MASTER THESIS HEALTH SCIENCES

IMPLEMENTATION OF A SHARED DECISION-MAKING INTERVENTION IN ADVANCED PARKINSON'S DISEASE – A MULTI-CENTER, MIXED METHODS FEASIBILITY STUDY

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PREFACE

In front of you lies my master thesis “Implementation of a shared decision-making intervention in advanced Parkinson’s disease – a multi-center, mixed methods feasibility study”. This thesis was written to obtain the Master of Science degree in Health Sciences at the University of Twente and is the result of my work conducted at the Radboud university medical center from March 2020 to October 2020.

My graduation has been a very interesting and educational time, which came with expected and unexpected challenges. The COVID-19 pandemic made my graduation into an experience that I never would have imagined prior to the start. Two weeks after the start of my graduation period, I had to work from home, physical meetings were canceled and meetings with my supervisors were converted to phone or video calls. Despite the challenges that came with this unusual shift in the organization of the graduation process, I am very glad that I could continue working on this research during the pandemic. Overall, my graduation was highly educational and showed me the challenges and rewards of analyzing a (mixed methods) study and greatly contributed to my development as a researcher.

I would like to thank my supervisors Marjan Meinders, Frouke Nijhuis, Janine van Til and Ria Wolkorte for their guidance, feedback and support during my graduation period. Marjan, your extensive feedback, advice and great expertise in conducting and guiding research were very valuable and highly improved this thesis. You made me look more critical at my own work which I will keep with me for the rest of my academic career. Frouke, your enthusiasm and passion to improve decision-making in Parkinson’s disease and providing care in general are admirable and strongly motivated me during my graduation. I really enjoyed our collaboration and discussions and I want to thank you for including me in this research. Janine, your critical feedback on the project from a perspective outside the Radboud was very valuable and much appreciated. Ria, thank you for your willingness to join this project during the final stage. Your input on my final report was very helpful. Last but certainly not least, I want to thank my parents, brother, sister and girlfriend for their support during my graduation period.

I hope you will enjoy reading this thesis!

Bas Schippers

Nijmegen, 12th of October 2020

ABSTRACT

Background: Selection of a suitable treatment option in advanced stage Parkinson's disease is a complex decision. Integrating available evidence, professional expertise and patient preferences to reach an optimal decision is paramount, which can be facilitated through shared decision-making (SDM). We have developed an intervention to support SDM that consisted of 1) a one-page Option Grid™ patient decision aid, 2) a website with supplementary information, including a value clarification tool for patients and 3) an instruction for neurologists and PD nurse specialists on SDM and the use of the Option Grid and website. In this study, we aim to evaluate the feasibility of this SDM intervention in terms of its level of implementation, acceptability and efficacy from a patient's perspective.

Methods: We performed a multi-center, mixed methods feasibility study with an uncontrolled pre-post intervention design. Neurologists (n=5) and PD nurse specialists (n=7) from five hospitals participated. Patients enrolled in the pre-intervention group (n=20) received information and decision support as usual and patients in the post-intervention group (n=13) were exposed to the SDM intervention. The level of implementation was measured based on patient's utilization of and interactions with components of the intervention. The acceptability was evaluated on the intervention's readability, comprehensiveness, layout and amount of information and efficacy was measured on patient's perceived level of SDM, decision quality and preferred and experienced roles in the decision process.

Data was collected using questionnaires, interviews, field notes and by tracking patient's logging behaviour of the website.

Results: Adequate levels of implementation were reached (9/10 (90%) used the Option Grid, 10/13 (77%) used the website and 9/13 (69%) used the value clarification tool). Interviews with patients revealed that the Option Grid and website were mainly used as information source and not as starting point for discussing treatment options and patient preferences. For the acceptability, patients stated to be satisfied with the intervention overall. The amount, presentation and readability of information was perceived as good. In terms of efficacy, the intervention improved patients' knowledge on treatment options (post-decisional knowledge test performance: pre=55%; post=65%; $p<0.01$), but did not improve perceived levels of SDM ([Mdn. SDM-Q-9: pre=73; post=73; p=0.821], [Mdn. CollaboRATE: pre=85; post=89; p=0.677]). Preferred and experienced roles agreed in 9/19 (47%) and 5/13 (38%) patients in the pre- and post-intervention group respectively (p=0.471).

Conclusions: Implementation of the SDM intervention seemed feasible but improvements on incorporating the Option Grid and value clarification tool during consultations and eliciting (role) preferences are necessary to take full advantage of the potential of the SDM intervention to support SDM during consultations.

Keywords: Shared decision-making, Parkinson's disease, feasibility study, mixed methods design, decision aid

LIST OF ABBREVIATIONS

PD	Parkinson's disease
DBS	Deep brain stimulation
LCIG	Levodopa-Carbidopa intestinal gel
CSAI	Continuous subcutaneous Apomorphine infusion
SDM	Shared decision-making
DA	Decision aid
CPS	Control Preference Scale
DCS	Decisional Conflict Scale
MoCA	Montreal Cognitive Assessment
IQR	Interquartile range

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INTRODUCTION

Patients with advanced stage Parkinson's disease (PD) develop motor and non-motor complications that impact their quality of life (1, 2). Deep brain stimulation (DBS), Levodopa-Carbidopa intestinal gel (LCIG) and continuous subcutaneous Apomorphine infusion (CSAI) have shown to improve motor function and quality of life in advanced stage PD patients (3, 4). However, selection of a treatment option that best suits patients' preferences and disease characteristics is a complex process. Applying evidence-based medicine to this decision is challenging due to a lack of clinical evidence that compares all three treatment options. A lack of treatment expertise, varying local treatment availability and own treatment preferences might, amongst other factors, hinder professionals in bridging this knowledge gap (5-8). Overall, these limitations may obstruct neurologists to fully inform PD patients on all treatment options. Additionally, patients do not feel sufficiently involved in the decision process (9). Applying the principles of shared decision-making (SDM) while deciding on an advanced treatment option may help to stimulate patients' involvement and improve evidence-based decision-making (10).

Fundamentally, SDM accepts the patients' rights to individual self-determination and autonomy, acknowledges that it is a desirable goal and supports patients in achieving this goal (11, 12). It is often seen as an approach that sits in the middle between the 'paternalistic' model, in which health care professionals decide what is best for patients, and the informed choice model, where professionals provide information to patients who then make their own decision (13). SDM represents the decision process where the professional and patient define the decision to be made, discuss their roles in the decision process, share information and corresponding evidence on available treatment options and elicit patient preferences to reach a shared decision (12, 14, 15). SDM increases patients' knowledge and involvement in the decision process, decreases their decisional conflict and improves satisfaction of consultations and the overall decision process (12, 16). SDM could thus potentially enhance the complex decision process of advanced treatment selection in PD. However, there remains a lack of guidance on how to incorporate SDM in daily clinical practice (12, 17). To stimulate the implementation of SDM in clinical decision-making, a variety of interventions have been designed. These interventions may include providing educational materials, training of patients and/or professionals, feedback meetings, reminders or patient-mediated interventions (18). A decision aid (DA) can also be used as (part of) an SDM intervention. A DA explicitly states the decision to be made, provides an overview of information about all treatment options and outcomes and helps patients to clarify their preferences and how they value different treatment aspects (19).

Patients with advanced stage PD often lack sufficient information on all treatment options and this remains one of the most important barriers to performing SDM in the decision process (6, 20). Implementation of a SDM intervention including a DA has the potential to overcome this barrier by informing and engaging patients in the decision process (6). As a SDM intervention specifically for this decision is not available, we have developed one which consisted of 1) an Option Grid™ patient decision aid that provides a one-page overview of available evidence on treatment options, 2) a website with supplementary information and a value clarification tool for patients and 3) an instruction to neurologists and PD nurse specialists that elaborates on the concept of SDM and includes an explanation of the use of the Option Grid and website (21). After development of an intervention, its feasibility should be examined to assess its acceptability by its intended users and suitability for actual implementation in clinical practice (22). Therefore, we aim to evaluate the feasibility of the SDM intervention by assessing its level of implementation, acceptability and testing its efficacy in daily clinical practice in a mixed methods research design. In this report we present on these outcomes from the patient's perspective.

