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Value of patient decision aids for shared decision-making in kidney failure

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Abstract

Background: It is unknown how often Dutch patient decision aids are used during kidney failure treatment modality education and what their impact is on shared decision-making.

Objectives: We determined the use of Three Good Questions, 'Overviews of options', and Dutch Kidney Guide by kidney healthcare professionals. Also, we determined patient-experienced shared decision-making. Finally, we determined whether the experience of shared decision-making among patients changed after a training workshop for healthcare professionals.

Design: Quality improvement study.

Participants: Healthcare professionals answered questionnaires regarding education/patient decision aids. Patients with estimated glomerular filtration rate <20 mL/min/1.73 m^2 completed shared decision-making questionnaires. Data were analysed with one-way analysis of variance and linear regression.

Results: Of 117 healthcare professionals, 56% applied shared decision-making by discussing Three Good Questions (28%), 'Overviews of options' (31%–33%) and Kidney Guide (51%). Of 182 patients, 61%–85% was satisfied with their education. Of worst scoring hospitals regarding shared decision-making, only 50% used 'Overviews of options'/Kidney Guide. Of best scoring hospitals 100% used them, needed less conversations ($p = 0.05$), provided information about all treatment options and more often provided information at home. After the workshop, patients' shared decision-making scores remained unchanged.

Conclusions: The use of specifically developed patient decision aids during kidney failure treatment modality education is limited. Hospitals that did use them had higher shared decision-making scores. However, the degree of shared decision-making experienced by patients remained unchanged after healthcare professionals

were trained on shared decision-making and the implementation of patient decision aids.

KEYWORDS
education process, kidney failure, patient decision aids, quality improvement, shared decision-making

INTRODUCTION

The global incidence of kidney failure is rapidly increasing (Thurlow et al., 2021). Kidney failure has a significant global economic impact and influence on the daily life of the individual patient. Patients not only have to deal with complications of kidney failure, but also face an intensive education process regarding the different treatment options, that is, conservative care and kidney replacement therapies (KRT). In current practice, patients sometimes experience that they are not offered all treatment options or that certain treatment recommendations are not well reasoned (Van Dulmen et al., 2022). In a decision process regarding kidney failure treatment options, all available relevant medical knowledge should be combined with the medical characteristics of an individual patient, and with his or her personal values and preferences to ensure a shared decision that is evidence-based and patient-centred (Renal Physicians Association, 2010).

The model for sharing in medical decision-making was first described in 1972 (Veatch, 1972), but it was not until 1997 that an article was published which provided more clarity regarding the actual shared decision-making (SDM) model (Charles et al., 1997). Since then, numerous articles regarding SDM for patients with kidney disease have been published (Ho et al., 2020; Lee et al., 2019; Verberne et al., 2019) and the use of SDM is incorporated in national and international kidney guidelines (Farrington et al., 2016; Federatie Medische Specialisten, 2016; Inker et al., 2014; Renal Physicians Association, 2010). Although many guidelines advocate the use of SDM in the care for patients with kidney disease, studies have shown that a large proportion of patients with kidney failure do not experience their decision on kidney replacement therapy as a shared one (Dahlerus et al., 2016; Verberne et al., 2019). To improve this situation, patient decision aids (PDAs) and other tools for SDM for this specific group of patients have been developed.

LITERATURE REVIEW

PDAs are defined as 'evidence-based tools designed to help patients make specific and deliberated choices among healthcare options' (International Patient Decision Aids Standards (IPDAS) Collaboration, Stacey et al., 2017). PDAs are important tools that can promote SDM, because they are specifically developed to support the SDM process and serve to structure and supplement the information provided by healthcare professionals (HCPs) (Stacey et al., 2017; Winterbottom et al., 2020). The latest Cochrane review, regarding PDAs for treatment or screening decisions, shows that PDAs increase patients' knowledge of risks and benefits and have a positive effect on the communication between patients and HCPs (Stacey et al., 2017). But no studies concerning PDAs for patients with chronic kidney disease (CKD) were included (Stacey et al., 2017).

