoms, a decision map, an overview of options, and OPDG – Danish version. In addition to the PDA, some other tools are available: four videos with four different patients, a folder with photos and drawings, a peritoneal dialysis catheter, and a needle for haemodialysis. All tools are to be shown and discussed with the patient.
4. WHAT – PROCEDURES	Three meetings are to be arranged between the patient and his or her relatives and a dialysis coordinator: The first meeting – a choice talk: to create an understanding of why a choice about dialysis mode has to be made and which options there are to choose between. The second meeting – an option talk: to provide insight into which options the patient has for dialysis, as well as discussing the advantages and disadvantages of each dialysis mode. The third meeting – a decision talk: to support the patient making a decision based on his or her informed preferences.
5. WHO PROVIDED	Six dialysis coordinators: Experienced nephrology nurses who have been trained in the why, what, and how of the SDM-DC. The initial training lasted two working days and has been followed up every six months by a one- or two-day refresher session.
6. HOW	The intervention is delivered face-to-face by the dialysis coordinator to the patient. The patient is encouraged to bring relatives to these meetings. The principles of SDM are used during the meetings: 1) the ideal and essential element of SDM; 2) the three-talk-model; and 3) the Ottawa Decision Support Framework. Three communication skills are used: 1) mirroring; 2) active listening; and 3) value clarification.
7. WHERE	The intervention is provided at the hospital in the outpatient clinic in a private room with access to a computer. The patient, relatives, and dialysis coordinator sit in chairs around a table. At one of the hospitals, the dialysis coordinator offered to provide the patient with one of the meetings at the patient's home.
8. WHEN & HOW MUCH	Patients are offered the intervention when they reach an eGFR below 20 ml/min. Each meeting is booked for one hour. When there is a need for an interpreter, the meeting is booked for one and half hours.
9. TAILORING	The intervention is tailored to each patient based on a decision need assessment. The number of meetings varies for each patient, with a variation between one and four meetings. Meetings are 'combined' by working with the aims from previous meetings at a later meeting. The tools are only used if they meet the needs of the patient or the dialysis coordinator.
10. MODIFICATIONS	Between October 2016 and February 2018, the support materials only had two videos. The next two videos were finished in February 2018. The folder with the pictures and drawings was ready to be used from January 2017.

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¹ The description is based on the TIDieR (Template for Intervention Description and Replication) Checklist.

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An evaluation of a shared decision-making intervention for dialysis choice at four Danish hospitals: a qualitative study of the patient perspective

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4 **An evaluation of a shared decision-making intervention for dialysis choice at four Danish**
5 **hospitals: a qualitative study of the patient perspective**
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9 Jeanette Finderup^{1, 2}, Jens Dam Jensen^{1, 2}, Kirsten Lomborg²
10
11

12 Department of Renal Medicine, Aarhus University Hospital, Denmark

13
14 ² Department of Clinical Medicine, Aarhus University, Denmark
15
16

17 Corresponding author

18 Jeanette Finderup, Department of Renal Medicine

19 Aarhus University Hospital

20 Palle Juul-Jensens Boulevard 99

21 8200 Aarhus N

22 Denmark

23 Phone: +4578452525

24 Email: jeajee@rm.dk
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33 **Keywords**

34 Shared decision-making, patient decision aid, complex intervention, qualitative evaluation
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38 **Abbreviations**

39 SDM: Shared decision-making

40 SDM-DC: Shared decision-making and dialysis choice

41 PDA: Patient decision aid
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Abstract

Objectives: To evaluate the 'Shared Decision-making and Dialysis Choice' (SDM-DC) intervention with regard to patients' experience and involvement.

Design: Semi-structured individual interviews and systematic text condensation for data analysis.

Setting: The SDM-DC intervention was implemented and evaluated at four different hospitals in Denmark.

Participants: A total of 348 patients had received the SDM-DC intervention, and of these, 29 patients were interviewed.

Interventions: SDM-DC was designed for patients facing a choice of dialysis modality. The available modalities were haemodialysis and peritoneal dialysis, either performed by patients on their own or with help from a healthcare professional. The intervention was tailored to individual patients and consisted of three meetings with a dialysis coordinator who introduced a patient decision aid named 'Dialysis Choice' to the patient.

Findings: The four main findings were: the decision was experienced as being the patient's own; the meetings contributed to the decision process; 'Dialysis Choice' contributed to the decision process; and the decision process was experienced as being iterative.

Conclusions: The patients experienced SDM-DC as involving them in their choice of dialysis modality. Due to the iterative properties of the decision-making process, a shared decision-making (SDM) intervention for dialysis choice has to be adapted to the needs of individual patients. The active mechanisms of the meetings with the dialysis coordinator were: 1) questions to and from the patient; and 2) the dialysis coordinator providing accurate information about the options. The overview of options and the value clarification tool in the decision aid were particularly helpful in establishing a decision-making process based on informed preferences.

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Strengths and limitations of this study

- Data richness was established by interviewing 29 patients. The interviews lasted on average 50 minutes with an information load of 23 normal pages on average.
- SDM-DC seems to be the first intervention based on the ‘three-talk model’, which is a well-cited SDM model.
- The whole research process has involved patients and healthcare professionals providing the intervention.
- The research only included Caucasian patients born in Denmark, and the findings are therefore limited to ethnic Danish patients.
- One of the developers of the intervention performed the interviews, but this challenge has been addressed in several ways.

For peer review only

Introduction

Patients with kidney failure must make a decision regarding dialysis modality, choosing either haemodialysis or peritoneal dialysis. Based on research, one modality is not uniquely better than the other (1-3). In order to offer the modality best suited to each patient's everyday lifestyle, international guidelines recommend involving the individual patient in the decision-making process, thus basing the decision on the patient's preferences (3). However, patient involvement does not always occur (4-6). For example, two studies from the USA showed that only 13% of patients experienced the decision process as shared decision-making (SDM) (7) and that patients over the age of 65 years did not experience the decision as a shared one (8). More recent studies indicate improvements in this area. A study from the UK that included routine measures of patient involvement at 27 different nephrology departments found that 69% of patients experienced SDM (9).

Based on SDM for dialysis choice, we developed and pilot tested an intervention called 'Shared Decision-making and Dialysis Choice' (SDM-DC) with the purpose of involving patients and their relatives in the decision-making process (10). In this article, we document patients' perspectives on using the SDM-DC intervention at four different hospitals in Denmark.

Background

A study of patient involvement in dialysis choice suggested that SDM could improve patients' experiences of involvement in the decision (11). A Cochrane Review indicated that an intervention based on SDM and supported by a patient decision aid (PDA) increased patients' experience of involvement (12). Another Cochrane Review focusing on PDAs showed middle-quality evidence that PDAs increase the proportion of people who are active in decision-making (13).

The SDM-DC intervention was developed in 2015 and then described and pilot tested (10). It includes a PDA, named 'Dialysis Choice', and is designed for patients with kidney failure who must make a decision regarding their future dialysis mode: haemodialysis or peritoneal dialysis. Both options may be performed by patients on their own or with help from a healthcare professional. SDM-DC is structured according to the 'three-talk model' (14) and consists of three meetings between the patient and his or her relative(s) and a dialysis coordinator. The dialysis coordinators have been trained to deliver the intervention using tailoring (15) based on a decision needs assessment and using three different communication skills: mirroring, active listening and value clarification (16-18). The PDA is designed to be utilised both at and between the meetings with

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4 individual patients and relatives who may be joining them. Two videos with personal stories are
5 available to be shown and discussed at the meetings if the patient needs to hear a personal story.
6 Patients and healthcare professionals have been involved in the development of the intervention and
7 the PDA (19). The decision aid is based on a systematic literature search where possible. Further,
8 the PDA is inspired by three other decision aids (20-22). The PDA is in paper format. It has been
9 accepted for the A to Z Inventory of Decision Aids – <https://decisionaid.ohri.ca/> – and assessed
10 according to the International Patient Decision Aids Standards (23). The PDA consists of a set of
11 tools: a decision map, an overview of uremic symptoms, an overview of options, and the Ottawa
12 Personal Decision Guide (24-25). A detailed description of the SDM-DC intervention can be found
13 in the supplementary material. The pilot test confirmed that SDM-DC was useful in encounters
14 between individual patients and a dialysis coordinator at a Danish university hospital but that
15 further research was needed to gain insight into the patients' experiences of involvement and the
16 implications for their choice of dialysis mode (10).
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28 **Aim**

29 The aim of this study was to evaluate the SDM-DC intervention with regard to patients' experience
30 and involvement.
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35 **Methods**

36 This study is part of a larger project evaluating the SDM-DC complex intervention (26-27). As
37 recommended for complex interventions (28-30), we first conducted a qualitative evaluation. The
38 quantitative evaluation is in review for publication elsewhere (31). Since October 2016, the
39 intervention has been delivered at four hospitals in Denmark by six different dialysis coordinators.
40 The inclusion criteria for the intervention were adult patients with chronic kidney disease referred to
41 a department of renal medicine with an eGFR below 20 ml/min measured by a 24-hour urine test.
42 Exclusion criteria were patients who had decided on palliation, patients with a living donor and a
43 set date for transplantation, and patients not able to participate due to cognitive impairment. The use
44 of an interpreter was not an exclusion criterion.
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Patient and public involvement

Patients and healthcare professionals have been involved in the whole research process (32-34) through an advisory board consisting of six dialysis coordinators and two patients. The two patients on the board have not been part of the intervention but are part of the target group for it. The first author and the advisory board met every six months during the research process. For this study, the advisory board has contributed particularly to the validation of the themes and inspiration for the discussion.

Data collection

We collected data through individual interviews with patients after they had participated in SDM-DC. We conducted interviews between 1 February 2017 and 8 August 2018. The patients were interviewed consecutively after receiving the intervention. The patients decided on their own where the interview would take place and whether their relatives would participate or not. The first author, who does not perform the intervention, conducted the interviews. The individual interviews were conducted according to Kvale and Brinkmann's guidelines (35) with a semi-structured interview guide. The purpose of the individual interviews was to gain a clear insight into how the patients experienced the impact of SDM-DC on their involvement in the decision-making process. The key elements in the 'three-talk model' (14) informed the content of the interview guide, which was structured chronologically around the first talk, the second talk, the third talk and decision support, from initial preferences to informed preferences and the decision. We adapted the interview guide for each interview according to how the patient, prior to the interview, had answered two questionnaires: the Shared Decision-making Questionnaire (36) and the Decision Quality Measurement (20), not changing the initial questions but making the follow-up questions more specific. During the interviews, the communication skills of mirroring and active listening were used (16-17). First, mirroring was used to bring patients' experiences to the forefront. Active listening, such as retelling the patient's story, then allowed patients to adjust their story if they wished. At the end of every interview, the interviewer summarised the patient's story so the patient could comment on this summary. The purpose of the interviews was not to question the decision the patient had made or to convey information. One patient was emotionally moved by the interview and was offered a new meeting with the dialysis coordinator.

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Ethical considerations

Participation in the intervention was based on consent for care and treatment. According to Danish legislation, this type of research is exempted from ethical approval. The Danish Data Protection Agency (jr. 1-16-02-456-16) approved data management. A third person obtained written consent from patients before their participation in the interviews.

