

Patient Decision Aid Development for Older Adults With End-Stage Kidney Disease in Singapore



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Introduction: In managing end-stage kidney disease (ESKD), older adults face a decision regarding whether to undergo dialysis or manage symptoms through kidney supportive care (KSC). This article describes the development of a patient decision aid (PDA) that is designed specifically for older adults with ESKD.

Methods: The decision context of the PDA was to choose a treatment between hemodialysis, peritoneal dialysis, and KSC. The development process used insights obtained from qualitative interviews with patients, informal caregivers, and health care providers. The PDA was then developed in English and Mandarin and was pilot-tested with patients, caregivers, and health care providers. We finalized the PDA based on feedback from pilot testing and performed a preliminary evaluation based on the International Patient Decision Aid Standards (IPDASi v4.0) criteria.

Results: The final PDA consists of 2 booklets and a video. During pilot testing, patients and caregivers reported high levels of ease of understanding and usefulness with $\geq 92.5\%$ providing agree/strongly agree responses for the "Content"-related criteria, and $\geq 75\%$ providing agree/strongly agree responses for the "Development Process and Effectiveness"-related criteria. The final PDA met 10 of 12 IPDASi v4.0 criteria.

Conclusions: This PDA was found useful during pilot-testing. It will be used during renal counseling in Singapore to help older adults with ESKD and their caregivers make informed decisions on which treatment option is best for the patients.

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KEYWORDS: caregivers; decision aid; end-stage kidney disease; older adults; shared decision making

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Global incidence of ESKD is on the rise,¹ especially among older adults.² In managing ESKD, older patients face a complex decision regarding whether to undergo dialysis or manage symptoms with medications and a controlled diet, termed KSC or conservative management. Although dialysis has been considered the first-line treatment for ESKD,³ it offers little survival benefit compared with KSC for patients aged 75 and older with multiple comorbidities.^{4–7} Dialysis patients also report higher burden of disease,⁸ higher

rates of hospitalization, and higher costs compared with KSC patients. As a result, international organizations such as the Kidney Disease Improving Global Outcomes recognize KSC as a viable treatment choice for this patient subpopulation.⁹ However, studies from Singapore, the setting of this study, and elsewhere show that patients not only lack awareness of KSC as a viable option, but also often choose dialysis with little understanding of the expected costs, survival, and quality of life implications of this choice.^{10,11} As a result, it is unsurprising that decisional regret is common for older dialysis patients.^{12–14}

Patients also reported accepting dialysis because of pressure from informal caregivers (those who provide care to family/friends without payment) who may be equally uninformed,¹⁵ or because physicians tend to represent dialysis as necessary for survival.¹⁶ Previous

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studies have shown that differences in knowledge and/or status (socioeconomic or power) between patients and their physicians may impede the chances of patients from seeking a treatment that they truly prefer.^{16,17} This is especially common in some Asian societies in which reverence or a more paternalistic view of physicians is common.¹⁸

These findings suggest that older adults with ESKD and their caregivers can benefit from a PDA to help them select a treatment that aligns with patient values and preferences.¹⁹ PDAs have been shown to increase patients' knowledge, involvement in decision making, and congruency between informed values and treatment choices, and decrease decisional conflict.^{20–25} We developed a PDA for older adults with ESKD (aged 70 and older) and their caregivers to achieve 2 objectives: (i) to provide balanced and neutral information about ESKD for all relevant treatment options (i.e., peritoneal dialysis [PD], hemodialysis [HD], and KSC), and (ii) to help patients understand their values and treatment goals so that they can make treatment decisions that align with their preferences. As caregivers are an integral part of the decision-making process in Singapore,^{16,26} they were included in the PDA development as well.

Development of the PDA was guided by the International Patient Decision Aid Standards (IPDAS) Guidelines.²⁷ The purpose of this paper was to describe the development of this PDA. The methods section of the paper outlines the steps used in development of PDA. These included (i) qualitative interviews with patients, caregivers, and health care providers; (ii) design of the booklets and production of the video as a PDA; (iii) pilot testing of the prototype PDA; and (iv) preliminary evaluation of the final PDA. The results section outlines the findings from each step and the content of the final PDA. The discussion presents (i) how this PDA is different from the other PDAs on the same decision context, (ii) lessons learned from the PDA development, (iii) limitations, and (iv) implementation of the PDA in clinical practice.

METHODS

Qualitative In-Depth Interviews

The purpose of the in-depth interviews with patients and caregivers was to investigate the decision-making process, and factors that influenced their treatment decision to inform the development of the PDA. The inclusion criteria for patients were as follows: diagnosis of incident chronic kidney disease stage 5; estimated glomerular filtration rate <10 ml/min; ≥ 70 years of age; and currently receiving PD, HD, or KSC. Eligible caregivers had to provide support for a qualified patient and be ≥ 21 years old. All participants were identified

through physician referrals or from medical records and recruited during their clinic visits at Singapore General Hospital. Detailed information on the methods and findings are provided in a separate article.¹⁶

We also formed an external advisory panel independent from the research team to receive feedback on all aspects of the PDA development. The panel consisted of 2 nephrologists, 1 palliative care physician, 1 renal nurse, 2 medical social workers, 2 renal coordinators, and 1 patient representative. The purpose of the qualitative interviews with the advisory panel members was to understand their perspectives on the needs of older patients when choosing a treatment and how PDAs could help them make an informed decision. The interview questions were tailored to the occupational roles of each member ([Supplementary Material S1](#)). Members were selected through purposive sampling of patients with ESKD and their health care providers from different specialties.

Two research coordinators conducted each interview. The interviews were audio-recorded, transcribed, coded, and thematically analyzed. We used QSR Nvivo 10 for managing the data.

