



# Development and Acceptability of a Kidney Therapy Decision Aid for Patients Aged 75 Years and Older: A Design-Based Research Involving Patients, Caregivers, and a Multidisciplinary Team

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**Rationale & Objective:** Many older adults prefer quality of life over longevity, and some prefer conservative kidney management (CKM) over dialysis. There is a lack of patient-decision aids for adults aged 75 years or older facing kidney therapy decisions, which not only include information on dialysis and CKM but also encourage end-of-life planning. We iteratively developed a paper-based patient-decision aid for older people with low literacy and conducted surveys to assess its acceptability.

**Study Design:** Design-based research

**Setting and Participants:** Informed by design-based research principles and theory of behavioral activation, a multidisciplinary team of experts created a first version of the patient-decision aid containing 2 components: (1) educational material about kidney therapy options such as CKM, and (2) a question prompt list relevant to kidney therapy and end-of-life decision making. On the basis of the acceptability input of patients and caregivers, separate qualitative interviews of 35 people receiving maintenance dialysis, and with the independent feedback of educated layperson, we further modified the patient-decision aid to create a second version.

**Analytical Approach:** We used descriptive statistics to present the results of acceptability surveys and thematic content analyses for patients' qualitative interviews.

**Results:** The mean age of patients (n=21) who tested the patient-decision aid was 80 years and the mean age of caregivers (n=9) was 70 years. All respondents held positive views about the educational component and would recommend the educational component to others (100% patients and caregivers). Most of the patients reported that the question prompt list helped them put concerns into words (80% patients and 88% caregivers) and would recommend the question prompt list to others (95% patients and 100% caregivers).

**Limitations:** Single-center study

**Conclusions:** Both components of the patient-decision aid received high acceptability ratings. We plan to launch a larger effectiveness study to test the outcomes of a decision-supporting intervention combining the patient-decision aid with palliative care-based decision coaching.

Complete author and article information provided before references.

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Kidney Med. 5(7):100671.  
Published online May 16, 2023.

doi: 10.1016/j.xkme.2023.100671

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Informed kidney therapy decision making is an ethical imperative.<sup>1</sup> Transplantation generally offers more longevity and better quality of life<sup>2</sup>; however, many older patients with multiple comorbidities<sup>3</sup> are not eligible—leaving them a choice of conservative kidney management (CKM) or dialysis.<sup>4,5</sup> In such cases, guidelines endorse CKM as a treatment choice if it aligns with patients' goals.<sup>6,7</sup> In these often-fraught situations, patient education is of paramount importance because, in the absence of adequate information, poor-quality decision making<sup>1,8</sup> and dialysis regret are more likely to happen.<sup>9</sup>

Patient-decision aids (PDAs) may strengthen informed decision making by supporting kidney therapy decision-making conversations between patients and clinicians.<sup>10</sup> However, for a PDA to be effective, all treatment options need to be presented clearly and without bias.<sup>11,12</sup> Although progress is being made,<sup>13</sup> suitable materials, particularly for adults ineligible for kidney transplant,<sup>14</sup> are few.<sup>15,16</sup> One review of PDAs for patients with kidney disease showed that only 5% of the materials were written at the recommended reading level for limited health literacy populations (grade 5)

and most were written at above the average US reading level (grade 8).<sup>16</sup> Moreover, many PDAs about kidney therapy options do not present CKM as a treatment option.<sup>15</sup>

A lack of suitable PDAs may be partly driven, by disciplinary silos. Layperson-targeted writing is difficult because it requires the understandings of decision-making psychology,<sup>17</sup> health literacy,<sup>14,18</sup> digital literacy (if online),<sup>19</sup> communication,<sup>20</sup> and the actual subject matter at hand.<sup>8,17,21</sup> In addressing this vital need for cross-disciplinary collaboration to develop a PDA for kidney therapy decision making, design-based research is a promising approach. Design-based research is an iterative, participatory, and frequently mixed-methods approach in which experts and stakeholders collaborate in the development cycles to produce a satisfactory educational intervention.<sup>22</sup> In this article, we report how our team used a design-based research approach to recruit multidisciplinary experts; develop a theory-based checklist to guide decisions for PDA development; test it for acceptability; and refine the PDA based on patient, caregiver, and educated layperson inputs. The PDA promotes behavioral

