

Digital health technologies for shared decision making

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Digital health technologies for shared decision making

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Editorial: Digital health technologies for shared decision making

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KEYWORDS

patient decision aids (PtDAs), shared decision making (SDM), digital health (DH), artificial intelligence (AI), human factors, values, preferences, design

Editorial on the Research Topic

Digital health technologies for shared decision making

Current and emerging digital health technologies (DTHs) present a broad spectrum of opportunities to support and advance traditional approaches to shared decision making (SDM). In this evolving field, a key challenge lies in discerning where, when and how to best utilize DTHs to enhance SDM-related processes and outcomes. The articles in this Research Topic “*Digital Health Technologies for Shared Decision Making*” present a snapshot of current developments and viewpoints on this challenge.

DHTs can help to understand, reach and support patients across their healthcare journey (1–3). Höppchen et al. consider how suitably designed DHTs can target and leverage human factors to improve patient engagement. Based on the use case of cardiac rehabilitation, the authors examine barriers and facilitators to patient engagement across the stages of healthcare from awareness to SDM. They present the implications of their findings for the design and implementation of DTHs.

Within the healthcare journey, complex treatment pathways can present various key moments for SDM at which patient preferences, values and experiences can significantly influence the course of treatment (4). With a focus on intensive care, Göcking et al. apply patient journey mapping to identify and generate a structured overview of preference-sensitive moments during treatment at which timely engagement of patients can aid preparation, facilitation and reflection about shared decisions. The authors consider the strategic implementation of DTHs at these moments to align patient care with patient needs, values and preferences.

One strategy for facilitating alignment between patient care and their needs, values and preferences is the use of Patient Decision Aids (PtDAs). These aids aim to help patients better prepare for and participate in the SDM consultation (5). While digital capabilities can facilitate this aim, they also present challenges in PtDA design and use (6). With a focus on PtDAs for treatment selection in depression, Sedloková et al. identify, evaluate and compare the strengths and weaknesses (in terms of e.g., accessibility, information

design, personalization, adaptability) of analogue and digital PtDAs in relation to their effectiveness in promoting patient engagement in SDM.

Human factors, like depression and anxiety, can influence how patients process information and decisional situations, impacting the design considerations for digital health tools (7). Depression and anxiety are associated with altered patterns of risk perception, involvement in decision making and experience of decisional conflict in SDM (8, 9). Fanio et al. report on the unique challenges of designing a PtDA for anxious patients. With a focus on atrial fibrillation, the authors consider the incorporation of specific design features to facilitate a supportive digital environment with which to mitigate effects of anxiety on information and decision making.

A key strategy for effective SDM is to support collaboration between patients and healthcare professionals (10). Wurhofer et al. examine the practical application of a digital tool for collaborative planning in cardiac rehabilitation and its impact on SDM. Based on their findings, the authors identify opportunities for supporting collaboration before, during and after SDM and consider the digital implementation of corresponding design features to facilitate SDM (i.e., *SDM-supportive design*).

Artificial intelligence (AI) and DHT have the potential to enhance SDM in different ways. Early studies can provide important insight to shape further development and refinement of AI in SDM. Singh et al. focus on orthopaedic practice in an early phase translational design, feasibility and usability study. They develop and evaluate an interactive approach for integrating knowledge of patient preferences and priorities into the SDM consultation. The authors consider this approach in the context of informing the development of an AI-based personalized Health Recommender System for SDM.

Eiskjaer et al. consider a different AI-based approach to generating personalized patient support in SDM. Based on spinal disorders, the authors present a tool that applies predictive analytics to generate evidence-based insights into a patient's treatment options and the likely outcomes of these. These insights are used in SDM to personalize and encourage collaborative dialogue about these options. The authors consider factors that can drive or hinder the use of this tool for SDM.

To facilitate collaborative dialogue in SDM, Lin et al. evaluate an opponent model-based approach to SDM. This model simulates the interactive process in which a patient's initially vague preferences are distilled into more actionable insights as a patient engages in collaborative dialogue with their physician, gains clarity about their preferences, and reaches more informed and confident decisions. The authors examine this model in the context of developing treatment plans that fit individual preferences and consider its relevance for future application in SDM.

The integration of AI-enhanced DHTs in SDM raises sensitive and ethically challenging issues. Based on assisted suicide, Spitale et al. create AI models to extract and classify

patient case reports from real-world data. The authors take these reports as a basis for examining the potential feasibility, challenges and dilemmas of using AI to help physicians navigate complex ethical issues about patient care, confidentiality and professional responsibility.

In summary, the preceding contributions seek to develop an evidence-led understanding of when, where and how DHTs can facilitate effective support for SDM. The diverse foci of these contributions hint at a broad range of potentially unmet needs and insufficiencies in SDM across multiple areas of healthcare and within the patient healthcare journey that suitably designed and implemented DHTs might help to address. Together, these contributions are also illustrative of the complexities of tailoring DHTs to diverse human factors relevant for effective engagement in SDM while integrating DHTs in the broader context of traditional SDM solutions and the healthcare practices, workflows and environments in which SDM is or could be situated. With these challenges in mind, research ranging from early conceptual thinking to mature technical developments and the evaluation of the effectiveness of existing and emerging DHTs for supporting SDM are needed (11). This research could lead to the formation of a body of practical design and implementation knowledge about ways in which DHTs can enhance SDM-related processes and outcomes.

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Designing for patient decision-making: Design challenges generated by patients with atrial fibrillation during evaluation of a decision aid prototype

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Shared decision-making (SDM) empowers patients and care teams to determine the best treatment plan in alignment with the patient's preferences and goals. Decision aids are proven tools to support high quality SDM. Patients with atrial fibrillation (AF), the most common cardiac arrhythmia, struggle to identify optimal rhythm and symptom management strategies and could benefit from a decision aid. In this Brief Research Report, we describe the development and preliminary evaluation of an interactive decision-making aid for patients with AF. We employed an iterative, user-centered design method to develop prototypes of the decision aid. Here, we describe multiple iterations of the decision aid, informed by the literature, expert feedback, and mixed-methods design sessions with AF patients. Results highlight unique design requirements for this population, but overall indicate that an interactive decision aid with visualizations has the potential to assist patients in making AF treatment decisions. Future work can build upon these design requirements to create and evaluate a decision aid for AF rhythm and symptom management.

KEYWORDS

shared decision-making, atrial fibrillation, prototype, decision aids, iterative design, health informatics, mixed-methods

Introduction

Shared decision-making (SDM) is an increasingly embraced practice in modern medicine when there is clinical equipoise between all possible treatment options, and a patient's values and goals of care should be considered alongside the evidence about outcome (1). The SDM process is aided by the use of decision aids, which are structured tools that explicitly describe the decision to be made and present unbiased information about options, including the option of taking no action. Prior studies

have well established that decision-aids improve patient knowledge, patient involvement, and decision quality (2, 3). Decision aids are commonly delivered in a digital format, which allows the information to be rapidly updated, tailored to the individual person, and more precise timing of delivery in the decision-making process (4).

Patients with atrial fibrillation (AF) could benefit from a decision aid to compare AF treatment outcomes, risks and benefits, and alignment with personal care goals. AF is the most common type of cardiac arrhythmia, and its prevalence is steadily rising (5). Treatments for AF include medications or catheter ablation, a minimally invasive procedure that involves destroying the cardiac tissue believed to be causing the arrhythmia. Both treatment pathways have their own set of associated risks, benefits, and outcomes. The decision is complicated by the fact that, while catheter ablations are recommended in evidence-based guidelines for symptomatic patients (6), patients may continue to experience persistent AF and associated symptoms even after the procedure (7, 8). Thus, the treatment choice should come from a nuanced consideration of the anticipated benefits and potential risks.

Despite being an ideal scenario for SDM, little research or decision aid development has been conducted to support patients as they choose a rhythm and symptom control strategy for AF. In fact, a recent study demonstrated that very few AF patients engage in SDM with their care teams or even understand their treatment options (9). In our previous work, we report that AF patients have unique needs that create a challenging set of design requirements—specifically, a propensity for anxiety about their cardiac status but a desire for knowledge and data (10).

With these design challenges in mind, the aim of this Brief Research Report is to describe the development and preliminary evaluation of an interactive decision aid for patients with AF. A secondary objective was to explore data visualizations for communicating the risk of outcomes from each treatment option by evaluating participants' comprehension and preferences.

Materials and methods

Study design

We followed the International Patient Decision Aid Standards (IPDAS) Collaboration guidelines for creating high-quality patient decision aids (3), which outlines several steps that should be taken when developing decision aids. Following the first several steps of the IPDAS guidelines, in prior work we defined the scope of the decision aid, conducted needs assessments with patients and clinicians, determined the format and distribution plan, and reviewed and synthesized evidence about treatment options as well as optimal decision aid design. We defined the scope as helping patients with AF learn about two treatment options for rhythm and symptom management,

antiarrhythmic medication or catheter ablation, including how each option works and its risks and benefits. The decision aid is intended to be used by patients during a cardiac electrophysiology visit to discuss treatment options for AF, as well as before or after the visit. Our needs assessment with 15 patients and 5 clinicians underscored the need for decision aids in this specific treatment decision, and generated suggestions regarding the format and delivery of the decision aid (10). In the present study, we build on this prior work by describing the next two steps of the IPDAS guidelines: (1) prototyping and (2) alpha testing to evaluate comprehensibility and acceptability. This study was approved by the Weill Cornell Medicine Institutional Review Board.

Prototype design and development

Prototype development occurred in three phases: low-fidelity prototyping, high-fidelity prototyping, and expert feedback incorporation. **Figure 1** outlines the design process. During low-fidelity prototyping we created a set of hand-drawn rough sketches, which we iterated upon until agreeing upon a design theme and common elements (**Supplementary Figure S1**). During this stage, we sought feedback from clinical experts who provided input on the content, color palettes, and general flow of the decision aid. We then created high-fidelity prototypes using Adobe XD, a prototyping software suite which was chosen for the purposes of creating an interactive prototype suitable for real-time collaboration and extensive version histories. We again iterated upon these prototypes until the entire research team was satisfied with the content and visual elements in the prototypes. During this stage, we sought feedback from experts in SDM, decision aid design, and data visualization, which led to further changes to the prototypes. Specifically, the experts suggested personalizing results by demographics and medical histories to avoid a “one size fits all” message to the treatment outcomes, incorporating more information about AF and treatment options so patients can explore the decision aid on their own before visits, and incorporating an open-ended question section for patients to add their preferences and questions. They also recommended studying visualizations for communicating symptoms and quality of life given the dearth of literature on this topic, as we describe below.

The final interactive prototypes were used for alpha testing with patients, shown in **Figure 2**.

Supplementary Table S1 describes key design choices of our final prototype after incorporating feedback from our project team and external experts. In terms of user experience (UX) design, we sought out the software industry's standards for icon layout, color palette, font choices. We based our UX standards off of Apple's Human Interface Guidelines (11), Google's Material Design (12), and Nielsen's ten 10 usability

Decision Aid Development

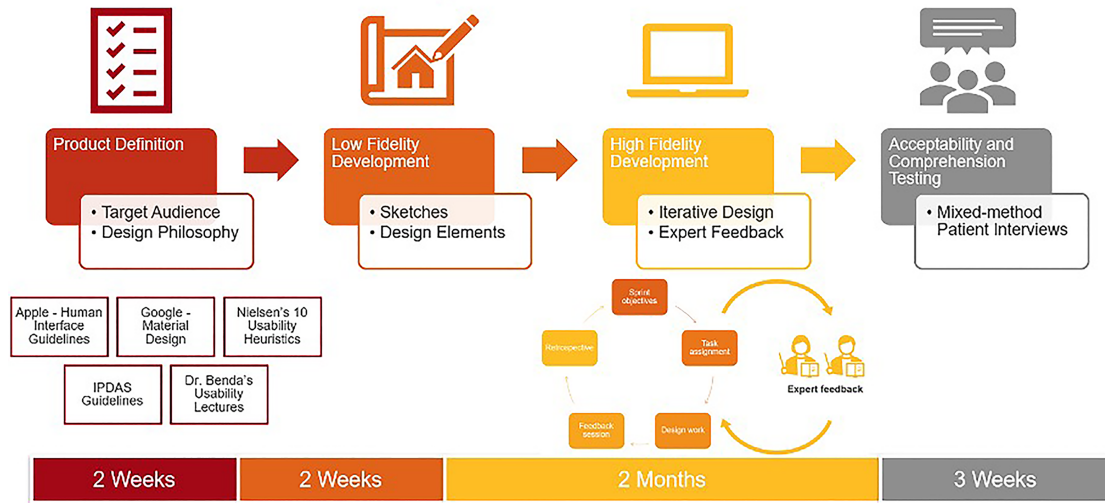


FIGURE 1
Decision Aid development.

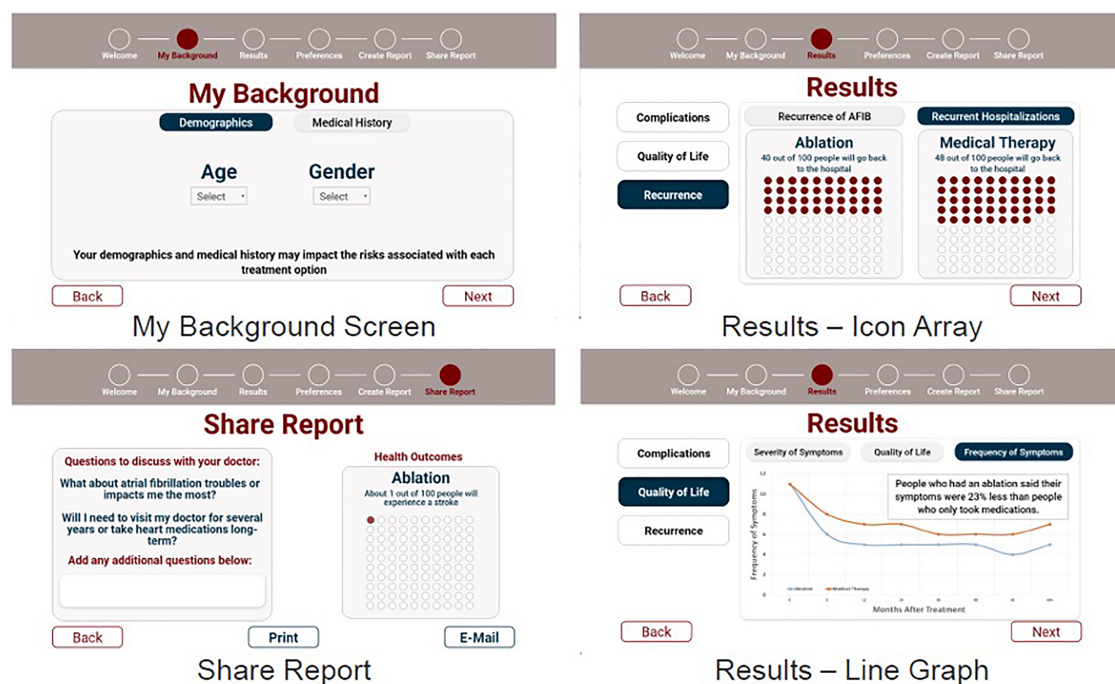


FIGURE 2
Final high-fidelity prototypes used in alpha testing.

heuristics (13). Accessibility and inclusive design were prioritized to ensure that the decision aid can meet the needs of a diverse target audience and includes elements such as font, size, shape, and color of each component (14). For this

reason, we also followed gerontological design principles (15), such as consistent linear navigation and large touch-targets to support usability among older adults, who are the predominant age group of AF patients.

The information presented in the decision aid came from a recent meta-analysis of catheter ablation vs. medication therapy (16) and a separate clinical trial reporting symptoms and quality of life outcomes (8).

To determine how to present the information, we performed a literature review of past decision aids studies to identify evidence about which visualizations are most effective at communicating evidence. We chose to use data visualizations because numerous studies have shown that visualizations are better understood or preferred in communicating the probability of an outcome as compared to text alone (17–21). Prior studies specifically report that pictographs are the most widely comprehended visualization for communicating binary outcomes (e.g., having a stroke or not after the treatment) compared to other visualizations or text alone (17, 18, 20, 22, 23). Prior studies also recommend using the same denominator (e.g., 5 in 100 people will experience this outcome) for consistency when presenting multiple outcomes using ratios and percentages (21, 24, 25). Therefore, we adopted these visualization principles when presenting information about binary outcomes in the prototypes.

However, we found there is far less literature on how to communicate symptom experiences and quality of life in decision aids. One prior study testing the comprehension of symptom visualizations between text, text plus visual analogy (such as a gas gauge or weather icon representing symptom status), text with a number line, and text with a line graph showed that comprehension for the visual analogy was significantly higher than text alone or other visualizations (26). However, this study was focused on returning patients' personal symptom data to them, rather than projected population-level symptom outcomes in a decision aid.

Therefore, we explored comprehension of similar visualizations in the different context of SDM. Specifically, we created four visualization options showing symptom and quality of life outcomes: line graph, gauge, text with cartoon, and text alone (Supplementary Figure S2). The text alone option was the control condition. We created a version of the text alone that also included a cartoon image explaining that information should be contextualized to the individual patient, at the suggestion of experts who evaluated our high-fidelity prototypes. The gauge was selected because visual analogies were previously reported as well comprehended in older adults with cardiovascular disease (26). The line graph, although less well comprehended in prior work, most easily allowed us to display multiple data points over time. We evaluated comprehension of the four visualization options during alpha testing.

Alpha testing

Alpha testing involves evaluating early stage prototypes with patients for usability and comprehension (27). The outcomes of

interest in alpha testing were (1) objective comprehension of data visualizations included in the decision aid, measured using the International Organization for Standardization (ISO) 9,186 method (2, 28) decision aid acceptability, measured using the Decision Aid Acceptability Scale (29). We aimed to recruit 15 participants based on our prior experience with user-centered design studies and published guidance (10, 30–32), with the option to terminate recruitment early if thematic saturation in qualitative data was reached. Thematic saturation occurs when no new information is being obtained and participant responses become redundant with prior responses (33).

To conduct alpha testing, we recruited patients who had recently undergone catheter ablation at an urban hospital affiliated with New York Presbyterian-Cornell hospital in Queens, New York. The cardiology team at the hospital generated a list of potential patients, who were then contacted by phone or email and invited to participate *via* Zoom. All participants provided verbal consent to participate before each session. Each participant was compensated for their time with a \$25 gift card.

During each session, we collected baseline socio-demographic information, preferences for involvement in medical decision-making measured using the Controls-Preferences Scale (34), health literacy (35), subjective numeracy (36), graph literacy (37), and experiences of decisional conflict relating to the decision to undergo ablation measured using the Decisional Conflict Scale (38).

After completing baseline surveys, participants were shown a series of screens displaying the high fidelity prototype. We collected qualitative data regarding general reactions and suggestions for improved usability, appearance, and satisfaction, and administered the Decision Aid Acceptability Scale.

Participants were then shown the four visualization options showing symptom and quality of life outcomes: line graph, gauge, text with cartoon, and text alone. The order in which visualizations were shown was randomized for each participant, known as counterbalancing, to prevent potential order effects (39). Objective comprehension was measured for each of the four visualizations.

All sessions were audio-recorded and transcribed *via* NVivo automated transcription software. The transcripts were then reviewed by two members on the research team and verified against the original recording to confirm accuracy. Qualitative data was analyzed using general thematic analysis (40). To ensure rigor in qualitative approaches, we conducted independent coding, triangulated results with quantitative surveys, and discussed results with other stakeholders to confirm credibility. To ensure rigor in qualitative approaches, we conducted independent coding, triangulated results with quantitative surveys, and discussed results with other stakeholders to confirm credibility. During the analysis, one coder analyzed the transcripts to identify themes that were

reviewed and confirmed by a second coder. The emerging findings were discussed and coders independently confirmed when thematic saturation had been reached. Quantitative survey data was analyzed using basic descriptive statistics of mean, central tendency, and frequency. Qualitative and quantitative data were triangulated and the integrated findings were discussed with other key stakeholders (cardiologists and cardiac nurses) for veracity.

Results

Participant characteristics

Recruitment concluded after five participants were enrolled in alpha testing because thematic saturation was reached. Participants (two female and three male) had an average age of 60.2 years (SD = 7.7) (**Table 1**). The majority of participants were non-Hispanic/Latino White with high education levels and high technology experience. All had adequate or more than adequate financial resources and owned a laptop and an iPhone. The majority also had high willingness to engage in decision making with their care teams (controls-preferences), high health literacy, moderate subjective numeracy (mean score 13.6 out of 18, with higher scores equating to higher numeracy), but mixed levels of graph literacy.

Acceptability and comprehension

The acceptability of the decision aid and objective comprehension of the visualizations are presented in **Table 2**. On average, the mean scores for the Welcome Page, Background and Health Results screens were higher than the Preferences, Create Report and Share Report screens, indicating higher acceptability. Four of the five participants found the decision aid to be helpful, but two thought the decision aid provided too little information to help a patient reach a treatment decision.

Regarding objective comprehension, all five participants correctly comprehended the text only, text plus cartoon, and gauge visualizations. Three of the five participants correctly comprehended the line graph. The majority of participants (three of the five) reported that the gauge visualization was their most preferred visualization.

Qualitative feedback

Themes from the qualitative analysis are provided below. Illustrate quotes are provided in **Supplementary Table S2**.

TABLE 1 Participant characteristics ($n = 5$); mean (SD) or n (%).

Age	60.2 (7.7)
Gender	
Female	2 (40%)
Male	3 (60%)
Race	
White	4 (80%)
Asian	1 (20%)
Ethnicity: Not Hispanic/Latino	5 (100%)
Education	
High school or less	1 (20%)
College degree	2 (40%)
Master's degree	2 (40%)
Finances	
More than enough	2 (40%)
Enough	3 (60%)
Computer Ownership	5 (100%)
Smartphone Ownership	5 (100%)
Internet Usage (in the last 30 days)	
1–2 h/day	1 (20%)
5 + h/day	4 (80%)
Controls-Preferences	
Make the final selection after seriously considering my doctor's opinion	2 (40%)
Have my doctor and I share responsibility for deciding what treatment is best	3 (60%)
Health Literacy: adequate	5 (100%)
Subjective Numeracy	13.6 (3.0)
Short Graph Literacy	
1/4 Correct	1 (20%)
2/4 Correct	1 (20%)
3/4 Correct	2 (40%)
4/4 Correct	1 (20%)

Theme 1: desire for data and evidence

Most participants showed a strong desire for data and evidence, some even requesting more data than what was presented in the prototypes. All participants stated they would like to understand more about from where the evidence originated, with citations to the original trials or guidelines providing the evidence, and guidance on how they should contextualize the evidence for themselves.

TABLE 2 Decision aid acceptability and visualization comprehension survey results ($n = 5$); mean (SD) or n (%).

Acceptability (0–5; 5 = most acceptable)	
Page 1: Welcome Page	3.2 (0.84)
Page 2: Background	3.4 (0.55)
Page 3: Health results	3.0 (1.22)
Page 4: Preferences	2.4 (1.14)
Page 5: Create Report	2.4 (1.14)
Page 6: Share Report	2.4 (1.14)
The amount of information was:	
Too little	2 (40%)
Just right	3 (60%)
Would you have found this useful when you underwent an ablation?	
Yes	4 (80%)
No	1 (20%)
Do you think we included enough information to help a patient decide on having an ablation or not?	
Yes	3 (60%)
No	2 (40%)
When would you like to view this information?	
Before you see a doctor	2 (40%)
After you see a doctor	3 (60%)
Visualization comprehension	
Text only	5 (100%)
Text plus cartoon	5 (100%)
Gauge	5 (100%)
Line graph	3 (60%)
Visualization preferences	
Text only	0
Gauge	3 (60%)
Line graph	1 (20%)
Text plus cartoon	1 (20%)

Theme 2: preference for simplified language rather than medical terms

Since all participants were already familiar with AF and had exposure to many AF-related terms prior to the interview, they were mostly successful in comprehending the language used in the prototype. However, they still showed a preference for simplified language rather than medical terms, on some screens they required more detailed explanations about certain terms.

Theme 3: more details on treatment options are required

Most participants wanted more information about the treatment options available to them. One participant stated that they would like to see more treatment options other than ablation and medication, and what could be the potential outcome if the treatment did not work. Another participant suggested that patients tended to overestimate the benefits of surgical treatment and thought it would be beneficial for the decision aid to temper expectations by providing more details on potential treatment outcomes and pushing for discussions with a provider.

Theme 4: both digital and physical versions are important

All participants responded positively to accessing the decision-aid electronically, which participants noted was especially helpful when the COVID-19 pandemic caused anxiety around in-person visits. They also noted it facilitated communication around decision-making with care teams and caregivers. Email, text, website, participant portal and mobile app were all mentioned by participants as preferred strategies for electronically accessing a decision aid. However, participants also expressed the need to obtain physical copies of results for people with lower digital literacy, and liked having an option to print results from an electronic decision aid.

Theme 5: preference to use decision aid with care teams

Despite the overall high acceptability of the decision aid, participants reported a preference to review the decision aid with their doctor or other member of their care team to weigh the risks and benefits of each option. Participants were mixed regarding whether they would prefer to view the decision aid before or after consulting with their doctor.

Theme 6: visualizations could affect participant sentiments

Visualizations provoked both positive and negative emotional responses from participants. One participant stated that certain images in the prototype caused anxiety and triggered negative sentiments, such as the heartbeat graphic on the welcome screen. Another participant reported that viewing the cardiac outcomes caused anxiety, and that cartoon images of patients caused confusion and concern. However another participant reported that the gauge data visualization was visually appealing and lifted their mood.

Discussion

Summary of findings

In this study, we developed and evaluated prototypes of an AF decision aid using the steps outlined in the IPDAS guidelines for decision-aid development. Our evaluation of the interactive decision aid prototype revealed high acceptability of many pages of the decision aid. However, three important design challenges emerged: managing patient anxiety, visualizing symptom outcomes, and designing for broad accessibility. These design challenges will be critically important to address as the prevalence of AF continues to rise and the number of patients needing decision support around treatment options rises with it. In AF, many decision aids have been developed to help patients choose a stroke-preventing medication (anticoagulant); these decision aids have led to more SDM occurring between clinicians and patients and lowered patients' cognitive load and decisional conflict (41–44). Thus, well-designed decision aids for patients selecting a rhythm and symptom control strategy may have an equally positive impact on decisional outcomes. Below we describe these design challenges in greater detail and potential solutions to explore in future work.

Challenge 1: manage patient anxiety without withholding information

Patients in our study wanted more information, but also noted how easily they could become anxious about their cardiac status. Patients requested detailed data about treatment pathways and potential adverse outcomes. At the same time, they described worrying constantly about their cardiac status and fear of those same adverse outcomes. In some cases, viewing a graphic image of a heart in our prototypes was enough to generate worry. Prior studies have indeed reported that many patients with AF struggle with anxiety symptoms (45–47). Moreover, some studies have shown that providing too much information can, in some cases, deteriorate decision quality (48).

Therefore, there exists an interesting paradox in this patient populations' information needs. Our findings suggest that patients need to see more comprehensive information presented in a straightforward manner in medical decision aids. Specifically, sources of evidence for the data being displayed should be clearly cited with hyperlinks for further reading; patients reported wanting to verify sources of data themselves. Patients also expressed a clear desire for explanations that used simple, non-medical jargon, even when they were familiar with certain medical terms. Consistent and non-medical terms are shown to reduce patient confusion (49). As in prior studies (42, 44), patients in our study

strongly preferred to discuss their treatment options with their care team rather than view the decision aid independently. The context provided by healthcare professionals could also ameliorate anxiety. Finally, visualizations should be carefully examined to avoid causing anxiety and fear.

Challenge 2: determine how to visualize symptom outcomes

Prior work has established the benefits of using visualizations to communicate evidence; patients report increased comprehension of probabilities of different outcomes occurring with each treatment option (17–23, 42). In our study, patients preferred and comprehended visualizations better than text alone. For probabilities with binary outcomes (e.g., likelihood of an adverse event occurring), studies support the use of icon arrays as the most comprehended visualization (50).

However, less is understood about the best visualizations of potential symptoms and quality of life outcomes. Symptoms and quality of life are typically measured through patient-reported outcomes measures (PROMs) which have different scoring mechanisms, making numerical comparisons difficult. For this reason, in prior studies, visual analogies such as the gauge visualization of personal PROM scores are well comprehended compared to text alone or line graphs (26). However, patients in our study reported wanting to see numerical scores, and felt that visual analogies overly simplify these measures and do not capture nuanced changes in PROMs over time. At the same time, only three of the five participants objectively comprehended line graphs (where nuanced changes were displayed in more detail), and only one participant preferred it. Adding another layer of complexity is the desire for patients to personalize data visualizations based on their personal health history, demographics, and other factors that may affect outcomes. It is possible that visual analogies paired with a “details on demand” approach, providing numerical symptom and quality of life scores plotted over time and customized to the patient, may represent a promising visualization option which should be further explored.

Challenge 3: design for broad accessibility

Inclusive design principles ensure that applications “are accessible to, and usable by, people with the widest range of abilities within the widest range of situations” (51) and should guide every user-centered design project. While we consulted gerontological design principles (15) when creating prototypes, additional user needs and user groups should be considered. For example, the unique design needs of people with disabilities

should be solicited (52). Many patients engage in SDM with the support of their caregivers (53), who should also be considered end users in usability studies.

More fundamentally, the creation of an electronic vs. a paper-based decision aid also creates barriers to access that should be carefully considered. In general, Internet use among racial and ethnic minority, low income, and older adult populations is steadily rising (54). However, one study showed that the use of digital information declined among older cohorts, but found that the physical vs. digital disparities were significantly lower among people with no college education (55). In another study, patients preferred printed medication information and had mixed responses to electronic information (56). In our study, patients preferred to have both physical and digital copies available of our decision aid's information. Creating printable screens of an electronic decision aid is one way to create broad accessibility for patients depending on their preferences.

Strengths and limitations

In this study, we followed IPDAS guidelines closely and were able to demonstrate effectiveness and quality in the development and evaluation of the decision aid. We found success in being able to leverage several sources of widely accepted knowledge, including existing literature (for data visualization strategies), experts in atrial fibrillation and decision aids (for feedback), and industry design and heuristic standards (for our design philosophy). Our study was limited primarily by the small sample size due to thematic saturation being reached after only five participants were enrolled, which may narrow the generalizability of findings. Moreover, the sample did not include a wide range of older adults based on age or technology comfort, which may further limit generalizability. In future work we plan to refine the prototype based on the feedback provided and continue testing with larger samples of participants. This will be a critically important step to avoid creating intervention-generated inequities (57), and advance the goal of creating a highly usable and useful decision aid for AF patients to be tested in clinical trials.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving human participants were reviewed and approved by the Weill Cornell Medicine Institutional Review Board. Written informed consent for participation was

not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

JF, BW, and EZ: drafted the manuscript and participated in data collection and analysis. MRT: conceived of the study, obtained funding, led data collection, and provided critical feedback on manuscript drafts. DJS: provided critical feedback during data collection, analysis, and on the manuscript drafts. All authors contributed to the article and approved the submitted version.

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Conflict of interest

MRT is a consultant for Boston Scientific Corp. and has equity ownership in Iris OB Health, Inc. BW is employed by Oracle/Cerner. EZ is employed by Broadmoor Solutions Inc. and is a consultant for Sanofi Pasteur.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fdgth.2022.1086652/full#supplementary-material>.

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Patient preferences as human factors for health data recommender systems and shared decision making in orthopaedic practice

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Background: A core set of requirements for designing AI-based Health Recommender Systems (HRS) is a thorough understanding of human factors in a decision-making process. Patient preferences regarding treatment outcomes can be one important human factor. For orthopaedic medicine, limited communication may occur between a patient and a provider during the short duration of a clinical visit, limiting the opportunity for the patient to express treatment outcome preferences (TOP). This may occur despite patient preferences having a significant impact on achieving patient satisfaction, shared decision making and treatment success. Inclusion of patient preferences during patient intake and/or during the early phases of patient contact and information gathering can lead to better treatment recommendations.

Aim: We aim to explore patient treatment outcome preferences as significant human factors in treatment decision making in orthopedics. The goal of this research is to design, build, and test an app that collects baseline TOPs across orthopaedic outcomes and reports this information to providers during a clinical visit. This data may also be used to inform the design of HRSs for orthopaedic treatment decision making.

Methods: We created a mobile app to collect TOPs using a direct weighting (DW) technique. We used a mixed methods approach to pilot test the app with 23 first-time orthopaedic visit patients presenting with joint pain and/or function deficiency by presenting the app for utilization and conducting qualitative interviews and quantitative surveys post utilization.

Results: The study validated five core TOP domains, with most users dividing their 100-point DW allocation across 1–3 domains. The tool received moderate to high usability scores. Thematic analysis of patient interviews provides insights into TOPs that are important to patients, how they can be communicated effectively, and incorporated into a clinical visit with meaningful patient-provider communication that leads to shared decision making.

Conclusion: Patient TOPs may be important human factors to consider in determining treatment options that may be helpful for automating patient treatment recommendations. We conclude that inclusion of patient TOPs to inform the design of HRSs results in creating more robust patient treatment profiles in the EHR thus enhancing opportunities for treatment recommendations and future AI applications.

KEYWORDS

patient preference, shared decision making, human-factors design, health recommender system, treatment efficiency, treatment outcome preference

1. Introduction

Design of patient-centered digital health systems, specifically clinical decision support systems (CDSS), has provided a foundation for consolidating and improving clinical processes and decision making since the 1960s (1). Data-evidence based decision support systems (DSS) have been researched, developed, and applied in various clinical settings for over four decades with the application of decision trees, knowledge graphs and statistical approaches for clinical decision making (2–4). Amongst the many challenges present in current AI-based treatment DSSs is the ability to identify and include human factors, such as a range of personal preference and social determinants of health, to quantify data-evidence. As such, patient-centered and AI-powered treatment DSSs remain a work in progress. In this paper, we present the design and inclusion of one important human factor, patient treatment outcome preferences, into patient-centered clinical DSS and discuss implications for moving towards an AI-powered approach.

1.1. Human factors challenges in the design of health recommender systems

Recommender Systems (RSs) are a type of DSS broadly defined as information systems that are capable of analyzing previous usage behavior and making some sort of recommendations for solving new queries (5). Some real-life applications are commonly found in consumer markets such as online shopping recommendations (Amazon), music and entertainment recommendations (YouTube, Netflix) and search recommendations (Google). RSs are broadly categorized into data filtering frameworks: content-filtering, collaborative filtering, and hybrid filtering (6). For example, YouTube might recommend a video to a user based on her prior video viewing activity, or the activity of users that have similar user or viewing profiles as the index user. There are multiple variations of RSs such as context-aware systems, knowledge base systems and many applications in a wide variety of fields (6). With the emergence of AI in recent years, Health Recommender Systems (HRSs) have quickly emerged as a growing field of research (7). In a typical HRS, a recommendable item of interest is a piece of medical information such as a selected physician or treatment option. Usually, HRS suggestions are driven by individualized health data such as documented in an electronic health record (EHR) or personal health record

(PHR). A subset of such HRSs is aimed at making preferred healthcare choices. The information that feed into such systems is the user profile, which could be a patient profile in a PHR or EHR in the form of a personalized health knowledge graph (8), a provider profile (9) or a combination of both (10).