Design of the Booklet and Production of the Video

We identified key content areas based on the findings from the literature review, and qualitative interviews. Detailed content was drafted and reviewed for accuracy by health care providers in the study team. The language was checked for ease of understanding using the Simple Measure of Gobbledygook readability formula. Once the English content was drafted, it was translated to Mandarin by professional translators, then reviewed and revised by the Mandarin-speaking research team members. These 2 languages are spoken by 72% of the households in Singapore.²⁸

For the video testimonials, eligible patients and caregivers were identified based on the same criteria used for qualitative interviews. For those who agreed to participate, the video recordings occurred at a place of the participant's choice and were conducted by the study team in English and/or Mandarin based on the participant's preference. After filming, the study team reviewed the raw video testimonials and selected content that best addressed the informational needs of patients and caregivers based on key topics identified through the qualitative interviews. The content was arranged to present a coherent flow and provide balanced information with positive and negative perspectives on each treatment. A professional voice actor narrated the script in English and Mandarin and voice actors dubbed English interviews into Mandarin and vice versa. Two versions of the video were produced:

one fully in English with Mandarin subtitles, and another fully in Mandarin with English subtitles.

Pilot Testing of the Prototype PDA

The aim of the pilot test was to receive feedback on the prototype PDA from patients, caregivers, and advisory panel members using IPDAS guidelines.²⁷ In line with the guidelines, the questionnaire was broken down into investigating: (i) *content* (3 questions for patients/caregivers and 2 for advisory panel) and (ii) *development process and effectiveness* (3 questions for patients/caregivers and 4 for advisory panel) of the PDA (see [Supplementary Material S2](#) for patient version). We also added open-ended questions to explore the opinions of patients and caregivers on the PDA's ease of understanding and helpfulness in making a treatment decision, whereas those for the advisory panel explored views on content accuracy, effectiveness, and feedback on unnecessary or important missing information.

We used the same recruitment process and eligibility criteria as for the qualitative interviews with patients and caregivers. The only difference was for patients. Eligible patients were those visiting the renal clinic for counseling but had not chosen a treatment yet.

For patients and caregivers, pilot testing involved a renal counseling session with the PDA. Trained counselors explained the booklet content and presented the video to patients and caregivers. After the counseling session was completed, research coordinators from the study team went through the structured questionnaire and open-ended questions with the patients and caregivers. For the advisory panel members, the pilot test was conducted by 2 research coordinators. They first reviewed the PDA, and then answered the structured questionnaire and open-ended questions.

Results of the responses to the structured questionnaire were presented as percentages. Answers to the open-ended questions were summarized and reconciled by 2 of the authors.

Preliminary Evaluation of the Final PDA

The evaluation of the final PDA used the IPDASi v4.0 criteria that is used for evaluating the inclusion of minimum standard components in a decision aid.¹⁹ There are 12 criteria in total. If a criterion was met, it was scored "1" and was scored "0" otherwise. We also provided a total score.

RESULTS

Findings From the Qualitative Interviews

Some patients reported that the final decision was their own independent decision, whereas others reported that they were strongly persuaded by health care providers and/or family members to initiate dialysis,

although they were not initially keen on it. Patients, in general, reported that physicians' opinions held a lot more weight than their own. Based on these findings, we included a section in the PDA to prepare patients for decision making and communicating their preferences with their family and physicians. We also added a section for family caregivers on how to support and respect patients' decisions.

The factors that influenced treatment choice reported by patients were the loss of autonomy in daily life, financial burden, caregiving burden, experiencing increasingly severe symptoms, and disease progression. Caregivers also reported concerns regarding caregiving responsibilities and financial cost of treatment. Because these emerged as important factors in decision making, we decided to provide information on these topics for each treatment option in the PDA.

Of 26 main themes identified during the thematic coding process of the data from the qualitative interviews with the advisory panel members, the 7 most pertinent themes were used to inform the development of the PDA. The themes (more detail in [Supplementary Material S3](#)) were as follows: (i) the importance of respecting a patient's choice and goals in the decision-making process, (ii) the importance of family involvement in the decision-making process, (iii) differences in priorities between caregivers and the patients leading to family conflict, (iv) the importance of avoiding emergency hospitalization due to indecision, (v) the importance of maintaining a patient's quality of life, (vi) the misperception of "conservative management" as giving up on life and transitioning toward the use of "supportive care," and (vii) the importance of balanced presentation of information with regard to KSC.

Findings from the Pilot Testing of the PDA Patients and Caregivers

The PDA was pilot tested with 4 patients and 5 caregivers (4 spouses and 1 adult child). All pilot-test participants were Chinese. Two patients and 3 caregivers evaluated the English version, and 2 patients and 2 caregivers evaluated the Mandarin version. We did not observe any differences in the feedback to the English and Mandarin versions.

Findings from structured questionnaires. Patients and caregivers reported high levels of ease of understanding and usefulness with $\geq 92.5\%$ agree/strongly agree responses for the "Content" section and $\geq 75\%$ agree/strongly agree responses for the "Development Process and Effectiveness" section ([Table 1](#)).

Findings from open-ended questions. Patients and caregivers reported that the PDA was understandable, and most patients and caregivers reported that the

length of the video was acceptable, although one patient mentioned that he had difficulty concentrating. Another patient reported about hearing similar stories from friends and, thus, the PDA did not provide any new information or perspective. All other participants reported that the PDA helped them understand the advantages and disadvantages of the treatment options and helped them consider what was important. Patients also noted that the values clarification questions were useful in helping them make a decision (“Usefulness of Information” of Table 2). Illustrative quotes from the pilot test are provided in Table 2.

Advisory Panel

All 9 panel members were interviewed; however, one of the members had to leave the pilot-testing session before completing the questionnaire.

Findings from structured questionnaires. For the “Content” section, $\geq 77\%$ of responses from advisory panel members were agree/strongly agree. For the “Development Process and Effectiveness” section, $\geq 63\%$ of responses were agree/strongly agree, except “Usage of up-to-date scientific evidence” (Table 3), which received 40% agree/strongly agree.