### PLAIN LANGUAGE SUMMARY

When people get sick with kidney disease, they may have to make tough choices about how they want to be treated. It can be hard for older people with this condition to understand all their options, such as dialysis, conservative kidney management, or end-of-life planning. We created and tested a patient-decision aid with 2 parts: one part teaches about kidney disease and its treatment options, and the other part gives a list of questions to start conversations about treatment options with doctors. The guide was made with the help of patients, and most of the patients and their family members who used the guide found it helpful.

activation among patients and caregivers by emphasizing a choice, encouraging goal concordant decision making and incorporating question prompt list to think about various questions relevant to kidney therapy and end-of-life decision making.<sup>23</sup> We chose to design the PDA for people aged 75 years or older because of their frequent preference for quality of life over longevity,<sup>24</sup> less eligibility for transplantation,<sup>25</sup> limited life expectancy,<sup>26</sup> and modest to no gain in life expectancy with dialysis.<sup>27-29</sup>

## METHODS

### Assembling Experts and Outlining Requirements

#### Recruitment of Experts

The University of Rochester approved the IRB (STUDY00001645). The first step of a design-based research project is to recruit experts and work to identify design requirements for the intervention.<sup>30,31</sup> Recent critical definitions of health literacy have focused not only on patient knowledge but more particularly on knowledge transfer, that is, taking action based on what was learned.<sup>32</sup> Given these conceptualizations, we put together a group of interdisciplinary experts (referred to as the expert panel) by approaching them through email or in-person to ensure that our PDA was not just comprehensible by patients and caretakers but also actionable and clinically relevant. The experts included a nephrologist (FS); 3 palliative care physicians (FS, RKH, RME); a psychologist (PRD); 4 experts in communication and decision making (FS, RKH, PRD, RME); an expert in pragmatic intervention trials, patient activation, and racial disparities (KAF); and an expert in patient literacy and education (RJA); and an advisory group of 5 nephrologists. Experts provided feedback throughout the stages of the PDA development.