One important drawback in the design of HRSs' based on artificial intelligence in the clinical setting is their lack of AI explainability (11) and AI interpretability (12) for users who are expected to make decisions based on results. Furthermore, explainable AI algorithms have been criticized for over-complicating the models to make them difficult to understand. AI techniques are often criticized for the "black box" approach (13). Among other challenges, over reliance on data represented by labels and symbols makes it harder to understand the inside working of such black box AI methodologies and systems. To create human interpretable AI systems, human factors must be included in the design such that human interactions are represented with personalized nuances of perceptions, personalities, and choices across various domains (14). HRSs for treatment support in orthopedics, for example, might refer to health data found in EHRs and PHRs including patient demographics, comorbidities, and measured mobility and function scales. This data has limited interpretability, or relevance towards making a treatment decision as it requires inclusion of human preferences, priorities, and biases that are typically used for making real-world treatment decisions. We note the case of Predict+ for predicting success of total shoulder replacement surgeries. Predict+ is a machine learning based tool created in collaboration with Exactech that is used to predict complications that result from total shoulder arthroplasty; and patient satisfaction as a result of function improvement (15). The tool used EHR data including patient demographics, diagnoses, and treatment codes. The number and types of surgical complications, and level of satisfaction, are both outcomes that are heavily influenced by factors not collected in the EHR, such as patient preferences. This and other such applications lack important patient or provider preferences as a factor in the feature set.

Recent reviews have attempted to organize the theory behind HRSs. One recent systematic literature review of personalized HRSs provides an insight into AI-methodology based classification of HRSs (16). Another discusses the applications, AI and evaluation techniques of HRSs (7) and many others discuss various aspects of a HRS including impact, target population, recommendation domain, and recommendation

visualizations (17–19). However, a design science or design theory approach, providing a design framework for creating HRSs that include human factors in orthopedics remains to be seen. This is the focus of the current study.

It has been noted in recent years that a wider knowledge scope of human factors is beneficial for creating more effective recommender systems (20). A HRS inclusive of human factors in orthopedics should aim at achieving the ability to include finer nuances of provider-patient interaction, with a design framework for appreciation and anticipation of human preferences and priorities. Thus, human factors are a core requirement in the design of these systems. There are many potential human factors for a treatment decision HRS, such as patient health history, patient treatment preferences, provider biases, provider treatment profile, organizational treatment scope and constraints and finally, resources such as worker's compensation, provider availability and equipment or facility availability. The current study focuses on patient preferences regarding treatment outcomes.

1.2. Patient preferences for better treatment options and treatment decision making

Patients need the ability to communicate their treatment outcome preferences (TOPs) accurately and efficiently to their healthcare providers (21, 22). For this study, TOPs refer to a patient's interest in actively participating in his/her treatment decision making in a shared manner with his/her physician, particularly when multiple treatment options exist; each option having the likelihood of leading to a different set of outcomes. Different patients may prefer different sets of outcomes and thus are willing to accept tradeoffs in their treatments to achieve preferred outcomes (23–25). Currently, no existing system provides an efficient and timely approach to collect and communicate these preferences to support shared decision making (SDM) in orthopaedic practice (21, 26–28). Treatment outcome preferences may include the patient's prioritized desire for their treatment to reduce short term or long-term pain, get back to work as soon as possible, keep treatment costs low, or regain lost mobility.

Patients with new orthopaedic conditions or injuries usually have several treatment options that can affect several outcome domains (29) and patients can have different preferences over those outcome domains (21, 26–28). In addition, the orthopaedic clinical literature broadly acknowledges that treatment effects are likely heterogeneous across outcome domains across patients (30–32). Consequently, optimal treatment decisions in orthopedics are rarely “one-size fits all” and providers must help individual patients choose treatments aligned with each patient's clinical circumstances and preferences (22, 33, 34). The ability of orthopaedic patients to accurately and efficiently communicate preferences across outcome domains to their providers is vital for shared decision making (SDM) so patients can receive the treatment that best suits them (21, 27, 33). The collection and useful communication of patient preferences at the orthopaedic clinical encounter would radically transform patient-physician

interaction and promote SDM and patient-centered care by allowing for patient-specific information to inform treatment decisions (35).

Despite clear patient benefits to communicating patient preferences to providers (35–37), barriers exist to capturing this communication in current orthopaedic practice workflows. Electronic medical record (EMR) systems were created for fee-for-service medicine to document the care patients received and not their outcomes and the clinical measures commonly collected in EMR systems fail to capture the range of outcome domains valued by patients with orthopaedic conditions (pain, function, quality of life, etc.) (29, 35). Thus, no existing system provides an efficient and timely approach to collect and communicate patient information on outcome domains and patient preferences over those domains to support SDM in orthopaedic practice (26, 27, 34, 38, 39). An innovative process is needed to efficiently collect orthopaedic patient preferences and rapidly communicate this information into orthopaedic practice workflows to support SDM and improve patient-centered outcomes (40, 41).

Our broader hypothesis is that using patient preference profiles as an input into an HRS will help generate more effective treatment decisions. Our prior work indicates that patient preference profiles may be an important contributor for generating patient cohort selections with greater patient similarity and assisting with patient provider communications. Patient cohort selection may also lead to improved patient understanding and more desirable treatment options for patients. This study serves as an important precursor and evidence base for analyzing our broader hypothesis.

The goals of this study are to explore patient preferences as human factors in HRSs; then design, build, and test a mobile app that collects and reports baseline patient preferences and health status across orthopaedic outcomes to the provider for use in patient care; and assess implications for HRSs in orthopaedic care. A core component of the app is a *Direct-Weighting* (DW) preference assessment approach, originated from prior research, and applied in a touchscreen based interactive design. It is envisioned that patients will use the app prior to their first visit to an orthopaedic surgeon for a new orthopaedic condition or injury. DW approaches calculate patient-specific preference weights across outcomes by asking patients to disperse portions of a hypothetical “whole” across outcomes in a manner that reflects a patient's preferences (42). DW has low respondent burden but it requires respondents to make “implicit” comparisons which may be difficult to conceptualize (42). The DW approach has become generally accepted in the quality-of-life literature and it has been shown that patients dividing up pieces of a “pie” across quality-of-life domains yields valid representations of patient preferences across the domains (42–44). However, the DW approach has not been validated with specific clinical scenarios using a clinically focused set of outcomes or by using an interactive user experience embodied in a mobile software app. Drawing on prior research, we iteratively design and develop the app with input from prior DW research, informaticians, and clinicians and test the app with patients.

The rest of the paper is organized as follows: In the methods we describe the design, development, and user evaluation of the

preference app. Then we describe the thematic analysis results of the qualitative interview data, patient preference results, and results from a usability survey. In the discussion section, we connect the research objective to results and derive the need and impact of patient preferences as human factors for generating better treatment decisions.

2. Methods

We use a multi-method research approach to design, build, and evaluate a patient preference collection app with 23 first-time visit patients presenting with joint pain and/or function deficiency. We first identified five patient preference outcome domains that were the result of primary research by the research team. We first conceived of a list of potential patient preference outcome domains through a concept consensus building process via discussions with three orthopaedic surgeons and two physical therapists at one orthopaedic center in the Southeastern US. Three health services researchers also participated. The process resulted in the group agreeing on five preference domain areas. The research team then sought to validate the domains with patients in this pilot study. The preferences address possible outcomes, or those things that are important to a patient that she may want to communicate to her doctor regarding the impacts of orthopaedic treatment on her life. The items include asking the patient the following: “When considering treatment, it is important to me that the treatment I choose...”

- Q1. Reduces my long-term pain after treatment,
- Q2. Improves my function and ability to engage in my regular activities,
- Q3. Limits my out-of-pocket treatment costs,
- Q4. Minimizes the time required for treatment and rehabilitation,
- Q5. Limits the pain and discomfort I feel during treatment.

We incorporated these five question domains into the design of an android application to be presented to new patients in a regional orthopaedic clinic and research center. We applied a DW interaction method designed using input and feedback from orthopaedic researchers, surgeons, and experience design researchers.

We designed a mixed-method evaluation to study patient preferences using the DW approach, in which patients were asked to A. use the patient preference app, B. participate in a 30-minute interview, and C. complete a usability survey. Details of the employed methods are described below.

2.1. Patient preference app

We designed a prototype of an interactive mobile application containing a patient preferences direct weighting (DW) survey and preference visualization features (see [Figure 1](#)).

Screen 1 allows the test subject to be identified as an anonymous participant of the study. Screen 2 explains the DW

task to the user. Screens 3 and 4 illustrate the user’s direct weighting interaction. We utilized the previously identified patient preferences and adopted a 100-point bucket weighting design in which the patients were required to distribute and assign a total of 100 points into five treatment preferences. Patients were not able to assign more or less than 100 points across domains (Screen 4). Screen 5 is a pie-chart visual confirmation of the assigned weights and screen 6 is a confirmation of preference survey completion.

2.2. Evaluation setting

The research setting for this study was a large orthopaedic clinic in the Southern U.S. affiliated with a large integrated medical system. We adopted a purposive, criterion sampling strategy where we contacted every new orthopedic patient at the clinic to obtain a heterogeneous sample. A research coordinator contacted 100 new patients to invite them to participate in the study. Inclusion criteria included all new patients or patients visiting the clinic for new orthopaedic conditions in the age range of 18–80 years, with one or more of the following orthopedic conditions: shoulder, hip, elbow, knee, foot, hand, back and neck. Sampling occurred until qualitative data saturation was achieved. Twenty-nine (29) patients agreed to participate, with six (6) canceling prior to the interview, resulting in 23 total patients who participated in the app evaluation. Demographics of those patients who were contacted and participated in the evaluation are shown in [Table 1](#).

Three researchers: BS, AS and JB, all of whom are qualified health IT and health economist research experts, conducted the interviews. The evaluation was conducted 30 min prior to the regular patient check-in time of each participants’ orthopaedic appointment.

2.3. Data collection

Data was collected in three parts. First, in an in-person setting while sitting across a table from the interviewer, each participant was handed an Android device and used the prototype mobile app to input their treatment preferences using the DW method incorporated into the app. Participants awarded a total of 100 points spread across preference outcome categories including: (1) “Reduces my long-term pain after treatment”, (2) “Improves my function and ability to engage in my regular activities”, (3) “Limits my out of pocket treatment costs”, (4) “Minimize the time required for treatment and rehabilitation” and, (5) “Limits the pain and discomfort I feel during the treatment”. Next, they were asked a series of questions during a qualitative interview on their perceptions of the app and the direct weighting approach. Finally, participants were asked to complete a survey containing two sections: I. A 6-item section of a custom survey instrument on app usability, patient-provider communication, patient’s intention to use the app in the future, and perceptions about the treatment preference outcome domains represented in the app.

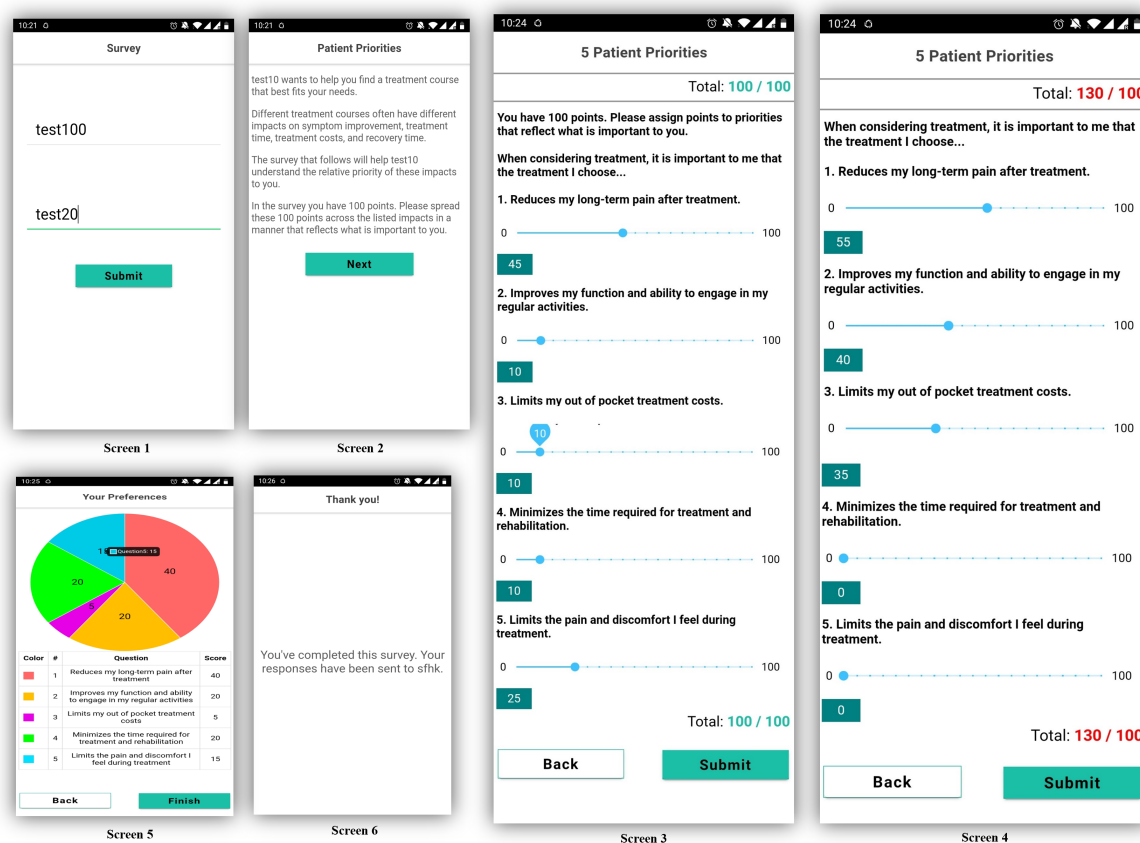


FIGURE 1
Patient preference app.

The survey was designed using an implicit 4 point Likert scale where we asked users to mark between strongly agree and strongly disagree [4 = Strongly Agree, 3 = Somewhat Agree, 2 = Somewhat Disagree and 1 = Strongly Disagree]. II. A validated instrument for mobile apps, “mHealth app usability questionnaire” (MAUQ) (45) survey section containing 18-items on ease of use, usefulness and interface satisfaction. The

TABLE 1 Participants' demographics.

	Called	Interviewed
Total	100	23
Gender		
Female	55	17
Male	45	6
Age		
Average Age	53	57
18–30 Years	9	1
31–40 Years	15	2
41–50 Years	12	4
51–60 Years	27	3
61–70 Years	31	10
71–80 Years	6	3
80 Plus Years	0	0

Bolded numbers represent total number of patients called and total number of patients who were interviewed, respectively.

section was based on a 7-point Likert scale (1 = Strongly Agree, 7 = Strongly Disagree). Please see Appendix A for a draft of the complete interview guide.

The semi-structured qualitative interviews touched on several aspects of patient choices and preferences as embodied in a mobile app. We asked participants questions about their perceptions of their treatment processes, as well as perceptions on the utility of the patient preference app for communicating with their provider. Example questions included:

- Please describe your general feelings about using the app.
- How do the preferences listed in the app capture the concerns that are important to you in the treatment of your condition?
- What others would you include in this list?
- What challenges do you see using this app?
- What benefits do you see using this app?
- How do you think this app (and your information that it is collecting) could be used as a part of your care?
- What suggestions do you have for improving the app?
- How has this experience affected the way you think and feel about your condition?

Questions were asked in a conversational manner to elicit deeper discussion from participants and drill down on additional topics of interest. Interviews were recorded digitally for later transcription.

All patients consented to participate prior to the study as well as in the interview. Other data collected during the interview included: date and time of interview, participant age range, gender. Interviews were audio recorded and then transcribed using pseudonyms in place of identifying information (e.g., patient name) using the format: XXN, where XX represents the interviewer code and N represents the number for each interviewer. No other patient identifiers were collected in the interviews. Each patient participant was provided with a \$30 gift card as an incentive for their time and participation.

2.4. Data analysis

The data from in-app patient preferences was analyzed for average weights, std. deviation, maximum and minimum weight for each preference as well as maximum variation across all cases. The survey responses were analyzed for mean scores for each of the six evaluation constructs.

Qualitative thematic analysis of the interview transcripts was conducted by using a peer analysis methodology in NVivo software. For this, two researchers independently conducted an inductive analysis of data to create preliminary codebooks and reconciled these codebooks to summarize emergent themes.

We used grounded theory (Figure 2) hypotheses to guide our analysis. The hypotheses include A. Allowing patients to express their treatment outcome preferences using a DW collection technique prior to their first visit for an orthopaedic condition induces and increases clarity of thought about the treatment outcomes they wish to achieve., B. The treatment outcome domain identified in our primary research presents the optimal set of patient preferences for their treatment outcomes., and lastly, C. Collection of patient’s treatment outcomes preference improves the patient-provider communication, shared decision making and patient

satisfaction on treatment decisions. We developed our interview guide based on these hypotheses and utilized this theoretical framework to guide the thematic analysis of the interview data.

3. Results

3.1. Patient preference weights

All 23 patients that participated in the study entered their personal patient preferences into the app during their in-person visit with researchers. Table 2 presents the results of their selected patient preferences as reported in the app. The most frequently weighted category was long-term mobility improvement ($M = 33.6$) followed by long term pain reduction ($M = 28.3$), limiting treatment pain/discomfort ($M = 14.7$), limiting time for treatment and rehabilitation (12.5), and limiting costs (10.8). In order to assess heterogeneity in preferences, we analyzed the extreme scoring for each question. The maximum weight that was given to each question by participants was—Q1: 45, Q2: 70, Q3: 50, Q4: 30 and Q5: 45. The minimum weight that was given to each preference was—Q1: 5, Q2: 0, Q3: 0, Q4: 0 and Q5: 0. Results demonstrate that all five core preference domains were utilized, with many users ($n = 6$) dividing their 100-point allocation across 1–3 domains. A patient attributing preference scores across all 5 preferences or setting scores close to the average was rare.

3.2. User experience and MAUQ survey results

Questions S1-S18 represent MAUQ portion in Table 3, whereas Q1-Q6 are general questions regarding the DW exercise in Preference App.

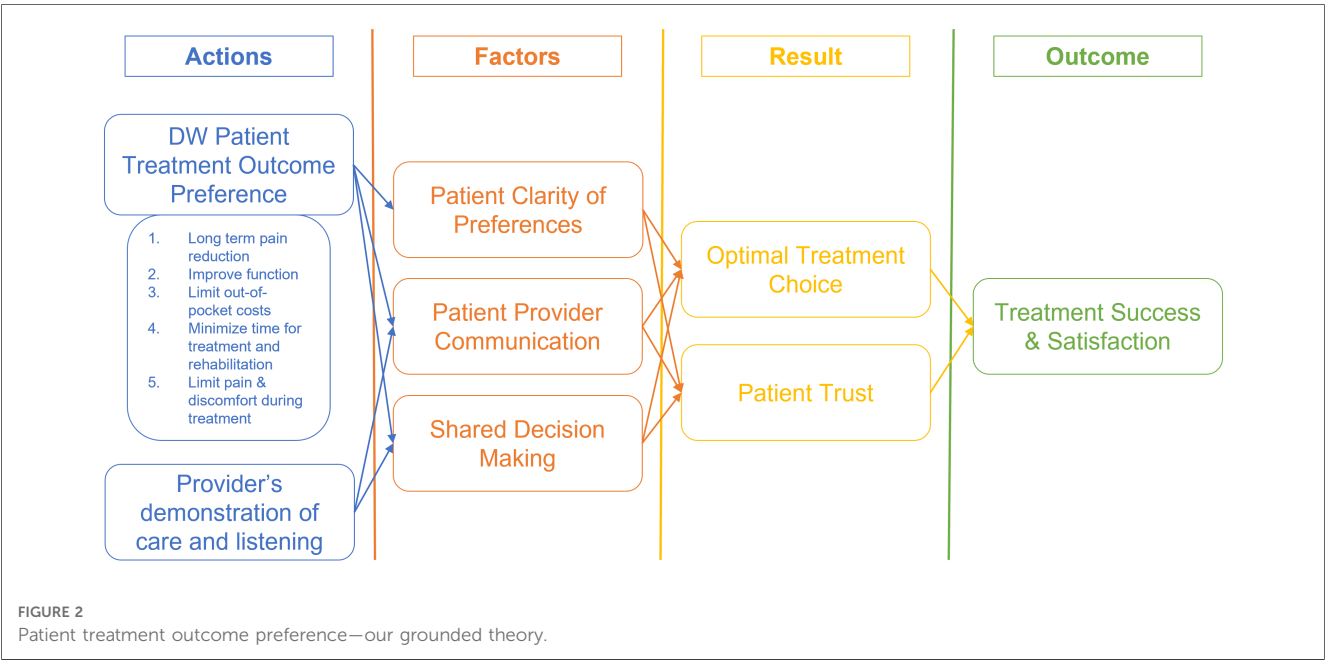


TABLE 2 Patient preference direct weighting survey results.

	Q1	Q2	Q3	Q4	Q5
Mean weights	28.47826087	32.60869565	12.17391304	12.3913	14.34783
Standard deviation	11.22444396	17.76549037	11.56268361	9.637706	9.920634
Max weight	45	70	50	30	45
Min weight	5	0	0	0	0
Patient closest to mean	30	30	15	10	15
Extreme cases	45	0	10	0	45
	5	70	10	5	10
	10	10	50	20	10
	25	25	10	30	10
	45	0	10	0	45

Results from the MAUQ survey showed overall positive results and the tool received moderate to high usability scores, patient participants agreed the most with “I feel comfortable using this app in social settings.” ($M = 1.6$, $SD = 0.88$), “The amount of time involved in using this app has been fitting for me.” ($M = 1.6$, $SD = 1.39$), “I would use this app again.” ($M = 1.7$, $SD = 1.69$), “The app was easy to use.” ($M = 1.65$, $SD = 0.78$), “It was easy for me to learn to use the app.” ($M = 1.6$, $SD = 1.16$), “The interface of the app allowed me to use all the functions (such as entering information, responding to reminders, viewing information) offered by the app.” ($M = 1.6$, $SD = 0.81$), “I could use the app even when the Internet connection was poor or not available.” ($M = 1.6$, $SD = 1.27$).

For general questions regarding the DW exercise in Preference App, patient participants agreed the most with “This exercise was easy to complete.” ($M = 1.15$, $SD = 0.39$), and “The directions were easy to understand.” ($M = 1.25$, $SD = 0.44$). They moderately agreed with “After reading the directions, I felt like I knew what to do.” ($M = 1.3$, $SD = 0.47$), “The list of concerns captured the important things to consider in selecting a treatment.” ($M = 1.35$, $SD = 0.59$), “The answers to this exercise will help me to talk with my doctors about my condition.” ($M = 1.3$, $SD = 0.57$) and “I would be willing to do a similar exercise (Where I assign points to different treatment factors) for other health issues, so that I can discuss treatment choices with my doctor.” ($M = 1.4$, $SD = 0.75$).

3.3. Thematic analysis of qualitative interviews

The usability questionnaire helped researchers understand the extent to which the preference domain questions, preference domain interactive features; and the app were usable, useful, and helpful for the participant. Interviews were conducted to assess a deeper understanding about the utility of using the patient preference app and its implications on patient care. Inductive, thematic, qualitative analysis resulted in finding several salient themes pertaining to benefits, challenges, and impacts of the patient preference app and associated impacts on the design of health recommender systems. These themes include: 1. Patient clarity in determining treatment preferences; 2. Patient

preferences as human factors for informing treatment options; 3. Understanding and trust in patient provider communication and shared decision making; 4. Usability and methods to improve usability of patient preference apps. In terms of overall results, patients described a positive response to the patient preference app. Patient responses served to sustain our hypothesis that patient preference communication is important for managing patient expectations of treatment. Themes discussed below include how the app facilitated patient preference communication and played a clarifying role for understanding treatment priorities for both patients and providers alike; enhanced communication and documentation of these priorities with providers, caregivers and other stakeholders; served as a self-evaluating medium for determining patient treatment success and satisfaction based on achievement of treatment priorities during the treatment process; and facilitated trust and a positive healthcare experience. Focusing on our theoretical understanding of the orthopedic treatment process, we arranged the responses into various themes below.

3.3.1. Patient clarity in determining treatment preferences

The app was reported to help patients think about how they prioritize preferences and how they would like treatment options to be personalized. Participants noted that treatment efficiency and success are related to the ability to communicate treatment expectations of the patient to the provider and the patient preference app facilitated an important precursor: patient understanding. The patient preference app was generally perceived to provide clarity in patients’ minds about their preferences as well as preparing them for their meeting with the provider. One patient noted, “*This is an important meeting for the patient, and so being prepared for it means you’re going to get the most out of it, and you’re not going to do that, ‘Oh my God, I can’t believe I forgot to ask him that.’ Which is what I often do.*” Another patient said, “*I may have thought about them [preferences], but I probably wouldn’t have said anything about them [preferences] unless the doctor actually asks you, where do you mind?*” One patient explicitly noted the intimidation felt when meeting and talking with a new provider, “*Well, it makes me think, ‘what am I going to say to him?’ Because I’ve never met*

TABLE 3 User experience (Q1-Q6) and MAUQ (S1-S18) results.

Question		Mean scores	Standard deviation
Q1 (1-4)	This exercise was easy to complete.	1.15	0.387553
Q2 (1-4)	The directions were easy to understand.	1.25	0.444262
Q3 (1-4)	After reading the directions, I felt like I knew what to do.	1.3	0.470162
Q4 (1-4)	The answers to this exercise will help me to talk with my doctor about my condition.	1.35	0.587143
Q5 (1-4)	This list of concerns captured the important things to consider in selecting a treatment.	1.3	0.571241
Q6 (1-4)	I would be willing to do a similar exercise (Where I assign points to different treatment factors) for other health issues, so that I can discuss treatment choices with my doctor.	1.4	0.753937
S6 (1-7)	I like the interface of the app.	2.25	1.650359
S7 (1-7)	The information in the app was well organized, so I could easily find the information I needed.	1.947368	0.97032
S8 (1-7)	The app adequately acknowledged and provided information to let me know the progress of my action.	1.85	1.182103
S9 (1-7)	I feel comfortable using this app in social settings.	1.6	0.88258
S10 (1-7)	The amount of time involved in using this app has been fitting for me.	1.6	1.391705
S11 (1-7)	I would use this app again.	1.7	1.688974
S12 (1-7)	Overall, I am satisfied with this app.	2	1.718304
S1 (1-7)	The app was easy to use.	1.65	0.782718
S2 (1-7)	It was easy for me to learn to use the app.	1.6	1.166055
S3 (1-7)	The navigation was consistent when moving between screens.	1.85	1.083473
S4 (1-7)	The interface of the app allowed me to use all the functions (such as entering information, responding to reminders, viewing information) offered by the app.	1.6	0.810643
S5 (1-7)	Whenever I made a mistake using the app, I could recover easily and quickly.	1.842105	1.332251
S13 (1-7)	The app would be useful for my health and well-being.	1.8	1.321755
S14 (1-7)	The app improved my access to health care services.	1.85	1.423962
S15 (1-7)	The app helped me manage my health effectively.	1.95	1.460954
S16 (1-7)	This app has all the functions and capabilities I expected it to have.	1.95	1.390288
S17 (1-7)	I could use the app even when the Internet connection was poor or not available.	1.6	1.274561
S18 (1-7)	This mHealth app provided an acceptable way to receive health care services, such as accessing educational materials, tracking my own activities, and performing self-assessment.	2.1	1.735796

him before. Am I going to be intimidated and not want to talk to him?" This patient felt that the preference information helped overcome that intimidation. Another patient noted the need for

effective communication channels between providers and new patients. "If you don't have that relationship with a doctor, that would be very beneficial to be able to communicate with him what your expectations are." said the patient continued, "It's [the preference app that's] going to prepare me a little bit more, to take a little more time to think about my answer instead of... I've never met him. So I don't know if he's one of those fire off questions or if he sits and asks, listens and asks you questions. So I'm going to take more time to answer or to think about my answer before I respond." The use of the patient preference app helped participants think more explicitly and prepare their minds about the preference responses they would give when asked by the provider.

Some patients assume that while discussing treatment options, the provider would only focus on better orthopaedic function and not the other preferences. One noted, "But I would suspect that along to improve my function ability, to engage in my regular activities, I'm guessing that in that consideration of treatment, that's going to be what he's going to bring to the table when it comes to my options for whether it's surgery or PT or injections." That same patient then expressed that the app helped inform her/him about his/her additional choices of preferences.

Another set of participant responses addressed the challenges with managing patient expectations and the benefits of the app for helping to do so. One participant described how the app provided a method to begin thinking about his/her expectations: "It gives them a starting point," she said. When asked about how the app helped them think about prioritizing their expectations, one participant noted: "Well, I mean, of course, it challenged me to prioritize and think about some things. It reinforced what my desire is, which is to improve my function and ability to engage in what I do." Another said, "... it helps me feel more directive, if you will. Of directing where I want the journey to go." The question of what a patient wants out of their treatment was an important one for several respondents. One noted, "... it makes me actually step back and be like okay, do I actually just want to have hardcore painful treatment and then be good for the rest of my life? Or do I want it to be a little bit more flowy? No, it definitely does spark a lot of: "Oh, what do I even want" It's really awesome." Another participant discussed how the app helps her self-reflect and ask clarifying questions to hone in on her treatment expectations stating, "It kind of gives me better ideas of what to expect and what kind of treatment I will get and all, that would be the main thing." Another stated, "I think that [it] really gets your brain moving and I think it gets your wheels turning and yeah, I think it's good like it is."

Some patients focused on better function as their major preferred outcome, "One of the reasons I want physical therapy is I will put up with anything to try and get better function here. I'll put up with anything as long as I can get to the end." Participants discussed how having clarity in preference priorities helps in developing explicit expectations for their treatment to be customized to their needs. As one patient described, "I think it'd definitely be super beneficial to show what you prioritize as opposed to... like some people might have crazy good health insurance, but I don't. So I said limiting my out of pocket

treatment cost because that's super important to me. And then being able to just share what actually matters the most, so that it can be a customized treatment for each person. So I think it's super beneficial to see each thing listed, like it's important. And then we get to decide what's most important to us."

Another patient emphasized the ability of the app to persuade them to evaluate tradeoffs between different available preferences, again to think about customized or personalized treatment. "So, you made me evaluate if having pain during the treatment was more valuable than getting rid of the pain long-term and things like that," she said. She continued, "So, making me have to deal with, again, giving the weightiness to the priorities." Another patient noted the tradeoffs, or the function of the app to think through tradeoffs, "Because what it made me do is it forced me to say, 'Well, the cost is not going to be as important as me getting the pain', but still, cost is important from a standpoint of getting the value". Another noted, "I'm less concerned about what the out-of-pocket treatment is. Everybody might not be in that position". Participants noted how the app assisted them to prioritize long-term vs. short-term pain options in a way that effectively communicates their goals. Explaining this, one patient said, "I think it makes me... at least going through each of these makes me want to hone in on them with him [the doctor] and talk about it. How much longer do I have? You know? And what does long term look like?"

All in all, the majority of participants commented on how the app provided a tool and method for thinking, or re-thinking priorities in a way to discuss those treatment preferences that are important to the patient. Such thinking brought personal clarity in terms of desired treatment preferences.

3.3.2. Patient preferences are important human factors for informing treatment options

Participants felt that patient preferences as represented in the mobile app provided a good representation for those things that are important to them. Further, they felt that those preferences are important inputs for determining treatment options. They wanted the ability to visually correlate tradeoffs between all possible treatment options and respective patient preferences. Speaking to the importance of a patient preference acting as a valid data point, one patient said, "Okay, this is my option based on the data, this is the best option. And the doctor is not just basing it on their own experience, but on the experience of the collective data. Yeah. Statistics." Similarly, one participant discussed the importance of being able to retrieve his preference profile data from the app database at any time to review and reassess, "it's very beneficial for me... ..To be able to access all my information like that."

Participants discussed their appreciation for the ability to set, view, change and communicate preferences across time. One said, "to be able to look back and see what your preferences were at different points in time with the doctor could also be of value." Referring to the same functionality, another patient affirmed wanting to review and possibly change preferences in the future. She said, "Yes [I would review or change my preferences in the future], but I think it would be after, after my first visit, because

sometimes you go and you think, okay, they gave me all this information, but I didn't ask if am I going to have a lot of stitches? Am I going to... I'm allergic to nickel, so they can't use staples. They have to use glue or they have to use sutures. Those things would probably come after I would have these...I would have questions after I had time to process some of the information I had."

Patients noted that treatment efficiency can be achieved by better understanding the goals of the treatment and how those goals can be met during the treatment. One participant stated, "I like to understand why and what they're [the doctors] going to do. That's really important to me. When I'm finished with this process, I want to know, or when I see my doctor, I want to know what his plan is? What should I expect from that plan? Yeah. That's about it. And what's he going to do?" In this regard, patients related how keeping track of treatment options and choices can help patient understanding and treatment efficiency.

Many patients appreciated the completeness of the preference choices domain in the app with positive statements. Participants found the list of five outcome domains adequate, sufficient and complete to convey their priorities associated with choosing a treatment. For example, one participant said, "Function, pain, cost, time and discomfort. Yeah, those are the big ones that hit me off the top of my head." The list of outcome domains were said to have been specific enough to be distinctly different from one another and well understood. In addition, the use of the app survey instrument helped patients to get understanding and clarity about their priorities associated with treatment choice. As noted by another participant, "... These [categories] actually, when I first looked at it, I was like, oh God, I've got to rate these, and they're going to be so close and similar that it's going to be hard to rate them. But actually, these were very specific." Overall, participants found the list of outcome domains to be complete. Some participants also expressed the need to have a discussion with their doctor about the treatment tradeoffs that would help them accomplish the best mix between their multiple preferences, and also, mechanisms to measure treatment success against the preference indications made in the app.

When asked about suggestions to add to the list of preferences, few patients noted the less frequent provider visits and less average number of provider visits required for the treatment as their preference. "I can't think of anything, no. Maybe even limit my actual doctor visits, but that kind of ties into that. Or limits the time in between my visits, because this is months and months that I had to wait in between each visit with my PA and my surgeon, was seven weeks later. So I would say the quickness of my treatment would be a good one. Like the speed through which I finish it all."

One patient noted the need for the ability to indicate a preference for maximum value treatment, if they are provided similar treatment choices. "If I had to think of one thing, I would say the biggest bang for the buck. So what treatment is going to maximize in the minimum?" They continued, "Time and cost. That's going to allow me to re-engage at my normal level of activity. What's going to give me the max for the minimum? So what is the max I need to put in? Do I need to go big upfront to

get the max? Or is it going to be incremental?" The patient concluded by summarizing their suggestion as finding the answer to the question: "Well, what's going to be that Delta? What's going to be that sweet spot?"

3.3.3. Understanding and trust in patient provider communication and shared decision making

The patient preference app in general enhanced patient's trust in the treatment, in the provider, and with the clinic. One participant said, "I think it enhances my view of the practice in general." Several other participants noted similar sentiment that the preference app provided a reassurance to them that the providers care about their concerns and want to understand their treatment priorities. This increased feeling of trust led patients to feel more confident in the treatment choices, shared decision making during the patient visit, and eventually treatment success and satisfaction.

Patients also noted that shared goal setting for the treatment increases with communication of patient preferences. "He should be able to say, 'It's going to be three months before you...' I had a knee replacement. I said to my doctor, 'When is the pain going to stop?' He said three months. It was to the day practically when he told me. I could do it. I just wanted to know when it was going to be over. That was the kind of stuff I wanted to know." Another patient notes, "Probably at that point, I want to know what he's going to do and what the outcomes should be. Farther along in the process I want to know about pain, I guess. But I think, I guess I can say when I had my knee replacement, he told me that we're going to do a nerve block and we're going to do this and this and this. And we've tried giving you... I mean, they've done some research and we want to try giving you Tylenol and big doses while you're here. Okay. And if that doesn't work, there's some other options. I guess just everything about the process. How many days will you be in the hospital? How many days will you not be in the hospital? How many times will I see you when I see you back."