Findings from open-ended questions. Advisory panel members encouraged using more neutral language when explaining treatment options. Specifically, terms such as “Pros” and “Cons” were criticized for potentially creating positive or negative bias toward decision factors that may otherwise have been assessed differently by each patient. There were also recommendations to reframe the description of KSC. For example, describing KSC as “managing symptoms without dialysis” was criticized for potentially creating bias by disregarding KSC as a treatment on its own, and referring to it as a result of not selecting dialysis. Advisory panel members also mentioned that the content on caregiver burden for PD was more extensive than that for HD. Some stated that content on the advantages of KSC and the graphics related to KSC were insufficient, and advised to shorten the video and provided suggestions on which sections to cut. Most of the advisory panel members found the values clarification questions useful (“Usefulness of Information” and “Overall Impression” section of Table 2), and suggested additional points for consideration about dialysis technicalities (e.g., clean space at home for PD).

Patients and caregivers focused on the length and usefulness of information, whereas health care providers focused more on the presentation of information and balance among treatment options (Table 2).

Revisions to the PDA Based on Pilot Testing

“Pros” and “Cons” of each treatment were reframed as “factors to consider” for a neutral tone. The term

Table 1. Results of pilot-testing questionnaire with patients and caregivers

Part A: Content	Percentage of responses that were either “agree” or “strongly agree”
Provides information about options in sufficient detail for decision making	92.5
Presents probabilities of outcomes in an unbiased and understandable way	95.8
Includes methods for clarifying and expressing patients’ values	98
Part B: Development process and effectiveness	
Uses plain language	100
Decision quality	75
Meets additional criteria if stories are used in the patient decision aid	87.5

“without dialysis” associated with KSC was removed from the booklet and video. We also included more content from the original video testimonials and more graphics related to KSC, and information regarding caregiver burden to portray all treatment options more equally.

Based on the feedback from the advisory panel members, we removed nonessential and repetitive parts to reduce the length of the video. The booklet was split into 2 booklets separating the values clarification section from the informational sections so that patients can easily share their answers to the values clarification exercise with their physicians.

Final PDA

The final booklets titled “My Choice for My Kidneys” consist of “Booklet 1: Information Guide for Elderly People With Kidney Failure” (27 pages) and “Booklet 2: Decision Guide for Elderly People With Kidney Failure” (7 pages). Booklet 1 consists of the following sections (1) what kidney failure is, (2) what your treatment options are, (3) how to choose a treatment, and (4) advice for caregivers (Table 4). Section 2 (“What your treatment options are”) provides an overview of all relevant treatment options for this patient subpopulation. Section 3 (“How to choose a treatment”) presents a guide on decision making followed by side-by-side comparison of all treatment options on expected survival, quality of life, side effects, treatment risks, and expected costs. To provide more perspectives for better understanding, the expected survival is presented in 2 formats: median survival (presented only numerically in terms of years) and 5-year survival rate (presented both numerically and pictorially) (Supplementary Material S4). As the survival rates are contingent on age, the expected survival data were presented for those aged 70 to 74 and ≥ 75 separately. Figure 1 includes sample pages.

Table 2. Illustrative quotes from the pilot test

Reactions	Video		Booklet	
	Positive feedback	Constructive feedback	Positive feedback	Constructive feedback
Overall impression	"It is informative and useful to me. It allows me to understand a bit." –PT "Having patients share their experiences [in the video] is good as [other] patients will be able to relate to the testimonials." –AP, renal counselor	"[The testimonials are] Quite different from what [we] have heard from the people that we know... I don't know, that's how our experience is." –CG, spouse	"Graphics are clear and good, and representative of meanings in the booklet." –AP, patient representative "The value clarification exercise is structured and allows the patient and caregiver to organize [their] thoughts." –AP, patient representative	"[Booklet 2] is simple and ok. Need to have more colors, cuter graphics, more visually appealing." –AP, physician "Graphics can be smaller to accommodate space for point form and larger font size." –AP, physician
Length	"The length is not bad." –PT "Should be ok, quite comfortable. Anything shorter and you can't get what they're trying to say..." –AP, physician	"Watching them say what they said, it seems like it's not bad. But listening to it took too long." –PT "It's a bit busy and long video for someone to absorb and make a decision at the end of the day. At the end of these 23 minutes, the layperson may not be clear." –AP, physician	Feedback not available.	"More point form than continuous prose [preferred]." –AP, physician
Usefulness of information	"Yes, yes it did help. At least I know peritoneal dialysis... Earlier on, I misunderstood... We previously didn't know the pros and cons. We knew, but it wasn't too clear. Now we understand it a bit more." –PT	"The difference is that I know about the treatment... I already know what it's all about. And you ask me 'Is there an impact?' I would say no, I mean, no need! So unless a patient is fresh, it's a different thing." –PT "Make a segment on shared decision making, it will be helpful to family members." –AP, physician	"Yes. [The values clarification section] has helped me consider [areas to consider when making a decision]." –PT "The tables are much clearer and offer details and considerations." –AP, physician	"Best interest of the patients would be to look at their treatment goal. What is important to them in life, and what are their concerns? [Booklet 2] should help the patient reflect. Do they just want to live on or do they feel like quality of life is important?" –AP, physician
Amount of information	Feedback not available.	"There are all sorts of pros and cons, but if you ask me to immediately repeat it now I will not be able to do so." –PT	Feedback not available.	"A lot of paragraphs, which can be daunting for elderly folks..." –AP, physician
Easy to understand	"Yes. It has helped us understand." –CG, spouse	"Understand is understand, but I'm scared." –PT	"Good that there is no medical jargon, quite layman." –AP, physician	Feedback not available.
Balanced presentation of treatment options	"Video is quite balanced. Various aspects of all the modalities." –AP, physician "Not biased and fairly balanced." –AP, physician	"PD sounds more troublesome than HD according to caregiver testimonials." –AP, physician	Feedback not available.	"Need more support information for KSC." –AP, patient representative
Areas of improvement	Not applicable.	"But I would've liked a little more in the video to show me what happens in uh, for HD and PD, they keep saying, oh, you know the sound will disturb your sleep, I mean how loud exactly is the sound? What's the set up like? ... From a caregiver point of view, which part do I have to be most careful with? ... to prepare myself that if I have to do it for you, how is it done? Maybe a visual on that?" –CG, child	Not applicable.	"[The] survival [section] is too sensitive. Can we make it selectively accessible? Usually before we talk about prognosis, we assess readiness for prognosis before revealing survival. You don't want to present this too early before the patient accepts the diagnosis... Collusion is rampant in Singapore. The caregiver may not want patient to see [the survival information]." –AP, physician

HD, hemodialysis; KSC, kidney supportive care; PD, peritoneal dialysis.