#### Identification of Core Requirements

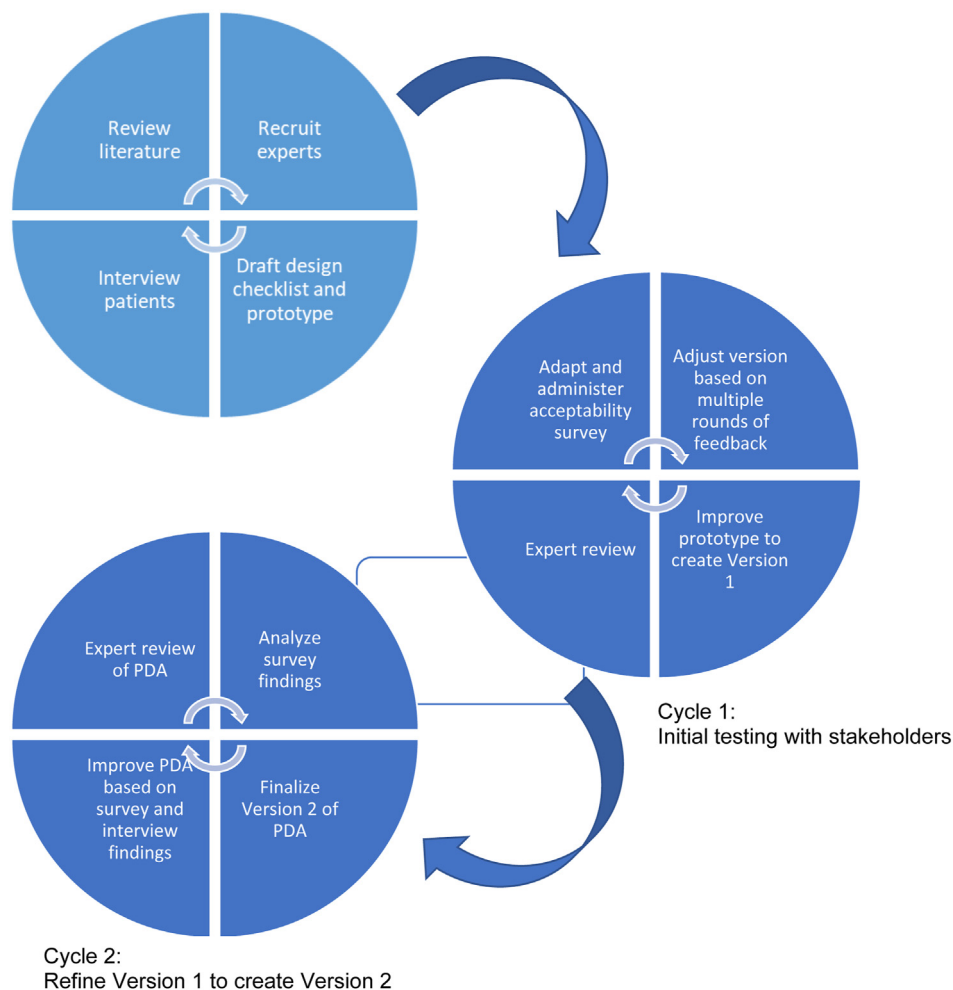
We created a checklist for PDA features derived from the theory of behavioral activation<sup>23</sup> and multiple frameworks and studies to eventually yield the best overall PDA (Fig 1; Table S1). To create this checklist, the first (FS) and the senior

(RJA) authors reviewed empirical evaluations of end-stage kidney disease-related PDAs, adapting International Patient Decision Aid Standards (IPDAS)<sup>11</sup> and the Patient Education Materials Assessment Tool (PEMAT)<sup>33</sup> to create design propositions (a checklist of features) covering both content and the best method of information presentation in the PDA. IPDAS is a widely used tool that provides standards for (1) presentation of treatment information and outcome probabilities, (2) consideration of patient goals and preferences, (3) disclosure of sources of evidence and author qualifications, (4) appropriate reading levels, (5) inclusion of stakeholder input throughout the development process,<sup>11</sup> and possible inclusion of patient narratives.<sup>34</sup> However, recent critical definitions of health literacy have focused not only on patient knowledge but also on patient knowledge transfer—that is, patients must be able to do something with what they learn.<sup>32</sup> To that end, increasing attention has been placed on populations with lower literacies: one recent review has used the PEMAT as a useful augment to IPDAS.<sup>35</sup> The PEMAT (<https://www.ahrq.gov/health-literacy/patient-education/pemat.html>) is a 26-item list that provides patient education material developers with guidance and a scale to rate actionability and understandability of materials; we incorporated PEMAT into our checklist. Although there is an overlap between IPDAS and PEMAT, several PEMAT items are not fully covered by IPDAS guidance on visual presentations, such as headings, captions, use of bullets (for readability), and inclusion of specific patient action steps.

#### Audience-Specific Requirements

Because of socioeconomic disparities and possible cognitive decline,<sup>36</sup> the recommended reading level for kidney disease materials is fourth to sixth grade.<sup>37</sup> However, reading levels, themselves, are necessary but not sufficient criteria for comprehension and acceptability.<sup>38(p816)</sup> Reading levels are computed based on word, sentence, and paragraph length, which may lead to undesired effects on PDAs aimed at populations with lower literacy. For example, it is important not to omit long words when they are the clearest way to convey meaning.<sup>39</sup> Moreover, authors of materials written to meet lower reading levels may be tempted to oversimplify the content or be childish in presentation.<sup>40</sup> We added criteria to the checklist to reflect the need for a lower-than-average reading level and avoidance of common pitfalls when documents are written at lower reading levels.