However, many PDAs have been developed for patients with CKD. In 2020, Winterbottom et al. conducted a review on PDAs specifically for patients with CKD, focusing on the choice between dialysis and conservative care (Winterbottom et al., 2020). They described 17 PDAs from five countries, which were available as booklets, PDF files or interactive websites. Winterbottom et al. concluded that the PDAs improved patient treatment decision-making, but the review did not report the actual use of PDAs by HCPs and patients. Recently, Engels et al. performed a scoping review regarding SDM in advanced CKD, focusing not only on PDAs but on all types of interventions to promote SDM (Engels et al., 2022). A total of 145 interventions were identified of which only 29 were PDAs, the rest consisted of prognostic tools, educational programmes and multicomponent initiatives. Only 37% of the PDAs were reported to have actually been implemented in clinical practice, and one PDA was evaluated for its effect on SDM. This PDA, called Dialysis Choice, led to SDM in more than 80% of patients (Finderup et al., 2020). PDAs are thus available for patients with advanced CKD, but actual use by HCPs and patients has not been evaluated so far.

In 2017, two PDAs were developed in the Netherlands, namely the 'Overviews of options' and the Dutch Kidney Guide. In addition, one other tool to support patients with SDM was developed, namely the Three Good Questions. The Dutch Kidney Patients Association recommends using all three during the kidney failure treatment modality education for quality improvement.

The Three Good Questions are: (1) What are my options? (2) What are the possible benefits and risks of those options? (3) What does that mean in my situation? They were developed in Australia in 2011, translated into Dutch and tested in 2015 (Shepherd et al., 2011, Patiëntenfederatie Nederland and Federatie Medisch Specialisten). These Three Good Questions are a first step in SDM between the patient and the HCP and can improve quality and safety of the education process (Shepherd et al., 2011).

The 'Overviews of options' charts is a PDA describing the answers to four/five frequently asked patient questions regarding certain treatment options, which are based on those developed by The Option Grid Collaborative (Elwyn, Lloyd, et al., 2013; The Option Grid Collaborative, 2012). Two Dutch 'Overviews of options' are

available: (1) Permanent damage to your kidneys: kidney replacement therapy or conservative treatment, and (2) Permanent damage to your kidneys: options for kidney replacement therapy ('Overviews of options').

Finally, the Dutch Kidney Guide is a website that contains videoclips of >40 patients who are treated with nine different treatment modalities, ranging from conservative care to various forms of haemodialysis, peritoneal dialysis and kidney transplantation (Dutch Kidney Guide). In these videoclips, patients explain the impact of these treatments on 19 domains of their daily lives. For example, patients describe the consequences of their treatment on eating/drinking, going on vacation, work and school, etcetera (Dutch Kidney Guide).

Despite the fact that much attention has been paid to the development of these PDAs and SDM tool, it is unknown how often they are used and studies have shown that there are barriers to their implementation (e.g., time constraints, lack of training on use of PDAs, disagreement with the content and format of PDAs) (Scalia et al., 2019). Furthermore, the impact of these tools on SDM in Dutch hospitals is unknown and whether their implementation can improve this.

STUDY AIMS

The objectives of our study are:

- To determine the use of the Three Good Questions, 'Overviews of options' and Dutch Kidney Guide by kidney HCPs during kidney failure treatment modality education in the Netherlands. We hypothesized that 75% of kidney HCPs were using them.
- To determine the experience of SDM among patients with advanced CKD in the Netherlands and the relationship with the use of the Three Good Questions, 'Overviews of options' and Dutch Kidney Guide.
- To assess changes in the experience of SDM among patients after a training workshop for kidney HCPs.

MATERIALS AND METHODS

Study design

We conducted a quality improvement study in which first questionnaires were distributed to kidney HCPs, between April and September 2018, and patients with advanced CKD, between April and November 2018, in 12 Dutch hospitals (2 academic, 10 nonacademic). The hospitals participated in the Dutch nOcturnal and hoME dialysis Study To Improve Clinical Outcomes (DOMESTICO), a multicentre cohort study among patients treated with dialysis in the Netherlands (van Eck van der Sluijs et al., 2019). We also obtained information on kidney failure treatment modality education in the 12 hospitals.