The preference app was noted in aiding to bring patient and provider on the same page by bringing clarity in exchange of patient preferences and expectations with provider understanding of problem and treatment options. "I think it would be beneficial, again, like I said, to ensure the patient and the doctor are on the same plane as far as, if you're having a surgery, your pre-care and your after-care. Make sure you're on the same wavelength as far as what you're expecting." Another patient noted, "Somebody calls you up and asks you, so I think you can say, 'Hey, I've got this great app that you can use to make sure that you and the doctor are on the same wavelength.'"

Another key benefit noted by patients in terms of patient provider communication and shared decision making is the evaluation of efficiency based on the shared goal setting after communication of patient preferences. Patients noted that preference app helps in enabling them to evaluate how their personal treatment goals were communicated, understood and implemented into treatment, as well as the overall efficiency of chosen treatment as a measure of "treatment success" and "treatment satisfaction". A patient spoke about evaluating the

treatment after the point of preference communication "...from the standpoint of rating the doctor at the end. How did he do?" Another patient noted, "It's all written, but it's a good way to, again, grade your therapist, your therapy" One patient stated the ability to explicitly evaluate the provider and treatment in MyCharts and noted that preference app will add to streamlining the treatment evaluation, "Yes. I mean, I use it in, I put most of my stuff in MyChart. They send surveys and, I don't know whether it's MyChart related, but [the health system] sends a survey after every doctor visit. How did the doctor do, how are the nurses, receptionist, et cetera. And I think that's a good tool for any organization to gauge how their people are doing and also to come up with means and mechanisms to do better."

Participants noted the clarity and the enhancement the use of a preference app brings to their communication with their provider. Participants noted ease in communicating difficult topics such as money constraints, as a participant noted, "... then also, if it's in the app, then it's in the patient's mind too, to discuss even if the doc doesn't bring it up..." Participants also noted that the app brings about their most important concerns to the table such that the discussion with the provider during visit revolves around that concern, thus bringing more focused treatment options specific to their needs. A participant quoted "... and it eliminates the fear for them so that they can communicate. And then hopefully when they get there, the doctor is able to ease their stress and say, 'Oh, okay, let's look at your long-term pain treatment or so-and-so and so-and-so,' and they'll be like, 'Oh my. You're reading my mind. I feel so good about this. This appointment...' because a lot of people don't. They don't think their doctors care." Another said, "And so if it's available to the doctor before you get to the visit, they already know what you need." Participants also agreed that communicating their treatment preferences with their doctor is improved with the use of the app, saved time during the visit and helped them focus their communication with the providers.

Participants discussed the transient nature of patient-provider relations, relating the importance of having a record of communications to share with providers as patients move from one to another. One stated, "Because you know, you see somebody else, this guy retires and you see the next guy. Oh, what did they do? Well, they did this and they did that. And then they said that that was what they needed to do at that time. I don't know."

3.3.4. Usability and methods to improve usability of patient preference apps

The patient preference app was described by participants as easy to use and simple in its overall functionality. For example, when asked about difficulty using the app, one user stated, "No. Pretty easy. I mean, I've had two strokes this year, and I had no problem navigating it..." One patient noted the clarity brought on by the preference visualization at the end of the app survey explaining, "I liked the visualizations. I liked it because of the color. So, the color made it clear for me. It let me see physically what my choices are."

Several patients likewise noted how the chart formatted visualization helped them to “clearly reaffirm responses before sending” to their providers. Patients also noted positively the ability to modify their responses at the final step before submission, which could be accomplished as many times as needed until visually satisfied with their direct weighting assignments.

Patients also discussed ways that the app could provide a more usable experience. Some patients noted the need to link it to EHR software utilized during the scheduling of the appointment and subsequent treatment visit. For example, one patient noted, “I think the app itself was fairly simple and self-explanatory. Just I think the capability of it linking with MyChart [patient portal] or being able to cross link with other MyCharts would be very beneficial.” While usability was generally high, ease of use was reported to reduce with increased age.

The amount of time required to complete the preference app survey was pointed to as a valuable signifier for improving the usability of the app. There were mixed responses in this regard with some believing the process was efficient while others thought improvement could be made. As one participant noted, “I mean, that part of the thing, if there’s more to the app than just that, then that’s fine. I mean, it takes two or three minutes.” Most people were able to complete the app survey in 2–5 min, however, there were exceptions as well where participants struggled with calculating the total weights on the fly.

In this regard, several patients discussed the usability of the direct weighting mechanism used in the app. One noted that some instructions might have been beneficial for understanding how to complete the app survey. Another patient expressed difficulty in following the instructions and suggested a more engaging strategy by dividing the instructions into multiple screens, so that the information on each screen is reduced.

A few patients noted the familiarity of using a Likert style scale over the DW technique used in the app, one noting, “Most of the surveys I’ve ever taken, you answered them with a one, 1 to 5 or 1 to 10 in response in terms of how important they were.” A different patient described how the expression of emotion as potentially more important than numerically assigning weights to preferences. The patient stated, “As them even being able to... maybe rating and ranking it from red being pain, to green, being not as much pain. Being able to use colors, to tell the intensity of the pain. Be able to express what’s going on, what they’re feeling. Yes. Versus it just being assigned numerically for them.”

Participants discussed challenges and benefits of the interactive DW approach. In general, patients discussed that the use of the 100-point constraint in the DW mechanism felt unfamiliar for a survey-based instrument, though the DW scoring also served its purpose to help patients compare and contrast different preference types and bring clarity to their thoughts about their preferences. One patient discussed her thought process while trying to figure out how to distribute points across categories, “...because I read all five [preference domains] first, and then I went and said, okay, if I had to rate this, I’m going to put this as 60, because this is the most important to me. But then I knew that I was going to have to start altering that what was most

important to me down and use my points to then kind of discern what was my least important and what was my most important, and then determine how that fit into the whole graph.” This patient’s summary sentiment was that his thought process assigning direct weights made for a more accurate and personalized score. Other patients noted that the self-evaluation inherent in the app was helpful, with one explaining, “So you made me evaluate if having pain during the treatment was more valuable than getting rid of the pain long-term and things like that. So making me have to deal with, again, giving the weightiness to the priorities.” Another patient thought the use of the app helped her bring stark clarity in her preferences and noted no need to modify the design of the app as it was very clear to her noting, “I think that really gets your brain moving and I think it gets your wheels turning and yeah, I think it’s good like it is.”

In general, patients found the DW mechanism to be thought provoking yet also required more effort than expected while applying math “on the fly.” Some older age participants found the DW approach more difficult in terms of allocating and totalling 100 points across 5 domains, as well as feeling less familiarity with the technology. Overall, a few patients noted the need to reduce the DW complexity in the app.

One patient stated, “I think the numbers... I got confused counting it all up. Does this fill in and then you fill in the rest or is it each one is its own?” Another patient noted, “If you’re considering an older person, I’m older, an older person, then you don’t want to have the person having to do the additions.” On the other hand, a younger patient expressed the need for a higher total score so that she could be more specific in her assignment of weights to preferences stating, “I didn’t find any challenges using the app, no. I would have liked to have more bandwidth, have more bandwidth for the communication. All I had was 100, so I may have wanted to have maybe double that or something like that so I could have been more specific with my responses.”

Suggestions for DW interface interaction improvement included instantiation of a token/points oriented DW preference scoring methodology where numbers could be directly input from the device number pad, rather than a 1–100 sliding scale approach. Participants noted that such a change could help improve preference weighting cognition and shared decision making with the provider.

On being asked about a possible solution, patients noted the need to modify the interface according to user’s age groups. One suggested, “So depending on the age group that you’re working with, you might have to make some adjustments. If you’re working with this app, let’s see, you had a way to say pick the age group and modify it according to the age group, 18 to 20, 40, 50, whatever and then you’ve made the modification and the 18 to 20 year olds shouldn’t be checking in that area where it’s 50 to 100 or 50 to 80 years, or whatever. You can make that modification.” Another patient suggested modifying the highest possible score with the DW technique according to the age group, “I think you need to reduce the numbers for the older [patients] and tell them to write it in if it’s more than 50 or more than 25, write it in.” And, “... [lowering the total number from 100] would help them

instead of them seeing that number in a hundred and getting that number stuck in their head, because you could say 25 is the highest you can go.”

Suggestions for interface improvement were also discussed to enhance usability and comprehension of the instructions on screen as some patients found some difficulty following the instructions provided on the app screen. One struggled with understanding the total weight limit noting, “*It wasn’t very clear that I couldn’t go over a 100.*” Another suggested simplifying the instructions and the wording of the preferences stating, “*I don’t know how to change it, but I feel like ... if you worded it ... a little less wordy, if that makes sense.*” One patient explained that they preferred prioritization of preferences over assigning weights to preferences, “*I think the prioritization is a better method.*” A few patients also noted assignment of coins or smiley faces or other such icons representing points across preferences might make the DW technique easier. One patient noted he would prefer filling in the weights directly in a text field instead of having to slide over within a specified limit. Some patients expressed the need to be able to modify responses at a later time in case they changed their minds about their preferences, with one responding, “*Just because I know I have to fill some stuff like this out for my physical therapy and sometimes I don’t think that way anymore and I wish I could go back, but I mean I can communicate that to them, but I wish I could go back and change it so that it looks different.*” Likewise, another patient noted, “*I would say only thing added is like the ability to change your answer. If you fill it out a week before, and then you were just in a ton of pain and you’re like, you know what, I do want to limit my pain, to be able to go back and change it.*” Furthermore, when asked about what other function patients might like to have in the app, some patients described the need to communicate with the provider through the app in preparation for their visit, with one explaining her reasoning, “*Well, if I need to take like a pain med before I come or certain things I need to put on like leg braces or arm braces or not put them all on things like that.*” These and other suggestions described less frequently by patients were recorded and prioritized for future consideration.

4. Discussion

There are several treatment outcome tradeoffs that could be made during the process of an orthopaedic treatment, and these have been presented in this paper. These options include reducing long-term pain after treatment, improving function and ability to engage in regular activities, limiting out of pocket treatment costs, minimizing the time required for treatment and rehabilitation, and limiting the pain and discomfort I feel during treatment. This app presented in this research has sought to bring some clarity to the patient in understanding these options through the design, development and testing process. Many patients want personalized treatment, vs. a standardized treatment that may or may not fit their needs, that considers personal health history and experiences with different providers and treatment outcome options. As a result, patients may want

their healthcare providers to communicate and enquire about those priorities during their visit. Providers also understand the importance of discussing priorities with their patients as being related closely with patient satisfaction. Due to limitations of time, lack of familiarity with a new provider, the pain and the discomfort caused by the patient’s orthopaedic condition and other such factors, patients may not prompt that opportunity. However, their expectation for a *successful* treatment innately includes their priorities. This may create a mismatch in the patient’s priority of preferences vs. the priority of preferences communicated to the provider. Participants in this study validated these concerns and issues and provided evidence as to the potential benefit of digital health means to help bridge a communications gap. Based on the study findings, the paragraphs below provide a discussion into five key areas that extrapolate on these concepts concerning our hypothesis that patient preferences are an important human factor for determining treatment options and suggests further the importance of facilitating patient-provider communications and shared treatment decision making.

4.1. Primary findings

The average mean scores for all survey questions leaned heavily towards *Agree* or *Somewhat Agree* indicating positive perspectives towards the app in terms of usability, acceptance, patient-provider communication, and completeness of treatment preference outcome domains. For the survey results, the highest scores (strongly agree) were selected for the question on the ease of use of the app procedure validating the simple and efficient design of the app from the patient’s perspective, indicating a positive acceptance of the app design. Lower scores were given to the question on interest in using a similar app for other healthcare conditions, indicating some agreement that the utility of the DW interaction is valuable enough to use more broadly, including the need to integrate the DW preference app into the EHRs. Qualitative interview analysis confirmed these results and are further discussed below.

4.1.1. Clarity in determining patient preferences

Among the many benefits of inciting a discussion about patient treatment outcome preferences, this study serves to validate the notion that the patient preference app as currently designed may help promote clarity about patient outcome preferences for patients. Based on the thematic analysis and results from interaction with patients, we note that the app demonstrated usefulness in causing patients to think about how they prioritize their treatment preferences and how they would like treatment options to be personalized. This thought process may further help patients to manage their expectations regarding their treatment. This may be especially important in a world where an increasing number of patients have high expectations regarding their treatment and recovery (46–49). For the participants of this study, the app seemed to help patients understand treatment outcome tradeoffs and how their

preferences in this regard affect their treatment choices. While treatment and outcome tradeoffs may exist in healthcare (50), we also found that there are trade-offs to be made in the design of the direct weighting (DW) technique in the app to help provide clarity in the patient's mind regarding their treatment options, including perceptions about their preferences and potential outcomes. Benefits of DW include persuading the patient to think about their expectations and really understand their chosen treatment preference domain. The app also may assist in bringing clarity to patient provider discussion during a patient visit, though this has yet to be tested. In the limited amount of time spent during the patient visit, the clarity achieved regarding patient preferences may result in creating a shared understanding between patient and provider. The patient preference app may also help with a patient's goal setting for her own treatment and recovery and thus ultimately increase patient confidence in treatment decision making.

4.1.2. Patient preferences are important human factors for informing treatment options

Human factors reference human emotions, behaviors, and cognitions related to the design, adoption, usage, and implementation of health technologies (51). Through this study we posit the need to include patient preferences as human factors for informing treatment options and create processes and technologies that facilitate this notion. Patient preferences provide invaluable social determinants of healthcare as individual preferences reflect personal sentiment and goal making—powerful constructs for determining positive health outcomes (46, 52, 53). Technologies that can accurately collect, communicate, and analyze patient preferences provide an important contribution to the informatics literature (54).

This study helped validate the completeness of outcome preference domains for orthopaedic treatment. Findings may also be useful for extending the use of these preference domains into other health specialties, perhaps with the most logical extension being other types of surgeries. In terms of the orthopaedic patient outcome preferences captured in the DW app, the mix of weights assigned by each patient differed across all patients indicating that a high degree of preference variation exists across patients. We concluded that participants demonstrated having a distinct combination of treatment priorities that was adequately captured across the five domain options. Pain alleviation, for both during the treatment and in the long-term, was the most heavily weighted preference across all patients. However, cost of treatment and time taken during treatment were also found to be important to many patients. The participants in this study demonstrated concern about their personalized needs as indicated by the heterogeneity of DW responses across preferences, suggesting the need for a tool such as this to capture and communicate such specificity to physicians. The patients also indicated a need to connect their preferences with treatment options, which further validates the need for collecting and analyzing preferences to facilitate relative decision making.

4.1.3. Patient provider communication for shared decision making and personalized treatment options

Findings from this study indicated that the preference app may help develop patients' trust in the healthcare facility, in the quality of service provided, as well as in the provider's understanding of their condition and treatment expectations. These are particularly useful findings for a few reasons. First, common healthcare quality measures include patient satisfaction. Increased patient trust may translate into more satisfied patients, an important goal for healthcare organizations (55, 56). Second, treatment goal setting is an important function during a patient visit and study findings indicate that the preference app may facilitate this process by conveying the preferences of the patient and contributing to shared decision-making. The enhanced patient clarity about personal preferences could be communicated in advance to the provider—at least that is the intention of this app.

This process, from the perspective of patients, could serve to enable communication during the patient visit to be directed towards setting treatment goals and plans, rather than spending valuable time discussing patient preferences. Indeed, participants noted the potential for the preference app to bring the patient and the provider to a common understanding about the patient's needs, enabling shared decision making.

4.1.4. Usability and methods to improve usability of patient preference apps

This study evaluated aspects of usability for the preference app as well as identified methods to enhance the interface to improve usability for various age groups and varied user requirements. One notable suggestion from participants was to improve the app instructions by breaking them into multiple pages, or to introduce an audio component to talk through the instructions to achieve a reduction in the instruction per page ratio. Patients also noted the need to enhance the app to consider the time needed to complete the preference survey. While these suggestions refer to the time and ability of the user to understand their desired preferences and assign representative weights, it also induces a thought process in the patient's mind regarding their preferences for treatment. Some patients expressed a need to go back and change their preferences as they were not satisfied with their responses made in the first attempt. This need further elongates the time taken to use the app and to indicate preferences. We consider this *time efficiency vs. user contemplation* as a valuable user experience design tradeoff allowing patients to arrive at a point of intellectual clarity regarding their preferences. Patients in this study who were already predetermined about their treatment preferences expressed an ability to finish using the app quicker than patients who needed time to think about their preferences, which further establishes the ability of the app to help bring clarity to patients about their outcome preferences.

Another tradeoff to consider in the user experience design is balancing clarity in patient preferences with the potential difficulty in assigning weights with the DW mechanism. While

many patients found it easy to specify the weights to the preference domains, some indicated a preference towards different methods, such as stack prioritizing the five preference boxes, directly inputting numbers, or assigning weights in the form of coins or other relatable icon (e.g., smiley faces) instead of numbers. Some patients found the numbers to be an intuitive method to assign weights while others indicated that numbers made them engage more and do more mental work to assign correct weights to their perceived preferences. While prioritization may be another useful way to express the priorities in preferences, we note that it is less specific than the DW technique utilized in the app, as it does not allow for two preferences to have the same priority. Many of these patients noted that the visualization at the end of the survey helped to evaluate their choices and understand their preferences. The ability to modify preferences was also appreciated by several patients.

Some reported difficulty adding up the domain totals when using the DW app survey as a result of age, or due to a lack of familiarity with the technique/technology. We concluded that modifying the DW score complexity might enhance the ease of use for older age groups. Integration of patient suggestions for alternative interface components may help to improve the user experience in future versions. Largely, patients found the app with DW technique to provide a simple and beneficial method for communicating patient preferences to their doctors, for building trust in the treatment process, and to participate in shared decision making with their providers. Patients validated the ease of use, sufficiency and completeness of the treatment preference outcome domains, highlighting that the preference app captures the most important patient priorities through the DW technique.

4.2. Implications for health recommender systems

The patient preference app provides a basic foundation for having the ability to set, view, change and communicate preferences across time and space for both patients and providers. When considering the design of recommender systems for healthcare (HRSs) (17), there is a need to correlate tradeoffs between options while also considering all possible treatment options. Participants in this study demonstrated that patient preferences are important for determining the most relevant and effective treatment options. Integration of these preferences into the design of HRSs may address the patient's personal needs and preferences in a more efficient manner that reduces patient-provider discussion time while also honing in on the most important factors for patients. Human factors built into HRS visualizations may also provide a means for presenting predictions on which data to present in the future to patients and providers for treatment options. Integrating patient preferences into the design of HRSs and treatment options may help influence the treatment choices and decisions which in turn brings patient understanding and satisfaction in these treatment decisions. This may further help in promoting treatment efficiency across time as well as accountability for the treatment goals set within the shared space of patients and providers.

We found the preference app also provides a potential framework for treatment efficiency evaluation. While this needs to be further explored in future studies, we believe that the patient preference outcome domains represented in the app provide key measures to evaluate fulfillment of patient treatment goals that associate with patient preferences. Inasmuch as patients and providers want to evaluate how treatment goals are communicated, understood, and implemented, as well as the overall effectiveness of a chosen treatment as a measure of "treatment success" and "treatment satisfaction", the preference app data may provide a framework for such evaluation. An HRS would require such an evaluation framework in order to provide information and predictive value to users. These measures may also relate closely to the value and importance of shared decision making and the ability to evaluate such. The app in this study provides a framework for the patient to visualize their preferences over time and correlate those preferences with the progress of their treatments over time, thus providing an evaluation of treatment outcomes while managing treatment expectations.

4.3. Limitations and future research directions

This study is limited to one orthopaedic practice location in the state of South Carolina. The study was limited to 23 patients at this practice, making the purposeful convenience sampling somewhat limited due to the location constraint and the patients who on their own accord made appointments with the practice during the study period. Although our patient recruiter made significant efforts to achieve a representative sample, 23 patients overall cannot represent the entire population of new orthopaedic patients. Nonetheless, the sampling was effective for an early phase translational design, feasibility, and user study. A larger number of patients may provide more varied demographics and broader insights. We also suggest a larger study in the future for a more inclusive analysis of patients across different locations.

Furthermore, a broader study is also needed to study the correlations between the preference app as a social determinant of health, including human factors for treatment and treatment "success" measures such as patient satisfaction, patient understanding, shared decision making and treatment efficiency. The impact of designing preferences as human factors in HRSs for treatment options also needs to be studied further.

5. Conclusion

We conclude that patients found the DW patient preference application in this study to provide a simple and beneficial tool for communicating patient preferences with their providers, for building trust in their treatment and for participating in shared decision making with their providers. Patients validated the sufficiency and completeness of the five treatment preference outcome domains, highlighting that the preference app captures the most important priorities adequately as well as defining

human factors for the design of patient-centered decision support systems. Further, the patient preference domains, associated data collection, decision support capabilities, and communication and decision making value offered to patients and providers provides a foundation for designing AI oriented health recommender systems in the future.

As patient preferences become more integrated into the care process for patients across a broad spectrum of health conditions, these results provide evidence for a DW approach and interactive design for patients to communicate their treatment preferences to their providers, and further need for evaluation of this approach across healthcare domains and regions as a valuable component of patient-centered engagement and quality care.

Data availability statement

Unfortunately, post publication, approved IRB protocol dictates that we destroy the interview files. However, survey data can be made available upon request to the corresponding author/s.

Ethics statement

The studies involving human participants were reviewed and approved by Pro00108647 University of South Carolina IRB. The patients/participants provided their written informed consent to participate in this study.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work, and approved it for publication.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Usability and performance expectancy govern spine surgeons' use of a clinical decision support system for shared decision-making on the choice of treatment of common lumbar degenerative disorders

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Study design: Quantitative survey study is the study design.

Objectives: The study aims to develop a model for the factors that drive or impede the use of an artificial intelligence clinical decision support system (CDSS) called PROPOSE, which supports shared decision-making on the choice of treatment of ordinary spinal disorders.

Methods: A total of 62 spine surgeons were asked to complete a questionnaire regarding their behavioral intention to use the CDSS after being introduced to PROPOSE. The model behind the questionnaire was the Unified Theory of Acceptance and Use of Technology. Data were analyzed using partial least squares structural equation modeling.

Results: The degree of ease of use associated with the new technology (effort expectancy/usability) and the degree to which an individual believes that using a new technology will help them attain gains in job performance (performance expectancy) were the most important factors. Social influence and trust in the CDSS were other factors in the path model. r^2 for the model was 0.63, indicating that almost two-thirds of the variance in the model was explained. The only significant effect in the multigroup analyses of path differences between two subgroups was for PROPOSE use and social influence ($p = 0.01$).

Conclusion: Shared decision-making is essential to meet patient expectations in spine surgery. A trustworthy CDSS with ease of use and satisfactory predictive ability promoted by the leadership will stand the best chance of acceptance and bridging the communication gap between the surgeon and the patient.

KEYWORDS

CDSS, UTAUT, PLS-SEM, usability, performance expectancy

Introduction

Approximately 10,000 spinal surgeries are performed yearly in Denmark. Given that the patient-reported success rate for the outcome of spinal surgery 1 year postoperative is as low as 70–80%, there is room for improvement. Shared decision-making has been suggested to improve patient-reported outcomes of a given treatment (1, 2).

Shared decision-making is an approach where clinicians and patients share their knowledge, thoughts, preferences, and experiences about treatment before reaching a decision. While surgeons have a detailed knowledge about treatment options and the clinical evidence, uncertainties, benefits, and risks of each alternative, patients have in-depth information about their own everyday life, as well as their concerns, preferences, and goals when presented with the different options—the synthesis might very well be difficult (3).

Shared decision-making between the surgeon and the patient with a spinal disorder is often empirical and based on the surgeon's recent experience with a specific group of patients. However, it seldom encompasses all the unique characteristics of an individual patient. As a result, the decision to choose surgery may be severely biased. Even if we had absolute knowledge of all the variables influencing the outcome of spinal surgery for a particular patient, it might still be challenging to analyze and process these in the available time.

Predictive modeling using artificial intelligence (AI) and machine learning (ML) offers a solution for achieving more accurate predictive modeling of the outcome after spinal surgery. A search on prediction models and spine surgery yields 2,352 publications (PubMed), with a sharp increase in the number of publications from 2010 and onward.

We suggest that predictive modeling using AI or ML of the outcome of spinal surgery can aid in making the right treatment decision for a patient with spinal disorders. We have constructed a clinical decision support system (CDSS) named PROPOSE for that purpose. Based on patient-reported outcome measures (PROM), real-time predictions are generated for the outcome after surgery, including quality of life (EQ-5D, Oswestry Disability Index), back and leg pain, walking distance, return to work, and risk of complications.

However, several notable AI projects have failed. The most prominent was IBM Watson. In January 2022, the IBM Corporation sold Watson Health as it was not profitable (4). Benda et al. (5) pointed out that trust in AI is important and challenging, especially important with AI systems because explainability is low for these systems—the black box effect.

Several CDSS targeted at spine surgeons are available free of charge on the internet, e.g., Moulton et al. (6), Fritzell et al. (7), and Andersen et al. (8). However, the amount of actual use of these systems is probably very low in clinical practice. Almost no traffic was detected when measuring the traffic on the websites for the Dialogue Support System, in accordance with the literature on the subject (9).

The actual use of an information technology (IT) system depends on several factors; the two most fundamental are perceived usefulness/performance expectancy and perceived ease of use/effort expectancy (usability). Performance expectancy is “the degree to which an individual believes that using a new technology will help him or her to attain gains in job performance.” Effort expectancy is the “degree of ease of use associated with the new technology.” Social influence is also fundamental and is defined as “the degree to which an individual perceives the importance of how others believe that he or she should use the new technology.” The theoretical model used to describe the relationship between these factors (plus several

more) and the behavioral intention and actual use is the Unified Theory of Acceptance and Use of Technology (UTAUT), first reported by Venkatesh et al. (10). In 2003, they developed the UTAUT model as a combination of several previous models from a range of disciplines. The goal is to explain technology acceptance to users. The original model consisted of four constructs, namely, performance expectancy, effort expectancy, social influence, and facilitating conditions. In 2012, the model was extended, with the UTAUT2 model directed at using consumer technologies. This model added hedonic motivation, price value, and habit to the original model. In the current context, we do not think hedonic motivation, price value, and habit are significant. Instead, we have added the composite variables trust, perceived risk, and resistance bias, which we suggest are much more meaningful, especially in the medical context. For a brief overview of the development of UTAUT models and criticism and advantages of the different models, we advocate going to <https://acceptancelab.com/unified-theory-utaut>.

This study aims to develop a model for the factors that drive or impede the use of an AI CDSS called PROPOSE, which supports shared decision-making on the choice of treatment of ordinary spinal disorders.

Methods

A web-based survey was opened to all participants of the Danish Spine Surgery Society (DRKS) and the Danish Orthopedic Society subspecialty meeting in the autumn of 2021. The questionnaire was based on the UTAUT model and extensions of this model. However, a number of questions concerning some demographic variables were also included. The questionnaire was distributed through a link to SurveyMonkey. A short PowerPoint presentation on PROPOSE (six slides) was made available for the participants as part of the survey, describing the system and showing details of the graphical user interface. All predictive models used in PROPOSE were constructed in R and R Studio using multivariate adaptive regression splines analysis, utilizing the packages “earth” and “caret.” Predictive models were implemented in a Microsoft Windows application coded in C# using Excel VBA. Before the meetings, PROPOSE had been used in three spine centers in Denmark, and some of the participants had used PROPOSE for some time, mainly in trial testing. All questions were obligatory and could be answered in 6–7 min. The seven-point Likert scale was used (from completely disagree to completely agree). The PowerPoint presentation and the Danish SurveyMonkey questionnaire are available as **Supplementary Material**. **Figure 1** shows an example of the user interface. Data were exported as an Excel file (available as a **Supplementary Material**) and later imported into R study (the R code available as a **Supplementary Material**) for further analyses. Data were analyzed using partial least squares structural equation modeling (PLS-SEM). The minimum number of participants was calculated using the inverse square root method (11). The PLS-SEM approach usually requires fewer participants and can handle non-normal data and composite variables (composite variables are essential in this study). Based on

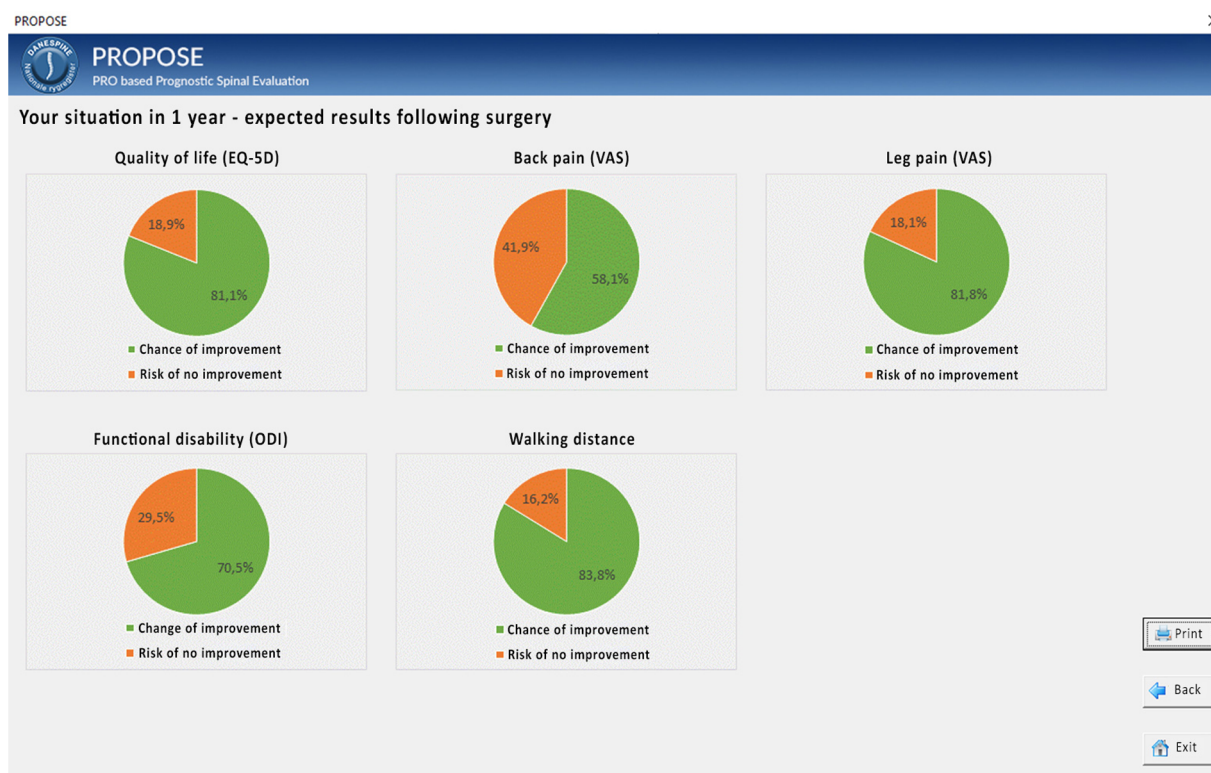


FIGURE 1
PROPOSE example: user interface for outcome after 1 year.

previous findings from the literature (12), the minimum path coefficient was set to 0.35, power to 0.8, and significance level to 0.05. We then calculated the minimum sample size for our model to be $N > 50$. The detailed data analysis followed the outline reported by Hair et al. (13). The measurement models indicator reliability, internal consistency reliability, convergent validity, and discriminant validity were analyzed initially. In accordance with Hair et al. (14) (chapter 2, exhibit 2.9), a reflective measurement model was chosen as the most adequate. **Figure 2** shows the preliminary model. Use behavior could not be assessed as only one-third of the participants had used PROPOSE, but this construct was analyzed in the multigroup analysis mentioned below. **Table 1** lists the indicator variables reflecting the constructs and the scale statements/questions to be answered (Likert scale 1–7). The Danish questionnaire is available as a **Supplementary Material**. **Table 2** demonstrates the *a priori* hypotheses. To assess indicator reliability, loadings above 0.7 were preferred, and all indicators with loadings below 0.4 were eliminated from the measurement model. The internal consistency reliability was assessed using the composite reliability ρ_C , Cronbach's alpha, and the reliability coefficient ρ_A . Convergent validity was evaluated using the average variance extracted (AVE). Alpha, ρ_C , and ρ_A values should exceed 0.7, while the AVE value should exceed 0.5. The heterotrait-monotrait ratio (HTMT) was calculated to evaluate discriminant validity. HTMT values should be below 0.85. For the structural model, collinearity issues were analyzed by calculating the variance inflation factor (VIF) values. VIF values above 5 were considered indicative of collinearity issues

among predictor constructs. The significance and relevance of the structural model relationship were assessed by applying bootstrapping. t values above 1.65 were considered statistically significant at the 10% significance level, which is commonly used in exploratory studies using PLS-SEM. The coefficient of determination (r^2) was used to measure the explanatory power of the model. r^2 values of 0.75, 0.50, and 0.25 were considered substantial, moderate, and weak, respectively. Multigroup analysis was undertaken using the variables age, gender, PROPOSE use, type of hospital, time in spine surgery, and personal innovativeness. The R package SEMinR (15) was the main package used for the data analysis—the R script is available as a **Supplementary Material**. Concerning ethics, participation was voluntary and anonymous and did not involve patients or any intervention. None of the participants received any financial reimbursement in relation to the survey. For that reason, no research ethics approval was necessary under Danish law.

Results

Table 3 shows the values of the demographic variables. All indicator loadings were above 0.7, except the indicator loading for the items (perceived risk) PR1, PR2, and PR4, which were all below 0.4 and, as a consequence, were eliminated from the model. PR3 had a loading above 0.7 and was retained. As the statement for the PR3 indicator showed significant similarity to the scale statements for resistance bias, we merged this into the

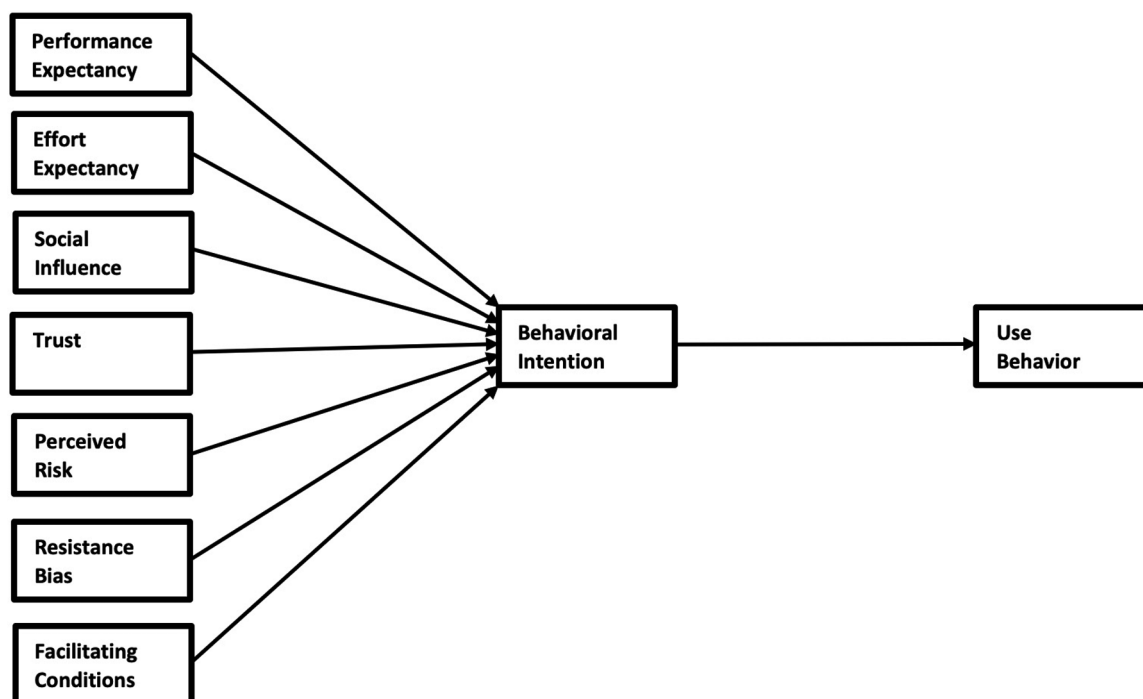


FIGURE 2
PROPOSE UTAUT preliminary model.

indicators for the construct resistance bias as RB4. The construct “facilitating conditions” showed questionable path loadings for some of the indicators as well as questionable convergent and discriminant validity in the analysis, and we chose to exclude this from the analysis. It also seems reasonable to assume that facilitating conditions are less relevant for the simple app in question. **Figure 3** demonstrates the values for alpha, ρ_C , and ρ_A . All AVE values exceeded 0.5 (0.60–0.80). All HTMT values were below 0.85. All VIF values were below 4. **Figure 4** shows the evaluation of the structural model through bootstrapping for the final model. Only the path coefficients for effort and performance expectancy were significant. The r^2 value for the model was 0.63—indicating that almost two-thirds of the variance in the model was explained. The adjusted r^2 value was 0.6. Both values indicate moderate explainability. The only significant effect in the multigroup analyses of path differences between two subgroups was for PROPOSE use and social influence ($p = 0.01$). None of the other multigroup analyses with the variables mentioned above demonstrated significant path differences (significance level of 0.05).