Other visual aspects that are not particularly mentioned in the PEMAT or IPDAS criteria but may be relevant to older adults—such as the use of large (at least 12 points), San Serif fonts, and the use of larger line spacing and page margins—were added to the checklist.<sup>35</sup> Evidence suggests that offering small manageable steps to promote patient activation and engagement with their health care is helpful; hence, we added a criterion that small actionable items must be highlighted throughout the PDA.<sup>23</sup> Considering patient engagement and their complex needs,<sup>41</sup> the patient literacy expert also suggested that the inclusion of deliberative words (such as can instead of should or need to when a



**Figure 1.** Research steps and processes undertaken during the patient-decision aid (PDA) development.

choice is available) may reduce implied paternalism.<sup>41,42</sup> We added a checklist item about patient-related nomenclature, that is, when a careful choice between patient, client, customer, and person/people was merited,<sup>43</sup> we opted to use person—when possible and patient—when context would not have been otherwise clear.

### Patient Needs Assessment Interviews

Patients receiving maintenance dialysis (n=35) were recruited from both inpatient and outpatient dialysis units after obtaining written informed consent. Six patients showed low literacy levels because they often or always needed help reading instructions, pamphlets, or other written material from their doctor. Patients were interviewed to better understand how they experienced dialysis education and what their perceived needs were (Items S1-S4). Twenty percent of the transcripts were coded by 2 coders (FS, SD) and the remaining transcripts by 1 coder (SD); all coders used an inductive content analysis approach. Five key themes emerged as follows: (1) perceived lack of dialysis education, (2) noncomprehension of education materials, (3) difficulty with self-directed web searches, (4)

openness to a variety of educational formats, and (5) desire for inclusion of patient stories and a patient community. The first theme was lack of dialysis education—some patients complained that they had not received any dialysis education or information, but “it would have helped.” Among patients who did receive education materials, some reported comprehension/acceptability (eg, “It saved my life.”), whereas others reported difficulty in comprehension/unacceptability (eg, “What did I just read? there was so much of it.” “Give me the bottom line.”). Patients reported attempting web searches but having difficulty locating information and indicated that they were open to print, digital text, or videos. Patients also asked for inclusion of patient stories in the education material and, as one patient wrote, a “preferably in-person” community “of patients with kidney disease.” The last item—connectivity to a patient community—was not explicitly part of IPDAS or PEMAT; hence, it was added to our checklist (Table S1).

### Implementation and Identification End Point

Our checklist presents a robust list of literacy requirements for an older person-targeted PDA, but the



We chose an action-centered title.

#### WHAT ARE SOME THINGS TO THINK ABOUT WHEN CHOOSING A TREATMENT?

You can make decisions that are right for you. You have treatment options available. Each option has risks and benefits. Here are some things to think about:

- You need to talk with your doctor about your goals. Together, you can discuss which treatments help reach your goals.
- Also, you may want to talk with your doctor about:
  - how long you may live.
  - how well you may live with different treatments.

#### Questions to ask:

"How long and how well would I live if I do dialysis or do not do it?"

We put QPL questions in key spots throughout the booklet.



We improved the quality of the images throughout the booklet. The picture above was an illustration drafted by a Ukrainian artist, used in the context that CKM is not “no care”; one can still see one’s doctor.

#### Summary of Treatment Options

Remember you can decide what option is best for you.

We have talked about three options:

1. No dialysis
2. Dialysis
3. Kidney Transplants

Talking to your doctor about goals can help you choose. We have also listed answers to common questions in this booklet.

We provided summaries and bullets throughout to make reading simpler.