METHODS

Study design

We performed a multi-center, mixed methods feasibility study with an uncontrolled pre-post intervention design, consisting of a series of questionnaires completed throughout the patients' decision processes and post-decisional interviews. This design enabled us to use the qualitative interviews with patients to enhance our understanding of the data obtained from the quantitative questionnaires (23, 24). We analyzed the quantitative and qualitative data separately, after which we combined both data sources per item of the feasibility study and interpreted results together.

Participants

We aimed to include a sample of 20 patients in the pre-intervention group and 20 in the post-intervention groups (25). We estimated that neurologists working in community-based hospitals consider three to ten PD patients for advanced treatment per year and therefore aimed to include five to ten neurologists. Neurologist were eligible to participate in the study if they 1) considered a minimum of five PD patients for advanced treatment per year and 2) collaborated with a PD nurse specialist in the same hospital. We intended to include neurologists with different levels of expertise on advanced treatments, representing academic and community-based hospitals.

Neurologists who participated in the study recruited patients based on the following inclusion criteria: 1) patients with advanced stage PD who were a suitable candidate for advanced treatment, assessed by their neurologist and 2) patients were eligible for all three treatment options at the start of the decision process. Patients who previously underwent advanced treatment for PD were excluded from participating in the study.

The intervention

The intervention consisted of the following elements to support SDM: 1) an Option Grid™ patient decision aid, 2) a website for patients with supplementary information and a value clarification tool and 3) a 1-h instruction for professionals. An Option Grid is a one-page, evidence-based overview of available treatment options and answers to frequently asked questions by patients (see figure 1) (26). The Option Grid was the key element of the intervention and was employed in the first encounter between patients and professionals with the aim of facilitating the discussion on treatment options.

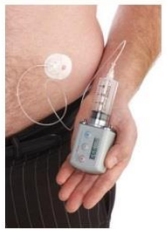
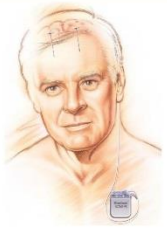
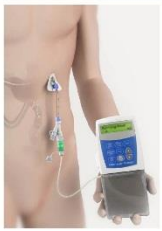
Once patients had received the Option Grid, their neurologist/PD nurse specialist referred them to the website with supplementary information, for which patients received a unique login code. The site contained an introduction video about the website itself, the Option Grid, additional detailed information on treatment options, including nuanced experiences of other patients and a value clarification tool (see figure 2). The aim of the value clarification tool was to assist patients to construct their preferences, using attributes of treatments that mattered most to them. Patients could fill in and print their responses to the value clarification tool and use it to start the discussion on important treatment aspects and treatment goals during consultations.

The main researcher (FN) provided an instruction to participating neurologists and PD nurse specialists once inclusion of patients in the pre-intervention group was completed. The instruction elaborated on the concept of SDM and included an explanation of the use of the Option Grid and website. FN provided paper-based tear pads of the Option Grid to stimulate its use during consultations. Instruction was not extensive as we aimed to analyze the utilization of the SDM intervention without any prescribed behavior, as the Option Grid will become publicly available without instruction after this study.

Overzicht van de behandelingen

Parkinson Keuzehulp

Met dit overzicht kunt u de drie behandelingen vergelijken met uw huidige behandeling. Dit is een kort overzicht van belangrijke vragen over de behandelingen. Voor meer informatie kunt u op "lees meer" in de tabel klikken.

	Apomorfine pomp	DBS	Duodopa pomp
Wat is het?	 Apomorfine wordt continu afgegeven met een pompje en naaldje onder de huid.	 Bij DBS worden hersengebieden gestimuleerd met elektroden.	 Levodopa wordt continu afgegeven met een pomp en een slangetje in de darm.
Wat zijn de effecten?	Kwaliteit van leven 53 van de 100 patiënten verbeteren Dagelijkse activiteiten geeft een verbetering,niet precies bekend OFF tijd 3 uur minder OFF tijd per dag	Kwaliteit van leven 61 van de 100 patiënten verbeteren Dagelijkse activiteiten 42 van de 100 patiënten verbeteren ON tijd 4 uur meer ON tijd	Kwaliteit van leven 65 van de 100 patiënten verbeteren Dagelijkse activiteiten 49 van de 100 patiënten verbeteren ON tijd 4 uur meer ON tijd
Wat zijn de risico's?	• van 100 patiënten met apomorfine krijgen: • 76 huidafwijkingen (76%), waarvan 6 ernstig (6%) • 11 duizeligheid (11%) • 17 stemming-,gedrags-problemen (17%)	• van 100 patiënten met DBS krijgen: • 2 hersenbloeding (2%) • 5 spraakproblemen (5%) • 21 stemming-,gedrags-problemen (21%)	• van 100 patienten met Duodopa krijgen: • 11 wondinfectie/ buikinfectie (11%) • 64 pompprobleem (64%) • 28 stemming-,gedrags-problemen (28%)

Overzicht van de behandelingen - Parkinson Keuzehulp

	Apomorfine pomp	DBS	Duodopa pomp
Heeft u nog pillen nodig?	meestal doorgaan met parkinson pillen mogelijk wat minder tabletten	vaak minder parkinson pillen dan ervoor soms kunnen de parkinson pillen gestopt worden	vaak kunnen de parkinson pillen gestopt worden
Wanneer komt u niet in aanmerking?	• dagelijkse verzorging pomp onmogelijk • lever/ nierproblemen • ernstige dementie	• ernstige depressie/ verwardheid • ernstige balans/ spraakproblemen • ernstige dementie	• dagelijkse verzorging pomp onmogelijk • maag/darm aandoeningen • ernstige dementie
Wat zijn voordelen?	• relatief eenvoudig • goed effect op kwaliteit van leven • weinig contraindicaties • proefbehandeling mogelijk	• beste onderzocht • goed effect op kwaliteit van leven • vaak minder pillen • relatief goedkoop	• redelijk onderzocht • goed effect kwaliteit van leven • vaak minder of geen pillen meer • proefbehandeling mogelijk
Wat zijn nadelen?	• minder goed onderzocht • uitwendig pompje • elke dag verzorging	• operatie nodig • minder mensen geschikt • proefbehandeling niet mogelijk	• operatie nodig • grote pomp om te dragen • elke dag verzorging

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Figure 1: Option Grid patient decision aid (in Dutch)