Discussion

We were able to confirm hypotheses 1 and 2. Effort expectancy or usability was the construct with the most significant influence on behavioral intention. Intentionally, we constructed the PROPOSE app with a careful choice of the number and type of variables, avoiding the need to enter the total score of PROM values and reducing the number of keystrokes to the absolute minimum.

The additional time needed to complete PROPOSE was minimal. In addition, the user interface was intentionally simple and based on surgeon and patient input. Even the short PowerPoint presentation of the user interface seems to have conveyed the simplicity of the PROPOSE app.

The performance expectancy—the degree to which an individual believes that using a new technology will help them attain gains in job performance—also significantly influenced behavioral intention. The information about the important metrics of the prediction model was not incorporated into the information given to the survey participants as they were not available at the moment. The discrimination or calibration performance and the internal or external validation of the detailed underlying prediction model were not mentioned. However, it did mention that the prediction model had been constructed using AI and was based on the national Danish quality register for spine surgery (DaneSpine). The multigroup analysis did not disclose significant differences in the relationship between performance expectancy and behavioral intention for participants depending on age, experience, or any of the other variables mentioned above. This finding might indicate a perceived universal need for more than empiricism and gut feeling.

Social influence—the degree to which an individual perceives the importance of how others believe they should use the new technology—was insignificant in the bootstrapped path model, but its path coefficient value was the third largest. It is reasonable to assume that social influence can influence behavioral intention, given the right circumstances. This implies that if the leadership makes using a CDSS mandatory, at least the intention to use the DSS will improve. In fact, it has been demonstrated that the mandatory use of a CDSS improves healthcare

TABLE 1 Variable items and scale statements.

	Scale statements
Performance expectancy	
PE1	I find PROPOSE useful in my job (9)
PE2	Using PROPOSE enables me to perform tasks quicker (11)
PE3	Using PROPOSE increases my productivity (10)
PE4	Using PROPOSE improves the outcome of my work (12)
Effort expectancy	
EE1	Propose is clear and understandable to me (13)
EE2	It was easy for me to become skillful at using PROPOSE (14)
EE3	I find Propose easy to use (15)
EE4	Learning to operate PROPOSE is easy for me (16)
Social influence	
SI1	People who influence my behavior think that I should use PROPOSE (17)
SI2	People who are important to me think that I should use PROPOSE (18)
SI3	In general, my hospital and department has supported the use of PROPOSE (19)
SI4	People whose opinion I value would like me to use PROPOSE (20)
Facilitating conditions	
FC1	I have the resources necessary to use PROPOSE (21)
FC2	I have the knowledge to use PROPOSE (22)
FC3	Health and IT personnel in the hospital are available to assist me with system difficulties (23)
FC4	I have adequate knowledge resources to help me learn about PROPOSE (24)
Behavioral intention	
BI1	I intend to use PROPOSE in the next 2 months (34)
BI2	I will use PROPOSE in the next 2 months (35)
BI3	I plan to use PROPOSE in the next 2 months (36)
Perceived risk	
PR1	There is a possibility of malfunction and performance failure, so PROPOSE might fail to deliver an accurate prognosis and could mislead my work with an inaccurate prognosis (45)
PR2	There is a probability that more time is needed to fix errors and nuances of the AI system PROPOSE (46)
PR3	I think using PROPOSE may cause psychological distress, as it could have a negative effect on my self-perception of the treatment plan (47)*
PR4	I am concerned that my patients' personal information and health details are insecure and could be accessed by stakeholders or unauthorized persons leading to lawsuits for the physicians and the hospital (48)
Resistance bias	
RB1	I do not want PROPOSE to change how I develop my treatment plan because the new system is unfamiliar to me (49)
RB2	I do not want to use PROPOSE because of past experience; these new high-tech products always fall flat during practical application (50)
RB3	I do not want to use PROPOSE because there is a possibility of losing my job as AI-assisted technology may do the work better than me (51)
Use behavior	
UB1	I have already used PROPOSE (52)
UB2	I recommend others should use PROPOSE (53)
UB3	Have you ever overridden PROPOSE after using it for some time (54)
Personal innovativeness	
PI1	If I heard about a new technology, I would look for ways to experiment with it (38)
PI2	In general, I am among the first of my colleagues to acquire a new technology when it appears (39)
PI3	I like to experiment with new technologies (40)
Trust	
T1	I trust PROPOSE to be reliable (41)
T2	I trust PROPOSE to be secure (42)
T3	I believe clinical decision support systems like PROPOSE are trustworthy (43)
T4	I trust clinical decision support systems like PROPOSE (44)

TABLE 2 Hypotheses.

Hypothesis 1	Performance expectancy positively affects surgeons' intention to use PROPOSE.
Hypothesis 2	Effort expectancy positively affects surgeons' intention to use PROPOSE.
Hypothesis 3	Social influence positively affects surgeons' intention to use PROPOSE.
Hypothesis 4	Trust positively affects surgeons' intention to use PROPOSE.
Hypothesis 5	Perceived risk negatively affects surgeons' intentions to use PROPOSE.
Hypothesis 6	Resistance bias negatively affects surgeons' intentions to use PROPOSE.
Hypothesis 7	Facilitating conditions positively affects surgeons' intentions to use PROPOSE.

quality (16). To further support this point, the only significant subgroup path difference was for PROPOSE use and social influence (source) and behavioral intention (target). Using the CDSS was almost mandatory for some time for those who had used PROPOSE. One cannot help but wonder why the mandatory use of a CDSS is undescribed in relation to spine surgery. Is this because the crucial model parameters are unknown to an extent where even the innovators themselves do not trust the CDSS or because they are unsure if the predictions are meaningful for the patients?

The group for which the use of PROPOSE was almost mandatory for a period of time was also the group with a higher number of experienced spine surgeons. The age of these experienced spine surgeons was also higher than the average age of all participants. A priori, we would expect younger surgeons to be more computer-literate and inclined to use a CDSS. Building on this postulate, we deduce that if social influence can impact the experienced more elderly surgeons, there is a probability that the group as a whole can be influenced to use a CDSS.

Trust and resistance bias are reciprocal entities. Both constructs had non-significant path loadings in the bootstrapped model. The coefficient for resistance bias had a negative sign and the smallest numeric value. The direction is as expected. The numeric value of the path component for trust was 1.7 times greater than that for resistance bias. Trust is an essential component in adopting a CDSS (17). Trust can be partitioned into benevolence belief (the CDSS acts in the interest of the clinician), integrity belief (the CDSS adheres to principles important to the clinicians), and competence belief (the CDSS can perform effectively) (9). The scale statements/questions for trust in our questionnaire probably do not reflect all three parts of trust. The statements mostly deal with competence belief, and we did not provide any data about the abilities, skills, and expertise of the CDSS as mentioned above. However, integrity belief could have been supported by the variables demonstrated in the user interface. Jansen-Kosterink et al. (9) found that benevolence and competence belief were the most important trust components. The participants had no actual knowledge of the competence of PROPOSE. They had none of the information required according to the TRIPOD (18) statement or PROBAST (19). Our advice is that, at a minimum, information about the number of patients, internal and external validation studies, discriminative ability, and calibration should be available on the website in question.

TABLE 3 Demographics.

Variable	N = 62
Age	42 (23–69) ^a
Sex	
Male	53 (85%)
Female	9 (15%)
Type of hospital	
University	44 (71%)
Other	18 (29%)
Time in spine surgery	
1 year or less	27 (44%)
More than 1 year	35 (56%)
PROPOSE use	
Yes	19 (31%)
No	43 (69%)

^aMedian, range.

A repository for prediction models in spine surgery would be highly valuable. An alternative is doing a literature search and finding the link to the predictive model hidden somewhere in the text or **Supplementary Material**. A repository could also enforce a quality description for all predictive models it contains (20).

The indicator reliability for the scale statements/questions concerning perceived risk (except PR3) was unacceptable and had to be removed from the measurement model. This might reflect the quality of the questions and the adaptability to the specific situation since most participants had not used PROPOSE. In addition, PROPOSE does not give one specific unambiguous advice but rather a series of aspects or proposals to be discussed with the patient in the decision-sharing process—in all probability, this works to minimize the perception of any perceived risk. The PR3 question or indicator is concerned with the professional autonomy of the participants, which can be pinpointed as the central clinician characteristic affected by a CDSS (9).

The construct “facilitating conditions” was excluded because of a lack of convergent and discriminant validity. We suggest that the simple PROPOSE app and the intuitive user interface largely abolish the need for any assistance. However, in the case of a more complex CDSS, the construct “facilitating conditions” was the most important factor influencing behavioral intention (12).

One of the limitations of this study is the low number of participants. The number of surgeons doing spine surgery is limited in a country with 5.8 million inhabitants, and we did our very best to recruit participants, expecting that a person-to-person contact at the two abovementioned meetings would increase willingness to participate in the survey. Some of the participants had minimal knowledge and experience with spine surgery. However, this limitation is somewhat counteracted by the increase in age span and information technology ability. In addition, we could have incorporated other variables in the model, used another model, or posed the questions differently. The UTAUT model and its derivatives are well-tested models for these scenarios. The r^2 values should be used with caution as it is a function of the number of predictor constructs—the adjusted r^2 value compensates for this fact. According to the established guidelines, both r^2 values can be characterized as moderate. Inventing a whole new model often results in low explainability. In the current scenario, other models such as the Fogg behavioral model could be of interest (21). The final important limitation is that most participants had not used PROPOSE and had to depend on a short presentation of the CDSS. This also means that the path between behavioral intention and use behavior could not be reviewed. However, usually, there is a strong correlation between behavioral intention and use behavior. It will be important to do a follow-up study incorporating both surgeon and patient opinion when PROPOSE is in full use.

Shared decision-making is extremely important to meet patient expectations; otherwise, some patients will be dissatisfied even when PROM values are improved significantly (22, 23).

We are supplying the usual goodness-of-fit (GOF) measures for the measurement and structural model but have not calculated any GOF for the total bootstrapped model. SEMinR currently cannot calculate GOF statistics for the total bootstrapped model. In the literature, an ongoing discussion on the relevance of GOF measures has not reached a definitive conclusion. We chose to adhere to the principles listed in one of our principal references on PLS-SEM (15), which is critical to using GOF measures. However, we are well aware that the use of GOF statistics is advocated by other researchers, including Schubert et al. (24). In addition, some members of the same group have pointed out

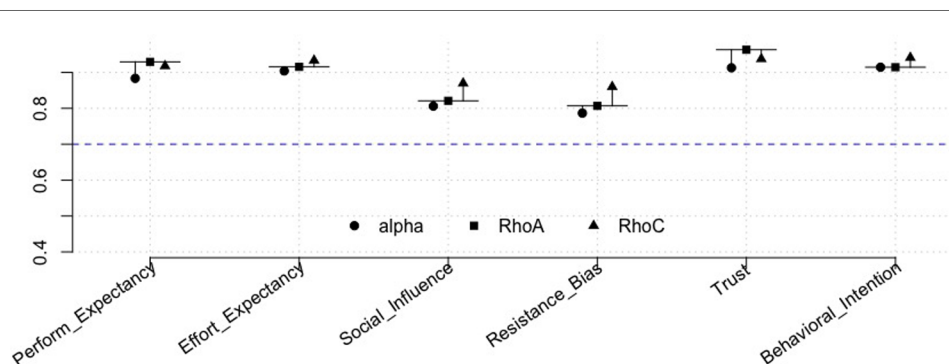
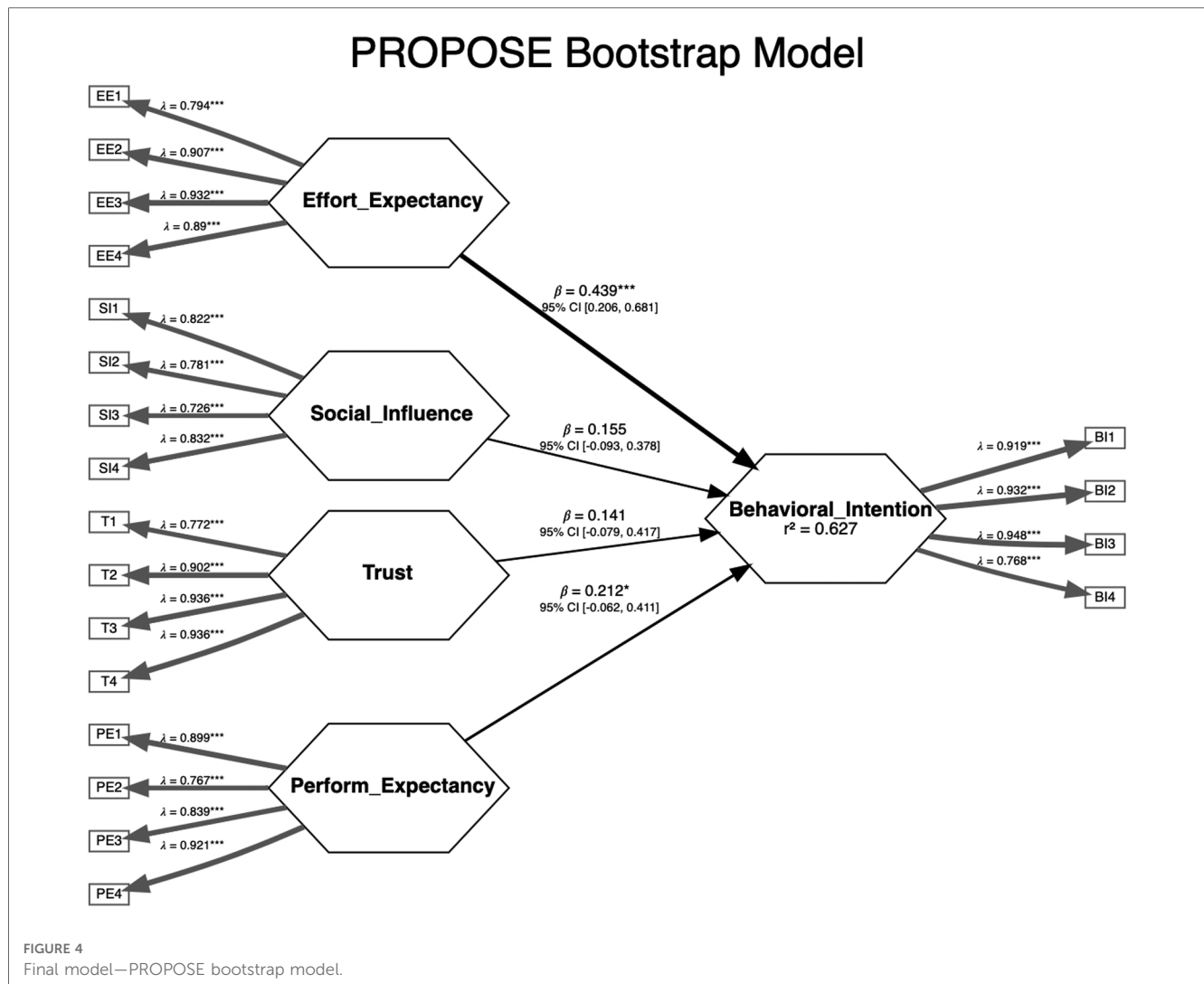


FIGURE 3
Internal consistency reliability.



that more research is needed to establish sound thresholds for these fit measures (25).

Shared decision-making using a CDSS with acceptable properties for the surgeon and the patients can fill some of the communication gaps. In conclusion, this study outlines the important properties of a CDSS that can enhance shared decision-making in spine surgery.

Conclusion

Effort expectancy/usability and performance expectancy were found to be the most important and the only significant constructs influencing behavioral intention to use the CDSS named PROPOSE. The r^2 value for the final bootstrapped model was moderate to substantial and certainly adds some credibility to the model. Though non-significant, there are indications that the construct “social influence” might improve the behavioral intention to use a CDSS. Improving trust/performance expectancy through detailed information on the internal and external validity of the CDSS should improve the behavioral intention to use a CDSS.

Data availability statement

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent from the participants was not required to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

SE: proposal for the study protocol, data acquisition, data analyses and statistics, manuscript writing for publication in

journal, and corresponding and first author. CP: review of protocol and manuscript, data acquisition, statistics, second author, and study spin-off from PhD study. SS: review of protocol and manuscript, data acquisition, and third author. MA: review of protocol and manuscript and last author. All authors contributed to the article and approved the submitted version.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

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Comparison of analog and digital patient decision aids for the treatment of depression: a scoping review

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Introduction: Patient decision aids (PDAs) are important tools to empower patients and integrate their preferences and values in the decision-making process. Even though patients with mental health problems have a strong interest in being more involved in decision making about their treatment, research has mainly focused on PDAs for somatic conditions. In this scoping review, we focus on patients suffering from depression and the role of PDAs for this patient group. The review offers an overview of digital and analog PDAs, their advantages and disadvantages as well as recommendations for further research and development.

Methods: A systematic search of the existing literature guided by the Cochrane Handbook for Systematic Reviews and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses - extension for scoping reviews (PRISMA-ScR) was conducted. Three electronic literature databases with the appropriate thematic focus were searched (PubMed, PsycInfo, and Web of Science). The search strategy used controlled and natural language to search for the key concepts decision aids and depression. The articles were selected in a two-step process guided by predefined inclusion and exclusion criteria. We narratively synthesized information extracted from 40 research articles.

Results: We included 40 articles in our review. Our review revealed that there is more focus on digital PDAs in research than in clinical practice. Digitalization can enhance the benefits of PDAs by developing tools that are more efficient, interactive, and personalized. The main disadvantages of both types of PDAs for the treatment of depression are related to time, dissemination, and capacity building for the health care providers. Digital PDAs need to be regularly updated, effective strategies for their dissemination and acceptance need to be identified, and clinicians need sufficient training on how to use digital PDAs. There is more research needed to study which forms of PDAs are most appropriate for various patient groups (e.g., older adults, or patients with comorbidities), and to identify the most effective ways of PDAs' integration in the clinical workflow. The findings from our review could be well aligned with the International Patient Decision Aids Standards.

Discussion: More research is needed regarding effective strategies for the implementation of digital PDAs into the clinical workflow, ethical issues raised by the digital format, and opportunities of tailoring PDAs for diverse patient groups.

KEYWORDS

patient decision aids, shared decision making, autonomy, depression, mental health, digitalization

1. Introduction

According to the World Health Organization (WHO), about 280 million people worldwide suffer from a depressive disorder rendering it a leading cause of disability in the world (1). Depression as a public health issue becomes even more challenging when we consider therapeutic options, such as different types of psychotherapy and psychiatric medication (2, 3). Even though there are effective, evidence-based treatments, only about one third of patients receive adequate therapy (4, 5). Some of the reasons for this problem are poor clinician-patient communication, insufficient knowledge of treatment options as well as insufficient inclusion of patients' views and preferences into the decision-making process (6–8). Therefore, the better inclusion of patient values and preferences into treatment decisions may play an important role in addressing the public health issue of depression (9, 10) by possibly enhancing the quality of treatment outcomes, through enhanced patient satisfaction and therapeutic adherence (11). Furthermore, the importance of involving patients and their values and preferences is consistent with best practices and clinical guidelines for mental health services (9, 12–14).

Patient decision aids (PDAs) are important tools for facilitating and achieving this aim. PDAs are evidence-based tools that inform patients about treatment options and go beyond mere informational materials by helping patients elicit their preferences, and thus preparing them for a consultation with a healthcare professional to engage in a shared decision making (SDM) process (15–17). PDAs aim at empowering patients by presenting the available evidence in an understandable manner, thereby encouraging the patients to be more involved in the decision making, reducing their decisional conflict, and aligning treatment decisions with patients' preferences and values (15, 16, 18, 19). These are important factors both for patient's empowerment and SDM that is based not only on information exchange but also on creation of a trusting relationship between a mental health care provider and a patient (17).

PDAs can be designed as stand-alone tools, as facilitators during the SDM process, or as a combination of both. There are several types of PDAs: they can be either developed in analog forms, e.g., as fact sheets, or in a digital format, such as websites or applications. Best practice standards for developing PDAs have been defined in the International Patient Decision Aid Standards (20, 21).

As in many other areas, novel IT technologies hold many promises also in the health care sector. This does not only apply to diagnostic tools or treatment options but also to decision making. Digitalization offers the opportunity to design PDAs in an interactive, personalized, and possibly more effective way to better engage patients and facilitate SDM for decisions regarding current and future care (22–24). Hence, digital PDAs have the potential to empower patients and orient healthcare towards patient- and value-oriented practice (10, 22, 24).

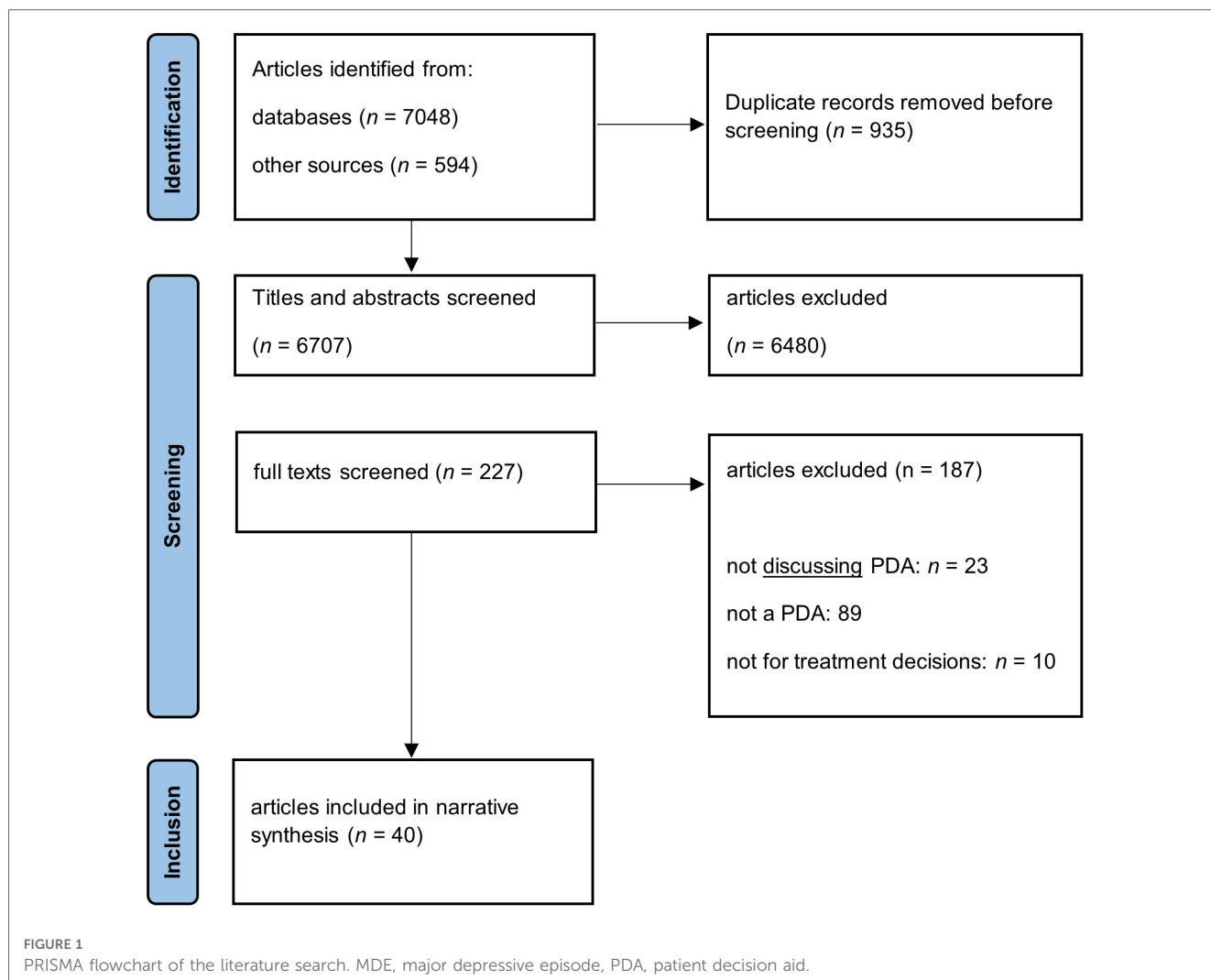
Previous research on PDAs has mainly focused on somatic conditions (18, 25, 26). A Cochrane review (18) showed the effectiveness of PDAs in terms of increased patient knowledge, decreased decisional conflict, and clarity about personal values. However, the majority of the 105 included studies in the review

focused on health decisions related to somatic conditions (18). A similar pattern can be seen in a recent review focusing on users' involvement in design and development of PDAs; also here, only about 2% of the included PDA projects belong to mental health (27). These reviews are used to formulate guidelines and checklists for development of PDAs (28, 29), but the patient groups with major depressive disorder and generally with mental disorders are underrepresented. The inclusion of patients and their preferences and values in the decision making process is at least as important in mental healthcare. Nevertheless, PDAs have only recently been researched in mental healthcare, even though patients with mental disorders in general and depression in particular are interested in taking a more active role in decision making (30, 31). The (qualitative) research specifically focusing on patients' experiences with PDAs and their involvement in the development of PDAs for the treatment of depression deserves more attention (30, 32). Furthermore, recent reviews have focused on quantitative results of randomized-controlled studies, thus neglecting a large part of the available evidence (33, 34). Current research on SDM in mental health care can provide valuable insights for future studies on PDAs as it offers a crucial context for understanding their utilization (11, 17, 35). Additionally, such research highlights important factors that contribute to the empowerment and active involvement of patients with mental health conditions in their treatment (17, 35).

To follow the current development driven by digital revolution and its potential, the aim of this scoping review was to characterize and compare digital and analog PDAs for patients with major depressive disorders by portraying both qualitative and quantitative evidence of their main advantages and disadvantages. Thereby, we define digital PDAs as tools that can be used with computers, mobile devices, or other digital devices. Analog PDAs are tools that are not in digital electronic formats. Instead, they typically use paper-based materials, such as flyers or booklets. This evidence synthesis provides a comprehensive understanding of the role of PDAs for patients' decision making as well as recommendations for further research and development.

2. Methods

As we intended to portray the existing literature on key characteristics of PDAs in depression (rather than provide a definitive, quantitative answer to a narrow question such as the effect of PDAs on decisional conflict in patients with depression), scoping review methodology was most appropriate for our study (36). As standard registries such as PROSPERO do not currently accept Scoping Reviews we did not pre-register the review (37). A systematic search of the existing literature guided by the Cochrane Handbook for Systematic Reviews (38) and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses—extension for scoping reviews (PRISMA-ScR) was conducted (see the PRISMA Flow Diagram in Figure 1) (39). Three electronic literature databases with the appropriate thematic focus were searched (PubMed, PsycInfo, and Web of Science). The search



strategy used controlled and natural language to search for the key concepts decision aids and depression (see **Supplementary Table S1**). The database search closed on December 31st, 2022. To compensate for eventual shortcomings of the database search, it was complemented with a search on Google Scholar, and, for all included articles, a search for citing articles on Web of Science and a hand search of the reference lists.

The articles were selected in a two-step process guided by predefined inclusion and exclusion criteria (see **Table 1**). To broaden the scope of our review, we did not restrict our search by publication date and included a variety of article types such as study protocols and reviews. Screening was done independently by ALW and JS. In both screening steps, ALW screened all records, while JS screened 20% including all references marked as “unsure” by ALW and a random selection of references. Disagreements were resolved by discussion among ALW, JS, and, if necessary, MT.

Data extraction was aligned with the aims of the study: summarizing advantages and disadvantages of using PDAs in general and digital vs. analog PDAs. During the extraction process, it became clear that it was not possible to differentiate between benefits and advantages or risks, challenges, and disadvantages, because the included articles did not differentiate

clearly between this terminology. Besides, the terminology used in the selected articles was not unified. That is why we decided to use general terms of advantages and disadvantages to refer to the potential positive and negative aspects of the use of digital and analog PDAs. The method of narrative synthesis (40) was chosen to gather a broad scope of knowledge to create an overview of PDAs for depression and guide further research. This method is well suitable since there are not many studies about PDAs for depression and given the variety of the chosen articles. To compare the digital and analog PDAs and provide an overview on the digital PDAs, the information extraction was clustered in accordance with the topics of advantages, disadvantages, and recommendations for both digital and analog PDAs. Data extraction was done by JS and checked by ALW.

This narrative synthesis was supplemented by tabulating the quantitative results. For ease of comparison across publications, effect sizes are presented wherever possible. For included studies reporting neither effect sizes nor sufficient information to calculate them although this should be possible given the study design, the corresponding authors were contacted with a request for additional information. Cohen’s *d* was chosen because it is appropriately widely used for continuous outcomes (such as

TABLE 1 Inclusion and exclusion criteria.

Included in this review were articles	Excluded from this review were articles
1. Discussing <ol style="list-style-type: none"> positive and/or negative aspects, (dis)advantages, benefits, or risks of or stakeholders' attitudes and opinions towards 	1. Mentioning, but not discussing PDA for MDE such as <ol style="list-style-type: none"> reviews that do not contain more information on PDA for MDE than is cited from the primary studies, such as (93) published PDA for MDE without any form of evaluation, such as (94)
2. Patient decision aids (PDA)—defined as <ol style="list-style-type: none"> objects, such as worksheets, booklets, apps, comics, videos, etc. designed for use by patients (together with a mental health professional or before/after a consultation—thus including encounter DA) as evidenced by, e.g., the use of easy, lay language, tailoring information to the individual, and/or visualization of numerical information, informing about several options and providing interventions to support patients' decision-making process (such as pro-con-lists or preference elicitation tasks), based on a neutral and balanced aggregation of scientific evidence, and aimed at an optimal decision process, not at a specific decisional outcome—for 	2. Not concerned with PDA, but rather <ol style="list-style-type: none"> decision support in the form of human interaction without using any tool, such as peer decision support aids not primarily intended for use by patients, such as communication aids or pharmacogenetic decision aids (95) mere information materials, such as (96) advertisement from pharmaceutical companies, such as (97), or aggregated data from online fora, such as (98) algorithm-derived treatment recommendations, such as (99)
3. Decisions about type and/or duration of treatment of	3. Not concerned with decisions about type and/or duration treatment of MDE, such as <ol style="list-style-type: none"> tools encouraging persons with depressive symptoms to access mental health care (100) generic decision aids (101)
4. Unipolar major depressive episodes (MDE) diagnosed by a mental health professional	4. Concerned with other conditions, such as self-reported depressive symptoms, positive depression screenings, dysthymia, organic affective disorders, or bipolar depression (102)
5. Published in a peer-reviewed journal listed in the Index Medicus (including reviews, opinion articles, editorials)	5. That are <ol style="list-style-type: none"> conference abstracts, such as (103) previous versions of reviews for which an updated version has been published, such as (104)
6. Written in English or German	6. Whose full text was not ascertainable, such as (105)

decisional conflicts) independent of the scale on which the outcome was measured (41). Cohen's d is computed as the difference of the two means divided by the pooled SD with values of 0.20, 0.50, and 0.80 signifying small, medium, and large effects, respectively (42). For publications not reporting Cohen's d , it was computed as follows: when raw data or descriptive statistics such as M and SD were reported, d was derived from these statistics. From CIs, the SD was computed as proposed by Higgins (43). From F statistics with one degree of freedom from t statistics, and from odds ratios, d was computed according to Borenstein (2019) (41), and from z and χ^2 statistics according to Rosenthal and DiMatteo (44). For pre-post-control between-subject designs, d was computed according to Morris (45).

3. Results

After two-step screening and applying our inclusion and exclusion criteria, 40 articles remained (see in Figure 1) that were used to synthesize evidence and information on disadvantages and advantages of the use of analog and digital PDAs as well as recommendations for their development. Table 2 shows the main characteristics of the 40 included publications for this review (15, 25, 26, 30–33, 46–78). More than one third of the articles focused on digital PDAs for patients with depression without any focus on a particular patient group (e.g., older adults or young adults). Very often, the articles included not only the patients' but also the clinicians' perspective on PDAs. Most PDAs were developed in interdisciplinary teams and in line with the International Patient Decision Aid Standards (61, 69, 70, 72).

3.1. Advantages

3.1.1. Advantages of both digital and analog PDAs

The mentioned advantages of PDAs and positive roles that PDAs can have for patients seeking treatment of depression were increased knowledge (25, 32, 46, 48, 50, 51, 54, 58, 62, 69, 70, 73, 75, 77), reduced decisional conflict (32, 55, 58, 62, 70, 72, 73, 77, 78), supporting decision-making (56, 62, 72, 76), elicitation of and treatment alignment with patients' preferences and values (26, 32, 46, 51, 54, 72, 76, 77), better preparation for and involvement in SDM (15, 26, 46, 48–51, 55, 63, 64, 69, 71, 72, 78), patients' satisfaction (46, 49, 51, 54, 62–64, 72), and more realistic expectations (51, 72). Furthermore, some studies pointed out that the use of PDAs in SDM did not increase the consultation time (25, 46, 49, 62, 63). Finally, an inclusion of personal stories was considered to be beneficial for patients' elicitation of their preferences because they could relate to people with similar experiences (48, 59, 68).

Supplementary Table S2 displays an overview of quantitative results from the included studies. These provide preliminary evidence for good acceptability, a reduction of decisional conflict, increase of patient involvement, adherence, and satisfaction by PDAs, without increase in consultation time. Data on other outcomes such as patient knowledge and clinical outcomes are inconsistent and/or scarce.

3.1.2. Advantages specific to digital PDAs

A variety of advantages or positive aspects specific to digital PDAs for the treatment of depression were discussed: digital PDAs are effective, easy and quick to use and access (50, 51, 54,

TABLE 2 Main characteristics of the included articles ($n = 40$).