Table 3. Results of pilot-testing questionnaire with advisory panel members

Part A: Content	Percentage of responses that were either "agree" or "strongly agree"
Provides information about options in sufficient detail for decision making	77
Presents probabilities of outcomes in an unbiased and understandable way	80
Part B: Development process and effectiveness	
Presents information in a balanced manner	69
Use up-to-date scientific evidence that is cited in a reference section or technical document	40
Disclose conflicts of interest	63
Meet additional criteria if stories are used in the patient decision aid	87.5

The decision guide booklet (Booklet 2) contains a values clarification method that aims to elicit a patient's preferences. The first section consists of 15 questions (Figure 2) that intend to help people choose between dialysis and KSC, and subsequently choose between PD or HD if they want to initiate dialysis. Information is provided on how patients' responses to these questions can be scored and linked to a recommended treatment choice based on the individual's final score. The second section consists of guiding questions that aim to help people share their concerns with their caregivers and physicians. Based on the Simple Measure of Gobbledygook readability formula, the final booklets scored grade-level 9 language.

The final video is 18 minutes long and includes an introductory message from a senior physician, animated description of the treatment options, testimonials from 5 patients and 5 caregivers, a summary of all the treatment options, and a closing message from the physician (Table 5). The participants were 2 PD dyads, 1 HD dyad and 1 KSC dyad, 1 HD patient, and 1 bereaved KSC caregiver. The testimonials feature these patients and their caregivers sharing their experiences with ESKD, changes in their daily lives, caregiver burden, positive and negative experiences with their selected treatments, their decision-making processes, and advice they have for newly diagnosed patients and caregivers. Sample scenes from the video are presented in Figure 3. The PDA (booklets and video) is available at <https://www.duke-nus.edu.sg/lcpc/research/projects-by-themes/retreat> for public viewing.

Findings from the Preliminary Evaluation of the Final PDA

Using the quality assessment of PDAs according to IPDAS v4.0 criteria,¹⁹ the final PDA met 10 of 12 criteria (Table 6). The missing components are description of psychosocial consequences of the treatment options and information on PDA update policy.

Table 4. Outline of the booklets

Booklet	Contents
Booklet 1: Information Guide for Elderly People With Kidney Failure	<ol style="list-style-type: none"> 1. What Kidney Failure is <ol style="list-style-type: none"> 1.1. What healthy kidneys do 1.2. When do kidneys fail 1.3. What the symptoms of Kidney Failure are 2. What your treatment options are <ol style="list-style-type: none"> 2.1. Dialysis <ol style="list-style-type: none"> 2.1.1. Peritoneal Dialysis (PD/Water Dialysis) 2.1.2. Hemodialysis (HD/Blood Dialysis) 2.2. Kidney Supportive Care (KSC/Conservative Management) 3. How to choose a treatment <ol style="list-style-type: none"> 3.1. Comparing your treatment options 3.2. What if you want to stop dialysis 4. Advice for family caregivers
Booklet 2: Decision Guide for Elderly People With Kidney Failure	<ol style="list-style-type: none"> 1. Understanding what is important to you <ol style="list-style-type: none"> 1.1. Choosing a type of dialysis 2. Discussing your concerns with your loved ones and doctor

We will fulfil these criteria in future revisions of the PDA.

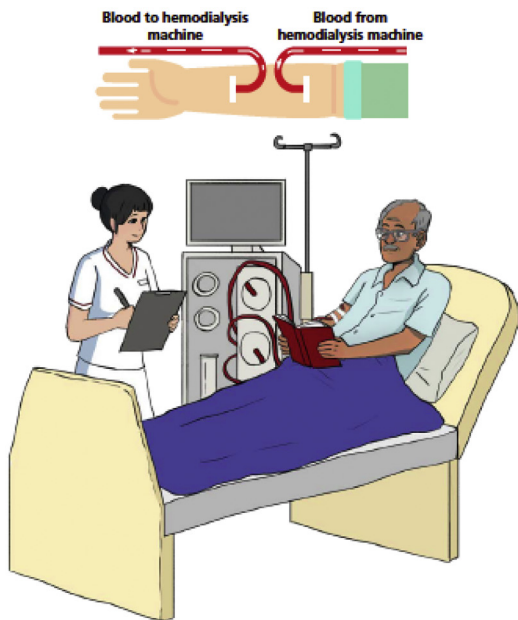
DISCUSSION

We developed a PDA for older people with ESKD to help them make an informed decision on which treatment would be the best fit for them. It is one of the few PDAs designed for older adults with ESKD.^{29,30} Of the other 2 identified, one³⁰ developed a PDA for older adults with ESKD but provides unequal amounts of information for supportive care (2 pages) and dialysis (9 pages). In addition, it does not provide the same type of information and or side-by-side comparisons for presented options. The other²⁹ is an educational video that does not contain a values clarification section, and hence would not be considered a PDA based on IPDAS guidelines.²⁷ There are 3 other PDAs for the same decision context, but these were not specifically designed for older patients, and therefore would not be appropriate for our population of interest. One³¹ was developed by Kidney Health Australia. It provides the same type of information and comparison for all treatment options, including kidney transplantation. Because a transplant is not a viable option for the target patient population in Singapore, this treatment option was excluded in our PDA. Another³² was developed by Alberta Health Services in the form of a Web-based interactive decision aid. It provides individualized information based on the respondent's answers. The last one³³ was recently developed by Kidney Research Yorkshire, and is a balanced and

2.1.2. Hemodialysis (HD/Blood Dialysis)

Features

- Usually done at a dialysis centre in Singapore.
- About 3 times a week.
- Each session takes around 4-6 hours.
- Most patients can go on with normal daily life when not receiving dialysis.