**Figure 2.** Examples of the key elements of the patient decision aid (PDA) (version 2.0). QPL, question prompt list.

expert panel still had to make certain collaborative design decisions during the PDA writing process. For instance, IPDAS suggest the inclusion of interactive elements such

as worksheets or question (prompt) lists.<sup>11</sup> The experts elected to include only question prompt lists<sup>44</sup> In oncology, question prompt lists have been shown to

**Table 1.** Demographics of Respondents for Acceptability Survey

Characteristic	Patients, n=21 (%)	Caregivers, n=9 (%)
Age, y (mean ± SD)	80.5 ± 4.9	69.6 ± 9.1
<b>Sex</b>		
Male	11 (52.4)	3 (33.3)
Female	10 (47.6)	6 (66.7)
<b>Income</b>		
≤50,000	13 (61.9)	5 (55.6)
≥50,001	6 (28.6)	3 (33.3)
Prefer not to answer	2 (9.5)	1 (11.1)
<b>Education</b>		
Grade 11 or below	4 (19.0)	0 (0)
Grade 12 or above	17 (81.0)	9 (100.0)
<b>Race</b>		
White	16 (76.2)	7 (77.8)
Black or African American	3 (14.3)	2 (22.2)
Mixed	1 (4.8)	0 (0)
Other	1 (4.8)	0 (0)
<b>Ethnicity</b>		
Hispanic or Latino origin	3 (14.3)	1 (11.1)
Not Hispanic or Latino origin	18 (85.7)	8 (88.9)
<b>Insurance</b>		
Medicare	18 (85.7)	NA
Medicaid/Medicare	2 (9.5)	NA
Private insurance (such as Excellus, Aetna, and Preferred Care)	1 (4.8)	NA

Note: One patient and 1 caregiver did not participate in the question prompt list acceptability survey.

promote patient-doctor discussions<sup>45-47</sup> but are increasingly being used in other fields<sup>48</sup>—including in nephrology.<sup>49</sup> One meta-review suggests that, overall, question prompt lists increase patient questions, particularly about prognosis.<sup>49</sup> Our team had to decide whether to deliver a one-size-fits all question prompt list—a simple list of questions applicable to most patients<sup>50</sup>—or a tailored, individualized list, perhaps narrowed down through the use of a website or worksheet.<sup>51</sup> In the end, we opted for a middle ground—we included a question prompt list with section titles/pages for each possible topic (eg, talk about your life, hopes, and worries), and an introduction encouraging patients to skim through the lists to hone in on topics of interest.

### Drafting Version 1

The goal of this cycle was to refine the prototype to produce a PDA version that could be tested with patients. The medical experts on the expert panel drafted the content to be included in the PDA. Then, the health literacy expert (RJA) rephrased the content to ensure readability. Subsequently, a nephrologist from the medical expert panel (FS) vetted and edited the reworded content to ensure accuracy.

### Acceptability testing of Version 1

To test the acceptability of version 1, we conducted 2 patient and caregiver surveys and solicited additional feedback from a focus group of public health graduate students and faculty at Rutgers University, New Jersey.

### Survey administration

To test acceptability, version 1 PDA with the question prompt list was mailed to the intervention patient and caregiver participants in the CKD-EDU study, a palliative care intervention to help adults aged 75 years or older with estimated glomerular filtration of ≤25 mL/min/1.73 m<sup>2</sup> with kidney therapy and end-of-life decision making. Each patient was asked to identify 3 people aged older than 21 years most involved in their care. Both patients and caregivers provided informed consent. The study team asked participants to read the PDA, circle personally relevant question prompt list questions, and bring their questions to a palliative care physician. At the end of the last intervention visit, participants were asked to complete 2 orally administered acceptability surveys: 1 for the education component and the other for the question prompt list component of the PDA. The group had adapted 2 previously published surveys to test the acceptability.<sup>50,52</sup>

### Additional feedback

We presented the PDA to a group of master-level (n=8) and doctoral-level students (n=10) and faculty members (n=4) and conducted an online focus group. We gave the PDA to this group, allocated 15 minutes to read, and asked for their feedback on version 1 using 14 predetermined questions (Item S2). The group suggested shortening the PDA length and making sure patients understand they have a choice and that their choice affects their quality and quantity of life, an aspect that is often absent from currently available PDAs.<sup>15</sup>

### Cycle 2: Moving Toward a Final, Version 2 of the PDA

Although version 1 received high rating on the patient survey (see the Results section), we made additional changes to the PDA based on the feedback from patients, caregivers, people receiving dialysis, educated laypeople, and the expert panel. Extracts of this version 2.0 are available in Fig 2. We are obtaining patient and caregiver feedback on version 2 in a separate study.