First author	Year	Language (s)	Decision	Type of PDA	Target group	Context of use	Stakeholders included
Abousheishaa et al. (46)	2022	E	Use of antidepressants	Analog		During mental health care encounter	Patients, psychiatrists, experts in shared-decision making in mental health
Alarcon-Ruiz et al. (33)	2022		Between forms of treatment	PDA in general	Adults		
Aljumah et al. (47)	2015	A	Use of antidepressants	Analog (booklet)	Adults (18–60 years old), newly diagnosed	Pharmacy visit for antidepressants	Unspecified experts
Aoki et al. (48)	2022	E	Discontinuing antidepressants	Analog (booklets)	Patients having achieved remission with monotherapy	Independently of health care encounters	Patients, health care providers, experts on depression and decision aids
Aoki et al. (49)	2019	J	Between forms of management	Analog (booklet)	University students with first episode	Between health care encounters, alone and during nurse encounter	-
Barr et al. (50)	2019	E	Between forms of management	Digital, tablet-based, static	Primary care patients	Before and during primary care encounter	Members of the public, Researchers, patients, caregivers, medical assistants, clinicians, depression experts
Beaulac et al. (51)	2016	E, F	Between forms of treatment when considering initiation, change, or (dis-) continuation	Digital, web-based and brochure version	Primary care patients	Independently of or before, during, or after a health care encounter	Mental health professionals, young adults
Brodney et al. (52)	2021	E	Between forms of management	Electronic (DVD) and analog (booklet)	Adults		
Broughton et al. (53)	2021		Antidepressant use during pregnancy	PDA in general	Women, pregnant or planning a pregnancy		
Dannenberg et al. (54)	2019	E	Between forms of management	Digital, tablet-based, interactive		In the waiting room before the primary care encounter	Researchers, patients, and primary care providers
Fisher et al. (55)	2021	E	Between forms of management	PDA in preparation	Patients with problematic alcohol use		Patients, family members, mental health care providers
Gordon et al. (56)	2016	E	Between forms of treatment	Digital, tablet-based, with personified interface	Low income, ethnic/racial minority pregnant women	In the waiting room before the clinical encounter	Low-income women with history of depression in pregnancy, prenatal care providers, administrators, mental health services researchers, an application developer
Hetrick et al. (30)	2008		Use of SSRI	PDA in general	Children and adolescents		
Hopwood et al. (25)	2020		Use of antidepressants	PDA in general			
Hussain-Shamsy et al. (57)	2022	E	Start or continue antidepressants during pregnancy	Digital, web-based, interactive	Adult women, pregnant or planning a pregnancy	Adjunct to, but for use outside of clinical care	Medical experts, members of the community, end users
Kivelitz et al. (59)	2018		About treatment setting	PDA in preparation	Adults		Patients
Kroenke (60)	2015		Between forms of treatment	PDA in general			
LeBlanc et al. (61)	2013	E	Between antidepressants	Analog (laminated cards, leaflet)	Adults	During the primary care encounter	Patients, clinicians, policy makers
LeBlanc et al. (62)	2015						
Loh et al. (63)	2007	G	Between forms of treatment	Analog (decision board)	Patients with depression in primary care setting	During primary care encounters	
Loh et al. (64)	2007						
Perestelo-Perez et al. (32)	2017	S	Between forms of treatment	Digital, web-based		Between primary care encounters	Patients, health professionals
Raue et al. (31)	2010	E, S	Between forms of management	Analog (one-page form)	Elderly (65+ years old) minority primary care patients	During primary care nurse encounter	-
Raue et al. (66)	2011						
Raue et al. (65)	2019						

(Continued)

TABLE 2 Continued

First author	Year	Language(s)	Decision	Type of PDA	Target group	Context of use	Stakeholders included
Reis (67)	2021	E	Between forms of treatment	Digital, web-based, interactive		Participant-initiated, unrelated to health care encounters	
Reuter et al. (68)	2022	E	Between forms of management	Digital, web-based application (additional paper copy)	Patients with coronary heart disease	In the waiting room before the primary care/cardiologist encounter	Patients, primary care providers, cardiologists, mental health care providers, administrators, developers, experts in user experience, behavior change, and patient activation
Rogojanski et al. (69)	2020	E, F	Between forms of treatment	Digital, web-based, static	College students	After a health care encounter	Researchers with backgrounds in psychology, psychiatry, pharmacy, and knowledge mobilization; health professionals
Shillington et al. (70)	2020	E	Between forms of augmentation	Digital, web-based, interactive	Adults with treatment resistant depression	In preparation of and during a mental health care encounter	Patients, a patient advocate, mental health professionals, researchers, an expert in shared decision making
Simmons et al. (26)	2011		Any decision regarding treatment	PDAs in general	Adolescents and young adults (12–24 years old)		Adolescents and young adults (12–24 years old), their caregivers
Simmons et al. (71)	2013		Any decision regarding treatment	PDAs in general	Adolescents (12–18 years old)		Health professionals
Simmons et al. (72)	2017	E	Between forms of management	Digital, website presented on tablet	Adolescents and young adults (12–25 years old)	In enhanced primary care encounter	Patients, caregivers, clinicians, experts in youth depression, shared decision making, and biostatistics
Simon et al. (73)	2012	G	Between forms of treatment	Digital, Web-based, interactive, tailored to the individual	Adults insured by a specific health insurance	Participant-initiated, unrelated to health care encounters	Tested by patients and health care providers
Weiss et al. (78)	2010						
Stacey et al. (15)	2008		Between forms of treatment	PDAs in general		Adults	Patients
Starks et al. (74)	2015	E	Depression management	Digital, tablet-based, interactive	Alaskan Native and American Indian people	Short version for use during a primary care encounter, and more comprehensive version for use outside of the encounter	Tribal health system leaders, the Indian Health Service Alaska Area Institutional Review Board and tribal research review committees, project steering committee, healthcare providers, software contracting firm, customer-owners, researchers
Vigod et al. (75)	2016	E	Use of antidepressants during pregnancy	Digital, web-based, interactive	Adult women, pregnant or planning a pregnancy	In addition to, but for use outside of clinical care in a specialist or non-specialist setting	Perinatal psychiatry experts, perinatal mental health providers, patient decision aids experts and a health care technology company
Vigod et al. (76)	2016						
Vigod et al. (77)	2019						
Khalifeh et al. (58)	2019						

Language(s) of the PDA: A, Arabic; E, English; F, French; G, German; J, Japanese; S, Spanish. PDA, patient decision aid; SSRI, selective serotonin reuptake inhibitor. Articles on the same PDA are group together.

67). They can give patients enough flexibility and time to use them when it is most suitable and comfortable for them without being rushed (54, 55, 75, 77). This should enable patients to be better prepared for the consultation with clinicians, formulate questions, or use the waiting time efficiently if the tools are used in the waiting room (54, 55). Furthermore, audio and visual components can be implemented in digital PDAs that can be particularly important for low literacy users (56). Digital PDAs can also offer more privacy, for example, when the tool is secured with a password (51, 75). They can be important for particular groups such as young patients as they are comfortable with this technology (67, 71, 72). Furthermore, digitalization allows for personalization and tailoring of PDAs (15, 30, 50, 69). Digitalization also allows greater scalability and adaptability of the PDAs in terms of both content (e.g., updates in the light of

new evidence or personalized content) and form (e.g., information online or in printable format) (50, 57, 75, 76). The scalability and adaptability can lead to further implementation of PDAs in other countries (57). More specific advantages, which are mentioned, were the possibility to include exercises that will prepare patients for decision making and help them understand how their decision making is influenced by relatives or friends (57, 75).

Finally, from the clinicians' perspective, a great advantage of digital PDAs used in SDM settings is the possibility to link them with electronic health systems, e.g., electronic health records or screening assessment tools (56). This will create better efficiency and allow real-time decisions (50, 54). Integration of digital PDAs can also lead to support evidence-based and patient-centered care (54, 72).

3.1.3. Advantages specific to analog PDAs

The only mentioned advantages specific to analog PDAs for the treatment of depression were that printed materials are important for patients without access to computers or the internet (46, 51), and that they are freely available from public and non-profit organizations (71). An overview of all advantages is in **Table 3**.

3.2. Disadvantages

3.2.1. Disadvantages related to both digital and analog PDAs

The challenges, which were discussed either in the general context of PDAs or for both digital and analog PDAs for the treatment of depression, were mainly related to the information provided in the PDAs. Both clinicians and patients raised concerns about PDAs that appeared to be too technical and too overwhelming, for example, in terms of content or wording that they provide (32, 48, 50, 51, 68). However, some patients and clinicians also reported that the material was insufficient (49, 50) or the presentation of treatment was conflicting information provided by a clinician (58). Patients' literacy needed for using PDAs that might present a challenging issue (50, 68). Finally, the use of PDAs might pose an additional burden for patients (58, 59) and increase their anxiety (58).

3.2.2. Disadvantages specific to digital PDAs

The common challenges discussed with digital PDAs for the treatment of depression were mainly connected with PDAs integration and implementation in the clinicians' workflow (50, 51). PDAs can play an important role to support SDM and hence, clinicians need sufficient training on how to properly integrate PDAs into their consultation (50). Another problematic issue might be the dissemination of PDAs (51). Finally, digital PDAs might not be suitable and easy to use for all groups of patients (54).

3.2.3. Specific to analog PDAs

In analog PDAs for the treatment of depression, it might be particularly challenging to regularly update evidence about the treatment (26). This challenge is intensified considering scarce resources—such as finances—for creating analog materials (26). **Table 4** displays an overview of all disadvantages.

3.3. Recommendations

3.3.1. Recommendations for both digital and analog PDAs

In the papers included in this analysis, several recommendations have been identified, which relate to both analog and digital PDAs for the treatment of depression (**Table 5** display an overview of

TABLE 3 Advantages of PDAs.

Digital	Analog	Both
Effective, easy and quick to use and access (50, 51, 54, 67)	For patients without access to computers or internet (46, 51)	Increased knowledge (25, 32, 46, 48, 50, 51, 54, 58, 62, 69, 70, 73, 75, 77)
Flexibility and sufficient time for the usage (54, 55, 75, 77)	Free available from public and non-profit organizations (71)	Reduced decisional conflict (32, 55, 58, 62, 70, 72, 73, 77, 78)
Inclusion of video and audio materials (56)		Supporting decision-making (56, 62, 72, 76)
More privacy (51, 75)		Elicitation of and treatment alignment with patients' preferences and values (26, 32, 46, 51, 54, 72, 76, 77)
More suitable for particular groups with high affinity for technology (67, 71, 72)		Not increased consultation time (25, 46, 49, 62, 63)
Personalization (15, 30, 50, 69)		Better preparation for and involvement in SDM (15, 26, 46, 48–51, 55, 63, 64, 69, 71, 72, 78)
Greater scalability and adaptability (50, 57, 75, 76)		Patients' satisfaction (46, 49, 51, 54, 62–64, 72)
Inclusion of exercises and involvement of family and friends (57, 75)		More realistic expectations (51, 72)
Better efficiency and real-time decisions (50, 54)		
Linkage with electronic health systems (56)		
Support of evidence-based and patient-centered care (54, 72)		

TABLE 4 Disadvantages of PDAs.

Digital	Analog	Both
PDAs integration and implementation in the clinicians' workflow (50, 51)	Challenging regular updates of evidence about the treatment (26)	Appropriate amount and form of information provided (32, 48, 50, 58, 69)
Resources for trainings for clinicians on how to integrate PDAs (50)	Not enough resources such as finances for the creation of PDAs (25)	Patient literacy (50, 68)
Dissemination of PDAs (51)		Usage can be perceived as additional burden (58, 59)
Not suitable for all patient groups (54)		

TABLE 5 Recommendations for future research.

Research focus	Relevance
Inclusion of a variety of patient groups (32, 51, 62, 70, 72)	Determination of effectiveness for a broad population. Identification of PDAs' accessibility for different health literacy levels. Enabling appropriate personalization of PDAs.
Identification of the precise role of PDAs in SDM and the optimal amount of information provided in PDAs (33, 48, 69, 72)	Important for PDAs acceptance, development, design and inclusion in the clinical workflow.
Implementation of PDAs (33, 46, 58, 62, 67, 68, 77)	Important for PDAs acceptance, development, design and inclusion in the clinical workflow as well as cost-effectiveness considerations.
Replication of studies (33, 48, 69, 72)	More robust evidence about the effectiveness of PDAs.

recommendations and their relevance) and correspond with the International Patient Decision Aids Standards: information in PDAs should be written in clear, understandable, concise, and simple language (46, 50, 51, 54, 57). Furthermore, careful wording about potential risks should be used (54, 70) as well as balancing them with positive effects (46). It was recommended that clear instructions or even education should be provided on how to use PDAs (48), particularly digital PDAs (54). Specific recommendations about the visual side of PDAs included recommendation for bright and attractive colors (46, 50), and the use of more visuals for risks and expected benefits of treatment options (46, 70). The inclusion of important stakeholders for designing and developing PDAs was also recommended (55, 58).

In terms of the content of PDAs for the treatment of depression, it was suggested to include both pharmacological as well as psychotherapeutic treatment options (69), and to include a broad range of questions regarding possible treatments (51), update the content regularly (e.g., every 2 years) or, alternatively, determine the “expiration date” of PDAs (50). One study recommended to consider a bias possibly inflicted by the order for which treatment options are presented (69). Furthermore, the inclusion of patients' values and preferences as well as personalized information based on their current social situation, religious and cultural beliefs, and prior knowledge was highlighted several times (26, 31, 74). This can be expected to encourage patients to raise issues, which are important for them and which they would not raise otherwise in the consultation with a clinician (26).

Tailoring PDAs to the needs of the target group was another recurring topic (31, 33, 51, 60). In the context of older adults, it was recommended to tailor PDAs for the treatment of depression in a way that the influence of cognitive impairment is minimized (31). Several studies highlighted the importance of designing PDAs for the treatment of depression for different subgroups of patients (51), such as specific age groups, ethnicities, educational level, and patients with medical comorbidities and other disabilities (31, 62, 70).

In terms of research, it was also recommended to include a variety of population groups as well as considerations of factors related to age and involvement of caregivers (72). Future research should replicate existing studies and focus in more detail on the extent to which PDAs are effective for the treatment of depression and adherence to treatment, and whether PDAs have uniquely positive effects on SDM (33, 48, 69, 72). Furthermore, more research is needed to determine the precise role of PDAs in SDM, to identify the optimal amount of information provided in PDAs

(69), and PDAs' accessibility for different health literacy levels (49, 50). Finally, it was recommended to conduct more research on implementation of PDAs (77), more specifically on facilitators and barriers for implementing PDAs (33, 46, 67, 68) as well as on cost-effectiveness of implementing and developing PDAs (58, 62).

In terms of use of PDAs for the treatment of depression, it was recommended to make PDAs interactive, use them on a regular basis (26), make them available at an early stage of decision making (69), include healthcare professionals such as clinicians or nurses to use PDAs with patients (31, 74), and to also include caregivers and relatives (26, 48). Particularly in the context of the last point, it was recommended to provide patients with PDAs before a consultation so that family and other important people for patients can be included in the decision process (49).

3.3.2. Recommendations specific to digital PDAs

Recommendations specific to digital PDAs for the treatment of depression mainly concerned their implementation in the clinical workflow (50, 51, 54, 68): PDAs could be delivered and accessed by patients directly at the clinic by using electronic tablets (50, 68). If linked with screening assessment, the waiting time could be used effectively, and this would allow real-time decision support (54). From a clinicians' perspective, it was recommended to implement PDAs into electronic medical record systems and make them accessible within a shared network (e.g., electronic charts) (50, 54). More research on how exactly such implementation can be reached is needed (54, 68). Finally, it was recommended to further study what forms of digital PDAs (e.g., mobile applications or websites) are most powerful for both patients and healthcare providers (51).

4. Discussion

This scoping review aimed at comparing digital and analog PDAs for patients with major depressive disorder by collecting evidence and information regarding advantages and disadvantages of their use as well as recommendations for their development. The main finding was that analog and digital PDAs increased the patients' satisfaction with the tool, enhanced knowledge, reduced decisional conflict and better preparation for SDM. There was only one advantage specific to the analog PDAs, namely that these PDAs are more suitable for people without access to technology such as computers or smartphones. Digital PDAs were deemed to be more efficient, flexible, more easily accessible and with the opportunity of personalization. The main disadvantages of both

types of PDAs for the treatment of depression are related to time, dissemination, and capacity building for the health care providers. Digital PDAs need to be regularly updated, effective strategies for their dissemination and acceptance need to be identified, and clinicians need sufficient training on how to use digital PDAs. Furthermore, there is more research needed to study which forms of PDAs are most appropriate for various patient groups (e.g., older adults, or patients with comorbidities), and to identify the most effective ways of PDAs' integration in the clinical workflow.

The findings from our review could be well aligned with the International Patient Decision Aids Standards (20, 21) that was often used as guidance in the development of PDAs. In both, there is a strong emphasis on presenting treatment options based on evidence that is regularly updated, presenting options in understandable language, including patients' values, and developing them in a way that can guide patients in SDM. The specific topic that was not discussed in our findings is the presentation of probabilities of outcomes. Our findings offer additional insights regarding tailoring PDAs to different patients' subgroups, need for specifying dissemination and implementation process of PDAs and inclusion of the role of families and significant persons in the decision making.

The review of the literature documents the growing interest in digital PDAs for patients with depression. These patients deem it important to be more involved in the decision-making process and have more information about the available treatment options (25, 26, 32). Digitalization offers greater scalability, flexibility, and personalization of PDAs, which would allow for a possibly more effective and tailored inclusion of patients' values and preferences into the decisional framework for therapeutic choices. The easy access, flexibility and personalization of digital PDAs might be especially beneficial considering patients' possible cognitive deficits such as lower motivation or poor concentration. Furthermore, an advantage of digital PDAs for the treatment of depression is its effective inclusion in the clinical workflow, which should facilitate evidence-based and patient-centered healthcare.

4.1. Research gaps and recommendations for further research

In general, more research is needed to systematically study the clinical effectiveness and possibly adverse effects of digital PDAs for the treatment of depression. The present review shows a high level of heterogeneity of approaches and measures of digital PDAs. Some studies were designed with a narrow focus on a specific patient group; other studies had a broad focus on PDAs from both clinicians' and patients' perspective. In addition, many studies used unvalidated instruments to measure the impact of the intervention, such as treatment adherence, patient knowledge, and goal concordance of care. This is in part explained by a lack of validated measurement instruments, e.g., for concordance of care with patient preferences and values (32). Another challenge for interpreting the existing evidence is the different study designs that ranged from purely descriptive studies and pilot testing in focus groups with baseline measures to randomized control trials (RCTs). This is in line with other recent recommendations for further

research on decision aids, which call for more RCTs in this field using checklists to ensure that all relevant factors are measured (79).

In the present scoping review, only 40 articles qualified for inclusion, although inclusion criteria were deliberately broad. This is a small number given the impact of depression on public health as well as on patients, who often wish to be included to a greater extent in the decision-making process about their treatment. This research gap is accentuated by the fact that half of the articles had to be excluded because the main (or the only) focus was on the use of decision aids by clinicians (see **Figure 1**). Even though clinicians' experience can offer valuable insight particularly regarding the role of PDAs in SDM (60), a stronger focus of future research should be on patients' experience. Interestingly, among the articles after the first screening step, PDAs powered by artificial intelligence (AI) were mainly developed for diagnostic or screening purposes (80, 81) even though the potential of AI could be used to contribute to personalized and tailored PDAs as well.

The development, challenges and research of PDAs for patients with depression can gain from taking inspiration from research on PDAs for somatic conditions such as osteoarthritis and cancer and for other mental disorders such as schizophrenia (18). Research in this area has shown that patients' experiences, understanding as well as quality of SDM was improved when digital PDAs contained visual aids such as icons and bar charts (82, 83). Another helpful feature in this context might be that information is presented in different formats such as writing, video and audio (84, 85). Assessing PDAs for readability and cultural sensitivity of different patient groups can be a strategy for ensuring proper personalization of digital PDAs (85). In terms of interaction with digital PDAs, more research is needed to establish an appropriate framework for personalized design that would also take into consideration emotional aspects of decision-making (86). Another suggestion related to improved interaction with digital PDAs was developing them with a flexible, dynamic design that would enable them to choose questions and topics depending on the patient's individual needs and preferences as opposed to having algorithmic predefined structure and questions (87). This can be particularly helpful for patients with depression that might suffer from cognitive deficits. However, more research is needed to identify the necessary features in this context.

The implementation challenges might be approached by the following strategies. Clinicians need training on how to effectively use PDAs with patients in the SDM process (84, 88). In addition, PDAs can have incorporated communication aids (84) and instruction sheets for their implementation in the clinical workflow (88). Finally, an efficient strategy might be to align PDAs and their development directly with clinical practice guidelines so that the PDAs reflect guideline content and guidelines contain passages on SDM and PDAs (82, 87, 89). This effort might be strengthened by collaborating with initiatives and stakeholders focusing on clinical practice guidelines, SDM and implementation of best available evidence (82, 87). Multistakeholder teams can also help with regular evidence update of information provided in PDAs (90). The quality of evidence in PDAs was identified as an important issue in several included studies in this review (26, 50, 75, 77). Furthermore, there was a strong recommendation to strengthen the evidence in a

recent evaluation of Ottawa Decision Support Framework for PDAs (80). Research on formulating guidance for evidence selection and summarization might be particularly helpful in this context (90).

In future studies, it is of importance to further improve the inclusion of preferences, values, and experiences of patients with depression in PDAs and SDM. More scientific studies, particularly qualitative studies, are needed to learn about patients' views, experience, and factors influencing acceptance and implementation of PDAs (91). Furthermore, the topics of personalization and appropriateness of different forms of PDAs for different groups deserve more attention as well as the potential for serious adverse events, such as suicide. Both could be achieved by following user-centered designs by developing PDAs to ensure that important stakeholders (55) and preferences and values of different patient groups are included (27). Gibson et al. (92) suggested giving patients the option to decide how much they want to be involved in the SDM process as this preference might change from patient to patient. It would be also interesting to study the precise role of PDAs in the SDM process; particularly, if there is a change in acceptance and effectiveness depending on the phase in the SDM process in which PDAs are used. Finally, even though privacy was listed as a positive aspect of digital PDAs in our results, more research from an ethical perspective is needed as digitalization in health care raises many challenges such as privacy issues, equality of access, or security. The fact that such ethical issues were not discussed is an important research gap.

4.2. Strengths and limitations

Strengths of this review are the systematic literature search with broad inclusion criteria, capturing the full scope of scholarly articles on advantages and disadvantages of PDAs for the treatment of depression. However, this review did not include research on self-help groups, online fora, or patient versions of clinical guidelines, that are probably often used as PDA although not meeting our PDA definition. Also, while we did not exclude articles based on the age of the target group of the respective PDA, due to differences in diagnostic categories between child and adolescent and adult mental health care, our search strategy was likely less sensitive towards articles on child and adolescent depression. The final limitation is that even though we included articles in German, we did not specifically search for articles in German databases.

5. Conclusion

The present scoping review suggests that in the field of PDAs for the treatment of patients with depression, more systematic and comprehensive research is needed to study the role of PDAs in the SDM process and to address the potential benefits as well as challenges that digitalized PDAs can offer. More research is also needed regarding effective strategies for the implementation of digital PDAs into the clinical workflow, ethical and equity

issues raised by the digital format, and opportunities of tailoring PDAs for diverse patient groups.

Data availability statement

The original contributions presented in the study are included in the article/**Supplementary Material**, further inquiries can be directed to the corresponding author.

Author contributions

JS, AW, and MT conceived the study including its methods. AW developed the search strategy, and screened all retrieved records, while JS screened 20% of the records and MT acted as arbiter in the case of disagreement between AW and JS. JS extracted the qualitative data and undertook the narrative synthesis. AW extracted the quantitative data, computed effect sizes and tabulated them. JS drafted the article apart from the methods section, which was drafted by AW. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fdgth.2023.1208889/full#supplementary-material>

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An opponent model for agent-based shared decision-making via a genetic algorithm

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Introduction: Shared decision-making (SDM) has received a great deal of attention as an effective way to achieve patient-centered medical care. SDM aims to bring doctors and patients together to develop treatment plans through negotiation. However, time pressure and subjective factors such as medical illiteracy and inadequate communication skills prevent doctors and patients from accurately expressing and obtaining their opponent's preferences. This problem leads to SDM being in an incomplete information environment, which significantly reduces the efficiency of the negotiation and even leads to failure.

Methods: In this study, we integrated a negotiation strategy that predicts opponent preference using a genetic algorithm with an SDM auto-negotiation model constructed based on fuzzy constraints, thereby enhancing the effectiveness of SDM by addressing the problems posed by incomplete information environments and rapidly generating treatment plans with high mutual satisfaction.

Results: A variety of negotiation scenarios are simulated in experiments and the proposed model is compared with other excellent negotiation models. The results indicated that the proposed model better adapts to multivariate scenarios and maintains higher mutual satisfaction.

Discussion: The agent negotiation framework supports SDM participants in accessing treatment plans that fit individual preferences, thereby increasing treatment satisfaction. Adding GA opponent preference prediction to the SDM negotiation framework can effectively improve negotiation performance in incomplete information environments.

KEYWORDS

shared decision-making (SDM), agent, auto-negotiation, genetic algorithm, opponent model

1. Introduction

Shared decision-making (SDM) is a treatment decision-making model proposed for humanitarian considerations and the needs of medical ethics (Cathy et al., 1997; Drake and Deegan, 2009; Stiggelbout et al., 2015), where at least one doctor and one patient participate in the process of making a treatment plan, which is based on information sharing. The resulting treatment plan considers the wishes of both parties. Unlike traditional decision-making models, such as the paternalistic model, the informed decision-making model, and the professional-as-agent model, SDM does not give decision-making power to either party but fairly combines the treatment preferences of doctors and patients (Cathy et al., 1997).

To some extent, SDM improves the compliance and satisfaction of patients in the treatment process, which increases the effect of treatment (Pieterse et al., 2019; Fiorillo et al., 2020).

The concept of SDM was first proposed by Veatch in 1972 (Veatch, 1972). In 1997, Cathy (Cathy et al., 1997) further clarified its definition and characteristics. After more than 40 years of development, SDM has gradually formed a complete system in the West (Coulter et al., 2011, 2022), including a complete theoretical system (Makoul and Clayman, 2006), patient decision-making aids (Thomson et al., 2007; Elwyn et al., 2013), SDM evaluation tools applied to different scenarios (O'Connor, 1995; Simon et al., 2006; Scholl et al., 2012), and relevant legal and policy support. However, at present, SDM is still a new concept in many countries and regions (Huang et al., 2015), and the clinical practice of SDM is not as effective as expected. Many factors influencing the effectiveness of SDM have been explored. According to Bomhof-Roordink et al.'s (2019) study, which analyzed SDM models presented before September 2019, the exchange of information on treatment plans is key to SDM and also forms the basis for patient participation. Many studies have come to similar conclusions and noted that the medical literacy of the patient has a significant impact on the exchange of information (Shen et al., 2019; Loftus et al., 2020; Alsulamy et al., 2021). Doctors also play a crucial role in the exchange of information. Song and Wu (Song and Wu, 2022) suggest that doctors have a responsibility to elicit preferences from patients, which requires good communication skills. However, a factor that should not be ignored is the need for long-term doctor-patient communication (Beach and Sugarman, 2019; Caverly and Hayward, 2020). However, it is difficult for busy clinicians to find enough time to implement SDM during consultations. Therefore, the current obstacles in SDM practice can be placed into two categories: (1) doctors are under heavy time pressure, which leads to insufficient time for communication between doctors and patients, and (2) subjective factors of both doctors and patients significantly influence decision-making (Covvey et al., 2019; Shinkunas et al., 2020).

To solve the above problems, this study suggests integrating artificial intelligence (AI) into SDM to reduce unnecessary subjectivity in decision-making and the high time cost associated with manual negotiation. This method has been applied in the research of clinical decision support systems (CDSSs) (Osheroff et al., 2004; Magrabi et al., 2019; Yang et al., 2019), which are software that matches the patient's characteristics with existing medical knowledge so as to provide doctors with evaluation suggestions for patients. Such medical knowledge can be obtained from a computerized medical knowledge base or from historical diagnosis data mining using AI. Many studies (Bright et al., 2012; Sutton et al., 2020) have proven that the application of a CDSS can help doctors improve the efficiency of diagnosis and reduce medication errors, thereby reducing department costs and improving service quality. However, in the process of giving advice, a CDSS considers the patient's physiological characteristics instead of the patient's personal preferences. Loftus et al. (2020) suggest that most CDSS methods are black-box models and are in conflict with the concept of patient-centered care. Because patient preferences are not considered in the recommendations, it is possible that the predicted outcomes may differ significantly from the patient's preferences. Other studies (Deegan, 2010; Almarino et al., 2018) have

proposed computerized decision aids to narrow the knowledge gap between doctors and patients, which would help patients make more informed choices according to their preferences, but the abovementioned time pressure remains unresolved.

To better focus on doctor and patient preferences and reduce time pressures, this study constructed an intelligent negotiation framework to support decision-making based on the SDM model (Elwyn et al., 2012). First, in the model, the doctor informs the patient that reasonable options are available. Second, the doctor lists the options and clearly describes their potential harm and benefits. Finally, the doctor elicits an expression of preference from the patient and judges whether to make a decision or postpone it. Obviously, decision-related choices are directly related to patient preferences. Doctors give professional advice to support patients in decision-making, which reflects a preference derived from medical expertise and diagnostic experience. Therefore, such choices can be considered a problem of negotiation. In order to represent these two individual preferences, an "agent" is used to represent doctors and patients in negotiations, which is the key to automating the negotiation framework.

An agent refers to a computer system in a complex and changeable environment (Wooldridge and Jennings, 1995); it has autonomy and social ability and is able to respond to the environment. An agent is able to express knowledge, belief, intention, and goal-oriented behavior. In other words, it always attempts to retain maximum benefits for participants with the goal of promoting the success of negotiation. Agent-based auto-negotiation helps participants come to an agreement that can bring them as much benefit as possible with reduced time costs (Lomuscio et al., 2003). However, one important factor in a successful negotiation is that the agent adapts its own strategy to the available opponent's information. Participants in SDM have difficulty fully disclosing their preferences, which may be due to failure in building trust between the doctor and patient or the doctor's inadequate conversation skills to make the patient comfortable enough to express a preference. Hence, adding a component of opponent preference predictions to the negotiation framework is necessary.

Agent-based auto-negotiation has been applied in fields such as electronic trade, power trading, resource distribution, and supply-chain planning in recent years. Many negotiation models have been proposed for different domains, mainly focusing on offer evaluation, concession strategies, and opponent models.

Offer evaluations are quite different between linear and non-linear negotiation domains. For continuous and linear negotiation domains, a suitable linear function is usually designed to evaluate the offer, as seen in the study by Amini et al. (2020). However, dealing with the non-linear and discrete negotiation domain is more complicated. Yang and Luo (2019) proposed a method to evaluate offers by ranking demand. Mansour et al. (2022) presented a hybrid negotiation method that adopts different offer-generation mechanisms to tackle both quantitative and qualitative issues. The preference-based method solves quantitative issues by calculating the reservation intervals of the agent, and the fuzzy similarity method solves qualitative issues by finding the most similar counteroffer to the last offer from the opponent. However, these methods do not consider uncertainty in participant preferences.

The concession strategy determines the agent's behavior toward giving up interests, including the opportunity and interval of the concession if conflicts exist between participants. Such methods can be divided into time-based strategies and behavior-based strategies (Faratin et al., 1998). Mirzayi et al. (2021) proposed an opponent-adaptive concession method that creates a concession neighborhood around the target utility of each round, and the radius of the neighborhood growth rate is determined by the negotiation time. Mansour (2020) presented an imitation offer ration tactic that considers both the current concession behavior of the agent and that offered by its opponent.

Many studies use predictions of opponent preferences to accelerate the convergence of incomplete information negotiation and adopt various learning algorithms to improve the accuracy of opponent models, such as Bayesian algorithms (Sim et al., 2008; Pooyandeh and Marceau, 2014; Yi et al., 2021), neural networks (Zafari and Nassiri-Mofakham, 2016), and reinforcement learning (Bagga et al., 2021a). Most of the research and applications of agent-based automatic negotiation models focus on linear values such as electronic market transactions and power transactions. For SDM, there are many non-linear problems. For example, the severity of medical side effects is discrete and difficult to express with a definite value, which means that the agreement of SDM has a large and discrete value space, making it more difficult to learn about the preferences of opponents.

Genetic algorithms (GAs) are also an effective method of promoting agreement in negotiation (Holland, 1975; Matos et al., 1998; Gao and Chen, 2010; de Jonge and Sierra, 2016). GAs use Darwin's "survival of the fittest" theory to simulate the evolution of natural populations in order to find the optimal solution. GAs are efficient in searching and are closer to the global optimum solution when faced with a large solution space (Lambora et al., 2019). Thus, many studies have used them for value-space searches. Bagga et al. (2021b) proposed a method using a GA to find Pareto frontiers in solving the problem of making Pareto optimal bids under uncertain opponent preferences from a multi-objective optimization stance. However, this study does not predict opponent preferences, as it is not an incomplete information negotiation environment. Ayachi et al. (2018) used GA in electronic trading to predict the reservation values and deadlines of their opponents and then adjust the agent's bid strategy based on the predicted opponent model. Choudhary and Bharadwaj (2019) developed a group recommendation system based on multi-agent negotiation, where a GA is used in the negotiation and recommendation-generation phases. First, the GA is employed to find the offer of maximum utility for each agent in the group and then to determine the ranking of the minimum distance from the preferences of all agents. Few studies have used GAs to predict opponent preferences in complex and large negotiation domains, such as multiple issues and non-linear domains. Particularly, in SDM negotiations, a treatment plan often contains multiple linear or non-linear issues.

In summary, to address time pressures while focusing on patient preferences in SDM, this study presents an agent-based negotiation framework using fuzzy constraints and a GA (ANFGA). The chromosome coding method, fitness function, and evolutionary method of the GA are redesigned for the prediction of an opponent model in a complex negotiation domain. The contributions of this study are as follows:

- We establish an agent model of doctors and patients by taking problems that need to be agreed upon in SDM as negotiation issues. The agent describes the preferences of the participants and uses fuzzy membership to represent the benefits of each value (Lin et al., 2022).
- We use GA to solve the problems caused by an incomplete information environment. The GA takes the bid as an individual in the population and updates the cognition of the opponent through population evolution.
- In experiments, we compare the prediction results of the GA with the real preference settings of opponents to verify the effectiveness of our model, and we compare the performance with other excellent agent models to prove that our model has better performance in SDM.

The rest of this article is structured as follows: In Section 2, we describe the definitions of problems and introduce our proposed model, ANFGA. In Section 3, we evaluate the negotiation presented and compare it with other state-of-the-art agents. In Section 4, we conclude the paper and discuss future research directions.

2. Method

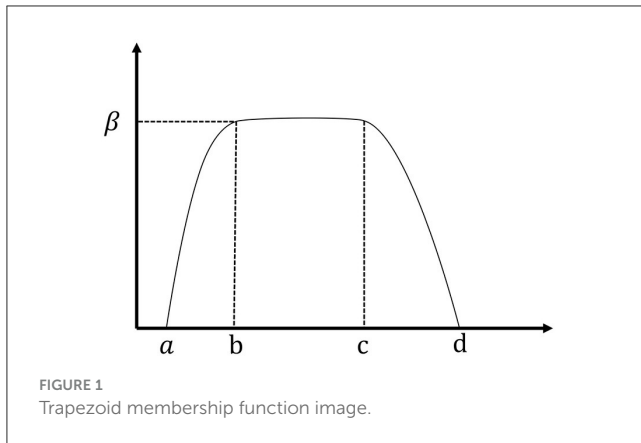
2.1. Auto-negotiation framework for SDM

There are two types of agents in SDM, *DA*, and *PA*, which represent doctors and patients, respectively. This study simulates a bilateral negotiation scenario, which means that only one pair of *DA* and *PA* are involved in the negotiation. The inputs of the model are the preferences of the doctors and patients, which are represented by a fuzzy membership function, and the number of functions is determined by the number of issues. The output of the model is a treatment plan, which is composed of multiple issue values. More details are provided in the section below.