Second, we determined the relationship between the use of the PDAs and SDM tool and the degree of SDM among patients with advanced CKD. Then, between October 2018 and March 2019, a workshop was provided to the kidney HCPs of the participating centres. During the workshop, information was provided regarding SDM and the PDAs and SDM tool with the aim to increase the implementation of SDM. Finally, we again distributed questionnaires to patients with advanced CKD, between December 2018 and April 2020, in the centres that had participated in the workshop. Completion of questionnaires was voluntary and completely anonymous. Supporting Information: Figure S1 shows the periods when the questionnaires were distributed and the workshop was conducted.

Our study did not require ethical approval, because—although it concerned medical scientific research—the participants were not subjected to procedures and did not have to adhere to rules of conduct [Central Committee on Research Involving Human Subjects (CCMO)]. This manuscript adheres to the Standards for Quality Improvement Reporting Excellence (SQUIRE) guideline (Goodman et al., 2016).

Healthcare professionals' questionnaire

The kidney HCP questionnaire consisted of six general questions about the kidney failure treatment modality education in their centre, four questions on familiarity with the Three Good Questions, 'Overviews of options', and Dutch Kidney Guide, two questions about what should be added or removed in the education process, and four questions focusing on SDM (Supporting Information: Table S1).

In the Netherlands, education usually starts when the patient's estimated glomerular filtration rate (eGFR) falls below 20 mL/min/1.73 m^2. Kidney failure treatment modality education is provided by a team of kidney HCPs consisting of nephrologists (in training), nurses, social workers and dietitians, and in some hospitals physician assistants or nurse practitioners are also involved (Bonenkamp et al., 2021). The questionnaire was distributed to all these kidney HCPs.

Patients' questionnaire

The patient questionnaire consisted of seven questions about the kidney failure treatment modality education, two questions about perceived barriers against home dialysis and 12 questions belonging to two SDM questionnaires, namely the nine-item Shared Decision Making (SDM-Q-9) and the collaboRATE questionnaire (Supporting Information: Table S2). The SDM-Q-9 contains nine statements which are rated on a six-point Likert scale (from 0 'completely disagree' to 5 'completely agree') (Kriston et al., 2010; Rodenburg-Vandenbussche et al., 2015). The collaboRATE contains three questions which are rated on a 10-point Likert scale (from 0 'no effort was made' to 9 'every effort was made') (Elwyn, Barr, et al., 2013).

The patient questionnaire was distributed to patients with advanced CKD (mostly eGFR<20 mL/min/1.73 m^2) who had completed the kidney failure treatment modality education. As mentioned earlier, patients' questionnaires were distributed before ánd after an SDM workshop was given in their hospital; from April to November 2018 and from December 2018 to April 2020. As a result, the study populations differ between these two periods, but remain from the same hospital.

SDM workshop

In collaboration with the Dutch Kidney Patients Association, we developed a workshop to educate HCPs about SDM and the use of the Three Good Questions, 'Overviews of options', and Dutch Kidney Guide in daily practice to stimulate implementation for quality improvement. During the period October 2018 to March 2019, the workshop was given in 10 of the 12 participating Dutch hospitals.

First, the results from the kidney HCPs' questionnaire and research on SDM was presented. Second, information was provided on Glyn Elwyn's SDM model in which the patient is guided to make a treatment choice according to three consecutive conversation types: choice talk, option talk and decision talk (Elwyn et al., 2012). Third, the background and content of the PDAs and SDM tool were discussed and it was discussed how these tools could be integrated into the existing kidney failure treatment modality education in that specific hospital.

Statistical analysis

First, we used descriptive statistics to assess the education process, the use of the tools and the SDM-Q-9 and collaboRATE scores in the participating hospitals. From the patients' questionnaire, the Likert scales of the SDM-Q-9 and collaboRATE were both converted into a score from 0 to 100, with a higher score indicating better SDM (Rodenburg-Vandenbussche et al., 2015). Second, a one-way analysis of variance (ANOVA) was performed to evaluate the difference in both scores between participating hospitals, using centre as independent variable, and both the SDM-Q-9 score (continuous variable, 0–100) and collaboRATE score (continuous variable, 0–100) as dependent variables, respectively. Subsequently, linear regression was used to explore differences between the best-scoring hospitals and the individual other hospitals.