Data analysis

To achieve a well-considered and well-documented analysis, we used a four-step systematic text condensation process (37-38). Systematic text condensation is a descriptive and explorative method for thematic cross-case analysis. During interviews, the first author performed some primary analysis and noted preliminary themes. These preliminary themes were discussed with the third author and the advisory board, which led to some changes. These themes were targeted in subsequent interviews with the following patients. The interviews were recorded and transcribed verbatim prior to data analysis, and the software program NVivo® 11 (39) was used for data management. Various features in NVivo® were used to support the different steps of the analysis process, and to ensure that analyses were both systematic and transparent. These features included Coding, Classification and Memos, and also Word Cloud to identify other preliminary themes, Text Search Query to find meaningful units that had been overlooked, and Matrix Coding Query to investigate whether a code could be attributed to some characteristic within the interview situation or interviewee. The first step in the systematic text condensation was naïve reading, which was performed to obtain an overview of the data. This was conducted continuously during the interview period. The second step was to identify and sort meaningful units by coding. The third step involved condensation of the meaningful units of interest in accordance with the aim of the study. All references from each source were condensed and written as narratives in the first person and present tense to represent each participant's story in relation to each specific code. The fourth and final step involved synthesizing the transcription of each finding. All condensed texts for each finding were aggregated into one text and formulated as narratives in the third person and past tense, including illustrative quotations.

Findings

The interviews took place between 14 days and 42 days after the intervention. Out of 59 patients invited for interviews, 33 accepted the invitation, but four of these patients were not able to participate due to their medical condition worsening. Table 1 shows the characteristics of the 29 patients who participated in the interviews side by side with the characteristics of the whole sample. The variation in the sample was close to the total sample for the intervention according to gender, age, hospitals, dialysis coordinators and the choice of dialysis mode.

Table 1. Participant characteristics*

	Intervention sample (n=349)	Interview I study sample (n=29)
	n (%)	n (%)
Sex		
Female	123 (35)	8 (28)
Male	226 (65)	21 (72)
Age (years)		
age < 50	38 (11)	0 (0)
50 ≤ age < 60	45 (13)	3 (10)
60 ≤ age < 70	94 (27)	9 (31)
70 ≤ age < 80	112 (32)	12 (42)
age ≥ 80	59 (17)	5 (17)
eGFR** (ml/min)		
eGFR < 10	82 (23)	3 (10)
10 ≤ eGFR < 20	244 (70)	26 (90)
eGFR ≥ 20	23 (7)	0 (0)
Chosen option		
Peritoneal dialysis	228 (65)	20 (69)
Home haemodialysis	26 (8)	4 (14)
Hospital haemodialysis	87 (25)	5 (17)
No decision	8 (2)	0 (0)
Number of meetings		
1	90 (26)	2 (7)
2	215 (62)	17 (59)
3	40 (11)	10 (34)
4	4 (1)	0 (0)
Hospitals***		
I	180 (52)	12 (41)
II	53 (15)	7 (24)
III	60 (17)	8 (28)
IV	56 (16)	2 (7)

*Data used in this table have been registered by the dialysis coordinators and are consistent with the documentation in the patients' electronic health records.

**eGFR is the abbreviation for estimated glomerular filtration rate.

***The roman numerals indicate each of the participating hospitals.

The interviews lasted on average 50 minutes, ranging from 26 to 73 minutes, with an information load of 670 normal pages in total, and 23 normal pages on average. Fifteen interviews were conducted at the hospitals and 14 in patients' homes. Eight patients chose to participate in the

interview together with a spouse, and 21 were on their own. Table 2 gives an overview of the category headings, codes and chosen quotations.

Table 2. An overview of the findings and chosen quotations[†]

Category headings^{††}	<p>The decision was experienced as being their own (28 participants & 66 quotes)</p> <p>At the first meeting, my son and daughter-in-law were with me. And when we drove home, we did not talk much about it. I let a few days pass and I thought, "Let them just go and... They should also have time to think a little, and I should have some time to think what I was going to say at the next meeting and all..." Then I talked to them. Then I asked, "What would you choose after the first meeting?" They would choose dialysis at the hospital. Then I said, "Well, it's funny that you say that because that's what I've decided, that's how I want it to be." I've decided this myself, and I think it's a good thing that it's not just the hospital saying what I'm going to do. I hope, because I have decided this myself, I must make the best of it when it can't be any different. Rather than saying that we have just decided this over your head and then say, "Oh, it's so annoying that they make the decisions." There is no one to blame if I think it's a bad decision. Only myself anyway. It is already hard enough. It's my own decision. I actually think it's quite important that you make the decision yourself. I'm old enough to do that. I have not been good at saying no before, but... It's my life and it's my choice and that's how it should be. [16]^{††††}</p>
Codes^{†††}	<p><i>Other decisions</i> (14 participants & 28 quotes)</p> <p>Well, that's probably the first time I've participated in a decision about my illness and treatment. I had an operation on my throat, and I was just told how it should be and when it should be. So I just had to show up. So far, I have just been to see my doctor to get to know how my illness was developing. I get medicine, but I have not been a part of that decision. I have no background to know anything about it, but [in this situation] I have done so. Well, I don't know. I would not have been surprised if you had just decided what to do, because the doctors usually decide everything. And I wouldn't know I had other options. [8]</p>
Category headings^{††}	<p>The meetings contributed to the decision process (29 participants & 95 quotes)</p> <p>If I should have done it [made a decision] without the meeting, it would have been hard. Because then I would have to read about it and I would really not understand a thing. I would not be able to see myself [which decision was right for me]. Now, the dialysis coordinator like explained the different scenarios to me. And it's in light of this I said that I want peritoneal dialysis. She [the dialysis coordinator] supported this – "I think this is right for you," she said. So no, no, it's my own decision – 100%. [10]</p>
Codes^{†††}	<p><i>Questions to and from the patient</i> (21 participants & 39 quotes)</p> <p>She [the dialysis coordinator] actually puts the questions she has to ask in a nice way. Not like a chainsaw. In a nice way. And I also think she manages to get some answers from people when she does it like that. I'm not an open person, I keep things to myself, and people have to lure things out of me. Her questions make me think about things. It gives me peace of mind to get rid of what I'm thinking about. I want to know what it is, and it must be reliable, what I'm told. And I always think I've received an answer. Because... that's life. Life has taught me that if I do not ask, I don't get any answers. Here, she asked her questions, because it was unfamiliar territory. I'm on shaky ground. I had the question, "Why is it haemodialysis you want, and why is it not peritoneal dialysis?" Then we talked about the differences. Well, what happens in my everyday life if I choose haemodialysis and what happens if I choose peritoneal dialysis? And I know that with peritoneal dialysis, I can have some equipment I can take around with me. [13]</p> <p><i>Accurate information was helpful for the patient</i> (12 participants & 20 quotes)</p> <p>It was positive to have the meetings with XX [a dialysis coordinator]. Because she told me a</p>

	<p>lot. And she had an answer ready when I asked. And I'm sorry to say, but some of them [other healthcare professionals], I call them circus clowns. They say "Ah, well..." and "I have to look into that" and "I will be back with an answer" and stuff like that. But XX [a dialysis coordinator], she did not act in that way. I asked and then she had the answers right at hand. [12]</p>
	<p><i>Bringing a relative into the meetings contributed to the decision process</i> (24 participants & 75 quotes)</p> <p>Well, it has meant a lot to me that my wife was with me at the meetings because we were able to talk about it afterwards. She is my extra pair of ears. I have some problems with hearing. It is nice to have somebody there with you, because you get emotional sometimes. So she's not just there because of my bad hearing. The information at the meetings gets me started thinking, I get emotional, and then I don't listen that well. We are in such a vacuum at the moment, waiting to get started with a new part of our life. It is primarily me, but of course also her. It affects everybody in our household. [13]</p>
Category headings^{††}	<p>The decision aid contributed to the decision process (29 participants & 70 quotes)</p> <p>But when you sit there starry-eyed and don't know anything, it [the decision aid] can help a lot. Also that you get more information about it [the decision]. [1]</p>
Codes^{†††}	<p><i>The overview of options contributed to the decision process</i> (18 participants & 28 quotes)</p> <p>The further we went down the list of options, the more it became clear to me that I want P-dialysis. That's what I want. That's the solution that suits my life and my need for freedom best. I think the different colours will do something for me. I heard what she told me, read the chart, saw the different colours when she pointed at them, it meant something to me. [3]</p> <p><i>The value clarification tool contributed to the decision process</i> (15 participants & 25 quotes)</p> <p>We were in a state of rebellion. We were a bit confused. Because we were not really aware of what was happening or should happen or what could happen. But then we worked with it at home and talked about it. We had an assignment to do at home that we went through together. The assignment made us arrive at this decision. I think it made us compare the different options. It gave us an overview because we could compare pros and cons. [23]</p> <p><i>The videos contributed to the decision process for some patients</i> (14 participants & 17 quotes)</p> <p>The best thing about it was the short video with the man who had lived with P-dialysis for 11 years, and it's obvious that he would rather live with dialysis than not live at all. And that kind of helped. He apparently seemed to be doing well. He seemed happy and satisfied. It helped me a lot, because I sometimes worry. I'm a little afraid of dialysis. It's a big deal to me and then... It was really good, because it made me less concerned about what it [dialysis] really would be, or it actually made my concern disappear. [19]</p> <p><i>Other patients contributed to the decision process sometimes</i> (13 participants & 38 quotes)</p> <p>I probably had some reservations from the start. Because I was hospitalised in April last year, and I was with a guy on peritoneal dialysis. He participated in biker meetings, and sometimes, he just had peritoneal dialysis and then he went out [biking] again. And if he could do it, so could I with my hobby as a dog trainer. I would also do it in that way. I got an impression of freedom he had. I didn't think so much about going on dialysis myself. But I saw it as a good experience, and something that was good, and the treatment was good. [8]</p>
Category headings^{††}	<p>The decision process was experienced as being iterative (28 participants & 140 quotes)</p> <p>So we have had the number of meetings we think we needed. But we don't know yet. The difficult thing here is that we are talking about something we imagine. It's like a trip we're going on. Then you have some expectations, but you don't know where it really ends. It's like when we start this, we'll get to know something, and it's great, what we are told, but we don't know if there will be any questions along the way, and there automatically will be. Afterwards, we had the experience, we bought the trip or we have been on it. I have become more sure of it [my decision], after the meetings, that is. At the kidney school [a 2-day Kidney school, each</p>

	day with a four hour information session on chronic kidney disease] they told me it should be peritoneal dialysis, or perhaps, but without deciding, but it was the decision I was more likely to make. And then after those meetings, I realised that it should be peritoneal dialysis. So, I made a decision, right. [5]
Codes^{†††}	<p><i>Dialysis choice came as a shock</i> (14 participants & 48 quotes)</p> <p>You have had diabetes for about 15 years; you haven't thought that it would mean that your kidneys failed at some point and that you have to have dialysis. [Interviewer] You thought then that you might lose a leg, but then I thought I haven't smoked since 1981. But I haven't thought about the kidneys. She told me that it's now time for dialysis or transplantation. It was a shock, I admit – like out of the blue. I was pretty shaken. And now, you have seen what kind of options you have and what the next step is... I decided at the third meeting because it was new to me and it was kind of a shock. It felt like the rug being pulled from under my feet. [26]</p> <p><i>Received new information during the interview</i> (11 participants & 35 quotes)</p> <p>Really good. Well, I'm already much more informed. [17] And I shouldn't tell you anything today, I just want to listen. It's you who should tell me something. [Interviewer]</p> <p>-----</p> <p>So, and then they say that, in the end, you can't pee. Well, now, what is that about? So, I can't imagine it, not being able to pee, and where and how does the pee accumulate? Do you at some point turn into a balloon? [27] Your urine production will slow down gradually. But then the fluid is removed by dialysis. It's the dialysis removing the urine because it draws out the fluid. [Interviewer]</p> <p><i>Not sure it was the right decision</i> (5 participants & 13 quotes)</p> <p>I try not to think about it from day to day. But now and then, you think, "What is it that I'll be going through?" And then I think, "Tubes in the stomach, that was unusually uncomfortable. Could I get peritonitis?" I think. But, of course, you can also get something with the other [dialysis modality], right? Yes, and I think many, many, many times about whether it was the right decision. Just think, you get this machine home with you and all those boxes, and they take up a lot of space. I don't know how much, but they are delivered by a truck. That sounds terrible, doesn't it? Do I have enough room? And how long is the tube that is going to reach the bathroom? And we have two cats who play around at night and have a wonderful time. They play with stuff. I think about how thirst will turn out. And it has to be totally clean, the room you sleep in [and use for dialysis]. [27]</p> <p><i>Preferred not to receive dialysis</i> (13 participants & 23 quotes)</p> <p>Well, you have to understand that I don't go around hoping for dialysis because, first of all, it doesn't look very sexy and, secondly, it limits me. It limits the life I would like to live, but I'm also realistic, I know it's coming. You should know that. Because I would have preferred to avoid it – who wouldn't? No, it's a choice between plague and cholera, there's no doubt about that. [10]</p> <p><i>'No dialysis' was not an option</i> (9 participants & 17 quotes)</p> <p>So, I decided after all that dialysis had to be better than just doing nothing. But we have talked about the fact that we are old, we have experienced a lot, nobody owes us anything in this life – no good and bad things. So that was part of my considerations. [19]</p>

[†]The quotations have been translated into English as accurately as possible.