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Getting started

- You will need a minor surgery at your arm to create access to your blood.
- However, the blood vessel needs 2-3 months after the surgery to be ready for dialysis.
- During this time, you can receive HD via a temporary access point through a plastic tube around your neck or chest.

Treatment process

- Every time you receive HD, needles will be placed in your arm.
- An artificial dialysis filter in the HD machine will clean your blood.

Logistics

- You will need to travel to a dialysis centre to get HD.
- There are centres all over Singapore. A healthcare provider can connect you with a suitable dialysis centre.

Key Factors to consider for HD

- Requires a minor surgery before starting dialysis
- About 3 sessions per week, 4-6 hours per session
- Have to travel to and from dialysis centre
- Nurses at the dialysis centre will perform dialysis for you
- Chance of meeting other patients at dialysis centre
- Needles will be used every time you get dialysis
- May feel tired after a dialysis session
- Stricter diet and fluid intake compared to PD
- Risk of infection
- On average, more expensive than PD
- You need to arrange with a dialysis centre when you travel abroad

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Use this table to consider the factors that may help you choose a treatment:

Your Kidneys, Your Plan	Dialysis		Kidney Supportive Care (KSC/Conservative Management)
	Peritoneal Dialysis (PD/Water Dialysis)	Hemodialysis (HD/Blood Dialysis)	
Your treatment	Dialysis at home, done daily.	Dialysis at a centre, done 3-4 times a week.	Medicine and monitoring by your medical team.
Getting Started	You need a surgery to create an access point on your belly.	You need a surgery to create an access point on your arm.	No preparation.
Treatment process	Clean dialysis fluid flows into your belly to remove toxins and fluids.	An artificial dialysis filter in the HD machine cleans your blood.	Manage your symptoms through diet and medicine.
Your suitability	May not be suitable if you had major surgery in or around your belly.	May not be suitable if you have a weak heart or poor blood vessels.	More suitable for people aged 75 and above with multiple health conditions or limited life expectancy ² .
Your treatment risks	Chance of infection. You need to keep the access points clean.		No treatment-related risks.
Your daily activities	Flexible dialysis schedule.	Fixed dialysis schedule.	Take medicine as prescribed.
Your diet	There are some food and fluid limitations.		
Your travel plan	You need to bring your PD equipment when you travel.	You need to arrange to go to a dialysis centre for HD wherever you travel. Insurance may not cover overseas dialysis cost.	You can travel if you feel well.
Your home	You need to store the dialysis bags and a small dialysis machine at home. You need to keep your home clean.	No impact.	No impact.
Your support	You may need help to do dialysis at home. Your caregiver will need training on how to do it. Nurses can be contacted 24 hours a day for support.	You may need someone to help you travel to and from the dialysis centre.	Your medical team can support you and your family when needed. You can request a community nurse to visit you at your home.

Figure 1. Sample pages from (English) Booklet 1: Information Guide for Elderly People With Kidney Failure.

carefully developed PDA for patients with ESKD. However, this PDA is also not tailored to older adults and does not reflect the demographic in Singapore, suggesting a localized PDA is needed.

The PDA we developed targeted both older patients and their caregivers, as the latter are an integral part of

medical decision making in Singapore.^{16,34} As results from our qualitative interviews pointed out that patients feel pressured to choose dialysis, the PDA had a section specifically for caregivers on how they can support their loved ones in making treatment decisions consistent with patient preferences, and the importance

1. Understanding what is important to you

Below are some questions that may help clarify your values and preferences. Please choose a point on the scale for the following statements:

1. Do you prefer a treatment that has the **smallest impact on your lifestyle** or a treatment that provides you the **longest possible survival**?

0 1 2 3 4

Minimum survival
Smallest impact on lifestyle

Longest possible survival
Largest impact on lifestyle

5. I am willing to **spend several hours** going through a treatment **regularly** (3 - 4 times a week, or daily).

0 1 2 3 4

Strongly disagree

Strongly agree

2. Do you prefer a treatment that has the **least treatment-related side effects and complications** or a treatment that provides you the **longest possible survival**?

0 1 2 3 4

Minimum survival
Least side effects

Longest possible survival
Most side effects

6. I am willing to accept **pain** (e.g. inserting needles) and **discomfort** (e.g. tiredness, dizziness) that might come with a treatment.

0 1 2 3 4

Strongly disagree

Strongly agree

3. Do you prefer a treatment that has the **lowest cost** or a treatment that provides you the **longest possible survival**?

0 1 2 3 4

Minimum survival
Lowest cost

Longest possible survival
Highest cost

7. I am willing to **arrange with overseas centres/companies** to continue with my treatment when I travel overseas.

0 1 2 3 4

Strongly disagree

Strongly agree

4. I am willing to have a minor **surgery** to start a treatment.

0 1 2 3 4

Strongly disagree

Strongly agree

How to interpret the score:

- The score ranges from 0 to 28.
- Patients with lower scores may lean towards KSC.
- Patients with higher scores may lean towards dialysis.

1.1. Choosing a type of dialysis

If you choose dialysis, you will have to decide between Hemodialysis (HD) and Peritoneal Dialysis (PD). Here are some questions that can help you decide which might be a better fit for you. Please choose a point on the scale for the following questions:

1. Do you prefer to **travel to a centre 3 - 4 times a week** for dialysis or have dialysis **at home every day**?

0 1 2

3 - 4 times a week
Travel to a centre

Does not matter

Every day
At home

5. Do you prefer to have dialysis through **needles inserted into your arm at every session** or through a **permanent tube (catheter)** at your belly?

0 1 2

Needles inserted into arm

Does not matter

Catheter at belly

2. Do you prefer dialysis with a **fixed schedule 3 - 4 times a week** or **flexible** (can vary by 1 - 2 hours) **daily dialysis**?