All statistical analyses were performed with SPSS Statistics version 26 (SPPS, Chicago, Illinois, USA).

RESULTS

Education process in participating hospitals

Of the 12 participating hospitals, 25% initiated the kidney failure treatment modality education at an eGFR between 25 and 30 mL/min/1.73 m^2, 33% between 20 and 25 mL/min/1.73 m^2 and 42% between 15 and 20 mL/min/1.73 m^2. In 67% of the hospitals there was a set format for the education process, which included a home visit in 75% of the hospitals. A median of seven (interquartile range 6–9) conversations were conducted with the patient during the education process. Only 25% of the hospitals reported that the Three Good Questions were used by patients during the kidney failure treatment modality education, while in 42% and 67% of the hospitals the 'Overviews of options' and Dutch Kidney Guide were used, respectively.

Use of patient decision aids and SDM tool in education

A total of 117 kidney HCPs (27% physicians, 8% physician assistants, 38% nurses, 14% social workers and 13% other) completed the questionnaire: 81% found the general impression of their own education process (very) good, 80% found the total number of consults good and 56% found the amount of information they provided good, while 28% found it too much. SDM was applied according to 56% of professionals, however only 28% reported that patients used the Three Good Questions, while HCPs themselves used the 'Overviews of options' in 31%–33% and the Kidney Guide in 51%.

Relation between use of PDAs and SDM tool and degree of shared decision-making

Between April and November 2018, 182 patients from the 12 hospitals completed the questionnaires: 71% found the education overall (very) good and 61% found the educational materials (very) good. Of the patients, 85% found the received amount of information about right and 82% found the total number of conversations about right (Figure 1a).

Figure 2a,b shows the SDM-Q-9 and collaboRATE scores of the participating hospitals. The mean SDM-Q-9 score was 75 ± 22 and the mean collaboRATE score 86 ± 14. The hospital that scored the worst on both questionnaires had a mean SDM-Q-9 score of 66 and a collaboRATE score of 77. The best scores on the questionnaires were encountered in two different hospitals: the highest mean SDM-Q-9 score was 87 and the highest collaboRATE score was 90.

Overall, no significant difference was found between hospitals in either score (one-way ANOVA: SDM-Q-9 $p = 0.70$; collaboRATE $p = 0.58$). However, when the hospital that scored best on the SDM-Q-9 was compared with the other individual hospitals, a significant difference was found with the hospital that scored worst on the SDM-Q-9 ($p = 0.03$).

When hospitals with the worst SDM-Q-9 score (<70) were compared to those with the best score (>77), only 50% of worst-scoring hospitals used the 'Overviews of options' and Kidney Guide, compared to 100% of best-scoring hospitals. The majority