^{††}The category headings are in **bold** in the text.

^{†††}The codes are in *italics* in the text.

^{††††}The numbers in square brackets are the identification numbers of the participants.

'The decision was experienced as being their own' was stated by 28 patients in different ways.

Some of the patients stated that they had made their decision together with their relatives; others stated that their relatives had not influenced their decision. Some patients stated that their relatives

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4 agreed with their decision. They stated that the healthcare professionals had not made the decision,
5 even though the dialysis coordinator had contributed to the decision process. For several patients, it
6 had been important that the healthcare professionals had confirmed their decision. One patient did
7 not directly express that the decision was his own [2]. This patient was over the age of 80, and the
8 focus for his decision process was whether to go on dialysis or not. Several patients stated that it
9 was important that the decision was their own because they thought it made the decision easier to
10 accept. None of the patients experienced being left alone with the decision process.
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18 *Other decisions.* Most of the patients had lived with disease for a long period. Most of them had
19 never before experienced being involved in a decision about their treatment. Most of the patients
20 felt that no decision had been involved in previous treatments at all. A few patients had experienced
21 participating in a decision about treatment before, but mostly, their experience was that the
22 healthcare professionals regarded patient involvement as an unwelcome interference. Such patients
23 wished that these healthcare professionals had invited them to take part in the decision process and
24 communicated some information to them, to enable them to participate.
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32 **The meetings contributed to the decision process.** All 29 patients reported that the meetings with
33 the dialysis coordinators had contributed to the decision process and that they would not have been
34 able to make the decision on their own without the meetings. The patients emphasised the relaxed
35 nature of the meetings as being significant. They felt they had time to go into the decision process
36 in depth.
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42 *Questions to and from the patient* were emphasised by most patients as a significant property of the
43 meetings. There was no relation to demographic, gender, age, or the dialysis coordinator. Questions
44 to the patients addressed the impact of the decision on their everyday life. The patients experienced
45 these questions as being asked in a nice, easy way. Questions from the patients were concerned with
46 practical issues. The patients felt confident they could ask the same questions several times.
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52 *Accurate information was helpful for the patient.* Some of the patients emphasised that information
53 communicated by the dialysis coordinator had been helpful in the decision process. These patients
54 stated that the information communicated should be detailed, accurate, and appropriate to their life,
55 and that information should be repeated. Two patients [2, 7] expressed that some of the information
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communicated by the dialysis coordinator had not been helpful; this appeared to be when the dialysis coordinator gave too much information at a single meeting.

Bringing a relative into the meetings contributed to the decision process. This was emphasised by most of the patients. They had chosen to bring a relative to be part of the meetings, most often a wife or husband but in some cases a daughter and son-in-law or a friend. Bringing a relative to the meetings was mentioned as “a habit”. These patients were used to bringing a relative to important meetings at the hospital and expressed that “being two” made it possible for them to ask more and different questions. They further emphasised the benefits of there being two people to listen. A few patients [6, 11, 17, 19, 29] did not bring a relative to the meetings. These patients explained that they did not have a significant other in their lives or that their significant others were too ill to participate in the meetings.

The decision aid contributed to the decision process. All 29 patients expressed that they could not have made their decision without help from the decision aid. The patients talked about the PDA as one tool and only mentioned two of the tools within the PDA specifically: the overview of options and the value clarification tool. Some of the patients mentioned the two videos, and they also mentioned other patients, although other patients are not an integrated part of the intervention.

The overview of options contributed to the decision process. This was expressed spontaneously by most of the patients. The tool had clarified or confirmed their decision. They had used the tool during the meeting, but also after the meeting and in preparation for the next meeting. Several patients stated that they had saved the tool and continued to use it.

The value clarification tool contributed to the decision process. Most of the patients stated spontaneously that the value clarification tool was particularly valuable. Several patients indicated specifically that this tool had contributed to the decision process and elaborated that the questions in the tool had enabled them to reflect, in particular the part where they write down pros and cons. Some patients had filled in the tool before the meeting using the value clarification tool, and others received help at the meeting to complete it.

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4 *The videos contributed to the decision process for some patients.* Some patients used positive words
5 in their descriptions of the videos. One patient reported that the videos had helped him change his
6 decision [25], one reported that the videos had removed his concern about dialysis [19], and one
7 that they had provided some concrete visuals of how dialysis takes place [13]. Three patients used
8 positive words about the videos but stated explicitly that the videos had not contributed to their
9 decision process [3, 4, 7]. One patient used negative words about the videos [16]. This patient had
10 made a decision before seeing the videos and would have preferred them to have a more practical
11 focus.
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20 *Other patients contributed to the decision process sometimes.* A number of patients in the sample
21 met other patients on dialysis. For some of this group, meeting other patients on dialysis contributed
22 to the decision process, but several of these patients [3, 11, 22, 25, 27] did not choose the same
23 option as the patient they had met. A few of the patients did not know why the patient they met had
24 chosen as they had. Other patients contributed to the decision process by making dialysis more
25 concrete and presenting possibilities. For some of the patients, it was scary to meet other patients on
26 dialysis.
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34 **The decision process was experienced as being iterative.** Only one patient did not mention the
35 decision process at all. This patient had only one possible dialysis modality. Four patients stated
36 that they had made their decision before the meetings, but all four had their decision confirmed
37 during the meetings. Nine patients experienced that their decision was made during the meetings.
38 One of these patients had made a decision beforehand but changed this during the meetings. Eight
39 patients experienced that their decision was made concrete at a meeting. Two patients made their
40 decision at the first meeting, three patients made their decision at the second meeting, and three
41 patients made their decision at the third meeting. Figure 1 gives an overview of when patients felt
42 their decision was made.
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51 **Figure 1. Overview of when the patients experienced the decision to be made**

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54 Nearly all participants experienced the decision process as iterative. Although they had made a
55 decision, they still needed to confirm this decision, to ask questions, and to reconsider it. There was
56 not only a single option suitable for each patient, but several patients decided on one option to start
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4 with (plan A) and then had a plan B and C.
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8 *Dialysis choice came as a shock* for half of the patients, although they had been known to the
9 departments of renal medicine for several years. That dialysis could actually be a treatment for them
10 occurred to the patients just before the meetings or during the meetings. Some of the patients knew
11 that dialysis might be an option someday, but they had ignored this knowledge and thought it was
12 not going to happen to them. One of the patients [10] was happy not to have received this
13 knowledge previously, but two of the patients [12, 23] stated that they would have preferred to have
14 known earlier. One patient [13] stated that he would have preferred to receive this knowledge in a
15 nice, easy way. Surprisingly, no correlation has been found between eGFR and dialysis choice
16 coming as a shock. Rather, it appeared to be experienced as a shock more often by patients at two of
17 the hospitals compared to those at the other two.
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27 *Received new information during the interview.* Some patients received new information about the
28 significance of the decision regarding dialysis modality during the interview. It was not the
29 intention for the interviewer to interact with the intervention, but the patients asked some questions,
30 and the interviewer tried to answer these questions briefly. The information given did not change
31 their decision. One patient had doubts after the interview and needed one extra meeting. This
32 meeting did not change her decision [27].
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39 *Not sure it was the right decision* was expressed by five patients. At the same time, they said that
40 there was nothing we could do to make them more certain about the decision. They stated that they
41 thought they would feel certainty when they first started dialysis.
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46 *Preferred not to receive dialysis* was expressed by some of the patients. They preferred not to
47 receive any dialysis treatment and characterised the options as a choice between two evils
48 associated with various problems and a loss of their present lifestyle. These participants still hoped
49 to recover and no longer be in need of dialysis.
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55 *'No dialysis' was not an option* was considered by some of the patients. This code was mainly found
56 among patients over the age of 80 years. The patients aged over 80 felt they still had something to
57 live for. Some stated that if their spouse died, they would reconsider their decision and perhaps
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4 choose 'no dialysis'. Most of the patients stated that they had considered these issues on their own,
5 but they had shared their consideration with the healthcare professionals.
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9 **Discussion**

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11 In summary, the patients experienced the decision as being their own, but both the meetings and the
12 PDA had contributed to the decision-making process. They experienced the decision-making
13 process as iterative. The discussion is divided into three sections. The first two sections correspond
14 to the aim, and the last section focuses on limitations of the study.
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19 *How did the patients experience the SDM-DC intervention in terms of their involvement?*