0 1 2

3 - 4 times a week
Fixed schedule

Does not matter

Every day
Flexible schedule

6. Do you prefer a **nurse** or **your caregiver/yourself** to administer your dialysis?

0 1 2

A nurse

Does not matter

Me/My caregiver

3. Do you prefer dialysis that is **less frequent** (3 - 4 times a week) or that allows a **more flexible diet**?

0 1 2

Stricter diet
Less frequent (3 - 4 times a week)

Does not matter

More flexible diet
More frequent (Every day)

7. Do you prefer to **interact with other patients** with kidney failure during dialysis?

0 1 2

Yes

Does not matter

No

4. Do you prefer dialysis that is **less frequent** (3 - 4 times a week) or that has **fewer side effects**?

0 1 2

More side effects
Less frequent (3 - 4 times a week)

Does not matter

Fewer side effects
More frequent (Every day)

8. Can you make a **clean space in your house** for items needed for dialysis?

0 2

No

Yes

How to interpret the score:

- The score ranges from 0 to 16.
- Patients with lower scores may lean towards HD.
- Patients with higher scores may lean towards PD.

You will need time to prepare for dialysis and to apply for funding if you are eligible. It is important to think ahead and make a timely decision.

Figure 2. Sample pages from (English) Booklet 2: Decision Guide for Elderly People With Kidney Failure.

of respecting these wishes. We also included a section on advising patients on how to reach a treatment decision and express their wishes to their physicians and caregivers. These sections are unique to our PDA when compared with others with the same decision context.

The patient and caregiver testimonials and explicit values clarification method are also unique to our PDA. We believe that an explicit and structured values clarification method linking responses to a specific treatment choice makes it easy for patients to

Table 5. Outline of the video

Video segment	Contents
Introduction	<ol style="list-style-type: none"> 1. Senior consultant introduction 2. Video overview
Kidney failure treatment options	<ol style="list-style-type: none"> 1. Overview of treatment options (nested decision tree) 2. Peritoneal dialysis (PD) <ol style="list-style-type: none"> a. Continuous ambulatory peritoneal dialysis (CAPD) b. Automated peritoneal dialysis c. Key points of consideration for PD 3. Hemodialysis (HD) <ol style="list-style-type: none"> a. Key points of consideration for HD 4. Kidney Supportive Care (KSC) known as conservative management <ol style="list-style-type: none"> a. Key points of consideration for KSC
Patient and caregiver testimonials	<ol style="list-style-type: none"> 1. Patient and caregiver introductions 2. Caregiver's duties and burden 3. Positive aspects of treatment 4. Negative aspects of treatment 5. Coping with illness 6. Decision making 7. Treatment goals 8. Advice to others
Summary	<ol style="list-style-type: none"> 1. Summary table 2. Conclusion by senior consultant 3. Credits

systematically consider various aspects of all treatment options, and in eventually choosing a treatment.³⁵

We faced several challenges in developing the PDA. First was the recruitment process for the video testimonials. Recruitment proved to be especially arduous due to the reluctance of older patients and caregivers to share their experiences on video. Participants reported discomfort with sharing their personal stories publicly, with some expressing fear of influencing others toward a particular treatment that they may regret later. Caregivers were also unwilling to participate because of their caregiving and other responsibilities. We were also unable to attain content on certain topics such as family conflict that were highlighted in our qualitative interviews as an important issue in the decision-making process. Nevertheless, we interviewed each recruited participant on both their positive and negative experiences to provide a balanced view of all treatment options.

Our inclusion criteria also posed some challenges. To ensure that patients had sufficient experience with their respective treatments, we required patients to have had a minimum of 6 months of experience with their treatment. However, because the time lapse, some older patients had trouble accurately recalling their decision-making process. In such instances, we gathered more input from the caregivers who were often-times younger and could remember the details better. Future developers of PDAs should consider recruiting

participants before decision making and interviewing them during the decision-making process.

Another challenge we faced was in managing potential sources of bias in decision making, such as formats, language, layout, and graphics. For instance, we intended to present both survival and mortality rates because literature has shown that framing affects a respondent's risk perception. However, because talking about death is a taboo in Asian societies,^{36,37} we decided to only present the survival rates to minimize distress and cognitive burden.

We also note that certain items in the pilot-testing survey for the questions related to "Usage of up-to-date scientific evidence that is cited in a reference section or technical document" scored poorly. For example, with regard to "The decision aid reports how often it is updated," the pilot PDA had not presented date of development/update but we included this information in the final version. Similarly, although the PDA referenced evidence from other similar studies, we did not describe detailed information about these studies in the PDA to avoid lengthening the booklet.

A limitation of our study was that only one patient representative was included in the advisory panel. Another limitation was that we were not able to test how the use of testimonials in our video affected people's judgments and opinions. There is currently no evidence on whether testimonials enhance or counter the effectiveness of a PDA to support making informed decisions.³⁸