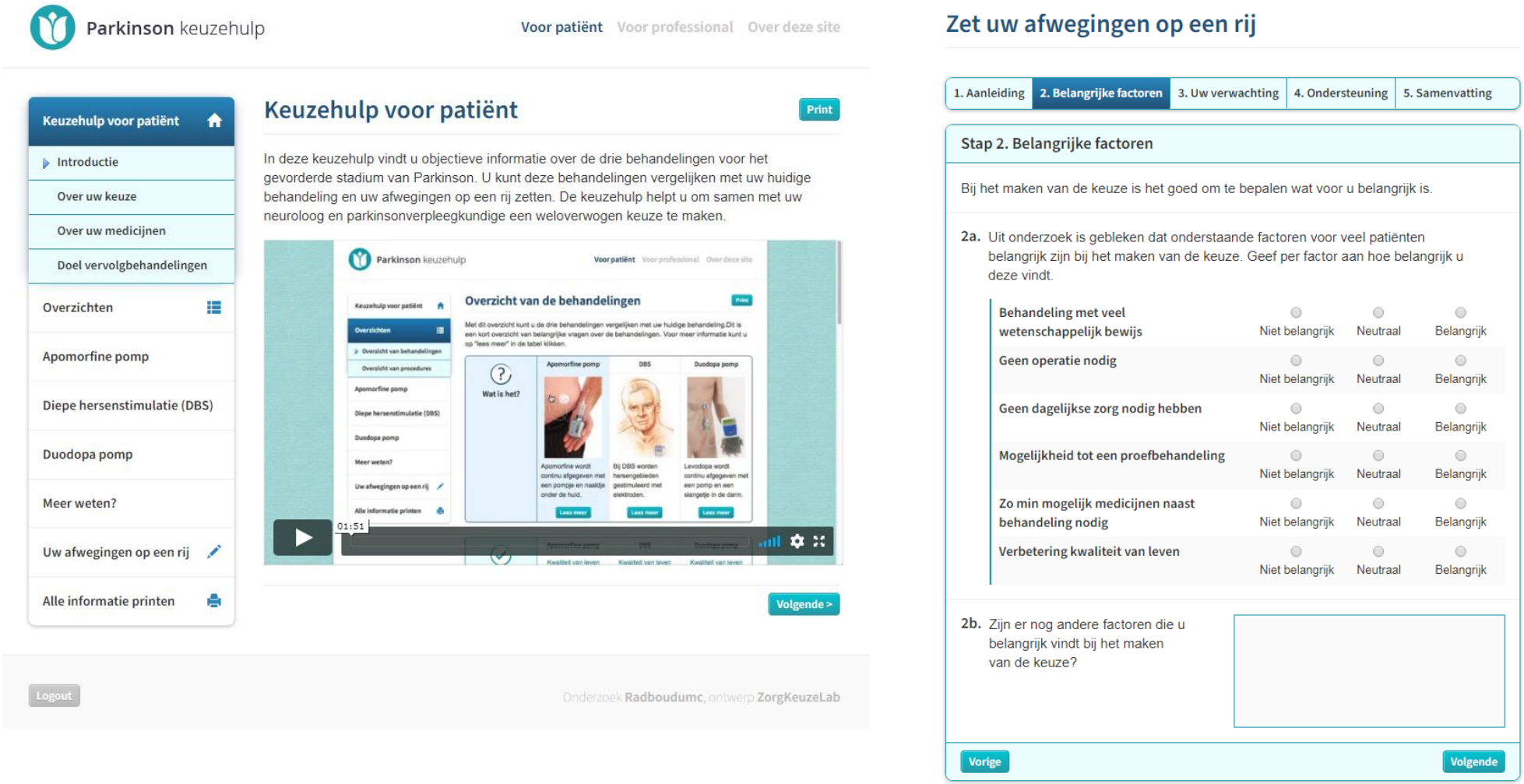

Figure 2: Overview of the homepage of the website of the SDM intervention (l) and an example of one tab of the value clarification tool (r) (in Dutch)

Procedures

Patients willing to participate received written information on the study from their neurologist or PD nurse specialist and subsequently signed an informed consent form. The first 20 included patients were enrolled in the pre-intervention group and received information and decision support from their neurologist and PD nurse specialist as usual. The decision process finished once a patient and their neurologist made a preliminary choice for a treatment and screening for that treatment started. Once 20 included patients finished their decision process, professionals participated in the instruction. All subsequently included patients were enrolled in the post-intervention group. These patients were exposed to the SDM intervention and thus had the opportunity to use the Option Grid and website throughout their decision process.

Outcomes measures

The outcome of this study was the feasibility of the SDM intervention, as assessed from a patient's perspective on three aspects: 1) level of implementation, 2) acceptability and 3) efficacy (21). Additionally, we measured contextual factors that could influence the implementation and outcomes of the intervention (27).

Level of implementation of the SDM intervention

The level of implementation intended to measure to what extent the SDM intervention was executed as planned. For this, we measured patients' utilization of the Option Grid, website and value clarification tool based on interviews (Option Grid) and tracking of patients' navigation behavior of the website (website and value clarification tool). Additionally, we asked which information sources patients from the pre- and post-intervention group used to reach their decision in a questionnaire. We further investigated the level of implementation during the interviews by asking patients to elaborate on their perceived interactions with the Option Grid and website and what facilitators and barriers they experienced in using them.

Acceptability of the SDM intervention

The aim of evaluating the acceptability of the intervention was to assess how the intervention was received by patients as it can predict whether the intervention will be adopted and used (22). For this, we measured readability, comprehensiveness, layout and amount of information of the Option Grid and website based on an 18-item questionnaire (see Appendix A). We further evaluated the acceptability by asking patients about their satisfaction and opinion of the intervention during interviews.

Efficacy of the SDM intervention

We tested the intervention's preliminary efficacy as part of the feasibility study in order to assess if the intervention showed promise of being successful (22). The efficacy of the SDM intervention was tested on two efficacy outcome domains. Firstly, we measured how patients experienced the decision process on predefined key elements of SDM, i.e. the level of SDM. To assess this, we used the validated SDM-Q-9 (28, 29) and CollaboRATE questionnaires (30, 31). Additionally, we evaluated patients' experienced role during the decision process based on the Control Preference Scale (CPS) (32).

- The SDM-Q-9 covers nine items that each describe one step in the SDM process and each item is rated on a six-point Likert scale ranging from 0 ('Completely disagree') to 5 ('Completely agree'). The overall score ranged from 0 to 100, with higher scores indicating higher levels of SDM (28, 29).

- CollaboRATE is a three-item questionnaire that measures how much effort was made by the neurologist on three core SDM items, i.e. information provision, preference elicitation and preference integration. Each item is rated on a 10-point Likert scale ranging from 0 ('No effort was made') to 9 ('Every effort was made'). We calculated the CollaboRATE score by summing patients' scores on each item and transforming the total score to a range of 0-100. Again, higher scores indicated higher levels of SDM (30, 31).
- The CPS rates patients' experienced roles in the decision process based on selecting one of five roles, i.e. patient alone, patient considering neurologist's opinion, shared, neurologist considering patient's opinion and neurologist alone (32).

Secondly, we assessed the efficacy of the SDM intervention by measuring the quality of the decision-making. We considered a decision to be of high quality if it was based on sufficient decision-specific knowledge ('level of informed choice') and aligned with personal values, which we measured based on a knowledge test and the Decisional Conflict Scale (DCS) respectively (33, 34).

- The knowledge test consists of 20 questions on treatment characteristics, eligibility criteria and effects and risks to tests patients' level of informed choice (see Appendix B). Patients were asked to name the treatment options they knew in another questionnaire, while the names of available treatment options were mentioned in the remaining questions of the knowledge test. We calculated scores in a percentage scale, with 0% indicating no correct responses and 100% indicating perfectly accurate responses.
- The Decisional Conflict Scale (DCS) assesses if the decision was based on personal values (35). The DCS includes 16 questions grouped into five sub-categories: uncertainty, informed, values clarity, support and effective decision. Each item was rated on a five-point Likert scale ranging from 0 ('Strongly agree') to 4 ('Strongly disagree'). We calculated the total and subgroup DCS scores by summing the corresponding items and rescaling the range to 0-100, where 0 indicates no decisional conflict and 100 extremely high decisional conflict (33, 34).

To gain more understanding of the reported quantitative measures on the SDM process, we asked patients to elaborate on the decision process during the interviews and explored how patients reached their final decision in both the pre- and post-intervention group.

Contextual factors

We identified three contextual factors that might have influenced the decision process and utilization of the SDM intervention. They included 1) cognitive impairment, assessed with the Montreal Cognitive Assessment (MoCA) (36), 2) treatment preference prior to the decision process and 3) patient's preferred role during the decision-making, i.e. do patients want to make the decision in a shared way, assessed with the CPS (32).

Data collection

Questionnaires

We asked each patient to complete a baseline questionnaire on socio-demographic and disease-related information immediately after inclusion. Additionally, patients completed the knowledge test to assess their baseline knowledge level.

Once the decision process ended, patients were asked to complete the SDM-Q-9, CollaboRATE, Control Preference Scale (preferred and experienced role), knowledge test and Decisional Conflict Scale. Additionally, we asked patients to complete a questionnaire capturing the four items on which we measured the intervention's acceptability.

Interviews

The main researcher (FN) interviewed all patients within four weeks after ending the decision process. The interviews took place face-to-face during a home visit and the patient's partner or relative was able to join the interview if they were present and willing to. The interviews were audio-recorded to facilitate post-interview transcription and analysis.