### Actionability

To emphasize self-efficacy and promote patient activation, we retitled the PDA from (Preparing for kidney disease treatment: your options, your decisions, your life) to a more concise and action-centered title (Choosing a kidney disease treatment) and added boxes with prompts into relevant sections of the PDA to make actionable steps more apparent. Patients had requested additional reading—we added links to additional educational materials and to patient communities.

**Table 2.** Patient and Caregiver Acceptability of the Kidney Therapy Education PDA\*

Question	Patients' Response, n=21 (%)	Caregivers' Response, n=9 (%)
<b>The booklet was very easy to read</b>		
Strongly agree/agree	19 (90.5)	8 (88.9)
Strongly disagree/disagree	2 (9.5)	1 (11.1)
<b>I thought the information in the booklet was clear</b>		
Strongly agree/agree	21 (100.0)	9 (100.0)
Strongly disagree/disagree	0 (0)	0 (0)
<b>I learned some new, helpful things from the booklet</b>		
Strongly agree/agree	20 (95.2)	9 (100.0)
Strongly disagree/disagree	1 (4.8)	0 (0)
<b>I knew most of the information in the booklet anyway</b>		
Strongly agree/agree	14 (66.7)	1 (11.1)
Strongly disagree/disagree	7 (33.3)	8 (88.9)
<b>I thought that the length of the booklet was about right</b>		
Strongly agree/agree	15 (71.4)	9 (100.0)
Strongly disagree/disagree	5 (23.8)	0 (0)
Missing	1 (4.8)	0 (0)
<b>I thought that the length of the booklet was too long</b>		
Strongly agree/agree	4 (19.0)	0 (0)
Strongly disagree/disagree	17 (81.0)	9 (100.0)
<b>I believed most of the information in the booklet</b>		
Strongly agree/agree	20 (95.2)	9 (100.0)
Strongly disagree/disagree	1 (4.8)	0 (0)
<b>I believed some of the information in the booklet</b>		
Strongly agree/agree	8 (38.1)	3 (33.3)
Strongly disagree/disagree	13 (61.9)	6 (66.7)
<b>The pictures helped explain things better</b>		
Strongly agree/agree	16 (76.2)	7 (77.8)
Strongly disagree/disagree	3 (14.3)	2 (22.2)
Not answered	2 (9.5)	0 (0)
<b>Treatment options (eg, dialysis) were clearly explained and easy to follow</b>		
Strongly agree/agree	19 (90.5)	9 (100.0)
Strongly disagree/disagree	2 (9.5)	0 (0)
<b>I think this booklet will help people</b>		
Strongly agree/agree	21 (100.0)	9 (100.0)
Strongly disagree/disagree	0 (0)	0 (0)
<b>I would recommend this booklet to someone choosing kidney disease treatment or dialysis options</b>		
Strongly agree/agree	21 (100.0)	9 (100.0)
Strongly disagree/disagree	0 (0)	0 (0)
<b>I liked the overall presentation of the booklet</b>		
Strongly agree/agree	21 (100.0)	9 (100.0)
Strongly disagree/disagree	0 (0)	0 (0)

### Pictures in the PDA

One of the main suggestions from the patients in the survey was to improve the pictures. We used The National

Institute of Diabetes and Digestive and Kidney Diseases Media Library (<https://www.niddk.nih.gov/news/media-library>), a searchable database of reusable images produced