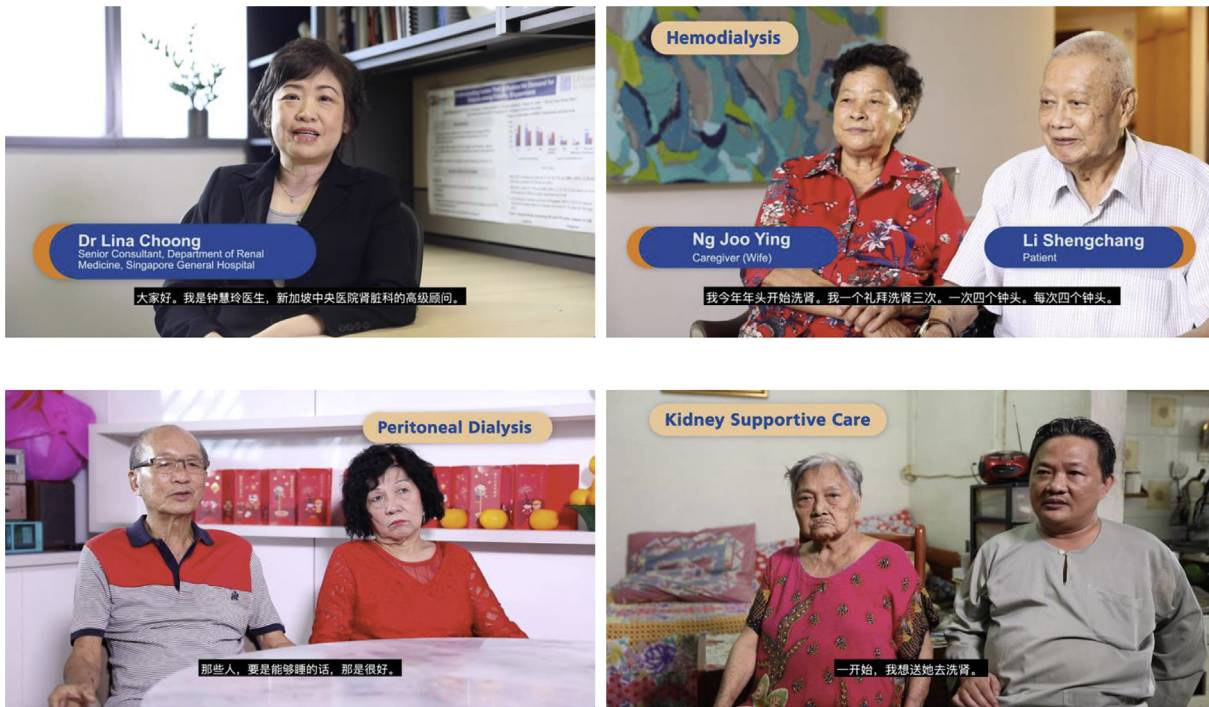
CONCLUSION

We developed a PDA, including booklets and video, to help older people with ESKD and their caregivers make informed treatment decisions. Pilot tests indicated that patients and caregivers found the PDA understandable and helpful in making a treatment decision.

Currently, people newly diagnosed with ESKD are offered renal counseling. Our PDA would be used during these counseling sessions for eligible older adults. First, the video would be screened to patients and caregivers. Following that, the counselor would hand them the booklets, going over them and answering any questions. We are currently in the process of designing a study to further test the efficacy of the PDA among this patient subpopulation. If successful, it will be made available in renal departments in Singapore hospitals.

DISCLOSURE

All the authors declared no competing interests.



Summary			
Factor	PD	HD	KSC
Your Treatment	Dialysis at home Daily	Dialysis at a centre, 3 to 4 times a week	Medicine and monitoring
Getting Started	Minor surgery	Minor surgery	No preparation
Treatment Process	Catheter in belly	Needles in arm	Diet and medicine
Your Treatment Risks	Infection	Infection	No treatment related risks

Figure 3. Sample scenes from the (English) video.

Table 6. Quality assessment of the PDA according to the IPDASi v4.0 criteria

	Whether criterion was met, and by which part of PDA
1. DA describes health condition or problem	Yes (Booklet and video)
2. DA explicitly states decision to be considered	Yes (Booklet and video)
3. DA describes the options	Yes (Booklet and video)
4. DA describes the positive features of each option	Yes (Booklet and video)
5. DA describes the negative features of each option	Yes (Booklet and video)
6. DA describes what it is like to experience the psychosocial consequences of the options	No. However, there is some discussion on the psychosocial consequences of the different treatments in the video testimonials.
7. DA shows the negative and positive features of options in equal detail (similar fonts/sequence/representation of statistical information)	Yes (Booklet and video)
8. DA provides citations to the evidence selected	Yes (Booklet)
9. DA provides a production/publication date	Yes (Booklet and video)
10. DA provides information about the update policy	No
11. DA provides information about levels of uncertainty around event or outcome probabilities	Yes (Booklet)
12. DA provides information about the funding source used for development	Yes (Booklet and video)
Total IPDAS score out of 12	10

DA, decision aid; IPDAS, International Patient Decision Aid Standards; PDA, patient decision aid.

PATIENT CONSENT

The RETREAT study was approved by SingHealth Institutional Review Board (reference: 2018/2350). All participants provided written consent to participate in the study.

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SUPPLEMENTARY MATERIAL

Supplementary File (PDF)

- S1.** Interview Guide for Advisory Panel Members.
- S2.** Pilot-Testing Questionnaire and Open-Ended Questions for Patients.
- S3.** Themes From Qualitative Interviews With Advisory Panel Members.
- S4.** Presentation of Expected Survival in the Booklet Decision Aid