2.1.1. Negotiation statement

Negotiation issues, which are denoted as $I = \{I_1, I_2, \dots, I_i, \dots, I_n\}$ here, indicate treatment plan choices such as period, cost, and side effects. Each issue has a finite set of k possible values, $I_i = (v_1^i, v_2^i, \dots, v_j^i, \dots, v_k^i)$, which denote the options of a choice. Selecting a value for each issue forms an offer, $O = (v^1, v^2, \dots, v^i, \dots, v^n)$, which represents an available treatment plan. All possible bid sets are called solution spaces. The Stacked Alternating Offers Protocol (Aydogan et al., 2017) is adopted in the framework, which means that the offers are provided in turn in the negotiation process by *DA* and *PA* until the negotiation concludes.

When receiving an offer from an opponent, the agent has to respond to the opponent with one of the following actions: *accept*, *offer*, or *reject*. The choice of action is based on the agent's preference and negotiation strategy, which are introduced in Section 3. Preference includes a set of weights, $\omega = \{w_1, w_2, \dots, w_i, \dots, w_n\}$, as well as a set of satisfaction functions, $\mathbf{F} = \{F_1, F_2, \dots, F_i, \dots, F_n\}$, where ω represents the



level of importance that the participants attach to each issue, and F maps the participant's preference for each value in the issue to a real value. Thus, an aggregated satisfaction function that expresses participants' satisfaction with offer O is defined as follows:

$$\Psi(O) = \sum_{i=1}^n w_i^* F_i(v^i), \quad (1)$$

where $w_i \in [0, 1]$ indicates the weight of the i th issue; $\sum_{i=1}^n w_i = 1$; F_i is the satisfaction function of the i th issue, and n is the number of issues.

2.1.2. Fuzzy constraint satisfaction

Most problems in SDM are difficult to describe with precise information. For example, the treatment period considered appropriate by the patient is often an interval rather than an exact value. Patients' expectations are also not evenly distributed over the interval values. In addition, there are many constraining relationships between different issues that are not precisely available but have a strong influence on the negotiation results. To describe and deal with such situations, a fuzzy theory proposed by Zadeh (1996) is integrated into the negotiation framework of SDM (Liu et al., 2020, 2022). Hence, the problem in the negotiation framework is formulated as solving a fuzzy constraint satisfaction problem (FCSP). Many studies (Safaeian et al., 2019; Bhuyan et al., 2021; Deng et al., 2021) have demonstrated that fuzzy constraints can be a good representation of the unclear and uncertain preference relationships of different decision-makers for common issues.

In our framework, participants' preferences are represented as a fuzzy membership function, $A(X)$, which indicates the level of belonging of X to fuzzy set A . For preference in SDM, X is a solution option for the problem, and $A(X) \in [0, 1]$ denotes the satisfaction with this option. In this way, the participants' uncertain preference for the problem is transformed into an accurate value. The trapezoid membership function is used in this study, as shown

in Eq. (2) and Figure 1.

$$A(X) = \mu_i(x) = \begin{cases} 0, & \text{if } x \leq a \\ \beta \left(1 - \left(\frac{x-b}{b-a} \right)^2 \right), & \text{if } a < x < b \\ \frac{1}{\beta}, & \text{if } b \leq x \leq c \\ \beta \left(1 - \left(\frac{x-c}{c-d} \right)^2 \right), & \text{if } c < x < d \\ 0, & \text{if } x \geq d \end{cases} \quad (2)$$

Among them, the parameters a , b , c , d , and β determine the specific form of the function. $X \in [b, c]$ can be expressed as the offer that the agent is most willing to accept. $X < a$ and $X > d$ represent the bid that the agent is most reluctant to accept. $X \in [a, b]$ or $X \in [c, d]$ represent different levels of satisfaction. Thus, Equation (1) can also be expressed as Equation (3):

$$\Psi(O) = \sum_{i=1}^n w_i^* \mu_i(v^i). \quad (3)$$

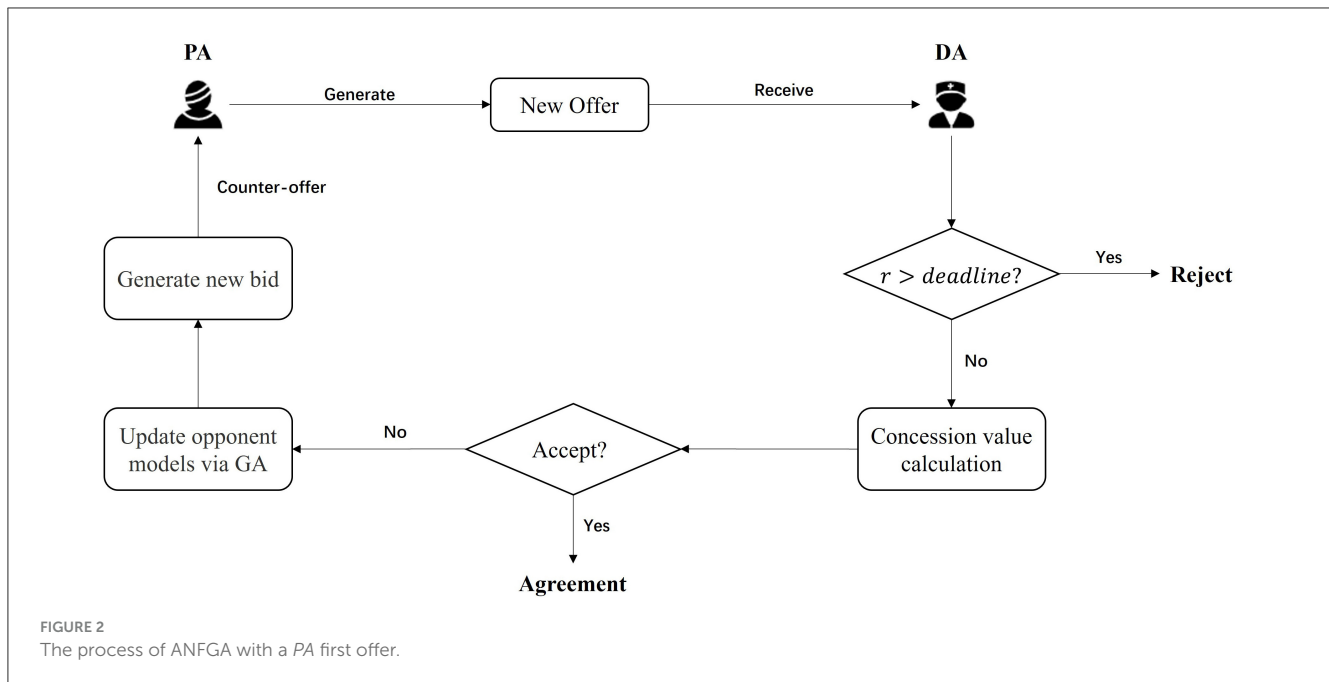
2.2. Negotiation strategy

Although the agent prefers a high-satisfaction offer, the opponents' preferences are frequently different or even contradictory. Appropriate concessions are necessary to prevent the failure of the negotiation. The negotiation strategy is designed to help the agent determine the appropriate concession pace and time, thereby increasing the success rate of negotiation and obtaining the maximum expected benefit. In incomplete information negotiation, the ability of opponent models to predict more information about opponents' preferences is an important factor in improving the efficiency of this process. Hence, an opponent model based on a GA is added to our model. The bidding process is similar between DA and PA. Figure 2 shows the progress of ANFGA with PA first offering a solution. PA sends an offer first, and if the current round is still before the deadline, the receiver calculates the concession value and decides whether to accept the offer. If accepted, the negotiation reaches an agreement, and the offer becomes the final solution. Otherwise, the counteroffer is generated and sent to the opponent via the GA update of the opponent model. In this section, we further introduce the negotiation strategist used in ANFGA, including the concession strategy and the opponent model.

2.2.1. Concession strategy

Concession strategies help users reduce their expectations at the appropriate moment to promote successful negotiation. To make more sensible decisions, the agent calculates the pace of concessions by evaluating three states: the opponent's response state, the agent's own internal state, and the environment state. These states represent the opponent's desire, the agent's own desire, and the environmental constraints. The method used in this study improves on the work of Chia-Yu et al. (2016).

For the opponent's response state, R , the agent considers the difference between offer A generated in the previous round and the current offer B received from the opponent, as well as the



initial offer, A_0 , and counteroffer, B_0 . The calculation is shown in Equation (4):

$$\sigma = 1 - \frac{G(A_0, B_0) - G(A, B)}{G(A_0, B_0)}. \quad (4)$$

$eG(A, B)$ is a measure of the distance between A and B for negotiation issue $I_i \in X$, as shown in Equation 5:

$$G(A, B) = \frac{\sqrt{\sum_{i=1}^{N_i} L(A_i, B_i)^2}}{n}, \quad (5)$$

where A_i and B_i denote the possibility distribution of A and B for negotiation issue $I_i \in X$, and n denotes the number of negotiation issues.

The agent's own internal state, M , considers the level of satisfaction, ρ , associated with the latest offer, A , and its tightness with the acceptance threshold, ε , where

$$\rho = \Psi(A), \quad (6)$$

$$\delta = 1 - (\rho - \varepsilon). \quad (7)$$

The environmental constraint E to which the agent is subjected during the SDM negotiation process is primarily a time constraint. Therefore, it can be expressed as a function of time (Faratin et al., 1998), as shown in Equation 8:

$$\tau = \lambda + (1 - \lambda) \left(\frac{r}{r_{\max}} \right)^{\frac{1}{\beta}}. \quad (8)$$

In this equation, r is the current round, r_{\max} denotes the negotiation deadline, and τ denotes the time constraint imposed on the agent during negotiation. $\lambda \in [0, 1]$ represents the minimum concession value when first receiving a counteroffer from the opponent. If λ is large, the concession value will be high, and the acceptance threshold will be low at the beginning of the negotiation,

which may lead to the agent easily accepting a low-satisfaction offer. $\beta \in [0, 1]$ is the concession rate for time, controlling the pace at which the threshold falls. If β is low, the less the concession value decreases each round, and the slower the acceptance threshold decreases, which may result in more negotiation rounds.

Based on Equation (8), we can obtain the opponent response state, $R = \{\sigma\}$, the agent's internal state, $M = \{\rho, \delta\}$, and the environment state, $E = \{\tau\}$. Thus, we can calculate the concession value:

$$\varepsilon = (\mu_\rho(\rho) \wedge \mu_\delta(\delta) \wedge \mu_\sigma(\sigma) \wedge \mu_\tau(\tau))^\omega. \quad (9)$$

The specific form of Equation (9) in this study is

$$\varepsilon = \frac{\left(1 - \frac{\sigma + \rho + \delta}{3} + \tau\right)^\omega}{4}. \quad (10)$$

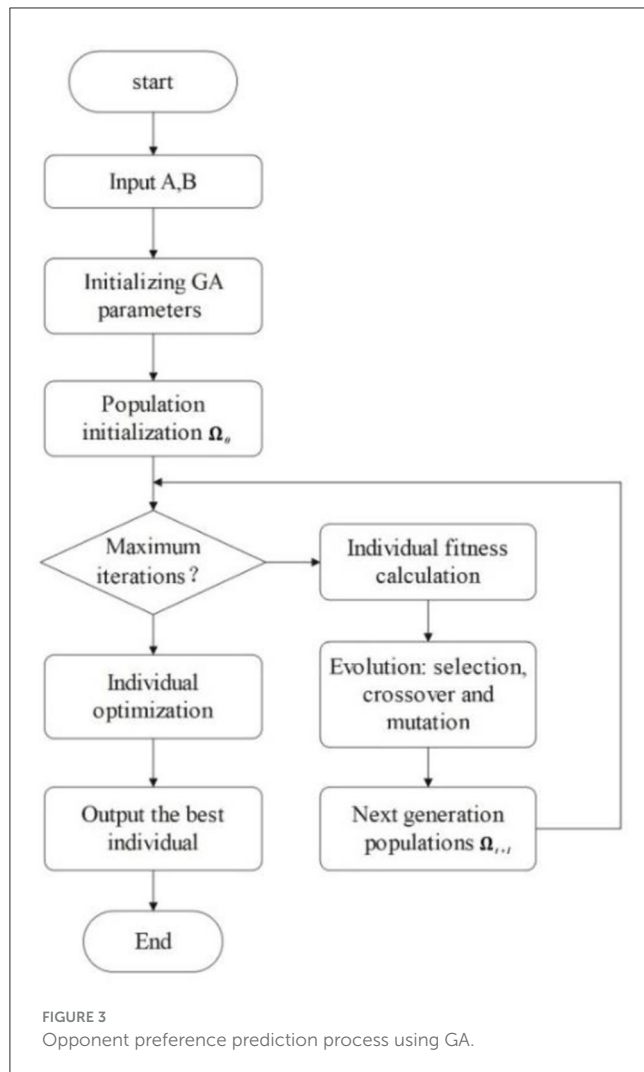
Furthermore, the acceptance threshold of the agent at each round of negotiation can be calculated:

$$\varepsilon_r = \varepsilon_{r-1} - \varepsilon, \quad (11)$$

$$Action_r = \begin{cases} \text{Accept, } \Psi(O_r) \geq \varepsilon_r \\ \text{Offer, } \Psi(O_r) < \varepsilon_r \end{cases} \quad (12)$$

where ε_r is the acceptance threshold of round r , O_r is the offer from the opponent in round r , and $Action_r$ represents the response from the agent (Accept or Offer). If the satisfaction of O_r is more than ε_r , the agent will accept the offer; otherwise, the agent generates and sends a new offer to the opponent.

From Eqs (9–11), it can be known that ω adjusts the rate of concessions. $\omega < 1$ implies a slower concession rate and expresses that the agent is unwilling to abandon too much interest in the negotiation, which represents a competitive concession strategy. $\omega = 1$ implies a faster concessions rate and expresses that the agent wants to facilitate a quick agreement by reducing the benefits,



which represents a collaborative concession strategy. $\omega > 1$ implies a win-win concession strategy, which lies between the first two strategies.

2.2.2. Opponent model

As it is difficult for both sides of the SDM to publish their preferences accurately and clearly, negotiations are conducted in an incomplete information environment. Furthermore, opponent information is necessary to accelerate the rate of negotiation convergence. Therefore, we use a GA-based approach to learn information about an opponent's preferences. There are three important components of GA: population, fitness, and evolution. These will be described in detail in this subsection. Figure 3 shows the process of the method, where A and B are the histories of the agent and opponent offers.

2.2.2.1. Population initialization

As defined in Section 2, the preference profile of the opponent has two parts: a set of weight preferences, ω , and a set of satisfaction functions, F . These parts form a binary set, $\Omega = \{(w_1, F_1), \dots, (w_n, F_n)\}$ and $w_i \in \omega, F_i \in F, i = 1, \dots, n$, which

represents the agent's preferences on each issue. Ω is a member of potential solution space, with multiple Ω forming a population $\Omega = \{\Omega_1, \Omega_2, \dots, \Omega_j, \dots, \Omega_m\}$, where m is less than the size of the solution space.

The GA randomly generates m individuals to form the initial population, which is its starting point for searching for the optimal solution. In the two parts of Ω , we assign each weight w_i by generating random numbers between 0 and 1 and then regularizing them to initialize the weight preferences of Ω . For the satisfaction functions, we assume that the shape of the opponent preference function is consistent with that of the agent. Hence, five parameters are used to describe the opponent's satisfaction function: a, b, c, d , and β . Considering the agent's own preference (a and d are the boundary values that the agent is willing to accept on the issue) and the convergence speed of the opponent's preference population, the parameters a and d can be fixed and kept consistent with those of the agent. Therefore, the satisfaction preference information of Ω can be initialized by assigning random numbers to b and c , and β is fixed to 1.

2.2.2.2. Fitness

The fitness function supports population evolution by evaluating the suitability of the individual in the current environment and current state. Excellent individuals will have a greater probability of being "inherited" by the next generation, which helps the population approach the optimal solution.

As the goal of SDM negotiations is to reach an agreement with the highest possible satisfaction for both parties, the fitness function can be defined as

$$f(\Omega_j) = f(\Omega_j^k, \Omega_j^{\bar{k}}) = \frac{1}{N_r} \left(\sum_{r=1}^{N_r} \Psi^k(A_r) * \Psi_j^{\bar{k}}(B_r) \right), \quad (13)$$

where Ω_j is an individual of the opponent's preference population, Ω_j^k is the agent's preference profile, $\Omega_j^{\bar{k}}$ is the opponent's preference profile, A_r and B_r are the offers of the agent and the opponent in round r , respectively, and N_r is the current negotiation round.

2.2.2.3. Evolution and generation of next populations

According to the principle of survival of the fittest, individuals with weak fitness in the population will be eliminated, whereas individuals with strong adaptability will survive and reproduce. In the algorithm proposed in this study, a certain number of excellent individuals are retained in the population evolution. The selection of individuals in the population adopts a method that combines an elite retention strategy with roulette selection.

The elite retention strategy refers to retaining a certain number of the best individuals in the population (the number in this method is e), as needed before individual crossover, which is directly inherited by the offspring population. This strategy method can prevent the optimal solution of a generation from being destroyed by crossover and mutation operations during the evolution process, thereby effectively improving the convergence of the GA.

Roulette selection, also known as proportional selection, refers to the probability of each individual being selected is proportional to its fitness. Its specific operations are as follows:

- Let Ω_k be an individual in the population, and its probability of being selected is:

$$P(\Omega_k) = \frac{f(\Omega_k)}{\sum_{j=1}^m f(\Omega_j)}. \quad (14)$$

- The individual is given a random number, $r \in [0, \sum_{j=1}^m f(\Omega_j)]$; if $\sum_{j=1}^k f(\Omega_k) > r$, Ω_k joins the next generation population; otherwise, the loop continues.
- Repeat step b $m - e$ times.

In order to ensure the diversity of the population, two excellent individuals from the population are selected as “parents” to generate new individuals (i.e., “crossover”). At the same time, there may be some “potential stocks” in the population, that is, individuals with a fitness level that is low currently but may increase after a few generations. To keep the potential stocks from being eliminated, they randomly get the chance to crossover. The parent individuals produce a child according to the crossover rules:

- The child copies partial preference information from the parents separately to form a complete individual preference.
- The child takes the average of the parents’ preference information to form its own preferences.

In addition, there is a mutation rate that allows the child’s partial preferences to possibly be assigned random values. This randomness can further help the model jump out of a local optimal solution and better approach the global optimal solution.

2.2.2.4. Termination

Based on the GA, populations evolve to obtain the best individuals for their environment. During this process, the population terminates when it reaches the maximum number of iterations, namely, when it runs out of environmental resources and can no longer evolve. At this point, the best individuals from the latest generation are selected as the optimal solution.

2.2.2.5. Optimal individual optimization

To avoid the uncertainty caused by multiple factors, a classification learning method is used to optimize the weighting information of the learned opponents. The specific process is as follows:

- The set of issues is divided into n categories based on the number of issues n : $C = (C_1, C_2, \dots, C_i, \dots, C_n)$, where C_i is a concession on the issue of the current counteroffer and $\sum_{I_i \in I} C_i$ is the sum of the concession values after several negotiations.
- Variable c , assigned to each category C , is used to mark the concession value of each variable on issue I .
- Suppose that D_i is the value domain of issue i , and the opponent makes a minimum concession each round in order to obtain a higher satisfaction value. In the multi-issue negotiation process, a larger overall concession for the issue implies a smaller weight. Hence, the proportional relationship between the weights can be expressed as

$$w_1 : w_2 : \dots : w_i : \dots : w_n = \frac{1}{D_1} : \frac{1}{D_2} : \dots : \frac{1}{D_i} : \dots : \frac{1}{D_n}. \quad (15)$$

- Performing the standard transformation, $\sum_{1 \leq i \leq n} w_i = 1$, we give weight to issue I_i :

$$w_i = \frac{\frac{1}{D_i}}{\sum_{i=1}^n \frac{1}{D_i}}. \quad (16)$$

- The final predicted opponent weights are expressed as follows:

$$w_i = \frac{w_i^g + w_i^c}{2}. \quad (17)$$

As the negotiation proceeds, the agent’s estimate of the opponent’s issue weights is continuously updated and approaches the true weights.

3. Experiment and result

To evaluate the proposed model, we simulate experiments using the ANFGA for multiple negotiations in different scenarios. The measures used to evaluate the model and the results of the experiments are presented in this section.

3.1. Evaluation metrics

The following three common metrics are used in this paper to evaluate the proposed model:

- Average Joint Satisfaction is the average joint satisfaction of the two parties who finally reached the negotiation, which reflects the fairness of the negotiation and is calculated as follows:

$$AJS = \frac{\sum_{t=1}^{T_{suc}} \Psi(A_t) + \Psi(B_t)}{T_{suc}}, \quad (18)$$

where T_{suc} is the number of successful negotiations.

- The average negotiation round represents the speed of successful negotiation and is calculated as follows:

$$ANR = \frac{\sum_{t=1}^{T_{suc}} R_t}{T_{suc}}, \quad (19)$$

where R_t is the rounds of the t -th successful negotiation.

- Negotiation Success Rate represents the ratio of the number of successful negotiations to the number of negotiations and is calculated as follows:

$$NSR = \frac{T_{suc}}{T_{all}}, \quad (20)$$

where T_{all} is the number of negotiations.

TABLE 1 Description of the agent used in the experiment.

Agent	Negotiation strategy
ANFGA-Competition	ANFGA uses a competitive strategy
ANFGA-Collaboration	ANFGA uses a collaborative strategy
ANFGA-Win-Win	ANFGA uses a win-win strategy
FCAN (Lin et al., 2022)	It uses the same concession strategy as the ANFGA but does not consider opponent preference prediction
ANF-TIME	Time-based negotiation strategy (Faratin et al., 1998) with fuzzy constraints
Complete information	ANFGA in a complete information environment

3.2. Experimental design

Table 1 shows the agent used in the experiment. To verify the validity of the performance of the negotiation model and the prediction of the opponent model, two types of experiments were designed:

- ANFGA is compared with ANF-TIME, which uses a time-based negotiation strategy under different time constraints and size solution spaces using three concession strategy types: competition ($\omega = 1.2$), collaboration ($\omega = 0.8$), and win-win ($\omega = 1$).
- The negotiation results are compared using ANFGA in two different environments: incomplete information and complete information. Complete information means that participant preferences, including weights and satisfaction functions, are public. In the incomplete information environment, an additional FCAN is added as a reference for the performance improvement of the opponent model.

Each agent performs 200 times in the different experiments (i.e., $T_{all} = 200$). The two parameters of the concession strategy used in Equation (8) are set to $\lambda = 0.1$ and $\beta = 0.25$, which means that we assume that all ANFGA participants are not overly concerned with time constraints. The parameters for the GA of ANFGA are as follows: $Population < uscore > Size = 100$, $Max_{Iteration} = 50$, $Mutation_{Rate} = 0.5$, and $Elite < uscore > Rate = 0.1$, which are determined by execution efficiency and model effectiveness.

The preference data used in the experiment are from the same questionnaire given in the Department of Pediatrics at Xiamen Hospital of Traditional Chinese Medicine as in the study by Lin et al. (2022). For the purpose of simulating more decision-making scenarios, including some extreme situations (e.g., a large number of issues or heavy time pressure), we generated more simulation preference data based on real data. Table 2 shows an example of preference data with five issues, which we use as input to demonstrate the model process more specifically. As shown in Table 2, preference is composed of the satisfaction function and weight for each issue, and the issue domain is below the issue name. Participants' satisfaction with each issue's value is determined by a trapezoid membership function, which is expressed as a four-tuple (Section 2.1.2). For example, PA's satisfaction on issue

TABLE 2 Participants' preference input on five issues.

Issue	Preference			
	PA		DA	
Cost (0–8k RMB)	(2, 3.5, 4, 6) _F	(0.2) _W	(4, 5, 7, 8) _F	(0.25) _W
Effective (1–10 rank)	(8, 9, 10, 10) _F	(0.1) _W	(6, 7, 8, 9) _F	(0.15) _W
Side-effects (0–100%)	(0, 0.05, 0.1, 0.2) _F	(0.2) _W	(0.1, 0.15, 0.2, 0.25) _F	(0.3) _W
Risk (0–100%)	(0, 0.02, 0.05, 0.15) _F	(0.3) _W	(0.05, 0.1, 0.15, 0.2) _F	(0.2) _W
Convenience (1–10 rank)	(8, 9, 10, 10) _F	(0.2) _W	(6, 7, 8, 9) _F	(0.1) _W

F means the satisfaction function of the issue, and W means the weight of the issue.

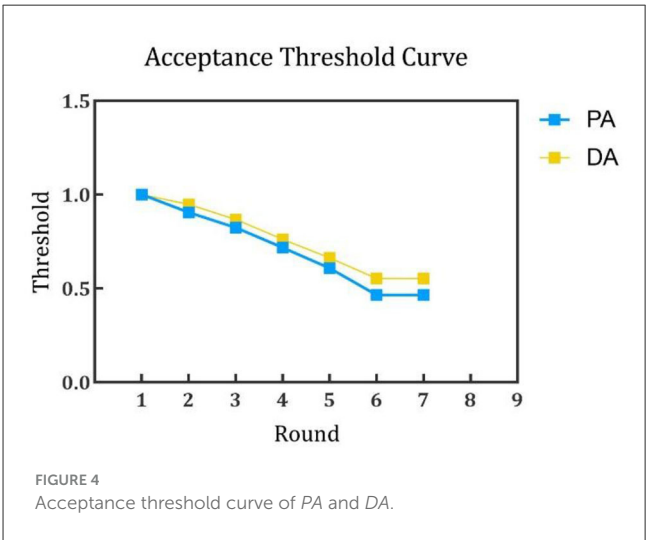


FIGURE 4 Acceptance threshold curve of PA and DA.

Cost is (2, 3.5, 4, 6)_F, meaning that the acceptable range of treatment cost is 2,000 to 6,000 RMB, and they are most willing to accept a treatment costing 3,500–4,000 RMB. Furthermore, weight is represented by a decimal value from 0 to 1, reflecting the importance of participants on the issue. For this case, the risk degree of the treatment plan is the most important for PA, whereas DA pays more attention to side effects.

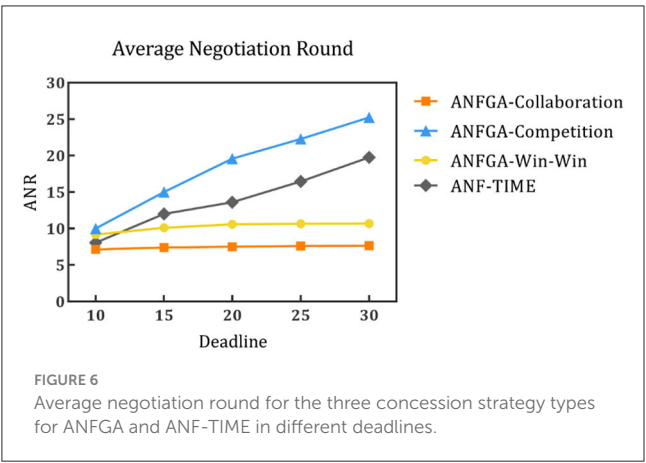
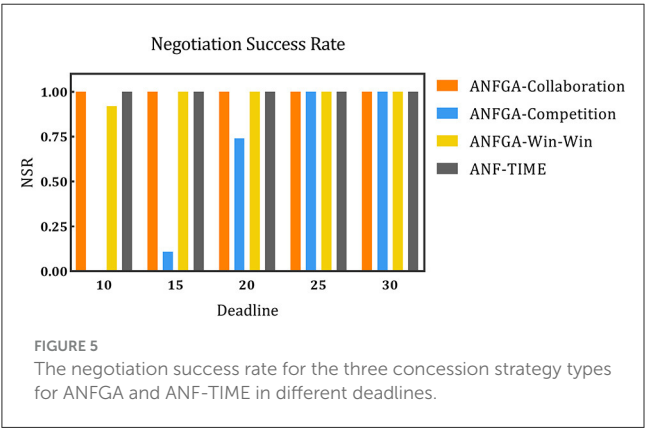
In addition, assuming that both PA and DA adopt collaboration strategies, the concession coefficient can be set as $\omega = 0.8$, so that the concession value and acceptance threshold can be calculated by Eqs (4–11). Through the process described in Section 2, PA and DA reach an agreement after seven rounds of exchange offers, and the aggregate satisfaction of both participants is 0.76 and 0.75, respectively. The acceptance threshold curve in each round and more details of the agreement are shown in Figure 4 and Table 3, respectively. Thus, the doctor and patient can determine the specific treatment content by comparing the negotiated results with the actual disease treatment plan.

3.3. Experimental results

To simulate negotiation scenarios with different time constraints, the deadline for the number of negotiations is

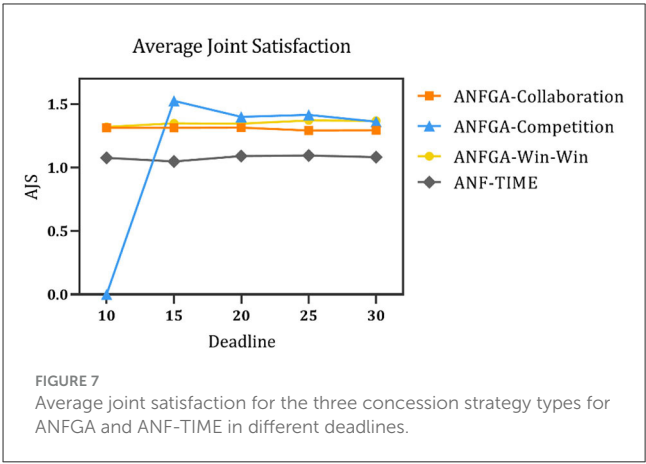
TABLE 3 Agreement.

Issue	Agreement
Cost	5.16
Effective	9
Side-effects	0.158
Risk	0.108
Convenience	9
Aggregate satisfaction	PA: 0.76, DA: 0.75



increased from 10 to 30, and the number of issues is fixed at $N = 5$. Figures 5–7 and Table 4 show the results for ANF-TIME and the three concession strategy types for ANFGA.

As Figure 5 shows, only ANFGA-Collaboration and ANF-TIME are able to maintain a 100% NSR at any deadline, and the other two agents show varying degrees of loss. In Figure 6, ANFGA-Collaboration requires the lowest ANR; in contrast, ANFGA needs more time to negotiate. Meanwhile, at larger deadlines, the ANR of ANF-TIME is more than that of ANFGA-Win-Win but still less than that of ANFGA-Competition. Figure 7 shows that ANFGA-Competition is able to reach the highest AJS under $deadline = 15$, whereas ANF-TIME maintains a lower AJS than the other two ANFGA types.



The above results show that ANFGA-Collaboration outperforms ANF-TIME for all metrics at any deadline, as ANF-TIME’s concessions only depend on the deadline without considering retaining their own interests and updating strategies from the state of the environment or opponent. In addition, although ANFGA-Competition brings greater satisfaction to both parties of the negotiation, it also involves more time costs and a higher risk of failure, as competitive strategies make the agent willing to spend time to receive more benefit for itself.

To simulate the negotiation scenario in different solution spaces, the negotiation deadline was fixed at $N = 20$, and experiments were conducted with the number of issues being set at 1, 3, 5, 7, and 9. The results are shown in Figures 8–10 and Table 5.

In Figure 8, all agents except ANFGA-Competition maintain 100% NSR under all issue numbers. In Figures 9, 10, similar to the first experiment, ANFGA-Competition is able to give the highest AJS agreement, but it still takes the most time. Furthermore, ANFGA-Collaboration outperforms ANF-TIME in all metrics.

From the above results, it can be seen that as the number of issues increases, the time required for negotiation becomes longer, and joint satisfaction decreases. Increasing the number of issues means the solution space becomes larger, making the search more difficult. At the same time, it takes more time for both parties to agree on all issues. Compared with ANF-TIME, ANFGA maintains a better and more stable performance in large solution spaces.

To validate the performance of the proposed model for opponent preference prediction, we used the same strategy to negotiate in both complete and incomplete information environments. In the complete information environment, the agent is allowed to obtain the opponent’s satisfaction function and weight of issues without prediction and then substitute them into Eqs (12), (16) directly. Figure 11 shows the results of this process at different deadlines. It can be seen that ANFGA has a better AJS compared with FCAN, but the former does not significantly improve ANR. ANFGA has ~ 0.1 distance to the complete information on both metrics. Figure 12 shows the negotiation results under different issue numbers. The distance between the three agents is smaller when the issue number is small, but when the issue number is large, ANFGA performs significantly better and is closer to the complete information than FCAN. As

TABLE 4 AJS and ANR of ANF-TIME and three concession strategy types for ANFGA in different deadlines.

Deadline	Metrics	ANF-TIME	ANFGA		
			Collaboration	Competition	Win-win
10	AJS	1.076	1.313	0.000	1.319
	ANR	8.075	7.130	10.000	9.197
15	AJS	1.047	1.312	1.525	1.348
	ANR	12.010	7.414	15.000	10.110
20	AJS	1.089	1.313	1.398	1.346
	ANR	13.600	7.500	19.583	10.600
25	AJS	1.095	1.292	1.415	1.371
	ANR	16.460	7.610	22.295	10.665
30	AJS	1.082	1.293	1.361	1.368
	ANR	19.765	7.665	25.245	10.690

Bold means the best performance among all comparison items.

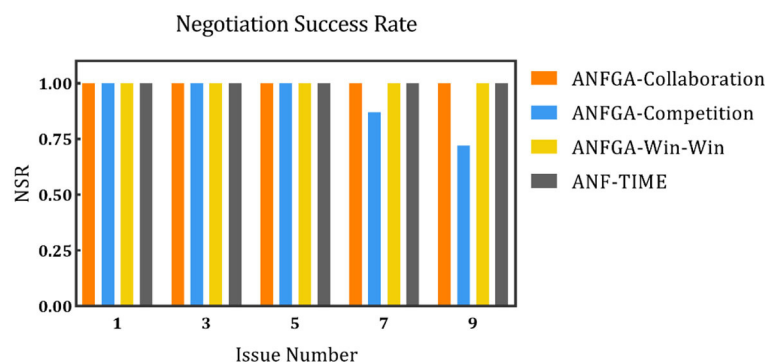


FIGURE 8

The negotiation success rate for the three concession strategy types for ANFGA and ANF-TIME in different issue numbers.

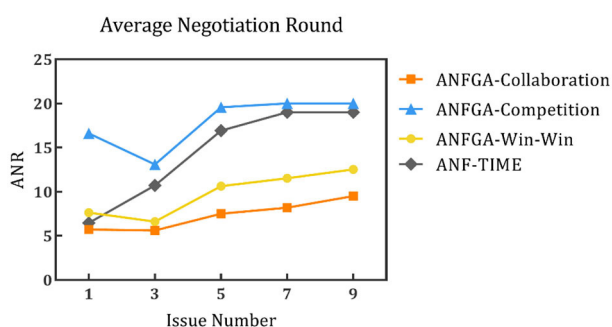


FIGURE 9

Average negotiation round for the three concession strategy types for ANFGA and ANF-TIME in different issue numbers.

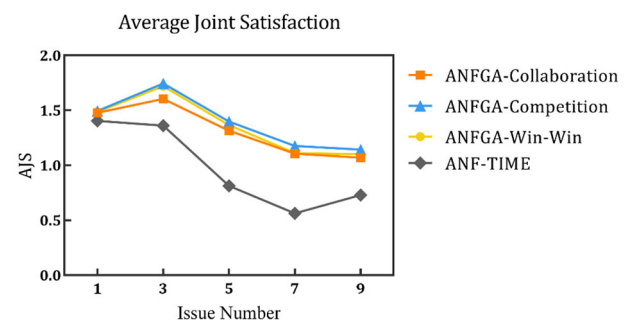


FIGURE 10

Average joint satisfaction for the three concession strategy types for ANFGA and ANF-TIME in different issue numbers.

can be seen from the above results, the addition of the opponent model provides a more satisfactory agreement between the parties and decreases the number of rounds required for negotiation, which effectively mitigates the problems caused by an incomplete negotiation environment.