**Table 3.** Patient and Caregiver Acceptability of the Question Prompt List

Question	Patients' Response, n=20 (%)	Caregivers' Response, n=8 (%)
<b>Did you completely read and understand the question prompt list?</b>		
Yes	20 (100.0)	8 (100.0)
No	0 (0)	0 (0)
<b>Did you find the question prompt list to be helpful?</b>		
Yes	8 (90.0)	8 (100.0)
No	1 (5.0)	0 (0)
Not answered	1 (5.0)	0 (0)
<b>Was the question prompt list easy to understand?</b>		
Yes	20 (100.0)	7 (87.5)
No	0 (0)	0 (0)
Not answered	0 (0)	1 (12.5)
<b>Were the questions relevant and useful to you?</b>		
Yes	19 (95.0)	8 (100.0)
No	1 (5.0)	0 (0)
<b>Did the questions help you put your questions and concerns into words?</b>		
Yes	16 (80.0)	7 (87.5)
No	4 (0.0)	1 (12.5)
<b>Did the question list help you come up with questions or concerns that you had not thought about before?</b>		
Yes	15 (75.0)	8 (100.0)
No	5 (25.0)	0 (0)
<b>Would you recommend that more doctors and patients use this sort of question list?</b>		
Yes	19 (95.0)	8 (100.0)
No	1 (5.0)	0 (0)

by the National Institutes of Health. We also used custom artwork drafted by a paid artist. We added a more attractive photograph and color scheme to the cover.

### Pictures scaffold additional information

The addition of pictures not only helped to make the PDA more aesthetically appealing but allowed for information to be conveyed simply. For instance, in response to patient desire to know more about peritoneal dialysis (PD), not only the authors (FS. and RJA.) added additional words, but they also improved the illustrations of PD to make them more informative. Previously, the booklet had only close-up images of a PD catheter. Inclusion of illustrations of people doing PD in natural settings (such as sleeping in a bed while using a cyclor) emphasized the home setting and equipment size.

## RESULTS

Table 1 provides the demographics of patients (n=21) and caregivers (n=9) who provided feedback on the educational component of the PDA. Of the 26 patients who received the CKD-EDU intervention, 21 completed the acceptability survey. Four (19%) patients showed grade 11 education level or less. Twenty-four patients received the CKD-EDU intervention, and 21 completed the survey. Table 2 and Box 1 provide the results of the acceptability survey for the educational component.<sup>52</sup> Approximately

91% of patients and 88% of the caregivers agreed the information was easy to read; 100% of both patients and caregivers felt the information was useful. Participants (90.5% patients and 100% caregivers) felt that the PDA “was easy to follow” when the PDA explained available treatment options. Patients reported learning new things from the PDA (95% patients and 100% caregivers). However, some patients felt they already knew most of the information in the book (67% patients and 11% caregivers). Patients perceived information in the PDA as accurate (95% patients and 100% caregivers); 100% of both patients and caregivers agreed the book would help people and they would recommend the book to patients choosing a kidney disease treatment option. Overall, participants perceived the look and feel of the PDA positively, although participants did identify some areas to improve in future versions. All caregivers and 71% of patients felt the length of the PDA was right, and 76.2% caregivers and 77.8% patients felt the images helped with the explanations. In addition, the qualitative responses of patients gave insight into areas the team may have missed. Within these responses, patients requested more information related to PD, information about traveling while being treated by dialysis, and references for additional reading.

Patients also responded positively about the usability and content of the question prompt list distributed with the PDA (Table 3; Box 1). All patients and caregivers felt they could completely read and understand the question

**Box 1.** Participants comments on the PDA and Question Prompt list

- Comments on the PDA
  - ◊ Could be more comprehensive depending on patient—could be more levels of comprehension and longer in length
  - ◊ Fix typing errors, show belt wrap for belly dialysis, show dimensions of machine, explain closet and space needed for peritoneal dialysis, and explain traveling on dialysis
  - ◊ It was well written
  - ◊ Refer to further source of info—more in-depth info
- Comments on the Question Prompt list
  - ◊ Images should show dimensions
  - ◊ Would integrate Question Prompt list with education booklet.

prompt list (100% patients and caregivers) and the list was helpful (90% patients and 100% caregivers). Participants also agreed that the list was relevant and useful (95% patients and 100% caregivers), helped put questions and concerns into words (80% patients and 88% caregivers), and helped come up with questions or concerns they had not previously considered (75% patients and 100% caregivers) and that they would recommend it for use by others (95% patients and 100% caregivers).