The interviews were semi-structured based on an interview guide. Key topics discussed during the interviews were: information sources used during the decision process, how patients reached their decision, how patients experienced the decision process and factors that made the decision more easy or harder for them to make. For the post-intervention group, we furthermore explored if the Option Grid decision aid was deployed and discussed during consultation and how patients used and interacted with the Option Grid and website. Additionally, we asked patients to elaborate on their satisfaction with these components and explored if they had perceived any barriers and facilitators to using them.

In addition to conducting the interview during the home visit, the MoCA cognitive test was also performed.

Navigation behavior of the website

We collected navigation behavior data from the website to measure the utilization of the online information and value clarification tool. Based on patients' unique login codes, we were able to identify which internet pages patients visited and how much time they spend on each page.

Data analysis

We present socio-demographic and disease-related data descriptively as medians with interquartile range (IQR) or as frequencies with percentages. We performed a Mann-Whitney U test (continuous variables) or a Fisher exact test (categorical variables) to statistically test differences in baseline characteristics, SDM-Q-9, CollaboRATE, CPS, knowledge test and DCS scores between both groups. A p-value < 0.05 was statistically significant and all quantitative statistical analyses were performed in SPSS (Statistical Package for Social Sciences, Chicago, IL, USA).
Required samples sizes in feasibility studies are often too small to achieve adequate power for statistical testing, while this is not its primary aim (22). In this study, statistical results were utilized to identify trends in efficacy of the SDM intervention with the overall aim of providing a preliminary indication of the success of the SDM intervention.

For the qualitative analysis, two independent researchers (FN and BS) analyzed the interviews based on the principles of thematic analysis (37). All audio-recordings were transcribed verbatim. FN and BS read and re-read the transcripts and independently coded two interviews. Codes were compared and discussed during a consensus meeting until both researchers agreed on one set of codes. This code list was subsequently utilized to code two to four transcripts independently after which the researchers met and updated the code list by adding, merging and modifying codes. This process was repeated until all interviews were coded. Once coding was completed, we developed candidate themes and subthemes by merging codes that formed patterns in the data. Candidate themes and included codes were then iteratively reviewed and revised to ensure that themes and codes were representative for the data. Differences in interpretation during this process were discussed until we reached consensus on a final set of themes and sub-themes. The collation of codes into themes and sub-themes was conducted separately for the interviews from the pre- and post-intervention group. This approach allowed us to analyze important aspects within groups as well as associations or discrepancies between (sub-)themes in both groups.

The qualitative analysis was performed in ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany). Quotes represented in the results were translated from Dutch.

Ethics statement

The study was approved by the Medical Research Ethics Commission CMO Arnhem-Nijmegen in the Netherlands (registration number 2014-1489). All patients gave written informed consent prior to participating in this study and permission to record the interview at the end of the decision process was granted by all patients.

RESULTS

Five neurologists and seven collaborating PD nurse specialists from five hospitals participated in the study, who included a total of 33 patients: 20 patients were enrolled in the pre-intervention group and 13 in the post-intervention group. One patient in the pre-intervention group withdrew from the study during data collection due to personal reasons and was excluded from the analysis.

The interviews were successfully conducted with all patients. However, one recording in the pre-intervention group was lost due to a corrupted audio file. Another interview (post-intervention group) was incorrectly recorded which was noticed directly after concluding the interview. FN summarized the patient's responses and sent the transcript to the patient to verify its correctness. The approved transcript was included in the analysis, resulting in a total of 31 interviews included in the qualitative analysis. The average duration of the recorded interviews was 36 minutes for the pre-intervention group (n=18) and 41 minutes for the post-intervention group (n=13).

Table 1: Socio-demographic and disease-related characteristics for the pre-intervention and post-intervention groups.

		Pre-intervention	**Post-intervention**	**P-value**
Sample size (n)		19	13	
Gender [men, n (%)]		12 (63)	12 (92)	0.101
Age [median (range)]		64 (54-69)	65 (50-67)	0.623
Current living situation [n (%)]	Alone, widow/widower	2 (11)	2 (15)	1.000
	With partner, living together/married	15 (79)	11 (85)	
	Nursing or caring home	1 (5)	0	
	Other	1 (5)	0	
Current employment [n (%)]	Full time	2 (11)	0	0.753
	Part time	1 (5)	1 (8)	
	Unemployed	16 (84)	12 (92)	
Highest educational level [n (%)]	Primary school	3 (16)	0	0.508
	Secondary school	5 (27)	2 (15)	
	Lower vocational education	8 (42)	7 (54)	
	Higher vocational education	2 (10)	2 (15)	
	University	1 (5)	2 (15)	
Disease duration [n (%)]	< 5 years	3 (16)	1 (8)	0.757
	5 - 10 years	12 (63)	10 (77)	
	> 10 years	4 (21)	2 (15)	
Self-reported Hoehn and Yahr stage [n (%)]	0	1 (5)	0	0.694
	1	6 (32)	3 (23)	
	2	2 (11)	0	
	3	5 (26)	6 (46)	
	4	4 (21)	4 (31)	
	5	1 (5)	0	
MoCA score [median (range)]		25.5 (19-30) *	27 (20-30)	0.489
MoCA score < 26 [n (%)]		9 (50) *	6 (46)	1.000

* One patient refused to complete the MoCA test while testing was expected to be too confrontational.

Socio-demographic and disease-related characteristics are summarized in table 1. All baseline characteristics were comparable between both groups and did not differ statistically significant. Results of the MoCA cognitive tests showed that considerable proportions of patients suffered from cognitive impairment (score < 26) in both the pre-intervention and post-intervention group.

We identified three major themes during our qualitative analysis. Firstly, the theme *the impact of having an initial preference* was an overarching theme, affecting patients' information collection process, the information exchange during consultation and implementation and use of the intervention. The second major theme related to the interactions with the intervention and its level of implementation was *the value of the SDM intervention during the decision process*. Lastly, *the patient's search for information* was identified as important theme when patients were asked to reflect on their decision process. Table 2 shows an overview of these themes, its sub-groups and corresponding codes.

The impact of having an initial preference.

During the interviews, most patients in both groups reported that they started the decision process with a preference for one treatment option. Patient's initial preferences were mainly shaped based on hearing experiences with an advanced treatment from one other patient. Depending on the experience of that patient being positive or negative, the discussed treatment option commonly became preferred or neglected prior to the decision process. Additionally, multiple patients had heard or read about one or multiple available options online or during consultations prior to the decision process. Beside patients having an initial preference, several patients reported that their neurologist started the decision process with a preference for one treatment option.

"Well, it was more that I started with the idea I got from tips from the [hospital], who said 'don't you think it is time to start thinking about DBS?'" (49 yrs, M)

Multiple patients reported that their own information search mainly focused on collecting information on their preferred treatment and less on other available options, due to their initial preference. This was also reported for the information exchange during consultations which commonly resulted in a limited and unequal discussion of available treatment options. Additionally, some interviews showed that patients' initial preferences were so definite that they were not interested in hearing or discussing information on other options. However, some patients reported that all available options were globally discussed even when they had an initial preference. Furthermore, patients in the post-intervention group reported that having an initial preference resulted in a targeted use of the intervention, focusing on collecting information on their preferred choice.

"Yes, we feel that it never was a choice because we already heard from one experienced patient how he felt. We went on the internet again and although we hardly knew about the other two options, we quickly looked at it knowing that is not what I want. To work with a pump outside my body at this age. I don't want that." (51 yrs, M)

Table 2: Overview of themes, sub-groups and corresponding codes resulting from the qualitative analysis.