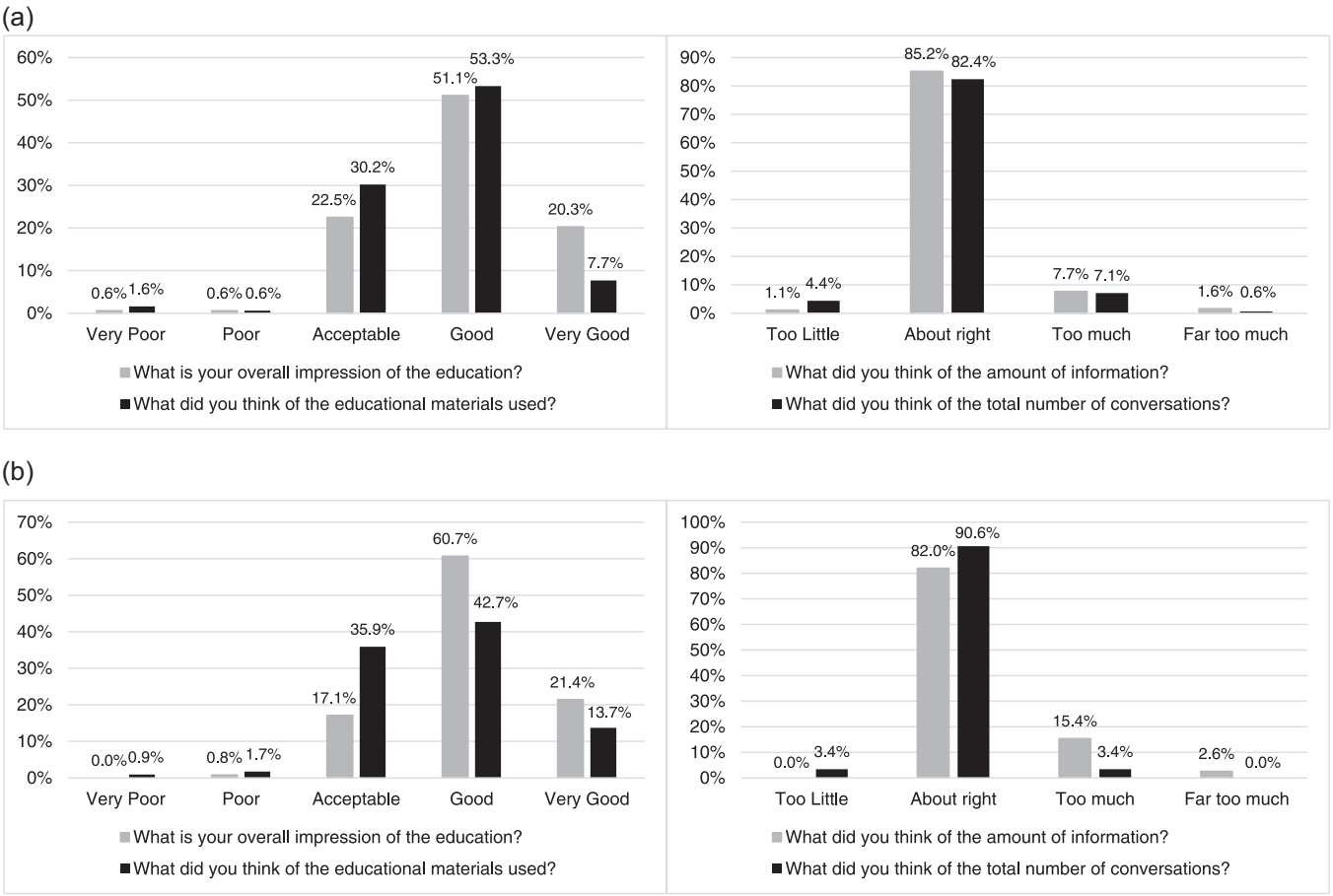

FIGURE 1 (a) Impression regarding education process during first period. (b) Impression regarding education process during second period.