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21 The purpose of the intervention was to involve patients in the decision-making process. **'The**
22 **decision was experienced as being their own'** was a significant finding, which demonstrates that
23 the patients experienced SDM-DC as involving them in the decision-making process. The SDM-DC
24 pilot test predicted this finding, because some of the patients did not experience the decision as a
25 shared decision, but their own decision (10). Due to the age of the patient group, this finding was
26 surprising when compared to a study focusing on the involvement of the over-65 age group (40).
27 That study showed that many patients were not involved in the decision-making process about
28 dialysis choice, but the patients who were involved, were more satisfied with their dialysis modality
29 (40). We found the patients experienced the decision process as iterative. SDM-DC is based on the
30 'three-talk model' by Elwyn et al (14). The simple version of the 'three-talk model' presents the
31 SDM process as linear, suggesting that patients go into the decision-making process without any
32 decisions and complete the process with a decision. In 2017, the 'three-talk model' was updated and
33 is no longer presented as a linear model, but a circular one (41). Both models have their advantages.
34 In clinical practice, it is easier to implement an intervention based on the linear model with clear
35 progression through the process. Nonetheless, it is worth noting that SDM-DC seems to be the first
36 intervention to apply the linear version of the 'three-talk model' (41). The model has been cited a
37 number of times elsewhere but only for presentations, workshops and training programmes. A
38 Canadian study found five phases in the decision-making process regarding dialysis choice: 1)
39 progress toward acceptance to be dialysed; 2) receive information; 3) take some time for personal
40 reflection; 4) seek the opinion and support of others; 5) re-evaluate one's choice (42). The
41 development of SDM-DC was not based on this framework, but our evaluation showed that most of
42 these phases have been met by the intervention.
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6 *How did the patients experience the SDM-DC intervention?*
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8 The patients highlighted two important elements of the meetings: 1) questions to and from the
9 patient; and 2) the dialysis coordinator providing accurate information about the options. The fact
10 that daily life with dialysis needs to be described as concretely as possible has been documented
11 elsewhere (43). The patients experienced the participation of their relatives in the meetings as an
12 advantage. This finding is in accordance with a study of the perspective of the relative, showing that
13 relatives felt involved in the decision-making process and that they had an important supportive role
14 (44). The dialysis coordinator provided decision coaching as part of the SDM process. The
15 definition of decision coaching is '*individualized, nondirective facilitation of patient preparation*
16 *for shared decision-making*' (45). In spite of this, the decision was made together with the dialysis
17 coordinators at the meetings and not afterwards with the physician. Decision coaching has, in other
18 studies, been shown especially to improve the patient's knowledge and involvement in decision-
19 making (45). The whole of the 'Dialysis Choice' PDA contributed to the decision-making process,
20 but the patients identified the overview of options and the value clarification tool as being
21 particularly helpful. An Option Grid is a specific type of overview of options, and research has
22 shown that, for some health decisions, an Option Grid supports patients in the decision-making
23 process (46). From a healthcare perspective, the Option Grid has been found to be easy to use to
24 facilitate patient involvement in the decision-making process (47). In general, Option Grids have
25 proven beneficial for sharing information but less useful for value clarification (48). In the
26 Cochrane Review of PDAs, value clarification is defined as an important part of a PDA and SDM
27 (13). The combination of the overview of options and the value clarification tool appears to be a
28 good one. In the development of our intervention and the PDA, we tried to meet all the decision
29 needs described for this patient population (11, 42, 49-51), but this study added two more decisional
30 needs for this patient population, namely that, the decision came as a shock to the patient and that
31 there is not only one choice but a plan A, B and C. These decisional needs should be implemented
32 into an SDM intervention for dialysis choice. The impact of stories on patient decision-making has
33 been unclear (52). The patients in our study felt the videos were not as unequivocally positive as the
34 decision aid. Nor was meeting other patients on dialysis an unequivocally positive finding.
35 Sometimes, other patients contributed to the decision-making process to a certain extent. The use of
36 narratives in decision aids has been a focus in the International PDA Standards collaboration since
37 the beginning (20). An experimental study has shown that patients are more likely to choose a
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4 dialysis modality presented by a patient rather than a healthcare professional, which is why caution
5 has been recommended in the use of patient stories (50). It seems that the patients in our study used
6 the videos and other patients more as inspiration and less as direction, thus complying with the
7 purpose of SDM to establish a decision process based not on uninformed preferences but on
8 informed preferences (14). How the intervention has contributed to this needs to be investigated
9 further.
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15 16 *Limitations*

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18 This study has some limitations. For a qualitative evaluation, 29 patients is a relatively large
19 number of participants. This number was chosen to give the right level of information power (53),
20 because the intervention was performed at four different hospitals, by six different dialysis
21 coordinators, and the patients had to decide between different options. Only Caucasian patients
22 were included, and the findings are therefore limited to ethnic Danish patients. If we had included
23 some ethnically non-Danish patients, the findings could have taken other directions. This is
24 indicated by a study showing that Japanese patients make decisions that are more consistent with
25 their network's wishes and preferences (54). One of the developers of the intervention carried out
26 the interviews in our study, and this is mentioned by Malterud as a point to pay attention to (37).
27 We managed this challenge in various ways: 1) the interviewer did not perform the intervention; 2)
28 the patients did not know that the interviewer had developed the intervention; and 3) the interview
29 findings were discussed with the advisory board. Furthermore, the patients expressed criticism of
30 the intervention during the interviews. The interviews were performed at least two weeks after the
31 intervention. Thus, some memory failure may have occurred since patients with an eGFR below
32 20ml/min may have cognitive deficit and short memory (55). We assume that the patients have a
33 better memory of the last meeting than the first meeting. We do not yet know the extent to which
34 the intervention has been performed as intended. In the sample, we found two patients who had
35 filled out the value clarification tool, but the dialysis coordinators had not used the homework
36 during the meetings. The dialysis coordinators, who are part of the advisory group, later explained
37 that they found the value clarification tool difficult to use in the beginning.
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54 **Conclusion**

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56 The patients experienced SDM-DC as involving them in their choice of dialysis modality. Due to
57 the iterative properties of the decision-making process, an SDM intervention for dialysis choice
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4 needs to be adapted to the needs of individual patients. The active mechanisms of the meetings with
5 the dialysis coordinator were: 1) questions to and from the patient; and 2) the dialysis coordinator
6 providing accurate information about the options. The overview of options and the value
7 clarification tool in the decision aid particularly contributed to the decision-making process based
8 on informed preferences.
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13 14 **Acknowledgements**

15
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19 in this study.
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23 24 **Conflicts of interest**

25
26 The authors declare no potential conflicts of interest with respect to the research, authorship and/or
27 publication of this article.
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29

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32
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34 Association, and the Danish Nurses Organisation.
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38 39 **Contributorship**

40 JF: Designed the project, collected and analysed data, and drafted the final manuscript.
41
42 JDJ and KL: Provided academic supervision, helped to draft the manuscript, and read and approved
43 the final manuscript.
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47 48 **Data sharing statement**

49 No additional data are available.
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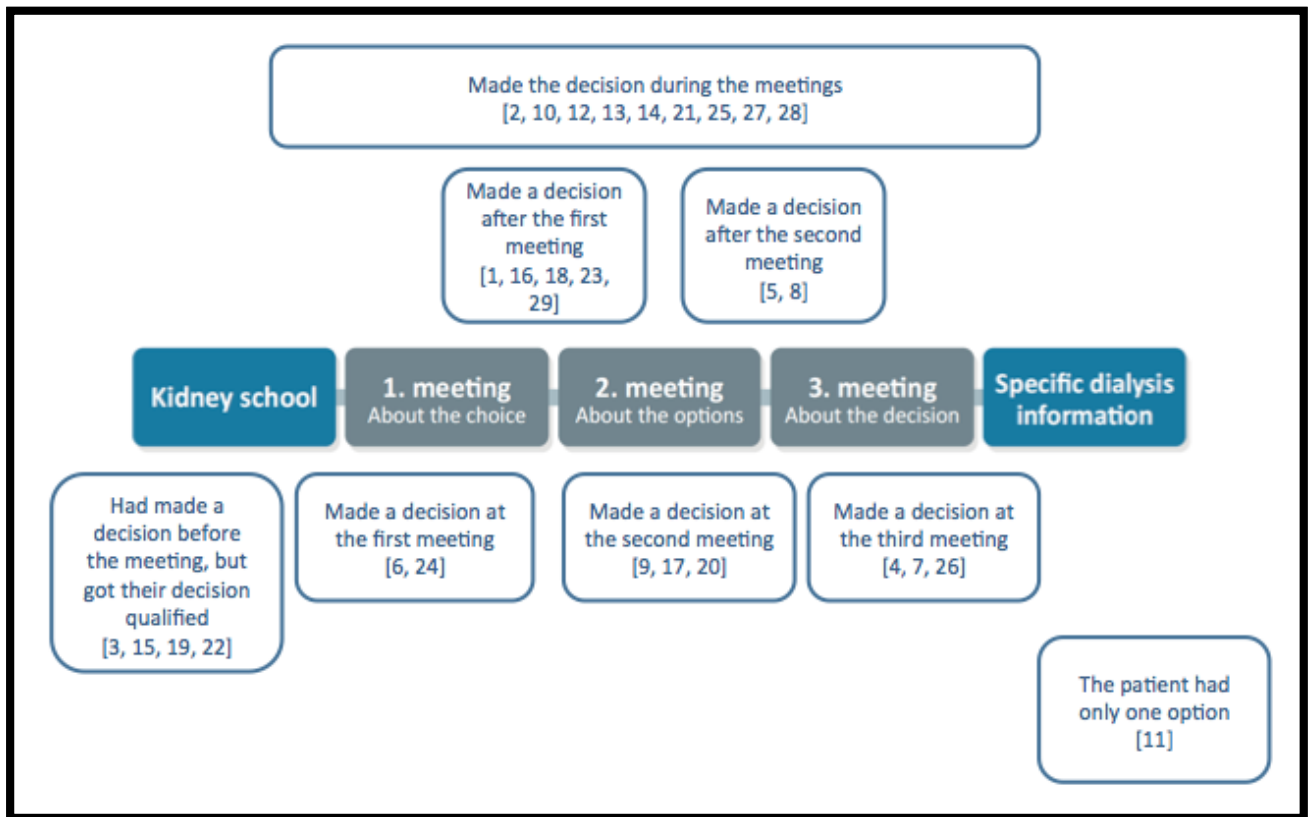
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Figure 1. Overview of when the patients experienced the decision to be made



Kidney school: A 2-day school, each day with a four hour information session on chronic kidney disease

A description of shared decision-making and dialysis choice (SDM-DC)¹

Item	Description
1. BRIEF NAME	Shared decision-making and dialysis choice (SDM-DC).
2. WHY	The intervention is an SDM intervention and achieving the ideal and essential elements of SDM stated by Makoul and Clayman [1]. The intervention is based on the first version of the three-talk model [2] consisting of three meetings, but also inspired by the Ottawa Decision Support Framework [3].
3. WHAT – MATERIALS	A PDA, called 'Dialysis choice', has been developed based on the method suggested by Coulter et al. [4], trying to meet the IPDAS criteria. The PDA consists of several tools: an overview of symptoms, a decision map, an overview of options, and OPDG – Danish version. In addition to the PDA, some other tools are available: four videos with four different patients, a folder with photos and drawings, a peritoneal dialysis catheter, and a needle for haemodialysis. All tools are to be shown and discussed with the patient.
4. WHAT – PROCEDURES	Three meetings are to be arranged between the patient and his or her relatives and a dialysis coordinator: The first meeting – a choice talk: to create an understanding of why a choice about dialysis mode has to be made and which options there are to choose between. The second meeting – an option talk: to provide insight into which options the patient has for dialysis, as well as discussing the advantages and disadvantages of each dialysis mode. The third meeting – a decision talk: to support the patient making a decision based on his or her informed preferences.
5. WHO PROVIDED	Six dialysis coordinators: Experienced nephrology nurses who have been trained in the why, what, and how of the SDM-DC. The initial training lasted two working days and has been followed up every six months by a one- or two-day refresher session.
6. HOW	The intervention is delivered face-to-face by the dialysis coordinator to the patient. The patient is encouraged to bring relatives to these meetings. The principles of SDM are used during the meetings: 1) the ideal and essential element of SDM; 2) the three-talk-model; and 3) the Ottawa Decision Support Framework. Three communication skills are used: 1) mirroring; 2) active listening; and 3) value clarification.
7. WHERE	The intervention is provided at the hospital in the outpatient clinic in a private room with access to a computer. The patient, relatives, and dialysis coordinator sit in chairs around a table. At one of the hospitals, the dialysis coordinator offered to provide the patient with one of the meetings at the patient's home.
8. WHEN & HOW MUCH	Patients are offered the intervention when they reach an eGFR below 20 ml/min. Each meeting is booked for one hour. When there is a need for an interpreter, the meeting is booked for one and half hours.
9. TAILORING	The intervention is tailored to each patient based on a decision need assessment. The number of meetings varies for each patient, with a variation between one and four meetings. Meetings are 'combined' by working with the aims from previous meetings at a later meeting. The tools are only used if they meet the needs of the patient or the dialysis coordinator.
10. MODIFICATIONS	Between October 2016 and February 2018, the support materials only had two videos. The next two videos were finished in February 2018. The folder with the pictures and drawings was ready to be used from January 2017.

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¹ The description is based on the TIDieR (Template for Intervention Description and Replication) Checklist.