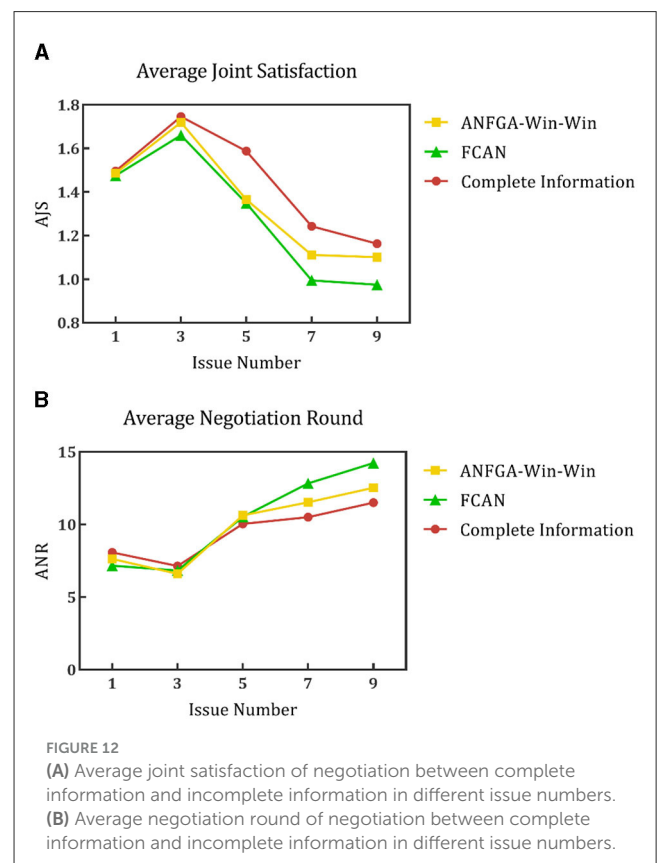
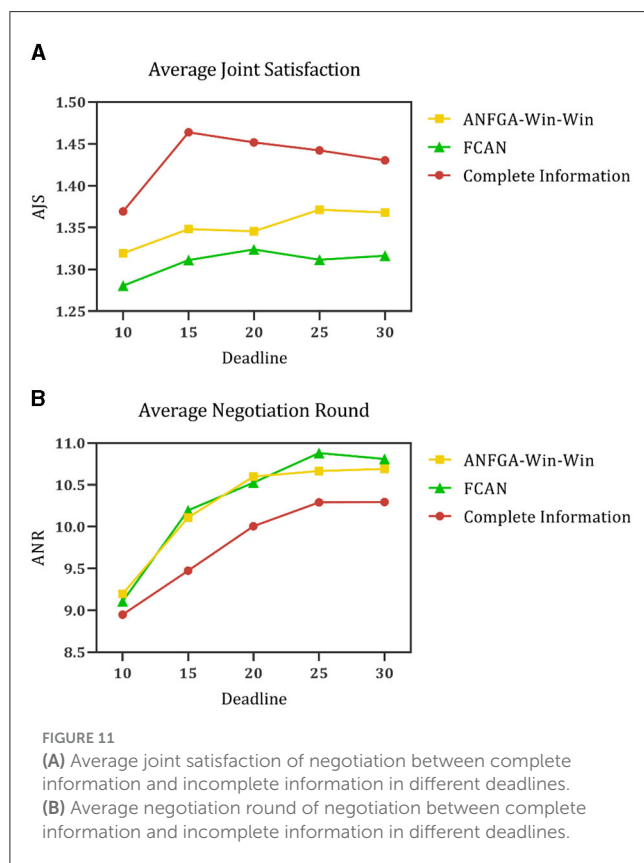
4. Discussion

Two experiments are conducted with three metrics to evaluate our model. The experimental results show that ANFGA has better performance than comparison work in both heavy time pressure

TABLE 5 AJS and ANR of ANF-TIME and three concession strategy types for ANFGA in different issue numbers.

Deadline	Metrics	ANF-TIME	ANFGA		
			Collaboration	Competition	Win-win
1	AJS	1.405	1.477	1.494	1.486
	ANR	6.460	5.720	16.610	7.625
3	AJS	1.360	1.604	1.744	1.720
	ANR	10.715	5.615	13.085	6.605
5	AJS	0.812	1.313	1.398	1.365
	ANR	16.925	7.500	19.583	10.635
7	AJS	0.563	1.105	1.177	1.111
	ANR	19.000	8.200	20.000	11.527
9	AJS	0.729	1.069	1.143	1.101
	ANR	19.000	9.500	20.000	12.527

Bold means the best performance among all comparison items.



and complex negotiation domains. Thus, our model is more adaptable to the real negotiation scenario of SDM. Among the three concession strategies of ANFGA, the results of the first experiment showed that the competition strategy required more negotiation rounds but possessed the highest joint satisfaction, the collaboration strategy needed the fewest rounds but had the lowest joint satisfaction, and the win-win strategy was a trade-off between the former two. These results are in accordance with our

assumption that our negotiation strategy is effective in expressing the concession preferences of different participants. In practice, doctors and patients can adopt different concession strategy types depending on their expectations of the outcome. The results of the second experiment showed that the effect of ANFGA in the incomplete information environment is closer to the effect of the complete information environment than the comparison model, which demonstrates that our model can deal well with

the problem of incomplete obtaining of opponent preferences in SDM.

5. Conclusion

SDM is considered an effective method for achieving patient-centered healthcare but is hampered by time constraints and personal subjective factors such as illiteracy of medical knowledge and lack of communication skills in its implementation. To reduce these negative effects and facilitate the implementation of SDM, this study proposes an agent-based auto-negotiation framework that aims for SDM participants to get close to the desired treatment plan with only a vague description of their preferences. For this purpose, to represent the uncertainty of doctor and patient preferences, a fuzzy member function is used to express this information. In addition, the above barriers also leave SDM in an incomplete information environment, with the preferences of the opponent being unavailable, making the SDM unsatisfactory and inefficient. Thus, GA-based opponent preference prediction was added to the negotiation framework, which helps the auto-negotiation model to converge faster and obtain a more satisfying solution. To verify the model, we performed simulated experiments with different information environments and different constraints. From the two metrics, AJS and ANR, it is evident that the proposed model has better performance than the agent without an opponent preference prediction strategy and remains stable under conditions of high time pressure and large solution space. The results also show that this model has promising potential when implementing the SDM between doctors and patients in real medical environments.

In the future, we will continue to maintain close contact with the clinic, collect relevant data, and conduct experiments in a real clinical environment in the next stage of our work. We also aim to improve the convergence and robustness of the model based on the results of its implementation.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

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Ethics statement

The studies involving human participants were reviewed and approved by Medical Ethics Committee of Xiamen Hospital of Traditional Chinese Medicine. The patients/participants provided their written informed consent to participate in this study.

Author contributions

K-BL and YL contributed to the conception, design, and first draft of writing. YW completed the code development and performed experiments. F-PH and Y-MY are responsible for data collection and interpretation. PL performed the statistical analysis. All authors contributed to the article revision and approved the final version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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A case for preference-sensitive decision timelines to aid shared decision-making in intensive care: need and possible application

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In the intensive care unit, it can be challenging to determine which interventions align with the patients' preferences since patients are often incapacitated and other sources, such as advance directives and surrogate input, are integral. Managing treatment decisions in this context requires a process of shared decision-making and a keen awareness of the preference-sensitive instances over the course of treatment. The present paper examines the need for the development of preference-sensitive decision timelines, and, taking aneurysmal subarachnoid hemorrhage as a use case, proposes a model of one such timeline to illustrate their potential form and value. First, the paper draws on an overview of relevant literature to demonstrate the need for better guidance to (a) aid clinicians in determining when to elicit patient preference, (b) support the drafting of advance directives, and (c) prepare surrogates for their role representing the will of an incapacitated patient in clinical decision-making. This first section emphasizes that highlighting when patient (or surrogate) input is necessary can contribute valuably to shared decision-making, especially in the context of intensive care, and can support advance care planning. As an illustration, the paper offers a model preference-sensitive decision timeline—whose generation was informed by existing guidelines and a series of interviews with patients, surrogates, and neuro-intensive care clinicians—for a use case of aneurysmal subarachnoid hemorrhage. In the last section, the paper offers reflections on how such timelines could be integrated into digital tools to aid shared decision-making.

KEYWORDS

shared decision-making, decision aids, subarachnoid hemorrhage, advance care planning, surrogate decision-makers, critical care

Introduction

Some clinical decision-making proceeds with little needed input from the patient, but most depends critically on the preferences of the person being treated. In the intensive care unit, it can be challenging to determine which life-deciding interventions align with patients' preferences since patients are often incapacitated and other means, such as advance directives and surrogates, which have inherent shortcomings, must be relied on for decision-making (1, 2). Managing such decision-making well requires a keen awareness of the preference-sensitive instances over the course of a patient's treatment.

Highlighting *when* patient (or surrogate) input is necessary can be foundational to properly supporting efforts to promote shared decision-making (SDM). The main aim of the present paper is to examine the need for the development of preference-sensitive decision timelines, and, taking aneurysmal subarachnoid hemorrhage (aSAH) as a use case, propose a model of one such timeline to demonstrate their potential form and value.

The structure of the paper is as follows: Part one explores the challenges of SDM in the context of critical care for which such timelines might be relevant; part two lays out a model timeline with the use case of aSAH; and part three explores the potential integration of such timelines into digital tools for SDM. The final section offers some reflections and concluding remarks.

Part one: relevant challenges in ICU SDM

SDM is a process whereby clinicians, drawing on their professional judgement and the best available scientific evidence, support patients, or those making decisions on the patient's behalf, to determine which treatments best align with the patient's values and goals of care (3–5). There are various models for decision-making (6, 7), but recent work has emphasized the value of shared decision-making. There is evidence that the loved-ones of critically-ill patients prefer for decision-making to be a collaborative process shared with clinicians, especially when it comes to decisions about withdrawing life-sustaining treatment (4, 8–12). Critical care societies and healthcare organizations internationally have strongly endorsed SDM (1, 4). For example, in a policy statement from the American College of Critical Care Medicine and American Thoracic Society, the authors write, “Clinicians should engage in a shared decision-making process to define overall goals of care (including decisions regarding limiting or withdrawing life-prolonging interventions) and when making major treatment decisions that may be affected by personal values, goals, and preferences” (1). The authors of the policy statement and others have pointed out, though, that there is confusion about what precise form SDM in the intensive care unit (ICU) should take and, importantly, *when* it should occur (1). Some have looked to address this. For example, Swiss experts (13) outline decision points at which treatment goals should be reassessed, e.g., when a patient has agreed to treatment in the ICU or when hypoxic brain damage has occurred following a complication. We believe such efforts to identify key moments for SDM are essential and could be further refined given the challenges present in the ICU.

Time plays a pivotal role in SDM in intensive care. While discussion of patients' goals and values is important for determining which critical care interventions are suitable, the urgency of patients' needs in the ICU makes it difficult to engage in SDM; outcomes can often be tied to the timeliness of the intervention, introducing a powerful time pressure (14, 15). Indeed, there is significant evidence to suggest that ICU clinician-family conferences about treatment planning often lack important elements of SDM (1, 4). For example, Khan and Muehlschlegel show that approximately one-third of conferences

did not include discussions about the patient's previously expressed preferences or values (16). Further research suggests that clinicians and surrogates do not follow existing recommendations for incorporating patients' values and preferences in 12%–50% of ICU-family conferences about goals of care (16, 17).

Time is a relevant factor for ICU decision-making not only in regards to urgency, but also because patients' preferences tend to evolve (18, 19). A key characteristic of shared decision making that needs to be considered is that goal of care discussions are often iterative, changing over time (14, 20). Even when impressions of the individual's goals and values remain stable, changing prognosis and the developing nature of the situation mean that treatment should be continuously re-evaluated to ensure it best reflects the patient's preferences (21–23). For example, a recent qualitative pilot study on decision-making and patient experiences of aSAH illustrated the need for systematic reassessment of the patient's will during the acute course of treatment (24). In the momentum of responding to crisis and sustaining life, treatment provided can diverge from care the patient would have wanted (25, 26).

Further complicating efforts for SDM, advance directives often have significant limitations and surrogates often struggle with their role (27–29). In their present form, advance directives often fall short of aiding patients to accurately consider their preferred future care and patients have trouble predicting the care they might want in the future as their healthcare status changes (19, 30). Moreover, advance directives sometimes lack the kind of information that clinicians and surrogates would need to assist them in determining which treatment best aligns with the wishes of an incapacitated patient (19, 31), and surrogates often feel ill-prepared (32, 33). These shortcomings matter: a study investigating retrospective agreement to treatment found that only 19% of patients surviving neurocritical care in a state of dependency would have agreed to receive the interventions that kept them alive had they had the capacity to be involved in treatment decision-making and known the outcome of the intervention (34). The consequences are experienced not only by patients, whose treatment may not reflect their preferences, but also by clinicians and surrogates. Surrogates of critical ill patients often suffer emotional distress related to the role they are asked to play (28, 29, 35) and the burden of navigating decisions around end-of-life and life-sustaining treatment has been identified as contributing to clinician burnout (36, 37). There is a need to improve the utility of advance directives and better support both clinicians and surrogates with the weight of making critical decisions on another's behalf.

In response, there have been calls to improve the support in place for these SDM processes in the context of critical care (17), and there is recognition that digital technology may have an important role to play (38). Attention has already been given to developing tools, particularly those that incorporate digital technology, to support elements of SDM, including materials to better prepare surrogates for their role (39) and aid patients in decision making (40); improved tools for prognostication to inform clinicians who carry out such conversations (38, 41); and

enhanced advance directives (30). Significant efforts have also aimed at training clinicians in how to engage in SDM (42). Less attention has been given, though, to developing materials that might help address the important shortcoming identified by the American College of Critical Care Medicine and American Thoracic Society in their policy statement: recognizing *when* shared-decision making should take place. More support is needed to increase the likelihood that SDM conversations take place at key moments so that patients' preferences are respected, especially in the context of intensive care where there are unique challenges.

Part two: a sample preference-sensitive timeline

The following section presents a sample preference-sensitive timeline for unexpected, severe brain injury, specifically for the case of aneurysmal subarachnoid hemorrhage (aSAH). The timeline is presented in the form of a graphical aid that highlights moments when the patient's goals and values are essential for informing care. To demonstrate the suitability of aSAH for such a timeline and how the condition speaks to SDM in the ICU, aSAH is first introduced below.

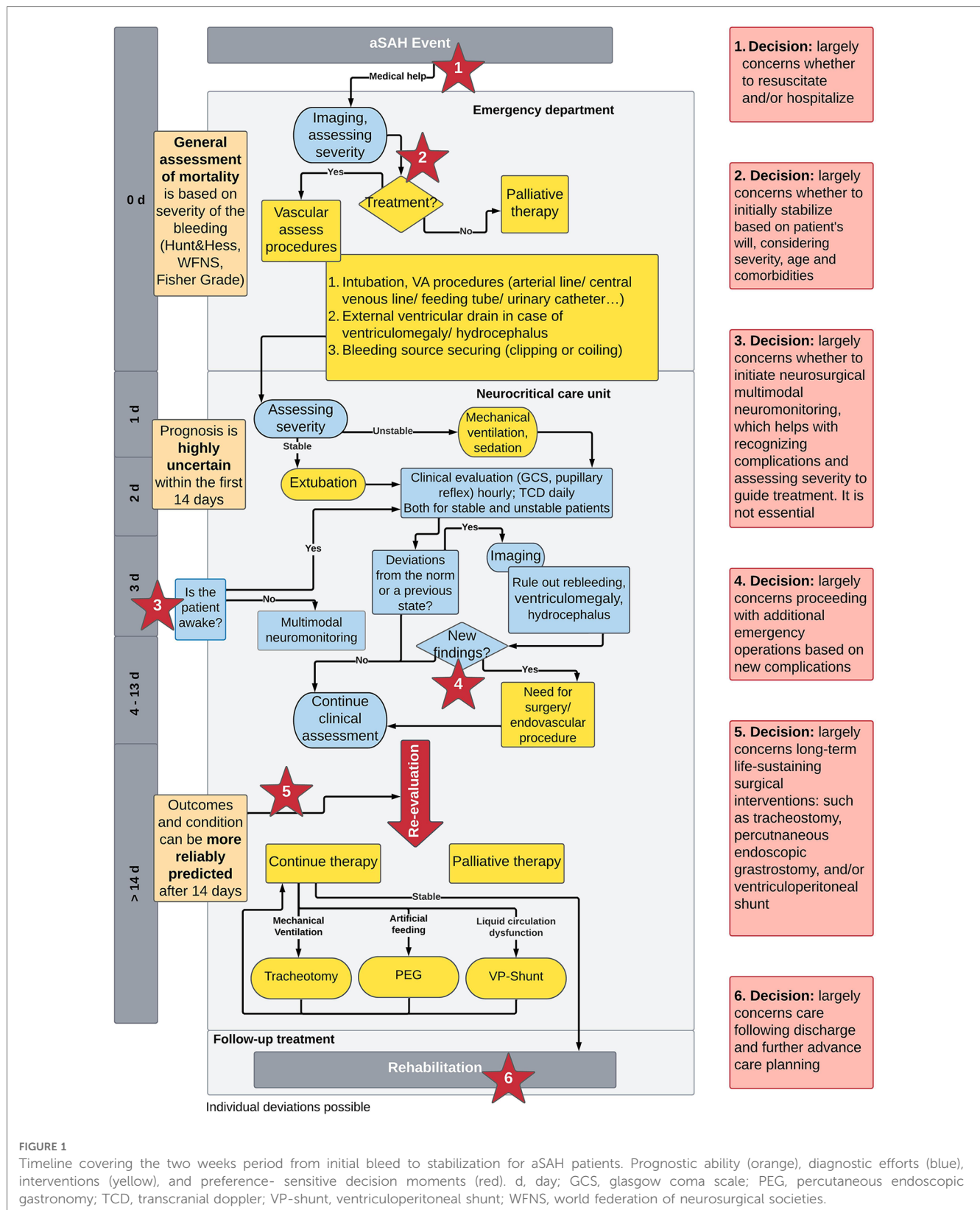
aSAH is a serious, sudden medical event, associated with significant mortality rates and high survivor morbidity (43). It affects about eight individuals out of 100,000 per year (44), half of whom are younger than 55 years old (45). Patients are often unconscious or neurologically impaired and unable to express their preferences; given their relative youth, many do not have advance directives (24). It is common for those who have been treated for aSAH to remain dependent on care from others following discharge; fewer than two thirds are found to live independently at 1-year follow-up (45). Survivors often have longstanding cognitive impairments that affect memory, language, and executive function (46). Some face challenges with basic activities of daily living such as feeding, dressing, and bathing (46). Fatigue and depression are also common (46). Survivors often contend with significantly reduced quality of life. Given the high risks and burdens, aSAH is a condition where knowledge of the person's goals and values is essential when it comes to considering which interventions to pursue. Recent guidelines for the treatment of aSAH have called for an emphasis on SDM (12).

In the case of aSAH, the person's condition can evolve rapidly and unpredictably, all-the-more so highlighting the need for regularly assessing whether care aligns with the person's preferences. There are many instances in the first two weeks following the initial bleed when quick decisions are necessary. The initial response to a ruptured aneurysm is usually to secure it through surgical clipping or endovascular coiling (47). Neurological and systemic complications can then occur, including early rebleeding, most commonly within the first 24 h (12), and potential elevated intracranial pressure (48), hydrocephalus (12), seizures (49), vasospasm or delayed cerebral ischemia (50) that tend to happen within 3–14 days of the initial

bleeding event (12, 51). Furthermore, aSAH patients frequently suffer from extracerebral complications such as cardiac injury, arrhythmias, and acute respiratory distress syndrome (52). Determining how to respond to these complications requires weighing the burden of the treatment and likelihood that interventions may lead to an intolerably low quality of life.

Drawing on existing guidelines for treating aSAH (12, 43), a recent qualitative study exploring patients' experiences with aSAH (24), and additional input from clinicians in the neurocritical care unit of the University Hospital Zurich, a timeline that highlights the critical moments for decision-making within the first two weeks following the initial bleeding event was developed. **Figure 1** displays the timeline. The descriptions of the key decision-making moments depend on the patients' goals and values.

- (1) Not all patients wish to be hospitalized following an emergency event. As such, the first preference-sensitive decision occurs immediately following the initial bleed and concerns the question of whether to initiate emergency aid and whether to transport the person experiencing aSAH to the hospital. Often, bystanders call for emergency help and medics proceed with stabilization and emergency transportation, but some people declare, or might have declared had they known about the option, not to be resuscitated and/or not to be hospitalized. Ideally, the person's underlying motives for declining such interventions are known to clarify appropriate alternatives.
- (2) Once the patient presents to the emergency department and aSAH has been diagnosed, it must be decided whether to secure the bleeding source to address the underlying conditions or whether to proceed with palliative treatment aimed at maximizing comfort and quality of life. This decision depends in large part on clinician judgement regarding what is appropriate and possible according to the severity of the bleeding and other factors affecting the person's condition, such as age and comorbidities. Efforts at basic stabilization are often systematically initiated upon presentation to the emergency department and are extremely time sensitive (53). Nevertheless, it is important to identify as best as possible what burden of treatment the person is willing to undergo and what degree of cognitive and physical disability following they might be ready to accept.
- (3) Around the third day of the patient's stay in the neurocritical care unit if the patient has not awoken, the surgical option of multimodal neuromonitoring to guide treatment and better-detect vasospasm to prevent delayed cerebral ischemia is considered (54). Since such monitoring is not essential for treatment and requires an invasive procedure, surrogates are asked to decide whether to give consent. Patients requiring this kind of care also often require maximal intensive care and deep sedation with an associated higher risk of side effects. Given the intensive and burdensome nature of this care and the fact that loved ones have had more time to process the situation, this can be a key moment to revisit the question of whether to pursue further interventions and



under what conditions it might align with the patient's preferences to instead opt for more limited or palliative care.

- (4) An inflection point occurs if there are new medical events or additional extracerebral or intracerebral complications

needing emergency neurosurgical or neuroradiological interventions. In these instances, the prognosis may worsen and other interventions, some with higher levels of burden, may become relevant. While clinicians may decide that

further intervention is not appropriate given the severity, often, deciding whether to proceed depends again on the degree of treatment burden and treatment outcomes the person would be willing to accept. Surrogates can be prepared in advance to consider such scenarios.

- (5) Around the 14th day after the aSAH event when the risk for vasospasm and delayed cerebral ischemia is lower and prognosis more reliable, it may be necessary to consider long-term life-sustaining interventions. These interventions are planned operations, such as mechanical ventilation, artificial feeding, or the continuous draining of cerebrospinal fluid by a ventriculoperitoneal shunt. At this point a clearer- but still uncertain- prognosis can be presented of physical disabilities and – less accurately – of the cognitive deficits. This becomes an important moment to consider whether long-term life-sustaining interventions should be established or whether palliative care better fits with the understood quality of life the person has expressed as being worth living.
- (6) Once patients are well-stabilized, choices are made regarding discharge from the ICU and attention can be given to anticipating preferred future care. Considerations regarding discharge include decisions about which forms and settings for rehabilitation are most appropriate, how families might structure support, and whether options such as nursing homes should be considered. Moreover, this is a critical moment to engage the patient and/or their loved ones in advance care planning to consider preferred care in the case of future health events, such as another rupture or a new aneurysm (12). Rehabilitation is a time to discuss the value of advance directives and the types of care questions that might arise in the future. First degree-family members can be made aware of their elevated risk for similar such conditions and counseled about how they might choose to engage with this knowledge, such as options for screening and treatment (55).

Part three: how such timelines can support SDM in intensive care

There are many possible applications for integrating timelines that highlight preference-sensitive decision moments into digital tools to support SDM in intensive care. Their use can be preparatory- before an event; facilitatory - during an event; and reflective - following an event. These applications are described below:

Preparatory

Such timelines might be used to create more refined and enhanced advance directives. Specifically in cases where someone is high-risk for a condition and creating a focused advance directive, incorporating such timelines in advance directives might significantly enhance the preparedness of the person considering their preferences and the clinical utility of the resulting advance directive by clearly illustrating the flow of

decisions and eliciting input regarding preference-sensitive decision moments with different options that affect outcome. Moreover, these timelines can be digitally embedded in such a way that they are interactive and capable of providing the user with more information about the contained terminology or procedures.

Facilitatory

Timelines can be embedded into electronic health records in a way that prompts clinicians with a reminder to engage the patient and their loved ones in SDM at certain stages of treatment. These reminders may be valuable to ensure that interventions aimed at treating, curing, and/or sustaining life are not maintained simply because they have been initiated. These prompts may support clinicians who are clear on the value of SDM but less sure when to initiate or revisit discussions in the flow of high-pressured decision-making.

Timelines can also be digitally shared with surrogate decision-makers once a patient has presented to the ICU as a way to prepare them for the moments when their input may be needed and support them in their role. As in the case of advance directives, these materials could be interactive with an informing function to better define terminology or explain procedures. Such timelines can complement discussions with clinicians, capturing information that has been discussed and illuminating questions that may need further clarification.

Reflective

Timelines may be important aids for evaluating care provided, both to determine if the choices aligned with a patient's preferences and to support clinicians in processing the experience. Such timelines can be used for formal or informal inquiry into retrospective agreement with received neurocritical care, elicited either from the patient him or herself and/or from those who played the role of surrogate depending on the person's capacity. Follow up questionnaires or interviews can be structured around the preference-sensitive decision moments. Moreover, debriefing difficult work situations is recommended for mitigating the risk of posttraumatic stress and burnout for ICU workers (56). Timelines may offer a framework to guide reflections on the care of critically ill patients in a way that supports clinicians in processing their role and responsibility.

Discussion and conclusion

It is important to consider the potential challenges and risks of using timelines as well as their broader possible application. These timelines present granularity and complexity (57, 58). Preparing patients or surrogates to comment on specific interventions may lead to declarations that are ill-fitting, conflict with best clinical judgment, or do not truly reflect the patient's goals (59) due to limited understanding (60). Such timelines may be hard to understand without expertise and/or lead to feelings of overwhelm (61, 62). They may introduce fears concerning possible future events (59) or increase retrospective

BOX 1 Methodology for developing timelines supporting SDM in intensive care.

1. Screen existing clinical guidelines to determine standard care pathways for the designated illness or injury.
2. Draft an outline of the main treatment options and frequent complications, specifying when they tend to occur.
3. Gain input from health professionals, patients, and surrogates about moments when treatment decisions must be made that rely on patients' preferences. This can draw on questionnaires, interviews, evaluation of medical records, advance directives etc.
4. Mark preference-sensitive decision moments and describe the essence of the choice.

dissatisfaction. The appropriate use of timelines requires thoughtfulness about how they are presented, when, and to whom (59). Their design should take the audience into account (63, 64) and include input from users regarding comprehensibility, usability, and utility (65). Ideally, these timelines should aim to support collaboration (1, 4). Other professional groups may also benefit from their use, such as spiritual counselors, social workers and members of ethics committees (59).

There is broad applicability for these timelines outside the use case of aSAH (59). Following the high-level methodology outlined in Box 1, we suggest these timelines be developed for other conditions where patients may be unable to participate in decision-making, the patient's status is likely to evolve, and quick decisions must be made. These timelines may have an important role to play in multi-component advance decision aids, potentially supported by artificial intelligence (AI) in the future (66). There is a need for continued interprofessional collaboration amongst ethicists, clinicians, developers, designers, and intended audience to create effective tools that support SDM (65).

Data availability statement

The original contributions presented in the study are included in the article/Supplementary Material, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical approval was not required for the study involving humans in accordance with the local legislation and institutional requirements. Written informed consent to participate in this study was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and the institutional requirements.

Author contributions

BG: Investigation, Methodology, Project administration, Visualization, Writing – original draft, Writing – review & editing.

SG: Investigation, Methodology, Writing – original draft, Writing – review & editing. AF: Investigation, Writing – original draft, Writing – review & editing. GB: Methodology, Resources, Visualization, Writing – review & editing. AG: Supervision, Writing – review & editing. NB-A: Conceptualization, Funding acquisition, Project administration, Writing – review & editing, Supervision.

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Conflict of interest

NB-A is a co-founder of PMB GmbH as well as part of the Research Topic's editorial team. She was not involved in the peer review or any editorial decision regarding this manuscript.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Exploring the role of AI in classifying, analyzing, and generating case reports on assisted suicide cases: feasibility and ethical implications

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This paper presents a study on the use of AI models for the classification of case reports on assisted suicide procedures. The database of the five Dutch regional bioethics committees was scraped to collect the 72 case reports available in English. We trained several AI models for classification according to the categories defined by the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act. We also conducted a related project to fine-tune an OpenAI GPT-3.5-turbo large language model for generating new fictional but plausible cases. As AI is increasingly being used for judgement, it is possible to imagine an application in decision-making regarding assisted suicide. Here we explore two arising questions: feasibility and ethics, with the aim of contributing to a critical assessment of the potential role of AI in decision-making in highly sensitive areas.

KEYWORDS

AI, artificial intelligence, assisted suicide, euthanasia, ethics committee, synthetic data, case classification

1 Introduction

In an age where artificial intelligence (AI) has emerged as a formidable tool in various fields and is increasingly used for judgment (Fogel and Kvedar, 2018; Niiler, 2019; Surden, 2019; Selten et al., 2023), it is imperative to explore its potential applications in domains that are sensitive and ethically challenging. This paper delves into one such realm, presenting an exploratory study that investigates the use of AI models for the classification of case reports related to assisted suicide procedures according to the standards defined by the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act (RTE, 2022),¹ the generation of fictional but plausible cases with fine-tuned AI models, and their potential impact on shared decision-making processes.

Our exploratory study primarily aimed to explore how AI models can extract relevant information from unstructured text on assisted suicide cases, potentially assisting and enhancing ethics committees' functions. To do so, we employed a diverse range of AI models for the classification of case reports based on their content. Results indicate that AI can

¹ Review procedures of termination of life on request and assisted suicide and amendment to the Penal Code and the Burial and Cremation Act. Senate, session 2000–2001, 26. 691, number 137 (2001).

efficiently categorize case reports and facilitate ethical decision-making by identifying key patterns and precedents, enhancing discussions and decisions in the bioethics domain. Moreover, we tested the possibility to generate synthetic plausible cases using a state of the art large language model, fine-tuned specifically for this task. Results highlight the potential yet immature role of AI-generated synthetic cases in bioethics decision-making, showing that while 60% of cases were plausible, further development and human curation are needed to fully harness their benefits for further use.

Incorporating AI into the domain of bioethics introduces ethical considerations of paramount significance (Ekmekci and Arda, 2020; Skorburg et al., 2020; Sinnott-Armstrong and Skorburg, 2021; Klugman and Gerke, 2022). This study recognizes and addresses the potential challenges and ethical dilemmas associated with the increasing reliance on AI for decision-making in this sensitive field, first and foremost automation bias (Klugman and Gerke, 2022). It underscores the critical importance of maintaining a human presence “in the loop” for making critical decisions and emphasizes the need for responsible and ethically sound implementation of AI technology.

1.1 Assisted suicide in the Netherlands

Bioethics, a multidisciplinary field at the intersection of multiple disciplines, including (among others) medicine, philosophy, psychology, anthropology, plays a crucial role in shaping the ethical framework of medical decision-making. Within this broader context, certain medical procedures and decision-making processes present intricate ethical challenges. Given its profound implications, the topic of assisted suicide presents one of the most challenging ethical dilemmas to address: the deliberate choice to help someone end their own life, while invoking profound moral considerations, demands rigorous scrutiny and informed deliberation (Frosch and Kaplan, 1999; Dees et al., 2013). In this light, bioethics serves as the compass guiding the ethical discourse surrounding assisted suicide. In the Netherlands assisted suicide and euthanasia are disciplined by the Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act (RTE, 2022) (see footnote 1). According to the act, euthanasia is the intentional termination of a person's life upon their request, while in physician-assisted suicide individuals self-administer medication prescribed by a doctor. These practices are permitted when carried out by a physician who complies with specific regulations (Buiting et al., 2009). After a physician performs euthanasia, they are required to notify the municipal pathologist by completing the appropriate notification form and submitting it during the post-mortem examination. The physician also provides a detailed report, which is mandatory under the Burial and Cremation Act. Failure to meet this requirement is considered an offense (RTE, 2022) (see footnote 1).

In addition to the detailed report, the physician typically includes other information, such as the patient's medical records, specialist letters, and the patient's advance directive. The municipal pathologist then sends this notification, along with the accompanying documents, to the relevant regional review

committee. This committee assesses the reports and the euthanasia procedure (RTE, 2022) (see footnote 1).

If the committee determines that the physician has met all the required criteria, they inform the physician in writing, concluding the review process. However, if the committee finds that the physician did not fulfill one or more due care criteria, they are legally obliged to report their findings to the Public Prosecution Service and the Health and Youth Care Inspectorate, which then decide on the appropriate actions (RTE, 2022) (see footnote 1).

The committee's evaluation includes examining whether the physician adhered to the due care criteria outlined in the law, legislative history, case law, as well as professional standards. They assess whether the patient's request was voluntary and well-considered, the patient's suffering was unbearable with no hope of improvement, and there were no reasonable alternatives. They also consider whether the physician informed the patient, consulted an independent physician, and executed the procedure with proper medical care and attention regarding due care criteria (RTE, 2022). The committees responsible for reviewing euthanasia notifications in the Netherlands categorize them into two groups: straightforward notifications (about 95% of cases) and those that raise questions (roughly 5% of cases). Straightforward notifications are reviewed digitally, and committee members can communicate through a secure network without the need for physical meetings. However, if any issues or uncertainties arise during the digital review, the notification's status may be changed to non-straightforward. Non-straightforward notifications are always discussed at committee meetings, and whether a notification falls into the straightforward or non-straightforward category depends on the complexity of the case or the clarity of the information provided by the physician (RTE, 2022). In order to explore and critically assess the potential role of AI in decision-making in this highly sensitive area, we therefore tried to classify these case reports based on the same categories prescribed by the Dutch law, i.e.: due care criteria complied with; acted in accordance with the due care criteria; voluntary and well-considered request; independent assessment; unbearable suffering without prospect of improvement; no reasonable alternative; exercising due medical care; straightforward case.

In acknowledging the significant legal dimensions of assisted suicide, it is crucial to recognize that the procedures and decisions within this study are deeply rooted in legal frameworks. While our approach primarily emphasizes the bioethical perspective, the intertwining of legal stipulations cannot be understated. The detailed legal processes, criteria for due care, and the stringent review mechanisms underscore the intersection of bioethics with legal considerations in assisted suicide. In this regard, our study also aligns with the emerging field of “legal tech”, wherein technology, especially AI, is leveraged to navigate, analyze, and streamline complex legal processes (McKamey, 2017; Soukupovand, 2021; Becker et al., 2023). This perspective opens up a broader dialogue, situating our research at the convergence of bioethics, law, and technological innovation, and highlights the potential of AI not only as a tool for ethical deliberation but also as an asset in understanding and operationalizing legal requirements in sensitive medical procedures.