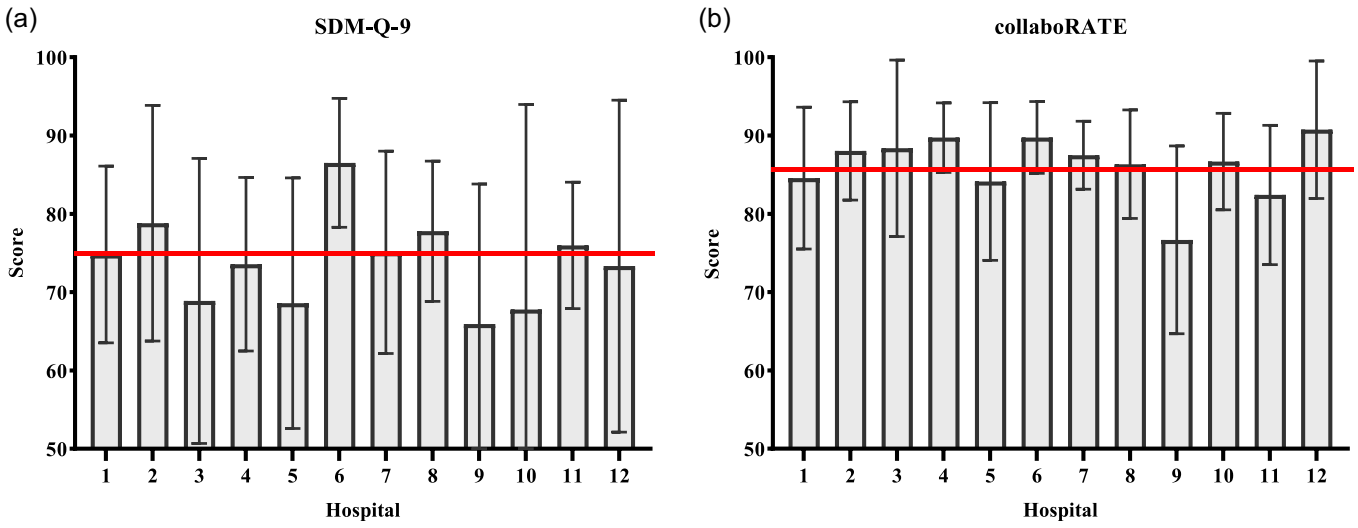

FIGURE 2 (a) SDM-Q-9 score of participating hospitals during first period. The red line indicates the mean SDM-Q-9 score of 75. (b) CollaboRATE score of participating hospitals during first period. The red line indicates the mean collaboRATE score of 86.

of worst-scoring hospitals started education for patients with CKD at an eGFR between 20 and 30 mL/min/1.73 m^2, while the best-scoring hospitals all started between 15 and 20 mL/min/1.73 m^2. The mean number of individual conversations between kidney HCPs and the patient was higher in worst-scoring hospitals than in best-scoring hospitals (8 ± 1 vs. 7 ± 1, $p = 0.054$). Although the number of conversations was lower, best-scoring hospitals provided information about all treatment options, including

nocturnal haemodialysis and conservative care, and more often provided information during a home visit.

Degree of shared Decision-Making after training HCPs

A total of 114 kidney HCPs from 10 hospitals joined the SDM workshop: 29 nephrologists (in training), five physician assistants/nurse practitioners, 40 nurses, 14 social workers, 13 dietitians and 13 other professionals. At nine of the 10 workshops also a patient with CKD was present, highlighting the patient perspective regarding the education process. The presence of a patient who could explain the patient perspective was considered a great additional value to the workshop. The workshop was appreciated with a 7.5 ± 0.4 on a range from 0 (worst) to 10 (perfect).

Between December 2018 and April 2020, 117 patients in 8 hospitals completed the questionnaires: 82% found the education overall (very) good and 56% found the educational materials (very) good. Of the patients, 82% found the received amount of information about right and 91% found the total number of conversations about right (Figure 1b).

The mean SDM-Q-9 score was 73 ± 24 and the mean collaboRATE score 89 ± 13. The worst scores on the questionnaires were encountered in two different hospitals: the lowest mean SDM-Q-9 score was 55 ± 20 and the lowest collaboRATE score was 86 ± 13. The hospital that scored best on both questionnaires had a mean SDM-Q-9 score of 77 ± 19 and a collaboRATE score of 94 ± 8. Figure 3 shows SDM-Q-9 and collaboRATE scores of the hospitals. Compared to the results of the first period (Figure 2), we found no difference in SDM-Q-9 and collaboRATE scores.

Overall, no significant difference was found between hospitals in either score (SDM-Q-9 $p = 0.86$; collaboRATE $p = 0.81$), not even if we compared the hospital with the best or the worst score to the other hospitals.

DISCUSSION

Our study shows that in the Netherlands, only 28% of HCPs report that patients use the Three Good Questions during kidney failure treatment modality education, while HCPs themselves use both 'Overviews of options' in only 31%–33% of conversations with patients and the Kidney Guide in 51%. Only 50% of hospitals with poorer levels of SDM, as judged by patients with advanced CKD, used the 'Overviews of options' and Kidney Guide, while 100% of hospitals with better levels of SDM were using them. Finally, the degree of SDM experienced by patients with advanced CKD remained unchanged after kidney HCPs were trained on SDM and the implementation of developed tools.