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An evaluation of a shared decision-making intervention for dialysis choice at four Danish hospitals: a qualitative study of the patient perspective

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An evaluation of a shared decision-making intervention for dialysis choice at four Danish hospitals: a qualitative study of the patient perspective

Jeanette Finderup^{1, 2}, Jens Dam Jensen^{1, 2}, Kirsten Lomborg²

Department of Renal Medicine, Aarhus University Hospital, Denmark

² Department of Clinical Medicine, Aarhus University, Denmark

Corresponding author

Jeanette Finderup, Department of Renal Medicine

Aarhus University Hospital

Palle Juul-Jensens Boulevard 99

8200 Aarhus N

Denmark

Phone: +4578452525

Email: jeajee@rm.dk

Keywords

Shared decision-making, patient decision aid, complex intervention, qualitative evaluation

Abbreviations

SDM: Shared decision-making

SDM-DC: Shared decision-making and dialysis choice

PDA: Patient decision aid

Abstract

Objectives: To evaluate the 'Shared Decision-making and Dialysis Choice' (SDM-DC) intervention with regard to patients' experience and involvement.

Design: Semi-structured individual interviews and systematic text condensation for data analysis.

Setting: The SDM-DC intervention was implemented and evaluated at four different hospitals in Denmark.

Participants: A total of 348 patients had received the SDM-DC intervention, and of these, 29 patients were interviewed.

Interventions: SDM-DC was designed for patients facing a choice of dialysis modality. The available modalities were haemodialysis and peritoneal dialysis, either performed by patients on their own or with help from a healthcare professional. The intervention was tailored to individual patients and consisted of three meetings with a dialysis coordinator who introduced a patient decision aid named 'Dialysis Choice' to the patient.

Findings: The four main findings were: the decision was experienced as being the patient's own; the meetings contributed to the decision process; 'Dialysis Choice' contributed to the decision process; and the decision process was experienced as being iterative.

Conclusions: The patients experienced SDM-DC as involving them in their choice of dialysis modality. Due to the iterative properties of the decision-making process, a shared decision-making (SDM) intervention for dialysis choice has to be adapted to the needs of individual patients. The active mechanisms of the meetings with the dialysis coordinator were: 1) questions to and from the patient; and 2) the dialysis coordinator providing accurate information about the options. The overview of options and the value clarification tool in the decision aid were particularly helpful in establishing a decision-making process based on informed preferences.

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Strengths and limitations of this study

- Data richness was established by interviewing 29 patients. The interviews lasted on average 50 minutes with an information load of 23 normal pages on average.
- SDM-DC seems to be the first intervention based on the ‘three-talk model’, which is a well-cited SDM model.
- The whole research process has involved patients and healthcare professionals providing the intervention.
- The research only included Caucasian patients born in Denmark, and the findings are therefore limited to ethnic Danish patients.
- One of the developers of the intervention performed the interviews, but this challenge has been addressed in several ways.

For peer review only

Introduction

Patients with kidney failure must make a decision regarding dialysis modality, choosing either haemodialysis or peritoneal dialysis. Based on research, one modality is not uniquely better than the other (1-3). In order to offer the modality best suited to each patient's everyday lifestyle, international guidelines recommend involving the individual patient in the decision-making process, thus basing the decision on the patient's preferences (3). However, patient involvement does not always occur (4-6). For example, two studies from the USA showed that only 13% of patients experienced the decision process as shared decision-making (SDM) (7) and that patients over the age of 65 years did not experience the decision as a shared one (8). More recent studies indicate improvements in this area. A study from the UK that included routine measures of patient involvement at 27 different nephrology departments found that 69% of patients experienced SDM (9).

Based on SDM for dialysis choice, we developed and pilot tested an intervention called 'Shared Decision-making and Dialysis Choice' (SDM-DC) with the purpose of involving patients and their relatives in the decision-making process (10). In this article, we document patients' perspectives on using the SDM-DC intervention at four different hospitals in Denmark.

Background

A study of patient involvement in dialysis choice suggested that SDM could improve patients' experiences of involvement in the decision (11). A Cochrane Review indicated that an intervention based on SDM and supported by a patient decision aid (PDA) increased patients' experience of involvement (12). Another Cochrane Review focusing on PDAs showed middle-quality evidence that PDAs increase the proportion of people who are active in decision-making (13).

The SDM-DC intervention was developed in 2015 and then described and pilot tested (10). It includes a PDA, named 'Dialysis Choice', and is designed for patients with kidney failure who must make a decision regarding their future dialysis mode: haemodialysis or peritoneal dialysis. Both options may be performed by patients on their own or with help from a healthcare professional. SDM-DC is structured according to the 'three-talk model' (14) and consists of three meetings between the patient and his or her relative(s) and a dialysis coordinator. The dialysis coordinators have been trained to deliver the intervention using tailoring (15) based on a decision needs assessment and using three different communication skills: mirroring, active listening and value clarification (16-18). The PDA is designed to be utilised both at and between the meetings with

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4 individual patients and relatives who may be joining them. Two videos with personal stories are
5 available to be shown and discussed at the meetings if the patient needs to hear a personal story.
6 Patients and healthcare professionals have been involved in the development of the intervention and
7 the PDA (19). The decision aid is based on a systematic literature search where possible. Further,
8 the PDA is inspired by three other decision aids (20-22). The PDA is in paper format. It has been
9 accepted for the A to Z Inventory of Decision Aids – <https://decisionaid.ohri.ca/> – and assessed
10 according to the International Patient Decision Aids Standards (23). The PDA consists of a set of
11 tools: a decision map, an overview of uremic symptoms, an overview of options, and the Ottawa
12 Personal Decision Guide (24-25). A detailed description of the SDM-DC intervention can be found
13 in the supplementary material. The pilot test confirmed that SDM-DC was useful in encounters
14 between individual patients and a dialysis coordinator at a Danish university hospital but that
15 further research was needed to gain insight into the patients' experiences of involvement and the
16 implications for their choice of dialysis mode (10).
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28 **Aim**

29 The aim of this study was to evaluate the SDM-DC intervention with regard to patients' experience
30 and involvement.
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35 **Methods**

36 This study is part of a larger project evaluating the SDM-DC complex intervention (26-27). As
37 recommended for complex interventions (28-30), we first conducted a qualitative evaluation. The
38 quantitative evaluation is in review for publication elsewhere (under review). Since October 2016,
39 the intervention has been delivered at four hospitals in Denmark by six different dialysis
40 coordinators. The inclusion criteria for the intervention were adult patients with chronic kidney
41 disease referred to a department of renal medicine with an eGFR below 20 ml/min measured by a
42 24-hour urine test. Exclusion criteria were patients who had decided on palliation, patients with a
43 living donor and a set date for transplantation, and patients not able to participate due to cognitive
44 impairment. The use of an interpreter was not an exclusion criterion.
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Patient and public involvement

Patients and healthcare professionals have been involved in the whole research process (31-33) through an advisory board consisting of six dialysis coordinators and two patients. The two patients on the board have not been part of the intervention but are part of the target group for it. The first author and the advisory board met every six months during the research process. For this study, the advisory board has contributed particularly to the validation of the themes and inspiration for the discussion.

Data collection

We collected data through individual interviews with patients after they had participated in SDM-DC. We conducted interviews between 1 February 2017 and 8 August 2018. The patients were interviewed consecutively after receiving the intervention. The patients decided on their own where the interview would take place and whether their relatives would participate or not. The first author, who does not perform the intervention, conducted the interviews. The individual interviews were conducted according to Kvale and Brinkmann's guidelines (34) with a semi-structured interview guide. The purpose of the individual interviews was to gain a clear insight into how the patients experienced the impact of SDM-DC on their involvement in the decision-making process. The key elements in the 'three-talk model' (14) informed the content of the interview guide, which was structured chronologically around the first talk, the second talk, the third talk and decision support, from initial preferences to informed preferences and the decision. We adapted the interview guide for each interview according to how the patient, prior to the interview, had answered two questionnaires: the Shared Decision-making Questionnaire (35) and the Decision Quality Measurement (20), not changing the initial questions but making the follow-up questions more specific. During the interviews, the communication skills of mirroring and active listening were used (16-17). First, mirroring was used to bring patients' experiences to the forefront. Active listening, such as retelling the patient's story, then allowed patients to adjust their story if they wished. At the end of every interview, the interviewer summarised the patient's story so the patient could comment on this summary. The purpose of the interviews was not to question the decision the patient had made or to convey information. One patient was emotionally moved by the interview and was offered a new meeting with the dialysis coordinator.

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Ethical considerations

Participation in the intervention was based on consent for care and treatment. According to Danish legislation, this type of research is exempted from ethical approval. The Danish Data Protection Agency (jr. 1-16-02-456-16) approved data management. A third person obtained written consent from patients before their participation in the interviews.

Data analysis

To achieve a well-considered and well-documented analysis, we used a four-step systematic text condensation process (36-37). Systematic text condensation is a descriptive and explorative method for thematic cross-case analysis. During interviews, the first author performed some primary analysis and noted preliminary themes. These preliminary themes were discussed with the third author and the advisory board, which led to some changes. These themes were targeted in subsequent interviews with the following patients. The interviews were recorded and transcribed verbatim prior to data analysis, and the software program NVivo® 11 (38) was used for data management. Various features in NVivo® were used to support the different steps of the analysis process, and to ensure that analyses were both systematic and transparent. These features included Coding, Classification and Memos, and also Word Cloud to identify other preliminary themes, Text Search Query to find meaningful units that had been overlooked, and Matrix Coding Query to investigate whether a code could be attributed to some characteristic within the interview situation or interviewee. The first step in the systematic text condensation was naïve reading, which was performed to obtain an overview of the data. This was conducted continuously during the interview period. The second step was to identify and sort meaningful units by coding. The third step involved condensation of the meaningful units of interest in accordance with the aim of the study. All references from each source were condensed and written as narratives in the first person and present tense to represent each participant's story in relation to each specific code. The fourth and final step involved synthesizing the transcription of each finding. All condensed texts for each finding were aggregated into one text and formulated as narratives in the third person and past tense, including illustrative quotations.

Findings

The interviews took place between 14 days and 42 days after the intervention. Out of 59 patients invited for interviews, 33 accepted the invitation, but four of these patients were not able to participate due to their medical condition worsening. Table 1 shows the characteristics of the 29 patients who participated in the interviews side by side with the characteristics of the whole sample. The variation in the sample was close to the total sample for the intervention according to gender, age, hospitals, dialysis coordinators and the choice of dialysis mode.

Table 1. Participant characteristics*

	Intervention sample (n=349)	Interview I study sample (n=29)
	n (%)	n (%)
Sex		
Female	123 (35)	8 (28)
Male	226 (65)	21 (72)
Age (years)		
age < 50	38 (11)	0 (0)
50 ≤ age < 60	45 (13)	3 (10)
60 ≤ age < 70	94 (27)	9 (31)
70 ≤ age < 80	112 (32)	12 (42)
age ≥ 80	59 (17)	5 (17)
eGFR** (ml/min)		
eGFR < 10	82 (23)	3 (10)
10 ≤ eGFR < 20	244 (70)	26 (90)
eGFR ≥ 20	23 (7)	0 (0)
Chosen option		
Peritoneal dialysis	228 (65)	20 (69)
Home haemodialysis	26 (8)	4 (14)
Hospital haemodialysis	87 (25)	5 (17)
No decision	8 (2)	0 (0)
Number of meetings		
1	90 (26)	2 (7)
2	215 (62)	17 (59)
3	40 (11)	10 (34)
4	4 (1)	0 (0)
Hospitals***		
I	180 (52)	12 (41)
II	53 (15)	7 (24)
III	60 (17)	8 (28)
IV	56 (16)	2 (7)

*Data used in this table have been registered by the dialysis coordinators and are consistent with the documentation in the patients' electronic health records.