REFERENCES

1. Luyckx VA, Tonelli M, Stanifer JW. The global burden of kidney disease and the sustainable development goals. *Bull World Health Organ.* 2018;96:414.
2. Nitta K, Okada K, Yanai M, et al. Aging and chronic kidney disease. *Kidney Blood Press Res.* 2013;38:109–120.
3. National Registry of Disease Office. Singapore Renal Registry Annual Report 2018. Available at: <https://www.nrdo.gov.sg/docs/librariesprovider3/default-document-library/singapore-renal-registry-annual-report-2018.pdf>; 2020. Accessed January 11, 2021.
4. Brunori G, Viola BF, Maiorca P, et al. How to manage elderly patients with chronic renal failure: conservative management versus dialysis. *Blood Purif.* 2008;26:36–40.
5. Smith C, Da Silva-Gane M, Chandna S, et al. Choosing not to dialyze: evaluation of planned non-dialytic management in a cohort of patients with end-stage renal failure. *Nephron Clin Pract.* 2003;95:c40–c46.
6. Tse DM-W. Experience of a renal palliative care program in a Hong Kong center: characteristics of patients who prefer palliative care to dialysis. *Hong Kong J Nephrol.* 2009;11:50–58.
7. Yong D, Kwok A, Wong D, et al. Symptom burden and quality of life in end-stage renal disease: a study of 179 patients on dialysis and palliative care. *Palliat Med.* 2009;23:111–119.
8. Seow Y-Y, Cheung YB, Qu LM, et al. Trajectory of quality of life for poor prognosis stage 5D chronic kidney disease with and without dialysis. *Am J Nephrol.* 2013;37:231–238.
9. Davison SN, Levin A, Moss AH, et al. Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: developing a roadmap to improving quality care. *Kidney Int.* 2015;88:447–459.
10. Finkelstein EA, Ozdemir S, Malhotra C, et al. Understanding factors that influence the demand for dialysis among elderly in a multi-ethnic Asian society. *Health Policy.* 2018;122:915–921.
11. Tonkin-Crine S, Okamoto I, Leydon GM, et al. Understanding by older patients of dialysis and conservative management for chronic kidney failure. *Am J Kidney Dis.* 2015;65:443–450.
12. Davison SN. End-of-life care preferences and needs: perceptions of patients with chronic kidney disease. *Clin J Am Soc Nephrol.* 2010;5:195–204.
13. Verberne WR, Konijn WS, Prantl K, et al. Older patients' experiences with a shared decision-making process on choosing dialysis or conservative care for advanced chronic kidney disease: a survey study. *BMC Nephrol.* 2019;20:264.
14. Tan EG, Teo I, Finkelstein EA, et al. Determinants of regret in elderly dialysis patients. *Nephrology.* 2019;24:622–629.
15. Morton R, Tong A, Howard K, et al. The views of patients and carers in treatment decision making for chronic kidney disease: systematic review and thematic synthesis of qualitative studies. *BMJ.* 2010;340:c112.
16. Han E, Haldane V, Koh JJK, et al. Perspectives on decision making amongst older people with end-stage renal disease and caregivers in Singapore: a qualitative study. *Health Expect.* 2019;22:1100–1110.
17. Wong SP, Vig EK, Taylor JS, et al. Timing of initiation of maintenance dialysis: a qualitative analysis of the electronic medical records of a national cohort of patients from the Department of Veterans Affairs. *JAMA Intern Med.* 2016;176:228–235.
18. Claramita M, Utarini A, Soebono H, et al. Doctor–patient communication in a Southeast Asian setting: the conflict between ideal and reality. *Adv Health Sci Educ.* 2011;16:69–80.
19. Winterbottom AE, Mooney A, Russon L, et al. Kidney disease pathways, options and decisions: an environmental scan of international patient decision aids. *Nephrol Dial Transplant.* 2020;35:2072–2082.
20. De Achaval S, Fraenkel L, Volk RJ, et al. Impact of educational and patient decision aids on decisional conflict associated with total knee arthroplasty. *Arthritis Care Res.* 2012;64:229–237.
21. O'Connor NR, Corcoran AM. End-stage renal disease: symptom management and advance care planning. *Am Fam Physician.* 2012;85:705–710.
22. Subramanian L, Zhao J, Zee J, et al. Use of a decision aid for patients considering peritoneal dialysis and in-center hemodialysis: a randomized controlled trial. *Am J Kidney Dis.* 2019;74:351–360.
23. van Weert JC, Van Munster BC, Sanders R, et al. Decision aids to help older people make health decisions: a systematic review and meta-analysis. *BMC Med Inform Decis Mak.* 2016;16:45.
24. Winterbottom AE, Bekker HL, Russon L, et al. Dialysis vs conservative management decision aid: a study protocol. *J Kidney Care.* 2018;3:179–185.
25. Winterbottom AE, Gavaruzzi T, Mooney A, et al. Patient acceptability of the yorkshire dialysis decision aid (YoDDA)

- booklet: a prospective non-randomized comparison study across 6 predialysis services. *Periton Dial Int*. 2016;36:374–381.
26. Ozdemir S, Jafar TH, Choong LHL, et al. Family dynamics in a multi-ethnic Asian society: comparison of elderly CKD patients and their family caregivers experience with medical decision making for managing end stage kidney disease. *BMC Nephrol*. 2019;20:1–9.
 27. Volk RJ, Llewellyn-Thomas H, Stacey D, et al. Ten years of the International Patient Decision Aid Standards Collaboration: evolution of the core dimensions for assessing the quality of patient decision aids. *BMC Med Inform Decis Mak*. 2013;13(Suppl 2):S1.
 28. Department of Statistics Singapore. General Household Survey 2015. Available at: <https://www.singstat.gov.sg/publications/ghs/ghs2015content>; 2018. Accessed January 11, 2021.
 29. Eneanya ND, Percy SG, Stallings TL, et al. Use of a supportive kidney care video decision aid in older patients: a randomized controlled trial. *Am J Nephrol*. 2020;51:736–744.
 30. Brown L, Gardner G, Bonner A. A randomized controlled trial testing a decision support intervention for older patients with advanced kidney disease. *J Adv Nurs*. 2019;75:3032–3044.
 31. Fortnum D, Smolonogov T, Walker R, et al. 'My kidneys, my choice, decision aid': supporting shared decision making. *J Ren Care*. 2015;41:81–87.
 32. Alberta Health Services. Conservative kidney management (CKM). Available at: <https://www.ckmcare.com/>; 2016. Accessed July 20, 2021.
 33. Winterbottom A, Mooney A, Russon L, et al. *A Dialysis and Conservative Care Decision Aid: Living with Kidney Disease*. Kidney Research Yorkshire, 2020.
 34. Ozdemir S, Jafar TH, Choong LHL, et al. Family dynamics in a multi-ethnic Asian society: comparison of elderly CKD patients and their family caregivers experience with medical decision making for managing end stage kidney disease. *BMC Nephrol*. 2019;20:73.
 35. Witteman HO, Gavaruzzi T, Scherer LD, et al. Effects of design features of explicit values clarification methods: a systematic review. *Med Decis Mak*. 2016;36:760–776.
 36. Chan CKL, Yau MK. Death preparation among the ethnic Chinese well-elderly in Singapore: an exploratory study. *Omega (Westport)*. 2009-2010;60:225–239.
 37. Ming-lin AC, Lang GS. Attitudes of Chinese elderly people towards death: practical implications for social workers. *Asia Pac J Soc Work*. 1998;8:50–63.
 38. Bekker HL, Winterbottom AE, Butow P, et al. Do personal stories make patient decision aids more effective? A critical review of theory and evidence. *BMC Med Inform Decis Mak*. 2013;13:1–9.