Although several studies have demonstrated the beneficial effects of PDAs (Stacey et al., 2017; Winterbottom et al., 2016), our study shows a lack of implementation of PDAs and an SDM tool for patients with advanced CKD. The implementation of such tools depends on aspects such as the notion of HCPs that they can improve their SDM skills, the willingness to use them and effective systems in which they are used (Joseph-Williams et al., 2021). Scalia et al. reported in their systematic review, which did not include studies regarding PDAs for patients with advanced CKD, that HCPs indicate time constraints, lack of training in the use of PDAs and disagreement about the content and format of PDAs, as the main barriers to the integration of PDAs (Scalia et al., 2019). Indeed, a lack of PDA implementation has also been described by Engels et al. (2022). Our study showed that 1 year after the publication of the Dutch tools, only 28% of the HCPs reported that patients used the Three Good Questions, while 31%–33% of HCPs used the

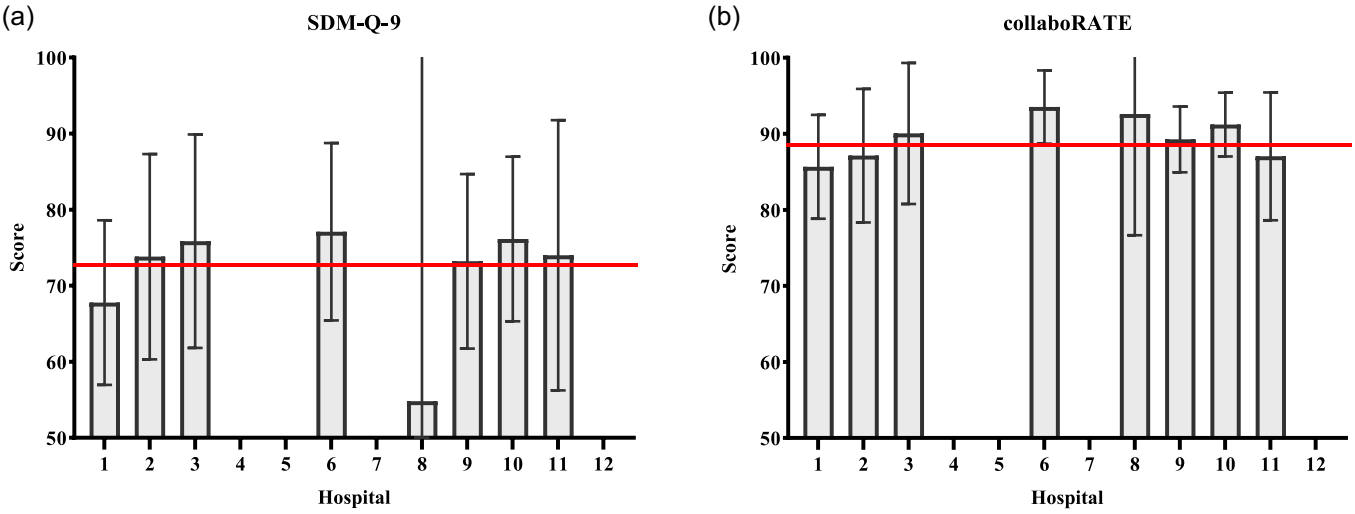

FIGURE 3 (a) SDM-Q-9 score of participating hospitals during second period. The red line indicates the mean SDM-Q-9 score of 73. During the second period only 8 of the 12 hospitals participated. (b) collaboRATE score of participating hospitals during second period The red line indicates the mean collaboRATE score of 89. During the second period only 8 of the 12 hospitals participated.

'Overviews of options', and only 51% used the Kidney Guide. Although we did not quantitatively investigate the reason for the limited use of the PDAs, qualitative analysis of the conversations with HCPs confirmed the aforementioned barriers. Future research should therefore focus on finding solutions to overcome these barriers.

For our study, we used the SDM-Q-9 and collaboRATE to investigate patients' perceived level of SDM. Of note, both questionnaires were not specifically developed for patients with CKD. Nevertheless, the SDM-Q-9 has been used in previous European studies concerning patients with CKD. In a Danish study, the SDM-Q-9 was used to evaluate an intervention, consisting of three meetings and a PDA called Dialysis Choice, for SDM regarding choice of dialysis modality (Finderup et al., 2018, 2020). During a pilot study among 16 patients, the average SDM score was 4.0, which converted to a total score of 0 to 100, equals a score of 80 (Finderup et al., 2018). During the final study among 148 patients, the mean SDM score was 86 (Finderup et al., 2020). Both scores were higher than the mean SDM-Q-9 score in our study, which was 75 before and 73 after the SDM workshop. The difference with the Danish study is that they excluded patients who chose conservative therapy, while our study did not, and they offered one PDA as opposed to two PDAs combined with one other SDM tool in our study.