**eGFR is the abbreviation for estimated glomerular filtration rate.

***The roman numerals indicate each of the participating hospitals.

The interviews lasted on average 50 minutes, ranging from 26 to 73 minutes, with an information load of 670 normal pages in total, and 23 normal pages on average. Fifteen interviews were conducted at the hospitals and 14 in patients' homes. Eight patients chose to participate in the

interview together with a spouse, and 21 were on their own. Table 2 gives an overview of the category headings, codes and chosen quotations.

Table 2. An overview of the findings and chosen quotations[†]

Category headings^{††}	<p>The decision was experienced as being their own (28 participants & 66 quotes)</p> <p>At the first meeting, my son and daughter-in-law were with me. And when we drove home, we did not talk much about it. I let a few days pass and I thought, "Let them just go and... They should also have time to think a little, and I should have some time to think what I was going to say at the next meeting and all..." Then I talked to them. Then I asked, "What would you choose after the first meeting?" They would choose dialysis at the hospital. Then I said, "Well, it's funny that you say that because that's what I've decided, that's how I want it to be." I've decided this myself, and I think it's a good thing that it's not just the hospital saying what I'm going to do. I hope, because I have decided this myself, I must make the best of it when it can't be any different. Rather than saying that we have just decided this over your head and then say, "Oh, it's so annoying that they make the decisions." There is no one to blame if I think it's a bad decision. Only myself anyway. It is already hard enough. It's my own decision. I actually think it's quite important that you make the decision yourself. I'm old enough to do that. I have not been good at saying no before, but... It's my life and it's my choice and that's how it should be. [16]^{††††}</p>
Codes^{†††}	<p><i>Other decisions</i> (14 participants & 28 quotes)</p> <p>Well, that's probably the first time I've participated in a decision about my illness and treatment. I had an operation on my throat, and I was just told how it should be and when it should be. So I just had to show up. So far, I have just been to see my doctor to get to know how my illness was developing. I get medicine, but I have not been a part of that decision. I have no background to know anything about it, but [in this situation] I have done so. Well, I don't know. I would not have been surprised if you had just decided what to do, because the doctors usually decide everything. And I wouldn't know I had other options. [8]</p>
Category headings^{††}	<p>The meetings contributed to the decision process (29 participants & 95 quotes)</p> <p>If I should have done it [made a decision] without the meeting, it would have been hard. Because then I would have to read about it and I would really not understand a thing. I would not be able to see myself [which decision was right for me]. Now, the dialysis coordinator like explained the different scenarios to me. And it's in light of this I said that I want peritoneal dialysis. She [the dialysis coordinator] supported this – "I think this is right for you," she said. So no, no, it's my own decision – 100%. [10]</p>
Codes^{†††}	<p><i>Questions to and from the patient</i> (21 participants & 39 quotes)</p> <p>She [the dialysis coordinator] actually puts the questions she has to ask in a nice way. Not like a chainsaw. In a nice way. And I also think she manages to get some answers from people when she does it like that. I'm not an open person, I keep things to myself, and people have to lure things out of me. Her questions make me think about things. It gives me peace of mind to get rid of what I'm thinking about. I want to know what it is, and it must be reliable, what I'm told. And I always think I've received an answer. Because... that's life. Life has taught me that if I do not ask, I don't get any answers. Here, she asked her questions, because it was unfamiliar territory. I'm on shaky ground. I had the question, "Why is it haemodialysis you want, and why is it not peritoneal dialysis?" Then we talked about the differences. Well, what happens in my everyday life if I choose haemodialysis and what happens if I choose peritoneal dialysis? And I know that with peritoneal dialysis, I can have some equipment I can take around with me. [13]</p> <p><i>Accurate information was helpful for the patient</i> (12 participants & 20 quotes)</p> <p>It was positive to have the meetings with XX [a dialysis coordinator]. Because she told me a</p>

	<p>lot. And she had an answer ready when I asked. And I'm sorry to say, but some of them [other healthcare professionals], I call them circus clowns. They say "Ah, well..." and "I have to look into that" and "I will be back with an answer" and stuff like that. But XX [a dialysis coordinator], she did not act in that way. I asked and then she had the answers right at hand. [12]</p>
	<p><i>Bringing a relative into the meetings contributed to the decision process</i> (24 participants & 75 quotes)</p> <p>Well, it has meant a lot to me that my wife was with me at the meetings because we were able to talk about it afterwards. She is my extra pair of ears. I have some problems with hearing. It is nice to have somebody there with you, because you get emotional sometimes. So she's not just there because of my bad hearing. The information at the meetings gets me started thinking, I get emotional, and then I don't listen that well. We are in such a vacuum at the moment, waiting to get started with a new part of our life. It is primarily me, but of course also her. It affects everybody in our household. [13]</p>
Category headings^{††}	<p>The decision aid contributed to the decision process (29 participants & 70 quotes)</p> <p>But when you sit there starry-eyed and don't know anything, it [the decision aid] can help a lot. Also that you get more information about it [the decision]. [1]</p>
Codes^{†††}	<p><i>The overview of options contributed to the decision process</i> (18 participants & 28 quotes)</p> <p>The further we went down the list of options, the more it became clear to me that I want P-dialysis. That's what I want. That's the solution that suits my life and my need for freedom best. I think the different colours will do something for me. I heard what she told me, read the chart, saw the different colours when she pointed at them, it meant something to me. [3]</p> <p><i>The value clarification tool contributed to the decision process</i> (15 participants & 25 quotes)</p> <p>We were in a state of rebellion. We were a bit confused. Because we were not really aware of what was happening or should happen or what could happen. But then we worked with it at home and talked about it. We had an assignment to do at home that we went through together. The assignment made us arrive at this decision. I think it made us compare the different options. It gave us an overview because we could compare pros and cons. [23]</p> <p><i>The videos contributed to the decision process for some patients</i> (14 participants & 17 quotes)</p> <p>The best thing about it was the short video with the man who had lived with P-dialysis for 11 years, and it's obvious that he would rather live with dialysis than not live at all. And that kind of helped. He apparently seemed to be doing well. He seemed happy and satisfied. It helped me a lot, because I sometimes worry. I'm a little afraid of dialysis. It's a big deal to me and then... It was really good, because it made me less concerned about what it [dialysis] really would be, or it actually made my concern disappear. [19]</p> <p><i>Other patients contributed to the decision process sometimes</i> (13 participants & 38 quotes)</p> <p>I probably had some reservations from the start. Because I was hospitalised in April last year, and I was with a guy on peritoneal dialysis. He participated in biker meetings, and sometimes, he just had peritoneal dialysis and then he went out [biking] again. And if he could do it, so could I with my hobby as a dog trainer. I would also do it in that way. I got an impression of freedom he had. I didn't think so much about going on dialysis myself. But I saw it as a good experience, and something that was good, and the treatment was good. [8]</p>
Category headings^{††}	<p>The decision process was experienced as being iterative (28 participants & 140 quotes)</p> <p>So we have had the number of meetings we think we needed. But we don't know yet. The difficult thing here is that we are talking about something we imagine. It's like a trip we're going on. Then you have some expectations, but you don't know where it really ends. It's like when we start this, we'll get to know something, and it's great, what we are told, but we don't know if there will be any questions along the way, and there automatically will be. Afterwards, we had the experience, we bought the trip or we have been on it. I have become more sure of it [my decision], after the meetings, that is. At the kidney school [a 2-day Kidney school, each</p>

	day with a four hour information session on chronic kidney disease] they told me it should be peritoneal dialysis, or perhaps, but without deciding, but it was the decision I was more likely to make. And then after those meetings, I realised that it should be peritoneal dialysis. So, I made a decision, right. [5]
Codes^{†††}	<p><i>Dialysis choice came as a shock</i> (14 participants & 48 quotes)</p> <p>You have had diabetes for about 15 years; you haven't thought that it would mean that your kidneys failed at some point and that you have to have dialysis. [Interviewer] You thought then that you might lose a leg, but then I thought I haven't smoked since 1981. But I haven't thought about the kidneys. She told me that it's now time for dialysis or transplantation. It was a shock, I admit – like out of the blue. I was pretty shaken. And now, you have seen what kind of options you have and what the next step is... I decided at the third meeting because it was new to me and it was kind of a shock. It felt like the rug being pulled from under my feet. [26]</p> <p><i>Received new information during the interview</i> (11 participants & 35 quotes)</p> <p>Really good. Well, I'm already much more informed. [17] And I shouldn't tell you anything today, I just want to listen. It's you who should tell me something. [Interviewer]</p> <p>-----</p> <p>So, and then they say that, in the end, you can't pee. Well, now, what is that about? So, I can't imagine it, not being able to pee, and where and how does the pee accumulate? Do you at some point turn into a balloon? [27] Your urine production will slow down gradually. But then the fluid is removed by dialysis. It's the dialysis removing the urine because it draws out the fluid. [Interviewer]</p> <p><i>Not sure it was the right decision</i> (5 participants & 13 quotes)</p> <p>I try not to think about it from day to day. But now and then, you think, "What is it that I'll be going through?" And then I think, "Tubes in the stomach, that was unusually uncomfortable. Could I get peritonitis?" I think. But, of course, you can also get something with the other [dialysis modality], right? Yes, and I think many, many, many times about whether it was the right decision. Just think, you get this machine home with you and all those boxes, and they take up a lot of space. I don't know how much, but they are delivered by a truck. That sounds terrible, doesn't it? Do I have enough room? And how long is the tube that is going to reach the bathroom? And we have two cats who play around at night and have a wonderful time. They play with stuff. I think about how thirst will turn out. And it has to be totally clean, the room you sleep in [and use for dialysis]. [27]</p> <p><i>Preferred not to receive dialysis</i> (13 participants & 23 quotes)</p> <p>Well, you have to understand that I don't go around hoping for dialysis because, first of all, it doesn't look very sexy and, secondly, it limits me. It limits the life I would like to live, but I'm also realistic, I know it's coming. You should know that. Because I would have preferred to avoid it – who wouldn't? No, it's a choice between plague and cholera, there's no doubt about that. [10]</p> <p><i>'No dialysis' was not an option</i> (9 participants & 17 quotes)</p> <p>So, I decided after all that dialysis had to be better than just doing nothing. But we have talked about the fact that we are old, we have experienced a lot, nobody owes us anything in this life – no good and bad things. So that was part of my considerations. [19]</p>

[†]The quotations have been translated into English as accurately as possible.

^{††}The category headings are in **bold** in the text.

^{†††}The codes are in *italics* in the text.

^{††††}The numbers in square brackets are the identification numbers of the participants.

'The decision was experienced as being their own' was stated by 28 patients in different ways.

Some of the patients stated that they had made their decision together with their relatives; others stated that their relatives had not influenced their decision. Some patients stated that their relatives

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4 agreed with their decision. They stated that the healthcare professionals had not made the decision,
5 even though the dialysis coordinator had contributed to the decision process. For several patients, it
6 had been important that the healthcare professionals had confirmed their decision. One patient did
7 not directly express that the decision was his own [2]. This patient was over the age of 80, and the
8 focus for his decision process was whether to go on dialysis or not. Several patients stated that it
9 was important that the decision was their own because they thought it made the decision easier to
10 accept. None of the patients experienced being left alone with the decision process.
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18 *Other decisions.* Most of the patients had lived with disease for a long period. Most of them had
19 never before experienced being involved in a decision about their treatment. Most of the patients
20 felt that no decision had been involved in previous treatments at all. A few patients had experienced
21 participating in a decision about treatment before, but mostly, their experience was that the
22 healthcare professionals regarded patient involvement as an unwelcome interference. Such patients
23 wished that these healthcare professionals had invited them to take part in the decision process and
24 communicated some information to them, to enable them to participate.
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32 **The meetings contributed to the decision process.** All 29 patients reported that the meetings with
33 the dialysis coordinators had contributed to the decision process and that they would not have been
34 able to make the decision on their own without the meetings. The patients emphasised the relaxed
35 nature of the meetings as being significant. They felt they had time to go into the decision process
36 in depth.
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42 *Questions to and from the patient* were emphasised by most patients as a significant property of the
43 meetings. There was no relation to demographic, gender, age, or the dialysis coordinator. Questions
44 to the patients addressed the impact of the decision on their everyday life. The patients experienced
45 these questions as being asked in a nice, easy way. Questions from the patients were concerned with
46 practical issues. The patients felt confident they could ask the same questions several times.
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52 *Accurate information was helpful for the patient.* Some of the patients emphasised that information
53 communicated by the dialysis coordinator had been helpful in the decision process. These patients
54 stated that the information communicated should be detailed, accurate, and appropriate to their life,
55 and that information should be repeated. Two patients [2, 7] expressed that some of the information
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communicated by the dialysis coordinator had not been helpful; this appeared to be when the dialysis coordinator gave too much information at a single meeting.