## Discussion

This study narrated the use of a design-based research approach to develop a kidney disease treatment option PDA for older people, which received high patient acceptability. We deemed the PDA acceptable because of its overall high (>75%) acceptability ratings, an acceptability threshold also used in other acceptability studies.<sup>53-55</sup> Notably, there have been several attempts at developing PDAs for older people with kidney disease,<sup>15</sup> and only recently did PDAs start including CKM as a treatment option for older people.<sup>13,56-59</sup> Our PDA is different from the previous PDAs because it not only provides kidney therapy options for older people with low literacy but also includes a question prompt list and encourages end-of-life planning—a feature often not present in other PDAs.

Our study has several strengths. One is the design-based research method approach that solicits the voices of multidisciplinary experts and stakeholders to make repeated iterative improvements throughout the development process.<sup>13,59,60</sup> Physicians, although skilled in their areas of expertise, may have not been trained to write materials suitable for laypeople.<sup>61</sup> As part of the PDA development process, we synthesized relevant frameworks, theories, and studies into a PDA design comprehensive checklist (Table S1), which could inform other related interventions. The content of our PDA also represents another possible strength: the use of question prompt

lists to aid dialysis and end-of-life decision making for older adults with CKD is new to the nephrology specialty; printed PDAs with detailed information on no dialysis option are not commonly available.<sup>62</sup> In fact, the inclusion of CKM as a treatment option in PDAs has been “hotly debated.”<sup>15(p21)</sup> The high acceptability of our aid—that features all possible treatment options such as CKM—may suggest inclusion of CKM in PDAs is helpful.

However, our study has limitations as well. We pilot tested the acceptability of the PDA in a small sample from a single center, making our findings less generalizable. Although we obtained feedback from patients and caregivers, they were not a part of the research team. We are unable to report the direct effects of PDA on actual comprehension, promoting communication, patient activation, person-centered decision making, and other health care outcomes. Future studies to examine these important outcomes and stakeholders’ feedback on incorporation of PDAs into the workflow are needed.

To conclude, we successfully developed and evaluated the acceptability of a PDA incorporating information about kidney therapy options and a question prompt list for older adults with CKD facing kidney therapy decisions. Both patients and caregivers provided high acceptability ratings to both the components of PDA and the experience gained by multiple rounds of feedback helped us improve the PDA. We plan to launch a large effectiveness study to test the outcomes of a decision-supporting intervention that combines the current PDA with palliative care-based decision coaching.

## SUPPLEMENTARY MATERIAL

### Supplementary File (PDF)

**Item S1:** Example qualitative interview questions related to kidney therapy education.

**Item S2:** List of focus group questions experts asked of experts when evaluating version 1.

**Item S3:** Acceptability questionnaire for the kidney education booklet.

**Item S4:** Acceptability questionnaire for the question prompt list.

**Table S1:** Checklist Derived From Theory, Frameworks, and Research Used to Develop the PDA.

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**Authors' Contributions:** Development of the PDA: FS, RJA; testing of the PDA: FS; refinement of the PDA: FS, RA; input on PDA: RKH, KAF, PRD, RME; qualitative interviews and analyses: SD. Each author contributed important intellectual content during manuscript drafting or revision and accepts accountability for the overall work by ensuring that questions pertaining to the accuracy or integrity of any portion of the work are appropriately investigated and resolved.

**Support:** Dr. Saeed is a recipient of the Carl W. Gottschalk Research Scholar Grant, the NIDDK career development award, the UR K12 award, and a grant by the Renal Research Institute.

**Financial Disclosure:** The authors declare that they have no relevant financial interests.

**Peer Review:** Received December 5, 2022. Evaluated by 3 external peer reviewers, with direct editorial input from the Editor-in-Chief. Accepted in revised form March 26, 2023.

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