Theme	*Sub-group*	*Codes*
The impact of having an initial preference	*Patient preference*	Patient prefers or neglects treatment option after hearing experience of one patient. Patient constructs preference through experiences of other patient(s) while being uninformed on other options. Televised documentary on DBS made patient prefer or neglect DBS as treatment option prior to the decision process.
	Professional preference	Decision process is initiated with a preference for one treatment by the neurologist.
	Consequence of preference(s)	Initial preference limits profoundness of information need and search by patient. Patient is not open for (information on) treatment options other than preferred one. Information in DA/consultation is filtered by patient due to having an initial preference. Preference of patient and/or professional decreases completeness and profoundness of information exchange during consultation. Not all options are discussed by professional due to preference of patient. Neurologist attempts to improve information exchange, but preference of patient hinders this. Patient does not have access to all information due to preselection of treatment by professional. Patient feels professional is directing towards one option while patient is not ready for a decision yet. Patient feels that professional emphasizes information for preferred treatment. Patient's information search is directed by professional's preference. Patient feels neurologist has different motivation for treatment choice (not patient centered).
The value of the SDM intervention during the decision process	*Patient's utilization of the DA*	Actual use of Option Grid and website by patient does not correspond to intended use by researchers. Option Grid is used as summary for consultations. Patient uses Option Grid and website to gain more profound information on preferred treatment option. Option Grid and website prepare patient for consultation. Option Grid and website provides more realistic expectations for treatments for patient. Patient is able to corroborate decision through Option Grid and website.
	Facilitators and barriers to using DA	Patients can easily access information provided on the Option Grid. Tear pad Option Grid provides patients with the opportunity to read printed version. Option Grid and website creates opportunity to easily discuss information on options with partner and others. Patient is unable to access online components in an easy way.
The patient's search for information	*Pre-intervention group:*	Profoundness of information provided on each treatment option differs. Treatment options are discussed in an unbalanced way during consultation. Not all aspects of preferred treatment by patient are discussed equally. Patient did not receive complete information on the effects and risks. Information from professionals on procedure after decision-making perceived as incomplete. Information from professionals on risks of treatment perceived as incomplete. Information brochure is only provided for one treatment by professional. Different information formats provided for different treatment options. Preference of patient and/or professional decreases completeness of information exchange. Patient wishes for balanced, unbiased overview of information on treatment options, but does not receive this. Patient feels necessitated to search for additional information on the internet. Patient's own information search is directed by professional's preference.
	Post-intervention group:	Discussing all available treatment options despite patient's/profesional's preference. DA increases knowledge and understanding of treatments other than initial preferred treatment. DA helped patient to collect information from one place. Patient searches for information on treatment options on specific topic based on what he/she read in the DA.

Level of implementation of the SDM intervention

The Option Grid, the key element of the intervention, was implemented in the decision process for nine out of ten patients. One patient was not offered the Option Grid and login codes for the website were not provided by the neurologist/PD nurse specialist. Subsequently, this patient was not able to use these components throughout his decision process. We were unable to identify the use of the Option Grid during consultations in three patients since this was not discussed during the interviews. However, these three patients did access the website for which the Option Grid was necessary and this indicates that these patients were exposed to the Option Grid.

Based on the analysis of patients' navigation behavior of the website, we identified that ten patients utilized the online information (10/13, 77%) of which all but one used the value clarification tool (9/13, 69%). Of all patients, 31% (4/13) reported to have discussed the summary of the value clarification tool with their neurologist and/or PD nurse specialist. Furthermore, analysis of patients' navigation behavior showed that four out of the ten patients that visited the website did not view all information pages but instead focused on one (n=1) or two treatments (n=3).

Almost half of patients in the post-intervention group reported the Option Grid and intervention's website as information source through which they received or searched information during the decision process (table 3). Patients from both groups mainly received/collected information during consultations with their neurologist/PD nurse specialist and/or by searching the internet themselves. The distributions of used information sources between both groups did not differ statistically significant (p=0.123).

Table 3: Overview of information sources via which patients received/searched information during the decision process for the pre-intervention (n=19) and post-intervention (n=13) groups.

	Pre-intervention [n (%)]	**Post-intervention [n (%)]**
Neurologist	18 (95)	12 (92)
PD nurse specialist	14 (74)	9 (69)
Internet	11 (58)	10 (77)
Treatment brochures	6 (32)	3 (23)
People in surroundings	3 (16)	2 (15)
Patient organization	1 (5)	2 (15)
SDM intervention	not applicable	6 (46)

The value of the SDM intervention during the decision process

The impression of patient's interactions with components of the intervention were captured in the theme *the value of the SDM intervention during the decision process*. Although 46% of the patients reported to have received or searched for information via the Option Grid and website in the questionnaire (table 3), interviews revealed that all patients exposed to the Option Grid read its information. Most patients stated that they used the Option Grid and the supplementary online information with a focus on their (initial) preferred treatment or to gain more profound information on the selected treatment option. Additionally, patients used the Option Grid and accompanying website as a summary for the information they received during consultations. Patients commented that the timing of deployment of the Option Grid by professionals at the end of the consultation contributed to this way of usage. Some patients reported that the SDM intervention allowed them to prepare for consultations by providing information, which improved their understanding of

information during consultations or increased their ability to start the discussion. Regarding the value clarification tool, patients stated that they mainly utilized it to reiterate their preference and/or knowledge with the aim of corroborating their preferred choice.

"The consultation was not guided by this [Option Grid]. It was presented to finish the consultation, like 'here you have it as a summarized overview'." (51 yrs, M)

"Yes, and the intervention provides you with more information, so you can start the consultation, or the dialogue better." (60 yrs, M)

Multiple patients reported that using the Option Grid and website was stimulated by the ability to easily access its information. Patients commented they could conveniently look at the printed version at moments they preferred and that it allowed them to easily share information with others. When patients did not use one of the components of the intervention, the primary reason was that they did not felt a need to use it, because they had already made a final choice or collected information from other sources. One patient stated he did not access the website as the link was provided on paper, while he would have preferred an online, clickable link.

"That is what I like, to be able to grab it [Option Grid] quickly to repeat for myself what everything was. […] And you can also show it to someone else." (65 yrs, M)

"No, I mostly based my choice on consultations with the neurologist and PD nurse specialist, who also showed me its [treatment devices] methods, how it looked and what it is. And also based on conversations I had alongside the consultations, at home and with other people in my surroundings. That was more guiding." (49 yrs, M)

The patient's search for information

Within the qualitative theme *the patient's search for information* we observed that patients from the pre-intervention and post-intervention group collected information in different ways. Patients from the pre-intervention group collected information on treatment options in an unstructured and unequal way. The dispersed nature of available information, different formats of folders and brochures and their initial preference for one treatment option were identified as factors limiting their information collection process. Patients furthermore reported that the unequal nature of information resulted in missing information to equally weight risks and effects of available treatment options and they wished to have received more detailed information on all options. Patients' personal wish to search for information also impacted their information collection process as most patients stated they were hesitant to search for information on the internet because of its perceived overrepresentation of negative experiences. Although not explicitly mentioned by patients, we encountered several cases where patients made a choice while having important questions regarding their final choice unanswered.

"I would want clear insight into how each option works, including a clear risk analysis that says that if we go for it this could be the outcome. Now it was a little hallelujah, that's what she[neurologist] said, and the risks were not discussed." (64 yrs, M)

"I absolutely do not look up information in the internet. In general, I always read negative stories, because if it is positive, people celebrate and it is not put on the internet." (43 yrs, M)

Patients in the post-intervention group collected information mainly from the Option Grid and supplementary website besides receiving and collecting information through their neurologist and PD nurse specialist, the internet and experiences of other patients. Patients stated that the Option Grid and website increased their knowledge and understanding of treatments other than their initial preferred treatment. When patients searched for additional information, their information collection process was commonly structured based on the elements represented in the Option Grid. Additionally, the Option Grid supported patients in ensuring they had not missed any important information to make an informed choice.

"Well, initially I knew most about Duodopa, way more than about Apomorphine. So I gained more understanding of which I thought, 'ahh so that works like that' or 'I did not know that'." (60 yrs, M)

Acceptability of the SDM intervention

We excluded the questionnaire from one patient from the acceptability analysis, while that patient was not exposed to the Option Grid and website. Overall, we found that 10/12 (83%) of the patients exposed to the Option Grid and/or website rated the amount of information as sufficient, while two patients found the information too limited. The explanation of treatment options and information on treatment effects was perceived best with 10/12 (83%) and 9/12 (75%) of patients scoring this as fair-good respectively. Less patients scored information on treatment risks (8/12, 67%), daily use (7/12, 58%), scientific evidence (7/12, 58%), procedures (7/12, 58%) and patient experiences (6/12, 50%) as sufficient (fair-good).