Bringing a relative into the meetings contributed to the decision process. This was emphasised by most of the patients. They had chosen to bring a relative to be part of the meetings, most often a wife or husband but in some cases a daughter and son-in-law or a friend. Bringing a relative to the meetings was mentioned as “a habit”. These patients were used to bringing a relative to important meetings at the hospital and expressed that “being two” made it possible for them to ask more and different questions. They further emphasised the benefits of there being two people to listen. A few patients [6, 11, 17, 19, 29] did not bring a relative to the meetings. These patients explained that they did not have a significant other in their lives or that their significant others were too ill to participate in the meetings.

The decision aid contributed to the decision process. All 29 patients expressed that they could not have made their decision without help from the decision aid. The patients talked about the PDA as one tool and only mentioned two of the tools within the PDA specifically: the overview of options and the value clarification tool. Some of the patients mentioned the two videos, and they also mentioned other patients, although other patients are not an integrated part of the intervention.

The overview of options contributed to the decision process. This was expressed spontaneously by most of the patients. The tool had clarified or confirmed their decision. They had used the tool during the meeting, but also after the meeting and in preparation for the next meeting. Several patients stated that they had saved the tool and continued to use it.

The value clarification tool contributed to the decision process. Most of the patients stated spontaneously that the value clarification tool was particularly valuable. Several patients indicated specifically that this tool had contributed to the decision process and elaborated that the questions in the tool had enabled them to reflect, in particular the part where they write down pros and cons. Some patients had filled in the tool before the meeting using the value clarification tool, and others received help at the meeting to complete it.

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4 *The videos contributed to the decision process for some patients.* Some patients used positive words
5 in their descriptions of the videos. One patient reported that the videos had helped him change his
6 decision [25], one reported that the videos had removed his concern about dialysis [19], and one
7 that they had provided some concrete visuals of how dialysis takes place [13]. Three patients used
8 positive words about the videos but stated explicitly that the videos had not contributed to their
9 decision process [3, 4, 7]. One patient used negative words about the videos [16]. This patient had
10 made a decision before seeing the videos and would have preferred them to have a more practical
11 focus.
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20 *Other patients contributed to the decision process sometimes.* A number of patients in the sample
21 met other patients on dialysis. For some of this group, meeting other patients on dialysis contributed
22 to the decision process, but several of these patients [3, 11, 22, 25, 27] did not choose the same
23 option as the patient they had met. A few of the patients did not know why the patient they met had
24 chosen as they had. Other patients contributed to the decision process by making dialysis more
25 concrete and presenting possibilities. For some of the patients, it was scary to meet other patients on
26 dialysis.
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34 **The decision process was experienced as being iterative.** Only one patient did not mention the
35 decision process at all. This patient had only one possible dialysis modality. Four patients stated
36 that they had made their decision before the meetings, but all four had their decision confirmed
37 during the meetings. Nine patients experienced that their decision was made during the meetings.
38 One of these patients had made a decision beforehand but changed this during the meetings. Eight
39 patients experienced that their decision was made concrete at a meeting. Two patients made their
40 decision at the first meeting, three patients made their decision at the second meeting, and three
41 patients made their decision at the third meeting. Figure 1 gives an overview of when patients felt
42 their decision was made.
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51 **Figure 1. Overview of when the patients experienced the decision to be made**

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54 Nearly all participants experienced the decision process as iterative. Although they had made a
55 decision, they still needed to confirm this decision, to ask questions, and to reconsider it. There was
56 not only a single option suitable for each patient, but several patients decided on one option to start
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4 with (plan A) and then had a plan B and C.
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8 *Dialysis choice came as a shock* for half of the patients, although they had been known to the
9 departments of renal medicine for several years. That dialysis could actually be a treatment for them
10 occurred to the patients just before the meetings or during the meetings. Some of the patients knew
11 that dialysis might be an option someday, but they had ignored this knowledge and thought it was
12 not going to happen to them. One of the patients [10] was happy not to have received this
13 knowledge previously, but two of the patients [12, 23] stated that they would have preferred to have
14 known earlier. One patient [13] stated that he would have preferred to receive this knowledge in a
15 nice, easy way. Surprisingly, no correlation has been found between eGFR and dialysis choice
16 coming as a shock. Rather, it appeared to be experienced as a shock more often by patients at two of
17 the hospitals compared to those at the other two.
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27 *Received new information during the interview.* Some patients received new information about the
28 significance of the decision regarding dialysis modality during the interview. It was not the
29 intention for the interviewer to interact with the intervention, but the patients asked some questions,
30 and the interviewer tried to answer these questions briefly. The information given did not change
31 their decision. One patient had doubts after the interview and needed one extra meeting. This
32 meeting did not change her decision [27].
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39 *Not sure it was the right decision* was expressed by five patients. At the same time, they said that
40 there was nothing we could do to make them more certain about the decision. They stated that they
41 thought they would feel certainty when they first started dialysis.
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46 *Preferred not to receive dialysis* was expressed by some of the patients. They preferred not to
47 receive any dialysis treatment and characterised the options as a choice between two evils
48 associated with various problems and a loss of their present lifestyle. These participants still hoped
49 to recover and no longer be in need of dialysis.
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55 *'No dialysis' was not an option* was considered by some of the patients. This code was mainly found
56 among patients over the age of 80 years. The patients aged over 80 felt they still had something to
57 live for. Some stated that if their spouse died, they would reconsider their decision and perhaps
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4 choose 'no dialysis'. Most of the patients stated that they had considered these issues on their own,
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6 but they had shared their consideration with the healthcare professionals.
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9 **Discussion**

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11 In summary, the patients experienced the decision as being their own, but both the meetings and the
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13 PDA had contributed to the decision-making process. They experienced the decision-making
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15 process as iterative. The discussion is divided into three sections. The first two sections correspond
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17 to the aim, and the last section focuses on limitations of the study.
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20 *How did the patients experience the SDM-DC intervention in terms of their involvement?*

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22 The purpose of the intervention was to involve patients in the decision-making process. **'The**
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24 **decision was experienced as being their own'** was a significant finding, which demonstrates that
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26 the patients experienced SDM-DC as involving them in the decision-making process. The SDM-DC
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28 pilot test predicted this finding, because some of the patients did not experience the decision as a
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30 shared decision, but their own decision (10). Due to the age of the patient group, this finding was
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32 surprising when compared to a study focusing on the involvement of the over-65 age group (39).
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34 That study showed that many patients were not involved in the decision-making process about
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36 dialysis choice, but the patients who were involved, were more satisfied with their dialysis modality
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38 (39). We found the patients experienced the decision process as iterative. SDM-DC is based on the
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40 'three-talk model' by Elwyn et al (14). The simple version of the 'three-talk model' presents the
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42 SDM process as linear, suggesting that patients go into the decision-making process without any
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44 decisions and complete the process with a decision. In 2017, the 'three-talk model' was updated and
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46 is no longer presented as a linear model, but a circular one (40). Both models have their advantages.
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48 In clinical practice, it is easier to implement an intervention based on the linear model with clear
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50 progression through the process. Nonetheless, it is worth noting that SDM-DC seems to be the first
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52 intervention to apply the linear version of the 'three-talk model' (40). The model has been cited a
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54 number of times elsewhere but only for presentations, workshops and training programmes. A
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56 Canadian study found five phases in the decision-making process regarding dialysis choice: 1)
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58 progress toward acceptance to be dialysed; 2) receive information; 3) take some time for personal
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60 reflection; 4) seek the opinion and support of others; 5) re-evaluate one's choice (41). The
development of SDM-DC was not based on this framework, but our evaluation showed that most of
these phases have been met by the intervention.

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6 *How did the patients experience the SDM-DC intervention?*
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8 The patients highlighted two important elements of the meetings: 1) questions to and from the
9 patient; and 2) the dialysis coordinator providing accurate information about the options. The fact
10 that daily life with dialysis needs to be described as concretely as possible has been documented
11 elsewhere (42). The patients experienced the participation of their relatives in the meetings as an
12 advantage. This finding is in accordance with a study of the perspective of the relative, showing that
13 relatives felt involved in the decision-making process and that they had an important supportive role
14 (43). The dialysis coordinator provided decision coaching as part of the SDM process. The
15 definition of decision coaching is '*individualized, nondirective facilitation of patient preparation*
16 *for shared decision-making*' (44). In spite of this, the decision was made together with the dialysis
17 coordinators at the meetings and not afterwards with the physician. Decision coaching has, in other
18 studies, been shown especially to improve the patient's knowledge and involvement in decision-
19 making (44). The whole of the 'Dialysis Choice' PDA contributed to the decision-making process,
20 but the patients identified the overview of options and the value clarification tool as being
21 particularly helpful. An Option Grid is a specific type of overview of options, and research has
22 shown that, for some health decisions, an Option Grid supports patients in the decision-making
23 process (45). From a healthcare perspective, the Option Grid has been found to be easy to use to
24 facilitate patient involvement in the decision-making process (46). In general, Option Grids have
25 proven beneficial for sharing information but less useful for value clarification (47). In the
26 Cochrane Review of PDAs, value clarification is defined as an important part of a PDA and SDM
27 (13). The combination of the overview of options and the value clarification tool appears to be a
28 good one. In the development of our intervention and the PDA, we tried to meet all the decision
29 needs described for this patient population (11, 41, 48-50), but this study added two more decisional
30 needs for this patient population, namely that, the decision came as a shock to the patient and that
31 there is not only one choice but a plan A, B and C. These decisional needs should be implemented
32 into an SDM intervention for dialysis choice. The impact of stories on patient decision-making has
33 been unclear (51). The patients in our study felt the videos were not as unequivocally positive as the
34 decision aid. Nor was meeting other patients on dialysis an unequivocally positive finding.
35 Sometimes, other patients contributed to the decision-making process to a certain extent. The use of
36 narratives in decision aids has been a focus in the International PDA Standards collaboration since
37 the beginning (20). An experimental study has shown that patients are more likely to choose a
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4 dialysis modality presented by a patient rather than a healthcare professional, which is why caution
5 has been recommended in the use of patient stories (49). It seems that the patients in our study used
6 the videos and other patients more as inspiration and less as direction, thus complying with the
7 purpose of SDM to establish a decision process based not on uninformed preferences but on
8 informed preferences (14). How the intervention has contributed to this needs to be investigated
9 further.
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15 16 *Limitations*