A German study used the SDM-Q-9 in 590 haemodialysis patients of whom 330 indicated they had received information about dialysis treatment options and 260 indicated they had received no information (Schellartz et al., 2021). Patients who received information had a higher SDM-Q-9 score than patients who received no information (77 vs. 44). The SDM-Q-9 score of the informed patients is consistent with the scores from our study that only included informed patients.

As confirmed by Engels et al., this is the first study to provide detailed insight into the use of PDAs and tools for SDM by kidney HCPs, the relation between their use and the degree of SDM, and the effect of an implementation training. Our study has some limitations. First, as mentioned before, the SDM-Q-9 and collaboRATE were not developed specifically for patients with CKD. However, the SDM-Q-9 has been used in previous studies concerning patients with CKD, and both the SDM-Q-9 and collaboRATE have been tested in patients with chronic diseases, making them very likely to be useful in patients with CKD as well (Elwyn, Barr, et al., 2013; Rodenburg-Vandenbussche et al., 2015). Second, the way patients completed the questionnaire might have been influenced by recall and response bias and the patients who completed the questionnaire during the two periods were different, since patients of the first period had already chosen a kidney failure treatment option and were obviously not going through the education process again. However, this does reflect daily practice. Third, the SDM scores were already quite high in the first period which may have led to a ceiling effect. Finally, the Three Good Questions do not meet the IPDAS minimum criteria (4 out of 12) (Joseph-Williams et al., 2014). However, in the Netherlands, the developed tools are the only structural aids available for SDM. Therefore, we find them a valuable first step towards more professional decision aids that do fully meet the IPDAS minimum criteria.

IMPLICATIONS FOR CLINICAL PRACTICE

Our quality improvement study provides an important insight into the use of the three Good Questions, 'Overviews of options', and Dutch Kidney Guide in the current kidney failure treatment modality education in the Netherlands. It shows that there is still a lack of implementation of these tools, but that its use can have a positive effect on the degree of SDM experienced by patients with advanced CKD. Our study underlines the importance for kidney HCPs, also in other countries, to ascertain the extent to which the available PDAs and SDM tools are actually implemented to make optimal use of them.

CONCLUSION

The use of specifically developed PDAs and SDM tools during kidney failure treatment modality education is limited. Hospitals that did use PDAs had higher SDM scores. However, the degree of SDM experienced by patients with advanced CKD remained unchanged after kidney HCPs were trained on SDM and the implementation of the PDAs and SDM tool. Future research should therefore identify the barriers to the use of such tools for SDM to achieve an optimal *shared decision*.

AUTHOR CONTRIBUTIONS

Anita van Eck van der Sluijs, Anna A. Bonenkamp, Brigit C. van Jaarsveld and Alferso C. Abrahams designed the survey. Anita van Eck van der Sluijs, Karen Prantl and Aase T. Riemann developed the workshop. Anita van Eck van der Sluijs, Sanne Vonk, Karen Prantl and Aase T. Riemann gave the workshop. Anita van Eck van der Sluijs, Anna A. Bonenkamp and Aase T. Riemann collected data. Anita van Eck van der Sluijs performed the statistical analyses. Anita van Eck van der Sluijs, Brigit C. van Jaarsveld and Alferso C. Abrahams interpreted the data. Anita van Eck van der Sluijs drafted the manuscript. All authors critically edited the manuscript and approved the final version.

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CONFLICTS OF INTEREST STATEMENT

A.E.S. has received speaker honoraria from Baxter Healthcare. A.C.A. has received speaker honoraria from Baxter Healthcare, Fresenius Medical Care, AstraZeneca and Vifor Pharma. All other authors declare no conflict of interest.

The results in this article have not been published previously in whole or part, except in abstract format.

DATA AVAILABILITY STATEMENT

The data underlying this article will be shared upon reasonable request to the corresponding author after approval of the DOMESTICO steering group.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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