All patients but one (11/12, 92%) felt that the information was represented equally for all treatments and readability was rated as good by all patients. Regarding the layout of the intervention, 11/12 (92%) of patients found the images to be clear while 9/12 (75%) found the images to be of actual added value. Overall, 10/12 (83%) of the patients who used the Option Grid and/or website would use them again in their decision process.

Most patients stated in the interviews that they were satisfied with the Option Grid and website and commented that information was understandable and represented in a clear and structured way. The majority of patients reported that the representation of risks and effects was hard or confrontational to see. However, most understood the need to know those treatment aspects for the purpose of comprehensiveness of the intervention and providing realistic expectations. The interviews revealed that some patients had trouble understanding the representation of treatment effects and risks. This led one patient to believe that the represented numbers were based on studies with 100 patients while another interpreted no improvement in quality of life inherently as a decrease.

"It [Option Grid and website] is all pretty clear. The options, the success rate, the side effects and the risks are all systematically represented. That was very useful." (67 yrs, M)

"I think that everything that should be mentioned is incorporated [on the Option Grid and website]. It is a clear story. There is nothing, in my opinion, no additional information that is not necessary." (65 yrs, M)

"[…] the effects and risks, that scared me, thinking '76% chance at skin infections and all that stuff.' Well, you should be realistic in knowing that you will not always have a good result and that is what it [Option Grid] states." (65 yrs, M)

Efficacy of the SDM intervention – level of SDM

In the pre-intervention group, most patients preferred making the decision in a shared way, while most patients in the post-intervention group preferred making the final decision alone while seriously considering their neurologist's opinion (see table 4). Differences in distributions of preferred roles between both groups were not statistically significant (p=0.125). Analysis of experienced roles showed that most patients experienced making the decision themselves while seriously considering their neurologist's opinion in both groups. Again, there were no statistically significant differences in the distribution of experienced roles (p=0.967). Overall, more patients in the pre-intervention group experienced the role they preferred in comparison to the post-intervention group (9/19 (47%) vs 5/13 (38%), p=0.471). When there was discordance between preferred and experienced roles in the pre-intervention group, 60% would have preferred a less active role. For the post-intervention group, this percentage was 75%.

Table 4: Control Preference Scale - distributions of preferred and experienced roles for the pre-intervention (n=19) and post-intervention (n=13) groups.

	Preferred role		**Experienced role**	
	Pre-intervention [n (%)]	**Post-intervention [n (%)]**	**Pre-intervention [n (%)]**	**Post-intervention [n (%)]**
Patient alone	4 (21)	1 (8)	6 (32)	3 (23)
Patient, considering neurologist's opinion	6 (32)	6 (46)	7 (37)	7 (54)
Shared	9 (47)	3 (23)	3 (16)	2 (15)
Neurologist, considering patient's opinion	0	2 (15)	2 (10)	1 (8)
Neurologist alone	0	1 (8)	1 (5)	0

Patients in the post-intervention group did not report higher levels of perceived SDM in comparison to the pre-intervention group based on the SDM-Q-9 questionnaire (see table 5). The median SDM-Q-9 score in both groups was identical (73) and did not differ significantly (p=0.821). Additionally, comparable median scores between both groups were found for each individual item.

Table 5: Level of SDM - SDM-Q-9 scores for the pre-intervention (n=19) and post-intervention (n=13) groups.

	Pre-intervention [median (IQR)]	**Post-intervention [median (IQR)]**	**P-value**
Overall SDM-Q-9 score	**73 (60-84)**	**73 (60-78)**	**0.821**
My doctor made clear that a decision needs to be made.	2 (0-3)	2 (2-3)	
My doctor wanted to know exactly how I want to be involved in making the decision.	3 (2-5)	4 (1-4)	
My doctor told me that there are different options for treating my medical condition.	4 (4-5)	4 (4-5)	
My doctor precisely explained the advantages and disadvantages of the treatment options.	4 (3-5)	4 (3-5)	
My doctor helped me understand all the information.	4 (3-4)	4 (4-5)	
My doctor asked me which treatment option I prefer.	5 (4-5)	4 (3-5)	
My doctor and I thoroughly weighed the different treatment options.	4 (3-5)	4 (3-5)	
My doctor and I selected a treatment option together.	3 (3-4)	3 (3-4)	
My doctor and I reached an agreement on how to proceed.	4 (3-5)	4 (3-5)	

Table 6: Level of SDM – CollaboRATE scores for the pre-intervention (n=19) and post-intervention (n=13) groups.

Overall CollaboRATE score	**85 (70-89)**	**89 (46-89)**	**0.677**
How much effort was made to help you understand your health issues?	8 (7-8)	8 (4-8)	
How much effort was made to listen to the things that matter most to you about your health issues?	7 (7-8)	8 (5-9)	
How much effort was made to include what matters most to you in choosing what to do next?	8 (6-9)	7 (4-8)	

The median overall CollaboRATE score in both groups was high (table 6). The score in the post-intervention group (89) was higher compared to the pre-intervention group (85) and this difference was not statistically significant (p=0.677). Although median overall and item scores were similar for both groups, considerable differences were found for the lower bound of the IQR.

Efficacy of the SDM intervention – decision quality

A considerable higher percentage of patients in the post-intervention group knew all available treatment options in comparison to the pre-intervention group (77% vs 53%, p=0.267). The median overall scores for the knowledge test at the start and end of the decision process in both groups can be found in table 7. Median performance of patients in the pre-intervention group at baseline (45%) was better compared to the post-intervention group (35%), but this was not statistically significant (p=0.850). However, the post-intervention group performed significantly better than the pre-intervention group on the knowledge test after making a decision (p<0.01).

We found minor differences in median overall DCS scores between the pre-intervention group (28) and post-intervention group (30), which were not statistically significant (p=0.940). Additionally, no differences between median scores for the *values clarity* subscale were identified. Patient in the post-intervention group reported to be more informed but less supported in comparison to the pre-intervention group.

Table 7: Decision quality - knowledge test and DCS scores for the pre-intervention (n=19) and post-intervention (n=13) groups.

	Pre-intervention [median (IQR)]	**Post-intervention [median (IQR)]**	**P-value**
Knowledge test			
Pre-decision performance (baseline)	45% (10%-55%)	35% (25%-52.5%)	0.850
Post-decision performance	55% (25%-55%)	65% (45%-77.5%)	<0.01
Decisional Conflict Scale	**28 (22-39)**	**30 (15-42)**	**0.940**
Uncertainty	50 (33-58)	42 (29-71)	0.791
Informed	33 (17-58)	17 (17-25)	0.170
Values clarity	33 (25-41)	33 (29-41)	0.570
Support	17 (0-33)	25 (13-50)	0.323
Effective decision	19 (0-31)	13 (0-41)	0.650

DISCUSSION

Interpretation of results

Assessment of the feasibility of the SDM intervention showed adequate levels of implementation at the patient level and that patients accepted the Option Grid and website. Additionally, we found that the intervention increased patients' knowledge on treatment options but that patients' perceived levels of SDM did not improve. Overall, these findings suggest that the SDM intervention is feasible on a patient level and that it has the potential to support PD patients in their decision process on advanced treatment selection. However, we found several factors that hampered the SDM intervention's capability to improve SDM during the decision process. We will next discuss these in further detail.

Although the level of implementation of the Option Grid and website at the patient level was adequate and comparable to other studies assessing the feasibility of SDM interventions (38, 39), implementation during consultation seemed poor. Interviews revealed that patients mainly used the Option Grid, website and value clarification tool as information source outside consultations. Furthermore, patients suggested that professionals did not use the Option Grid and value clarification tool as guide for discussing treatment options and patient preferences. Therefore, implementation of these components with their intended aim of facilitating discussion during consultation might not have been achieved and this could have limited the utilization of the intervention's potential to improve SDM. In this study, professional's actual utilization of and experiences with the Option Grid, website and value clarification tool remain unknown. Assessing the intervention's feasibility from a professional's perspective will allow us to identify these factors and might help to achieve implementation of the Option Grid, website and value clarification tool with its intended aim of facilitating discussion during consultations.