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18 This study has some limitations. For a qualitative evaluation, 29 patients is a relatively large
19 number of participants. This number was chosen to give the right level of information power (52),
20 because the intervention was performed at four different hospitals, by six different dialysis
21 coordinators, and the patients had to decide between different options. Only Caucasian patients
22 were included, and the findings are therefore limited to ethnic Danish patients. If we had included
23 some ethnically non-Danish patients, the findings could have taken other directions. This is
24 indicated by a study showing that Japanese patients make decisions that are more consistent with
25 their network's wishes and preferences (53). One of the developers of the intervention carried out
26 the interviews in our study, and this is mentioned by Malterud as a point to pay attention to (36).
27 We managed this challenge in various ways: 1) the interviewer did not perform the intervention; 2)
28 the patients did not know that the interviewer had developed the intervention; and 3) the interview
29 findings were discussed with the advisory board. Furthermore, the patients expressed criticism of
30 the intervention during the interviews. The interviews were performed at least two weeks after the
31 intervention. Thus, some memory failure may have occurred since patients with an eGFR below
32 20ml/min may have cognitive deficit and short memory (54). We assume that the patients have a
33 better memory of the last meeting than the first meeting. We do not yet know the extent to which
34 the intervention has been performed as intended. In the sample, we found two patients who had
35 filled out the value clarification tool, but the dialysis coordinators had not used the homework
36 during the meetings. The dialysis coordinators, who are part of the advisory group, later explained
37 that they found the value clarification tool difficult to use in the beginning.
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54 **Conclusion**

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56 The patients experienced SDM-DC as involving them in their choice of dialysis modality. Due to
57 the iterative properties of the decision-making process, an SDM intervention for dialysis choice
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4 needs to be adapted to the needs of individual patients. The active mechanisms of the meetings with
5 the dialysis coordinator were: 1) questions to and from the patient; and 2) the dialysis coordinator
6 providing accurate information about the options. The overview of options and the value
7 clarification tool in the decision aid particularly contributed to the decision-making process based
8 on informed preferences.
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15
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18 provided the interventions. The authors thank the advisory board and the patients who participated
19 in this study.
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25 **Conflicts of interest**

26 The authors declare no potential conflicts of interest with respect to the research, authorship and/or
27 publication of this article.
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34 Association, and the Danish Nurses Organisation.
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39 **Contributorship**

40 JF: Designed the project, collected and analysed data, and drafted the final manuscript.
41
42 JDJ and KL: Provided academic supervision, helped to draft the manuscript, and read and approved
43 the final manuscript.
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48 **Data sharing statement**

49 No additional data are available.
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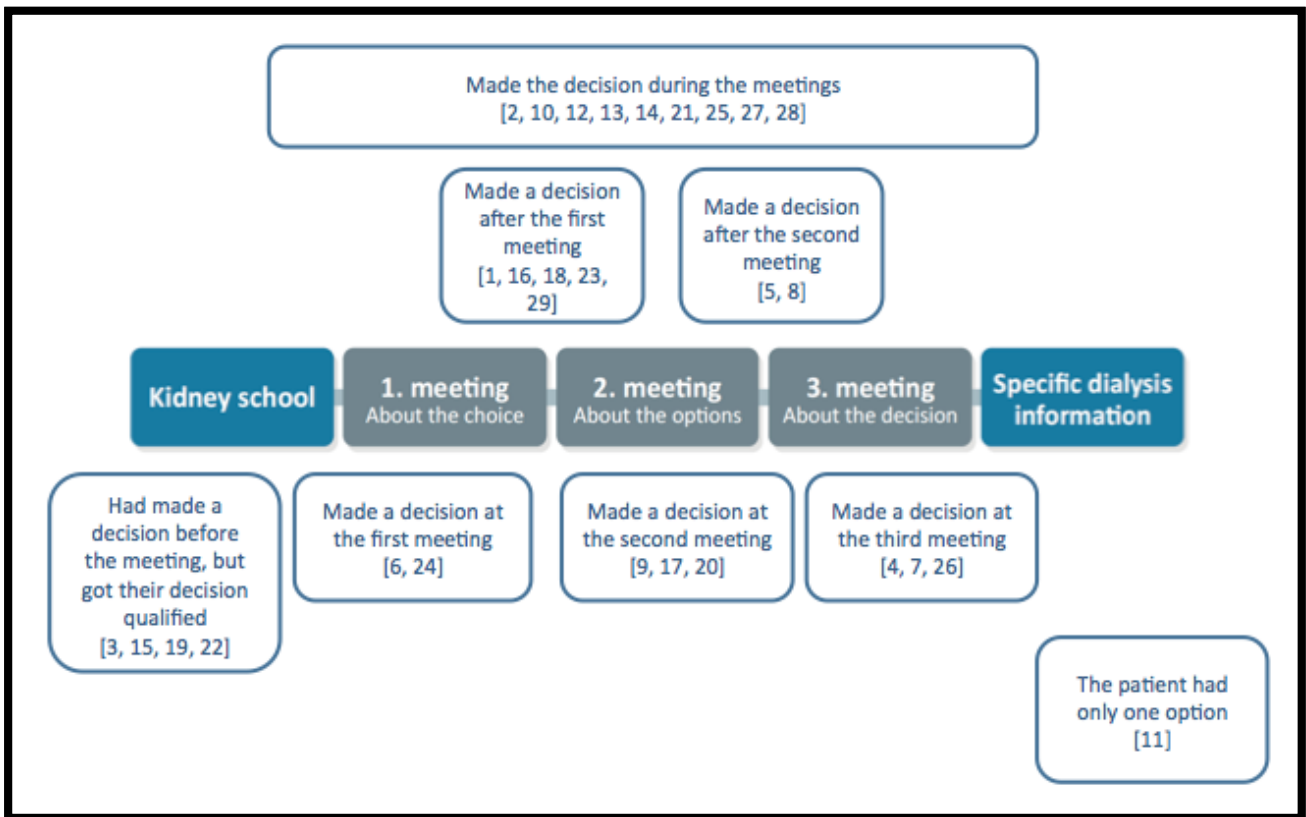
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Figure 1. Overview of when the patients experienced the decision to be made



Kidney school: A 2-day school, each day with a four hour information session on chronic kidney disease

A description of shared decision-making and dialysis choice (SDM-DC)¹

Item	Description
1. BRIEF NAME	Shared decision-making and dialysis choice (SDM-DC).
2. WHY	The intervention is an SDM intervention and achieving the ideal and essential elements of SDM stated by Makoul and Clayman [1]. The intervention is based on the first version of the three-talk model [2] consisting of three meetings, but also inspired by the Ottawa Decision Support Framework [3].
3. WHAT – MATERIALS	A PDA, called 'Dialysis choice', has been developed based on the method suggested by Coulter et al. [4], trying to meet the IPDAS criteria. The PDA consists of several tools: an overview of symptoms, a decision map, an overview of options, and OPDG – Danish version. In addition to the PDA, some other tools are available: four videos with four different patients, a folder with photos and drawings, a peritoneal dialysis catheter, and a needle for haemodialysis. All tools are to be shown and discussed with the patient.
4. WHAT – PROCEDURES	Three meetings are to be arranged between the patient and his or her relatives and a dialysis coordinator: The first meeting – a choice talk: to create an understanding of why a choice about dialysis mode has to be made and which options there are to choose between. The second meeting – an option talk: to provide insight into which options the patient has for dialysis, as well as discussing the advantages and disadvantages of each dialysis mode. The third meeting – a decision talk: to support the patient making a decision based on his or her informed preferences.
5. WHO PROVIDED	Six dialysis coordinators: Experienced nephrology nurses who have been trained in the why, what, and how of the SDM-DC. The initial training lasted two working days and has been followed up every six months by a one- or two-day refresher session.
6. HOW	The intervention is delivered face-to-face by the dialysis coordinator to the patient. The patient is encouraged to bring relatives to these meetings. The principles of SDM are used during the meetings: 1) the ideal and essential element of SDM; 2) the three-talk-model; and 3) the Ottawa Decision Support Framework. Three communication skills are used: 1) mirroring; 2) active listening; and 3) value clarification.
7. WHERE	The intervention is provided at the hospital in the outpatient clinic in a private room with access to a computer. The patient, relatives, and dialysis coordinator sit in chairs around a table. At one of the hospitals, the dialysis coordinator offered to provide the patient with one of the meetings at the patient's home.
8. WHEN & HOW MUCH	Patients are offered the intervention when they reach an eGFR below 20 ml/min. Each meeting is booked for one hour. When there is a need for an interpreter, the meeting is booked for one and half hours.
9. TAILORING	The intervention is tailored to each patient based on a decision need assessment. The number of meetings varies for each patient, with a variation between one and four meetings. Meetings are 'combined' by working with the aims from previous meetings at a later meeting. The tools are only used if they meet the needs of the patient or the dialysis coordinator.
10. MODIFICATIONS	Between October 2016 and February 2018, the support materials only had two videos. The next two videos were finished in February 2018. The folder with the pictures and drawings was ready to be used from January 2017.

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¹ The description is based on the TIDieR (Template for Intervention Description and Replication) Checklist.

Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups

No	Item	Guide questions/description	Answers
Domain 1:			
Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	The first author, JF (p5)
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	RN, MHR & PhD student (Not included)
3.	Occupation	What was their occupation at the time of the study?	Clinical Nurse Specialist & PhD Student (Not included)
4.	Gender	Was the researcher male or female?	Female (Not included)
5.	Experience and training	What experience or training did the researcher have?	Both first and last authors have performed several studies using qualitative interviews (Not included)
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	No relationship was established. A third person asked the patient about participation in the study (p5)
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>E.g. personal goals, reasons for doing the research</i>	A clinical nurse specialist in the area of renal medicine and a PhD student. They knew the aim of the study (p17)
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>E.g. Bias, assumptions, reasons and interests in the research topic</i>	The interviewer had developed the intervention. This was not known by the

			patients (p17)
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>E.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	A pragmatic approach. Kvale & Brinkmann was used for data collection, and Malterud was used for data analysis. Both have a pragmatic approach (p5-6)
Participant selection			
10.	Sampling	How were participants selected? <i>E.g. purposive, convenience, consecutive, snowball</i>	Consecutive (p5)
11.	Method of approach	How were participants approached? <i>E.g. face-to-face, telephone, mail, email</i>	By a third person, the dialysis coordinator, with an information leaflet (p5)
12.	Sample size	How many participants were in the study?	29 (p6-7)
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	26 refused to participate. We do not know their reasons. 4 dropped out because of a deterioration in their medical condition (p6)
Setting			
14.	Setting of data collection	Where was the data collected? <i>E.g. home, clinic, workplace</i>	Decided by the patient. Either at home or at the hospital (p5)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Decided by the patient. 8 relatives participated (p5)
16.	Description of sample	What are the important characteristics of the sample? <i>E.g. demographic data, date</i>	Sex, age, eGFR, decision, number of meetings (p6-7)

Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	An interview guide was developed based on the 'three-talk model'. The interview guide was adapted for each interview based on two questionnaires (p5)
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No (NA)
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	The interviews were recorded (p6)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Field notes were made after each interview (Not included)
21.	Duration	What was the duration of the interviews or focus group?	Mean duration was 50 minutes (range 26–73) (p7)
22.	Data saturation	Was data saturation discussed?	Saturation is not the goal for Malterud but information power (NA)
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No, but a summary was made at the end of each interview for the patient to confirm (NA)
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	One, but the coding was discussed with the two other authors and the advisory board (p6)
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Yes (p6)
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data (p6)
27.	Software	What software, if applicable, was	NVivo 11.0 (p6)

		used to manage the data?	
28.	Participant checking	Did participants provide feedback on the findings?	Two patients were part of the advisory board giving feedback on the findings (p4)
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? <i>E.g. participant number</i>	Yes, presented in Table 2 (p7-10)
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes (p7-10)
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes, presented in bold (p7-10)
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes, presented in italics (p7-10)

Allison Tong, Peter Sainsbury, Jonathan Craig; Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Health Care*, Volume 19, Issue 6, 1 December 2007, Pages 349–357, <https://doi.org/10.1093/intqhc/mzm042>