For efficacy of the SDM intervention, we observed that there was a considerable mismatch between preferred and experienced roles in the decision process in both the pre-intervention and post-intervention group. When there was discordance between experienced and preferred roles, most patients experienced a more active role than preferred. This observation is in line with findings from a previous study by Nijhuis et al. (6). The identified mismatch could indicate that explicit discussion and integration of patients' preferred roles in the decision process is currently still lacking (40). Furthermore, the decrease in agreement between preferred and experienced roles in the post-intervention group could be a reflection that more patients felt left alone in making the final decision (41). The mismatch between roles could make patients feel abandoned and unsupported in their decision process, which is underlined in this study by the higher DSC-score for the *support* subscale in the post-intervention group. The mismatch between preferred and experienced roles might also have contributed to the lack of improved levels of SDM in the post-intervention group (40). Overall, our results highlight the importance that professionals and patients explicitly discuss their preferred roles in the decision process and stimulating this discussion, possibly via the SDM intervention, can potentially improve SDM.

We found improved levels of knowledge in the post-intervention group, which can be explained by the fact that these patients had important information readily available within the Option Grid and website. Additionally, the dispersed and unequal way that patients in the pre-intervention group searched and received information could have hindered them to become fully informed on all treatment options and its characteristics. While inadequate information provision remains one of the most important barriers to SDM in other studies (6, 40), we argue that the Option Grid and website can reduce this barrier and support patients in participating in the SDM process.

Despite improved levels of knowledge in the post-intervention group, we did not see any improvements on SDM-Q-9 and CollaboRATE scores overall and on individual items regarding the provision of information. This observation can be explained by the high SDM-Q-9 and CollaboRATE median scores in the pre-intervention group, which, for the SDM-Q-9, has been reported by others (42, 43). The high baseline scores might be biased by patients feeling more important and involved in the decision process based on inclusion in this study or by social desirability bias, which could have masked improvements on the SDM-Q-9 and CollaboRATE measures (42, 44). Additionally, during the inclusion period of this study SDM received considerable attention in the Netherlands and was stimulated by several initiatives (45). This trend could have improved SDM during treatment selection for PD patients and might have contributed to the relative high SDM-Q-9 and CollaboRATE scores found for the pre-intervention group. The lack of improvement of the level of SDM can also be explained by the seemingly limited integration and discussion of the Option Grid during consultation. If patients mostly use the Option Grid and website outside consultation, it is expected that their knowledge improves without professionals improving their information provision to patients. Additionally, patients commonly do not know they are not informed on all options and that they are possibly making a choice based on incomplete information. Not knowing that they miss information might have led to an overestimation of the SDM-Q-9 scores on items regarding the provision of information in the pre-intervention group. Furthermore, the SDM-Q-9 and CollaboRATE mainly evaluate the professional's performance in the SDM process and these measures not directly capture improvements on a patient level. Known barriers to SDM on a patient level, such as not recognizing the contribution and importance of patient's own personal preferences could have improved the level of SDM, but this is not directly captured in these questionnaires (40).

Strengths and limitations

The major strength of this study is that it assessed the feasibility of the intervention both quantitatively and qualitatively, which allowed us to gain a profound understanding of the intervention's acceptability and implementation from a patient's perspective. During the qualitative analysis, all interviews were coded and discussed by two independent researchers, which improved the strength of the analysis and reduced any chance of missing or misinterpreting relevant statements in the transcripts.

However, this study was not without shortcomings and several limitations were identified. Although we anticipated difficulties with the inclusion of patients in the study in our protocol (21) and included the criteria that neurologist/PD nurse specialist had to considered a minimum of five PD patients for advanced treatment per year, we were unable to achieve the aim of including 20 patients in the post-intervention group. We found that one of the centers did not include any patients in the post-intervention group which largely contributed to this result. The limited numbers of inclusions in the post-intervention group could have limited the strength of the statistical analysis and could have decreased the generalizability of the interviews. However, while patients in the post-intervention group generally mentioned similar levels of utilization and satisfaction with the intervention, we argue that data saturation for the qualitative interviews was not considerably decreased by the missing inclusions.

Included professionals knew that we introduced an intervention that should have improved SDM. Although we asked professionals to provide care as they usually would, they might have changed their behavior in the decision processes of patients in the pre-intervention group as they knew that they were evaluated and recorded. Consequently, professionals could have made more effort to perform SDM than they usually do. Therefore, decision processes in the pre-intervention group might not accurately reflect current decision-making and reported SDM measures might overestimate the true level of SDM in daily practice. We expect that this limitation, in addition to the previously described factors, could have contributed to the high scores for the SDM-Q-9 and CollaboRATE in the pre-intervention group.

Additionally, patients might have used the internet, Option Grid and/or the intervention's website during the knowledge test, although we explicitly asked them not to. This might have improved patients' performance on the test and could have resulted in an overestimation of knowledge levels presented in this study. Analysis of logging data of the post-intervention group showed that patients did not use the intervention's website while completing the knowledge tests. However, the use of the printed version of the Option Grid during the knowledge test cannot be identified and the utilization of information sources during the knowledge test of patients in the pre-intervention group remains unknown.

Although we mostly used standardized questionnaires which have been validated and tested for reliability and acceptability, multiple patients reported to have experienced difficulties in understanding and interpreting some of the questionnaires regarding the efficacy of the intervention. A possible explanation for this might be the presence of cognitive impairment, which was the case in almost half of the included patients. Difficulties in answering questionnaires might have reduced the accuracy and reliability of patients' responses, which could have decreased the accuracy of these measures (46). We attempted to overcome this limitation by examining conflicting answers from questionnaires during the interviews.

CONCLUSION

Overall, patients accepted the Option Grid and website and were satisfied using it. The level of implementation of the Option Grid, website and value clarification tool at the patient level was feasible but the level of SDM did not improve. The intervention's utilization during consultations to actually improve SDM seemed limited and patients primarily used the intervention as information source. This improved their awareness and knowledge on available treatment options but did not seem to improve patients' overall perceived levels of SDM and a considerable mismatch between patients' preferred and experienced roles in the decision-making existed in both groups. These results indicate that improving patients' knowledge on treatment options outside consultations might not be enough to improve SDM and that preference elicitation and integration of decision roles might still be lacking. Therefore, attention should focus on stimulating patients and professionals to explicitly discuss their preferences and involvement in the decision process and coaching them to better incorporate the Option Grid and value clarification tool during consultations. This way, implementation of the SDM intervention with its intended aim is encouraged and we can take more advantage of the potential of the SDM intervention to support SDM during consultations.

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Appendix A: Questionnaire on the acceptability of the SDM intervention (in Dutch)

Toelichting bij deze vragenlijst

Het invullen kost ongeveer 10 minuten. Neem uw tijd om de vragenlijst in te vullen. U hoeft de vragenlijst niet in een keer te maken, zodat het niet te vermoeiend is voor u. Het is de bedoeling dat u altijd 1 antwoord kiest tenzij staat aangegeven dat u meerdere antwoorden mag kiezen.

Als u een antwoord wil veranderen zet dan een groot kruis door het foute antwoord en zet een pijl voor het ingevulde nieuwe antwoord.

1. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over de verschillende behandelingen:**
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

2. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over de risico's van de behandelingen:**
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

3. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over de effecten van de behandelingen:**
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

4. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over het dagelijks gebruik van de behandelingen:**
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

5. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over hoe goed de behandelingen zijn onderzocht:**
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

6. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over wat er gebeurt nadat u heeft gekozen voor een behandeling:**
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

7. **Kies 'slecht', 'matig', 'redelijk', 'goed' of 'uitstekend', om aan te geven hoe u de informatie vond over wat andere patiënten vonden van de behandeling**:
    - Slecht
    - Matig
    - Redelijk
    - Goed
    - Uitstekend

8. **Heeft u het gevoel dat er in de keuzehulp genoeg informatie wordt gegeven over de risico's van de behandelmethodes?**
    - Ja
    - Nee
    - Geen mening

9. **Is het taalgebruik in de keuzehulp begrijpelijk voor u?**
    - Ja
    - Nee
    - Geen mening

10. **Zijn de afbeeldingen die gebruikt worden in de keuzehulp duidelijk?**
    - Ja
    - Nee
    - Geen mening

11. **Hebben de afbeeldingen die gebruikt worden in de keuzehulp een meerwaarde naast de tekstuele informatie?**
    - Ja
    - Nee
    - Geen mening

12. **Leiden de afbeeldingen in de keuzehulp u af?**
    - Ja
    - Nee
    - Geen mening

13. **De hoeveelheid informatie in de keuzehulp was:**
    - Te veel
    - Te weinig
    - Precies goed

14. **Ik vond dat de informatie in de keuzehulp:**
    - Te veel neigde naar de Apomorfine pomp
    - Te veel neigde naar de DBS
    - Te veel neigde naar de Duodopa pomp
    - Te veel neigde naar de huidige medicatie
    - Alle opties werden gelijkwaardig aangeboden

15. **Heeft het onderdeel 'Zet uw afwegingen op een rij' u geholpen bij uw uiteindelijke keuze? Het maakt de keuze:**
    - Makkelijker
    - Moeilijker

16. **Heeft u de samenvatting uit de keuzehulp gebruikt in het gesprek met de neuroloog op de Parkinsonverpleegkundige?**
    - Ja
    - Nee

17. **Zou u de keuzehulp weer gebruiken indien u opnieuw zou moeten kiezen voor één van de behandelmethoden?**
    - Ja
    - Nee

18. **Denkt u dat er in de keuzehulp genoeg informatie gegeven wordt om een Parkinson patiënt te helpen met het maken van een keuze voor een behandelmethode?**
    - Ja
    - Nee

Hierbij bent u aan het einde van de vragenlijst gekomen. Wij danken u hartelijk voor uw moeite en tijd voor het invullen. U kunt deze vragenlijst terugsturen in bijgevoegde antwoordenvelop. Hierop hoeft u geen postzegel te plakken.
Heeft u nog vragen/opmerkingen? Neem dan alstublieft contact op met de hoofdonderzoeker, Frouke Nijhuis.

Email: [..]

Telefoonnummer: […]

Frouke Nijhuis

Appendix B: Knowledge test (in Dutch)

Toelichting bij deze vragenlijst

Het invullen kost ongeveer 10 minuten. Het is de bedoeling dat u geen hulpmiddelen gebruikt gezien het om parate kennis gaat. Neem uw tijd om de vragenlijst in te vullen. U hoeft de vragenlijst niet in een keer te maken, zodat het niet te vermoeiend is voor u. Het is de bedoeling dat u altijd 1 antwoord kiest tenzij staat aangegeven dat u meerdere antwoorden mag kiezen.

Als u een antwoord wil veranderen zet dan een groot kruis door het foute antwoord en zet een pijl voor het ingevulde nieuwe antwoord.

1. **Wat is een apomorfine pomp behandeling?**
   De apomorfine pomp is een behandeling waarbij
   - Continu apomorfine via een injectie in een spier wordt afgegeven
   - Continu apomorfine via een naaldje onder de huid wordt afgegeven
   - Continu apomorfine via een sonde in de dunne darm wordt afgegeven
   - Weet ik niet

2. **Een belangrijk risico van vervolgbehandeling met de Apomorfine pomp is**:
   - Het krijgen van buikpijn
   - Het krijgen van een bloeding in de hersenen
   - Het krijgen van huidafwijkingen
   - Weet ik niet

3. **Wanneer komt u NIET in aanmerking voor de Apomorfine pomp?**
   - Bij een leeftijd boven de 70 jaar
   - Bij lever/nierproblemen
   - Bij maag/darmaandoeningen
   - Weet ik niet

4. **Wat is DBS?**
   DBS is een behandeling waarbij
   - Er een bepaald gedeelte van de hersenen wordt gestimuleerd
   - Er een bepaald gedeelte van de hersenen wordt verwijderd
   - Er een bepaald gedeelte van de hersenen wordt weggebrand
   - Weet ik niet

5. **Een belangrijk risico van de vervolgbehandeling met DBS is:**
   - Het krijgen van een bloeding in de hersenen
   - Het krijgen van een bloeding in de maag
   - Het krijgen van een ernstige huidontsteking
   - Weet ik niet

6. **Wanneer komt u NIET in aanmerking voor DBS?**
   - Bij een leeftijd boven de 50 jaar
   - Bij ernstige geheugenproblemen
   - Bij maag/darm problemen
   - Weet ik niet

7. **Wat is Duodopa pomp behandeling?**
   Duodopa is een behandeling waarbij
   - Continu levodopa via een infuus in het bloedvat wordt afgegeven
   - Continu levodopa via een naaldje onder de huid wordt afgegeven
   - Continu Levodopa via een sonde in de dunne darm wordt afgegeven
   - Weet ik niet

8. **Een belangrijk risico van vervolgbehandeling met Duodopa pomp is:**
   - Een bloeding in de hersenen
   - Het losgaan van de sonde
   - Het ontstaan van misselijkheid
   - Weet ik niet

9. **Wanneer komt u NIET in aanmerking voor de behandeling met de Duodopa pomp?**
    - Bij een leeftijd boven de 70 jaar
    - Bij ernstige dementie
    - Bij lever/nier problemen
    - Weet ik niet

10. **Bij welke van de drie vervolgbehandelingen bestaat de grootste kans dat u helemaal kunt stoppen met het gebruik van pillen tegen de ziekte van Parkinson?**
    - Apomorfine pomp
    - DBS
    - Duodopa pomp
    - Weet ik niet

11. **Welke behandeling heeft het meeste effect op het trillen/beven?**
    - Apomorfine pomp
    - DBS
    - Duodopa pomp
    - Weet ik niet

12. **Bij welke behandeling is er GEEN dagelijkse verzorging nodig?**
    - Apomorfine pomp
    - DBS
    - Duodopa pomp
    - Weet ik niet

13. **Bij welke behandeling is er GEEN operatie nodig?**
    - Apomorfine pomp
    - DBS
    - Duodopa pomp
    - Weet ik niet

14. **Welke vervolgbehandeling is het beste onderzocht?**
    - Apomorfinepomp
    - DBS
    - Duodopa pomp
    - De behandelingen zijn allemaal even goed onderzocht
    - Weet ik niet

15. **Wanneer 100 mensen de apomorfine pomp krijgen, hoeveel mensen zullen er dan huidafwijkingen krijgen?**
    - Minder dan 33 mensen van de 100
    - Tussen de 33 en 67 mensen van de 100
    - Meer dan 67 mensen van de 100
    - Weet ik niet

16. **Wanneer 100 mensen DBS krijgen, bij hoeveel mensen zal dan hun kwaliteit van leven merkbaar verbeteren?**
    - Minder dan 33 mensen van de 100
    - Tussen de 33 en 67 mensen van de 100
    - Meer dan 67 mensen van de 100
    - Weet ik niet

17. **Wanneer 100 mensen DBS krijgen, hoeveel mensen zullen er dan overlijden?**
    - Minder dan 5 mensen van de 100
    - Tussen de 5 en de 10 mensen van de 100
    - Meer dan 10 mensen van de 100
    - Weet ik niet

18. **Wanneer 100 mensen de Duodopa pomp krijgen, hoeveel mensen zullen dan hun dagelijkse activiteiten merkbaar beter kunnen uitvoeren?**
    - Minder dan 33 mensen van de 100
    - Tussen de 33 en de 67 mensen van de 100
    - Meer dan 67 mensen van de 100
    - Weet ik niet

19. **Wanneer 100 mensen de Duodopa pomp krijgen, hoeveel mensen zullen dan pompproblemen krijgen?**
    - Minder dan 33 mensen van de 100
    - Tussen de 33 en de 67 mensen van de 100
    - Meer dan 67 mensen van de 100
    - Weet ik niet

Hierbij bent u aan het einde van de vragenlijst gekomen. Wij danken u hartelijk voor uw moeite en tijd voor het invullen. U kunt deze vragenlijst terugsturen in bijgevoegde antwoordenvelop. Hierop hoeft u geen postzegel te plakken.
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Email: […]

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Frouke Nijhuis