1.2 Importance of classification

The use of AI-based classifiers on case reports could play a role both in the workflow of ethics committees and in research on decision making processes around assisted suicide. Filing, assessing and classifying these case reports is prescribed by law in the Dutch system, as every report needs to be reviewed by the competent Regional Bioethics Committee to ensure the case complied with the regulations. Moreover, the study of case reports plays a relevant role in the field of bioethics (Arras, 2001; Braunack-Mayer, 2001; Thacher, 2006), as they offer valuable insights into the ethical dilemmas emerging from practice, offering a window into the intricacies faced by medical professionals and the consequences of their decisions (Parker and Dickenson, 2001), particularly in the context of assisted suicide (Meisel, 1996; Nicholson, 2013; Gilbert and Boag, 2019), and providing a foundation for informed decision-making and policy development. Through proper classification, it becomes possible to identify patterns, trends, and therefore to develop empirically informed ethical considerations in assisted suicide procedures (Emanuel, 1994; Brauer et al., 2015). This process can shed light on the factors influencing medical decisions and their ethical implications (Brauer et al., 2015). It not only aids in academic research, but also (and most importantly) informs medical professionals, policymakers, and clinical bioethicists in their need for a deeper understanding of assisted suicide practices and the moral questions that surround them. However, the volume of these reports can be overwhelming, making their classification and analysis a daunting task. It is here that AI systems could be applied to enhance and streamline the classification process, offering the potential to extract valuable insights from the wealth of data available.

1.3 Limitations of manual classification and role of AI in bioethics

Manually analyzing and sorting a substantial volume of case reports with traditional approaches such as thematic analysis (Clarke and Braun, 2017) is a labor-intensive and time-consuming task. Human limitations, such as fatigue and potential biases, can hinder the accuracy and efficiency of classification (Spitale et al., 2023). This creates a space for innovative approaches to streamline the process, ensuring that critical insights are not lost due to the constraints of manual labor.

It is important to note that, until recent years, text data, often referred to as “unstructured data”, could not be fully harnessed for its wealth of nuanced knowledge. While texts written in natural language are often simply called “unstructured data” this is inaccurate from the perspective of a linguist. Language expresses knowledge in all its nuances; what was lacking until recently was the ability to explore these nuances automatically. While coarse topics and general sentiment could be extracted, these approaches remained imprecise. The discovery of text understood literally as data is only recent (Grimmer et al., 2022). Advances in Natural Language Processing (NLP), exemplified by models like BERT (Devlin et al., 2019) and GPT (Brown et al., 2020), have unlocked the capacity to explore textual data's richness, allowing for a

more precise understanding of the intricate nuances within text. Such advances have broad implications, particularly in the field of bioethics, as they enable more accurate and comprehensive analysis of case reports (Cohen, 2023; Thirunavukarasu et al., 2023).

AI models are increasingly finding applications in various medical and bioethical domains, offering the potential to streamline processes and enhance decision-making (Skorburg et al., 2020; Thirunavukarasu et al., 2023). These technologies provide tools for automating tasks that were previously cumbersome and time-consuming, enabling medical professionals and bioethicists to focus on the ethical nuances of their work.

Using AI models for classifying case reports introduces numerous advantages: these models excel in efficiency, scalability, and the ability to process vast datasets rapidly. While not free from various forms of bias, AI bias is measurable and mitigatable (Nadeem et al., 2020; Liang et al., 2021; Liu et al., 2022). They can identify subtle patterns and trends that may elude human observers, contributing to a deeper understanding of the ethical considerations in assisted suicide procedures. AI models are therefore valuable allies in the effort to make sense of the ever-increasing volume of data with bioethical significance.

1.4 Synthetic case generation

Our study extends beyond classification, delving into synthetic case generation. In recent years, there has been a surge in interest regarding the use of AI-generated synthetic data to supplement case reports (Bélisle-Pipon et al., 2023; Spector-Bagdady, 2023; Victor et al., 2023). This approach holds the potential to revolutionize the training of AI models, for example by increasing the availability of non-straightforward cases, which as reported by the Dutch Regional Euthanasia Review Committees constitute only about 5% of the notifications (RTE, 2022). In order to train a model to recognize and classify them avoiding risks of overfitting, more would be needed for both training and testing. Moreover, generating synthetic data (Nikolenko, 2021) is useful because it solves privacy issues, as sensitive data can usually not be shared due to K-anonymity (Ciriani et al., 2007) problems. We therefore fine-tuned a GPT-3.5-turbo model (OpenAI, 2023) to generate synthetic case reports. These artificially generated cases, once assessed as plausible, hold promise not only for enhancing AI models' training on cases which are scarcely available and thus improving the classification results of AI systems (Chen et al., 2021), but also for serving as valuable educational tools for bioethicists, increasing the possibility to study a broader array of conflictual situations. These artificially generated cases, when designed with precision and assessed for plausibility, have the potential to complement real-world data, providing a broader, larger, on-demand, and more diverse dataset for training and analysis.

1.5 Data source

To conduct this exploratory study, we used the repository of case reports maintained by the Dutch regional bioethics committees (Regional Euthanasia Review Committees, 2017).

TABLE 1 Cases available in the Dutch Regional Ethics Committees database, organized per year and language.

Year	English	Dutch
2001–2011		53
2012		63
2013		107
2014		93
2015	9	82
2016	16	72
2017	15	97
2018	8	105
2019	24	102
2020		76
2021		130
2022		113
2023		87
Total	72	1,180

These 1,252 reports, 72 of which are available in English, served as our primary data source. The utilization of this database ensured that our study had access to a wide array of cases, enriching our investigation and enhancing the representativeness of our findings. The number of cases available in the database is described in Table 1.

2 Methods

2.1 Data collection

To gather data for our research, we utilized web scraping techniques to collect case reports available in English from the database of the five Dutch regional bioethics committees. The code used for data collection and the resulting data are available via this study's repository (Spitale and Schneider, 2023). The data collection process was organized and executed in python within a Jupyter notebook (Jupyter, 2023), ensuring optimized explainability and readability of the code used.

The primary data source utilized for this study was the official website of the Dutch regional bioethics committees, specifically the section dedicated to case reports on assisted suicide procedures, which is publicly available at <https://english.euthanasiecommissie.nl/judgments/>. The data retrieval process was structured to encompass all subpages on this website, categorized according to the year of publication.

For each subpage, we implemented web scraping techniques to capture a set of essential information, including the following key attributes:

1. **Case ID:** a unique identifier for each case report.
2. **Title:** the title of the case report.
3. **Publication Date:** the date when the case report was published.
4. **Link:** the URL link to the specific case report.

TABLE 2 Classes to predict in case classification.

Class	Type
Due care criteria complied with	y/n
Acted in accordance with the due care criteria	y/n
Voluntary and well-considered request	y/n
Independent assessment	y/n
Unbearable suffering without prospect of improvement	y/n
No reasonable alternative	y/n
Straightforward case	y/n
Exercising due medical care	y/n

5. **Introduction:** a brief introductory text accompanying the case report.
6. **Text:** the case report.
7. **Tags:** the relevant tags associated with the case report, which encompassed categories such as Age, Disorders, Due care criteria compliance, Judgment, Notifying physician, and Year of publication.

Upon successfully retrieving this information from the website, the resulting dataset was organized and exported as an Excel table. This structured dataset provided a foundation for the subsequent analysis and training.

It is important to note that, in this exploratory study, the focus was specifically on collecting and analyzing case reports available in English. While it would have been feasible to gather case reports written in Dutch and consider translation for analysis, the decision was made to work exclusively with the 72 cases available in English. This choice was driven by the study's scope and the avoidance of potential bias introduced by automatic translations. By concentrating on English-language cases, rather than including also machine translations of the cases available in Dutch, we aimed to ensure a consistent and unbiased analysis of the available data.

2.2 AI for case classification

In the pursuit of systematic classification of case reports in our dataset, a critical element of this study was the choice of document classification approaches. These models were used to predict various classes based on the multifaceted ethical and medical dimensions inherent to each case. The classes of prediction encompassed those described in the Dutch law. The classification process was designed to discern nuanced distinctions, such as whether due care criteria were complied with or not, whether medical care was exercised, and whether the case was considered straightforward or not. Classes to predict are summarized in Table 2.

2.2.1 Document classification with logistic regression

As a first method, we use supervised binary document classification to predict whether the committee agrees that euthanasia was justified (*yes*) or not (*no*). Document classification is

one of the most versatile methods (Grimmer and Stewart, 2013) for content analysis. As mainly words are used as features, irrespective of their contexts, the approach is also often called bag-of-words classification. We use up to three words in sequence, a simple trigram approach, which means that every word, bigram and trigram is a feature, as long as they occur more than 5 times in the corpus. This gave us 3,679 features.

In the very simple algorithm of Naïve Bayes, every *feature* is given the same weight, which means that the probability of a document *text* to belong to a class *C* is calculated as follows:

$$P(C|text) = P(C) \times \prod_{feature \in text} P(feature|C) \quad (1)$$

In linear or logistic regression, the training process also learns optimal weights for each feature from the training data. If linear regression were used for document classification, the formula would be:

$$P(C|text) = \sum_{i=0}^N w_i \times P(C|feature_i) \quad (2)$$

Where *N* is the number of features and *w_i* the weight of feature *i*.

Logistic regression further maps the linear value for the predictor to a probability, using the *logit* function. For further details on linear and logistic regression for document classification, see Jurafsky and Martin (2009).

We also apply standard methods against overfitting (Dormann et al., 2013), such as a frequency threshold of 5, 10-fold cross-validation and L2 regularization. In *X*-fold cross validation, a model is trained *X* times, with *X* – 1/*X* parts used for training and evaluation on the left-out part. The left-out part has size *N* * 1/*X*, and is always different for each of the *N* runs. The final model is built from the mean of the individual *N* models. Schreiber-Gregory and Jackson (2018) explains that the gist of regularization is to add a penalty to each model parameter. The effect of this smoothing technique is that the model generalizes better to the data instead of overfitting.

Document classification uses vector space models, in which there are typically as many dimensions as features. Raw frequency or better keyword metrics like TFIDF are used to represent each document. Similarity between documents, or also between words, is expressed by the similarity of the vector, using the cosine metric. The cosine of the angle between two vectors pointing into the same direction is 1, while the cosine of a right angle is 0. For document classification, feature by document matrices are used. In our data, we thus get a matrix of 72 documents times 3,679 features, a high dimensionality that is already taxing for calculations, and has the disadvantage that it cannot profit from feature similarity, e.g., the fact that in our texts *think*, *assess*, and *agree*, or *illness*, *disease* and *condition* are very similar.

As document classification models capture linear relations between features and classes, feature weights can be interpreted as salience or keyword measures. For instance, Schneider uses the feature weights to describe the differences between Swiss High German and German High German (Schneider et al., 2018). Disadvantages of linear models are that they cannot capture complex non-linear relationships, for instance negations, multi-word units or recognize similar words.

2.2.2 BERT NLI model

In order to recognize similar words, one can learn word similarity from large collection of contexts, exploiting the Firthian hypothesis (Firth, 1957). Language philosophy dating back to Wittgenstein (1958) has stipulated that words are defined in their context, and that word usage updates their meaning (Bybee, 2007). Contexts can also be calculated using vector space models, this time with word × word matrices instead of document × word or document × feature matrices as we have used them for document classification. While these, so-called distributional semantics models, perform well, they need very large amounts of texts, leading to matrices of 10,000 times 10,000 words and more, which are taxing to calculate in practice. Also, it has been shown that dimensionality reduction techniques such as SVD (Deerwester et al., 1990) do not only reduce dimensionality to more manageable values, but also add smoothing and recognize similar words, leading to a more performant input for the calculation of word similarities with vector models (Baroni and Lenci, 2010). Typically, 100–300 dimensions are used. More recently, predictive neural models have shown to perform better than vector models (Baroni et al., 2014). The corresponding representations, again typically using 100–300 dimensions, are compatible with distributional semantic models and are known as word embeddings.

While it is beyond the scope to explain neural networks, they can be thought of as an arrangement of neurons, where each neuron is a logistic regression, which either fires or not, like a neuron in the brain. In classical feed-forward networks, neurons are arranged in rows and layers, for instance five rows time five layers, leading to 25 neurons, where each row is connected to each other row in the subsequent layer. More recent neural network architectures have more complex layouts, with feedback to earlier layers (for instance RNN = recurrent neural networks) and increasingly more neurons. One successful layout type is known as transformers, a network type which manages particularly well to distinguish between relevant and irrelevant information, also across longer contexts, the mechanism is referred to as *attention* (Vaswani et al., 2023).

Like all supervised approaches, also these models learn to predict classes from large sources of training data. Typically, however, the training is not initially adapted to the task to be solved, and training data is several orders of magnitude larger, so large that the training cannot be performed on a normal desktop computer. These models are also called Large Language Models (LLMs).

As large amounts of data are key for all supervised methods, and as data availability is the bottleneck, the search for meaningful task for which almost infinite amounts of correctly annotated data is available is the prediction of the next word. This is the central task in BERT models, and also in GPT, with the difference that BERT predicts words both from left-to-right and from right-to-left. This method is also called *self-supervised*. It is supervised because a class is predicted (the next word), but it is completely data-driven like unsupervised approaches, as no external manual annotation is used. Self-supervised LLMs can be said to be models that are trained for the wrong task—unless you want to generate text automatically. These models have an excellent world knowledge but no task-specific knowledge. Task-specific knowledge can be added to them with further training

instances. Such fine-tuned models are available for many tasks, such as sentiment detection, Natural Language Inference, Question Answering, etc.

We use Natural Language Inference model (NLI) available to the community on huggingface, the BART large MLNI model (Facebook, 2023). It is based on the BART-large model (Lewis et al., 2019), which has been pretrained on several billions of text from web scrapes, Wikipedia etc. It has 406 million parameters (4.06×10^8). For the adaptation to NLI, it has been trained further with the 393,000 training instances of the multi-lingual NLI task *multi_NLI* by Facebook (Facebook, 2022). This model has not been adapted to the task of predicting assessment of euthanasia in any way, it is thus called a zero-shot model (Xian et al., 2020). It has only been adapted to the task of predicting which conclusions can be drawn from premises. But the model already knows enough about the world to have a relatively accurate concept of euthanasia, health, and patients, as the short dialogue with the Python Jupyter Notebook reveals, reported in Table 3. In this case, “euthanasia is” is the premise, and the probabilities for a set of given conclusions, ordered by probability, are output.

For the prediction of whether the committee thinks that euthanasia is justified, we use each report separately as a premise, and ask BART large MLI for the probabilities of the following conclusions:

- For class *yes*: “The committee agrees that euthanasia was justified”
- For class *no*: “The committee thinks that euthanasia was not justified”

We set the flag *multi_label* to FALSE, as this is a binary decision task, and so that the two probabilities add to 1.

Compared to GPT3 or GPT-4 (discussed in the next section) BERT models can still be run locally on normal desktop computers, at least for the application phase.

2.2.3 ChatGPT with GPT-4

GPT-3 and GPT-4 are also LLMs using transformers. They have been trained on even larger amounts of data. GPT-3 has 175 billion parameters ($1.75 \times 100,000 \text{ millions} = 10^{11}$), three orders of magnitude more than BART-large. Training a new GPT-3 model from scratch has been estimated to use 936 MWh (Lai et al., 2022).

The only task that GPT models have been trained for is to predict the next word. ChatGPT, which currently uses GPT-3.5 or GPT-4.0 (the latter is also known as ChatGPT-4) has been further fine-tuned to give reasonable, friendly and cautious answers. ChatGPT-4 has been shown to reach human or near-human performance in many tasks, for instance in creativity (Haase and Hanel, 2023). Ronan and Schneider (in preparation) show that ChatGPT-4 can pass an English linguistics exam (end of first semester, BA level). Concerning medical applications, Beaulieu-Jones et al. (2023) attest near-human surgery knowledge, while Liévin et al. (2023) report that ChatGPT-3.5 has “human level performance” on answering multiple-choice medical exam questions (USMLE and MedMCQA).

TABLE 3 Top 10 concepts related to euthanasia in the model and probability of the association between the concept and the premise “euthanasia is” (range: 0–1).

Concept	Probability
Assisted suicide	0.99
The end of life	0.98
Connected to suffering	0.98
Death	0.95
An ethical dilemma	0.91
A consequence of suffering	0.84
An ethical question	0.82
A consequence only permitted for extreme suffering	0.63
A reason for suffering	0.37
A patient	0.11

In comparison to BERT models, it becomes rapidly clear that its deep semantic model is superior. It offers detailed and well-argued answers, as illustrated by the answer to one report, reported below. as a prompt we used the question: “The background text X from a discussion on Euthanasia is ‘...’. Given X, does everyone agree that euthanasia was justified?” in which the quoted part (“...”) is each Euthanasia report separately. The output is reported below:

The background text X indicates there were disagreements between the medical professionals involved in this case about whether euthanasia was justified. The attending physician believed euthanasia was warranted, citing the patient’s unbearable suffering and lack of prospects for improvement. However, both the psychiatrist and the neurologist involved felt there were aspects of the patient’s condition, specifically psychological and emotional factors, which had not been adequately addressed and might have improved the patient’s quality of life. They both saw room for more treatment, making them less supportive of the decision for euthanasia. Furthermore, the committee overseeing this case expressed concern over the speed of the process, the lack of intensive communication, and the absence of consultation with relevant specialists, and did not seem to find the physician’s argument for euthanasia convincing. So, based on the information given, it is clear that there is not a consensus that euthanasia was justified in this particular case.

ChatGPT offers very flexible prompting possibilities. While it typically gives extensive answers, one can explicitly ask for short or for *yes/no* answers, or refer to the context of previous answers and questions. We use the following prompt template for the classification, in which the quoted part (“...”) is each Euthanasia report separately.

“The background text X from a discussion on Euthanasia is “...”. Given X, does the committee agree that euthanasia was justified? Please answer just with yes or no.”

2.3 Fine-tuning GPT-3.5-turbo for case generation

A fundamental aspect of this study was the development of a fine-tuned AI model (OpenAI, 2023) to generate synthetic case scenarios based on the knowledge extracted from real case reports on assisted suicide procedures. The process commenced with supervised fine-tuning to tailor the GPT-3.5-Turbo model specifically for the requirements of generating authentic and plausible case scenarios. This fine-tuning phase was essential to ensure that the AI model could perform optimally within the context of the Dutch Regional Bioethics Committees data. Data and code used for the fine tuning are available via this study's repository (Spitale and Schneider, 2023).

2.3.1 Training data

For the fine-tuning process, the training data was sourced from the previously scraped and categorized case reports. These case reports served as the foundation for educating the AI model on the intricacies and nuances of assisted suicide cases. According to OpenAI's (2023) documentation, fine-tuning data should be structured as follows:

- A “system” message, describing the role and the “persona” of the model;
- A “user” message, containing the prompt with the request;
- An “assistant” message, containing the completion.

2.3.2 System message—role and persona

To guide the fine-tuning process effectively, we defined a clear and specific role for the model:

“You are an AI assistant with expertise derived from extensive analysis of Dutch Regional Bioethics Committee data. Your primary function is to generate authentic and plausible scenarios involving requests for assisted suicide and the subsequent judgments. These case scenarios are intended to serve as valuable training material for bioethicists, ensuring they closely resemble real-world situations. Your role is to craft these scenarios with a high degree of realism and ethical complexity to aid in the comprehensive training of professionals in the field of bioethics.”

This role statement provides a framework for the model's behavior and the context within which it generates new case scenarios.

2.3.3 User message—input composition

The input for the fine-tuning process comprises two key components. First, a base prompt was established to set the context for the AI model. Second, the model's training data included the classes extracted from each case by the scraper during the data collection phase (as described in the Section 2.1) as “key parameters for this case report”. These classes represented the various ethical and medical dimensions of the case and provided the model with the specific context for generating case scenarios. The base prompt is detailed below:

“We will use the following parameters to generate a case report. This report will cover two main aspects:

Part 1: Request for Assisted Suicide

In this section, we will describe a case that involves a request for assisted suicide. The information to be included comprises the patient's age, their specific medical disorders, the due care criteria, the type of judgment involved, and the identity of the notifying physician. We will detail the case, the patient's medical condition, the diagnosis, and the underlying reasons for requesting assisted suicide.

Part 2: Dutch Regional Euthanasia Review Committee Judgment

In the second part of the report, we will delve into how the aforementioned case was deliberated by the Dutch Regional Euthanasia Review Committee. We will provide insights into the ethical and legal considerations that were debated by the committee and, ultimately, share the outcome of their deliberation.

The key parameters for this case report are as follows:”

2.3.4 Assistant message—output

The output specified in the data for the fine-tuning process was the text of the case reports gathered from the Dutch repository, as previously detailed in Section 2.1. These real-world case reports served as the source material from which the AI model was trained to produce synthetic case scenarios. The fine-tuning process played a pivotal role in refining the model's capabilities, enabling it to generate synthetic cases that closely emulated the intricate complexities and nuances present in the actual case reports—based on the variables detailed before.

After removing one of the cases from the training dataset (as each example in the fine-tuning data should not surpass 4,000 tokens, and this case was longer), the training dataset comprised a total of 246,060 tokens. The model was trained for three epochs.

By assimilating and distilling the wealth of knowledge contained within the authentic cases, the AI model became apt at crafting scenarios that authentically captured the ethical and medical dimensions inherent in the field of assisted suicide.

2.3.5 Case generation

The primary goal of the case generation process was to leverage the fine-tuned model described above to generate plausible and meaningful case reports based on various combinations of parameters representing key aspects of each case.

First, we defined a range of possible values for each of the classes representing essential elements of a case. These classes encompassed aspects such as age, disorders, due care criteria, judgment, and the notifying physician. We crafted 50 random yet meaningful combinations of these defined parameters (e.g., if “age” is below 60, the notifying physician cannot be a gerontologist). These random combinations allowed us to explore a wide spectrum of possibilities while ensuring that each case was coherent and plausible.

To guide the AI model in generating the synthetic case scenarios, we used a base prompt and the lists of values for the

classes described above. This prompt outlines the overarching context and expectations for each case:

“Write a case in which the regional ethics committee decides whether a patient can have access to assisted suicide based on these variables. The case should be described in about 300 - 800 words, and in any case no more than 1000.”

The prompts, completed with the random parameter combinations, were then passed to the fine-tuned model.

The input prompts and the corresponding outputs, representing the synthetic case scenarios, were saved in a pandas dataframe and subsequently exported as an Excel file. Data and code used for the fine tuning are available via this study's repository (Spitale and Schneider, 2023).

3 Results

3.1 Document classification

3.1.1 Document classification with logistic regression

We first describe the results obtained when using binary Document Classification with logistic regression and 10-fold cross-validation, the method described in Section 2.2.1.

We obtain a classification accuracy of 93.1%. Precision on the class n is 100%, which means that all cases predicted as n are actually n . Precision of the class y is lower however: five of the documents predicted as y are actually n , precision of y is thus $51/56 = 91\%$. In terms of recall, recall of y is 100%, while recall of n is $11/16 = 69\%$. The class y is much bigger; it is common for machine learning approaches to predict the larger class too often, in case of doubt the risk of error is smaller if the majority class, or in statistical terms the prior probability, is predicted.

The classification accuracy of 93.1% seems very good, but it must also be considered that the dataset is skewed: there are only 16 cases of n , compared to 56 cases of y . Accordingly, a dumb algorithm which only considers the prior and always classifies y already obtains an accuracy of 78%. The frequently used Kappa evaluation metric measures the improvement over the prior. It is defined as

$$\kappa = \frac{p_o - p_e}{1 - p_e} \quad (3)$$

where P_e is the expected probability of the prior, and p_o the observed probability, i.e., the accuracy. The Kappa value of our model is then 69%.

3.1.2 BERT NLI classification

We now describe the classification performance of the zero-shot BART NLI model that we have described in Section 2.2.2.

We used the prompt: “The background text X from a discussion on Euthanasia is ‘...’. Given X , does the committee agree that euthanasia was justified? Please answer just with yes or no.”

Its accuracy is $63/72 = 88\%$. Three cases that are predicted n are actually y , precision of class y is thus $53/56 = 95\%$. Precision of n is

lower (like in document classification, Section 2.2.1), $10/16 = 63\%$. The Kappa value is 44%. This means that the classification accuracy is only a bit less than halfway between random choice with the prior and actual classification.

3.1.3 Classification by ChatGPT with GPT-4

ChatGPT-4 classifies all 72 cases correctly, which corresponds to an accuracy, precision and recall of 100%. Although GPT-4 has not been fine-tuned for this task, it beats supervised bag-of-words document classification. It performs much better than the simpler zero-shot approach using a BERT model.

While this illustrates the superior deep semantics of GPT-4, we also need to consider a few points. First, the task is relatively easy for humans. The reports are written after the recommendation has been made, in order to defend it, they thus argue clearly for their case. Second, using the optimal prompt is crucial. In our initial experiments, we first used the prompt: “The background text X from a discussion on Euthanasia is ‘...’. Given X , does everyone agree that euthanasia was justified? Please answer just with yes or no.”

This prompt had a poor performance on the task, as all contested cases were answered with “no”. Fortunately, ChatGPT can also be used to find optimal prompts. Simply asking “why?” revealed a summary of the conflict and differences of opinions: by being able to answer follow-up questions and providing explanations, ChatGPT can mitigate the black box problem. Finally, ChatGPT is too calculation-intensive to be used large-scale. It needs complex architecture of servers with GPUs also for the application phase if latency is an issue, and asking GPT for millions of decisions leaves a large carbon footprint.

3.2 Case generation

We used the fine-tuned model described before to create a dataset of 50 distinct cases. Evaluating the plausibility of these generated cases was the focus of our process. Plausibility, in this context, refers to the degree to which a case scenario aligns with realistic and coherent narratives, consistent with the ethical complexities inherent in the training dataset. The plausibility assessment, performed manually by carefully reading each case, aimed to ensure that the synthetic cases produced by the model were meaningful. Conditions for deeming a case not plausible include the discussion of situations not disciplined by the Dutch law (e.g., “A 15-year-old boy who suffers from Duchenne muscular dystrophy will be taken to Switzerland by his parents to undergo euthanasia.”); impossible diagnoses (e.g., “Assisted suicide for a terminally ill patient with complex, life-threatening but not terminal disorders”); model hallucinations (e.g., “It is astonishing that the link between brain death and a clinical evaluation of due care, was being unclear is the production of greenhouse gases”).

The outcome of this evaluation is detailed in Figure 1.

It is essential to note that, while these results offer valuable insights into the capabilities of the fine-tuned gpt-3.5-turbo model, there is still room for improvement. Further fine-tuning and refinement of the model could enhance its capacity to generate

Plausibility of cases generated with fine-tuned gpt-3.5-turbo model

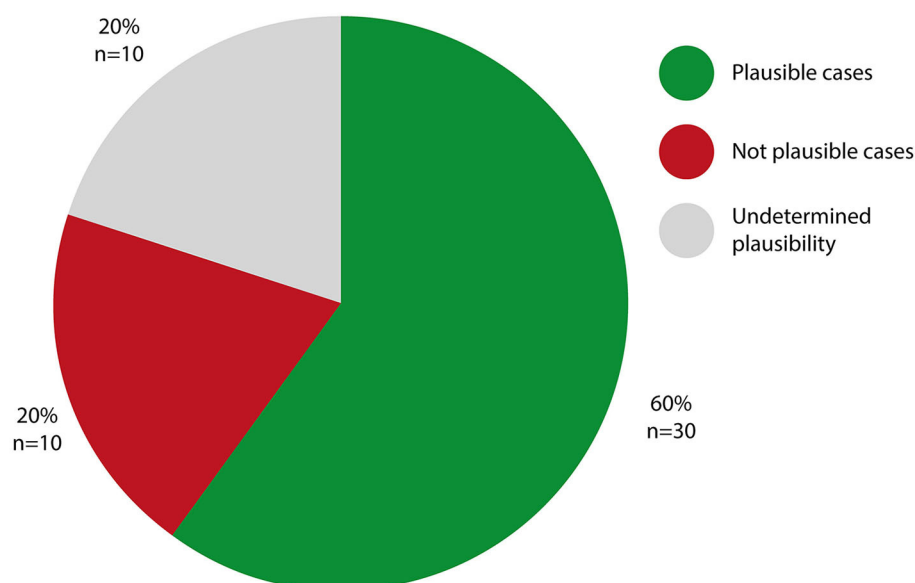


FIGURE 1

Plausibility of generated cases. Plausible Cases (60%): a total of 30 cases, representing 60% of the generated scenarios, were classified as plausible. These cases aligned well with the expectations of coherent and realistic case narratives. Not plausible cases (20%): 10 cases, or 20% of the dataset, were determined to be not plausible. These scenarios displayed inconsistencies or inaccuracies. Undetermined Plausibility (20%): in 10 cases, which accounted for 20% of the dataset, the model's output reached the token limit, preventing it from completing the case scenario. As a result, these cases were assigned "undetermined plausibility" status.

even more plausible and intricate case scenarios. The evaluation of plausibility remains a continuous process, striving to produce synthetic cases that closely resemble real-world situations and contribute to a deeper understanding of the ethical considerations within the realm of assisted suicide procedures in the field of bioethics.

4 Discussion

4.1 Possible uses of classifiers

It is important to emphasize that our primary goal in this exploratory study was not to develop systems able to formulate recommendations or to replace the essential function of an ethics committee. Instead, our aim was to initiate the process of understanding how specific and pertinent information related to assisted suicide cases can be effectively extracted from unstructured text.

The presented results offer valuable insights into the application of AI models for categorizing and analyzing case reports on assisted suicide cases. The results obtained in this study provide justification for a shift in the approach to case classification and feature extraction in this specific context, underscoring the potential for moving beyond the analysis of case reports containing the deliberations of ethics committees. Instead, they suggest a promising avenue for experimentation with feature extraction and case classification based on the raw case descriptions that are actively debated by the ethics committees themselves. This shift

holds the potential to streamline and enhance the decision-making process by offering a proactive assessment of cases, allowing for early identification of relevant ethical considerations.

AI-based classifiers, by efficiently analyzing and categorizing case reports, have the potential to expedite the identification of pertinent precedents and patterns, functioning as knowledge repositories, and facilitating the ethical evaluation of complex cases. This capability can empower more informed and collaborative decision-making processes: in discussions among stakeholders, they can provide an automated yet informed perspective that facilitates ethical conversations, alleviate the manual workload, and contributing to more comprehensive discussions and well-informed decisions. In particular, the finding that GPT-4 used via ChatGPT correctly classified all 72 cases in our binary classification shows that the deep semantics of these systems is nearing human levels also in this task.

4.2 Possible uses of synthetic cases

The findings of this study, where 60% of the generated synthetic cases were deemed plausible, with an additional 20% undetermined and 20% not plausible, shed light on the promising (albeit immature) potential of synthetic cases in the realm of shared decision making within bioethics. These results, while indicative of the current state of AI model capabilities, also point to the need for further fine-tuning on larger datasets to enhance their quality and usefulness.

Synthetic cases generated by AI models have the capacity to fill a critical gap by supplementing the often-limited real-world case data, particularly in situations where access to diverse and comprehensive case reports is restricted or safeguarded due to privacy and confidentiality concerns. Once subjected to manual human curation and selection for plausibility, these synthetic cases can emerge as valuable resources.

These curated synthetic cases can be instrumental in several ways:

- **Training AI models:** they can serve as a resource for training AI models, allowing them to learn from a broader spectrum of simulated scenarios. For instance, it can enhance access to non-straightforward cases, which, as noted by the Dutch Regional Euthanasia Review Committees, make up only around 5% of the notifications. Utilizing synthetic cases enables the training of a model to correctly categorize real cases while mitigating the risk of overfitting, thereby contributing to the quality and accuracy of AI-based analyses.
- **Research and experimentation:** the availability of synthetic cases facilitates research and experimentation in a controlled and ethical manner. This is particularly essential to ensure compliance with ethical guidelines and regulations while avoiding any breaches of *k*-anonymity and risks related to the privacy and confidentiality of actual patients.
- **Human Training:** synthetic cases can also play a role in augmenting the training of new bioethicists, medical professionals, and other stakeholders involved in the shared decision-making process. By providing additional practice in analyzing and making decisions on various assisted suicide scenarios (which can be generated on demand, specifying the desired parameters, such as the age of the patient, the underlying condition, or the compliance with the due care criteria), they can significantly enhance the skills and judgment of bioethicists, improving the quality of shared decision making.
- **Investigation of impact factors:** synthetic cases offer a controlled environment for exploring the impact of specific factors or variables on ethical decision-making. This can lead to valuable insights and potential improvements in bioethics.

Despite the significant benefits, it is crucial to acknowledge the limitations of synthetic cases, as they may not fully capture the complexity and uniqueness of real cases, and they need to be checked for plausibility. Therefore, human oversight and validation remain essential to ensure the appropriateness and accuracy of the generated synthetic cases in ethical training and decision-making processes. While these tools hold great promise, the human element remains indispensable, ensuring that ethical considerations and context-specific nuances are thoroughly addressed during the shared decision-making process.

4.3 The hybrid approach

A hybrid approach that combines the strengths of AI models and human expertise offers a promising path forward. Rather than seeking to entirely replace human bioethicists, this approach

envisions AI models as supporting tools, augmenting and assisting bioethicists in a manner that maximizes the benefits of both.

This hybrid approach ensures that AI models are not used to replace the critical human element in bioethics. Bioethicists continue to play a central role in addressing ethical nuances, contextual factors, and making the final decisions: they provide the essential ethical oversight and accountability in the decision-making process, ensuring that AI-generated classifications and insights align with ethical guidelines and regulations. Their expertise is crucial for validating and, if necessary, challenging AI-generated recommendations.

To explore the practical implications of a hybrid approach in practice, measured integration strategies should be considered. The initial step would involve gathering feedback from committee members through structured interviews or surveys. This feedback would be invaluable to better align this hybrid model with the real-world dynamics of the committees, and can help refine the approach, ensuring it meets both practical and ethical standards.

Subsequently, we suggest a tentative incorporation of AI tools in the committees' workflows, primarily for preliminary analysis of case reports. This could potentially assist in highlighting complex ethical issues for more focused human deliberation. To ensure relevance and efficacy, this approach could be illustrated through small-scale case studies, designed to further test AI's utility in identifying key ethical considerations in assisted suicide cases. This pilot would involve a gradual and closely monitored introduction of AI tools, accompanied by a robust feedback mechanism for continuous assessment and improvement. This careful and methodical approach aims to ensure that the integration of AI supports and augments the committees' essential ethical decision-making processes without overstepping its intended auxiliary role.

5 Conclusion

In the complex and sensitive domain discussed in this paper, the role of AI models and human bioethicists is unmistakably distinct. While the AI models showcased in this study have demonstrated significant potential, it is vital to underscore that we are far from the point where human bioethicists can be replaced by artificial intelligence. The intricacies of ethical decision-making, the need for nuanced contextual understanding, and the inherent value of human empathy and judgment remain indispensable.

However, what this exploration tried to illuminate is a path toward a plausible future in which AI models serve as assistive tools, complementing the expertise of human bioethicists. The results presented here indicate that AI models can efficiently classify, analyse, and create case reports, assist in ethical evaluations, and offer insights that contribute to more comprehensive discussions.

Future research in this field can delve into further fine-tuning AI models on larger and more diverse datasets to enhance their plausibility in generating synthetic cases, improving the quality of AI-generated insights and recommendations. Another interesting future direction is the exploration of models of collaboration between AI models and human bioethicists: understanding how these partnerships can be optimized, roles defined, and ethical oversight maintained is crucial. This is closely related to the development and refinement of ethical frameworks that guide the

use of AI in bioethics, addressing issues such as transparency, accountability, and the mitigation of potential biases to ensure responsible and ethical AI applications. Finally, for the time being there are no standardized validation and benchmarking procedures for AI models in bioethics. These procedures are needed to ensure that AI recommendations and classifications meet a certain quality and ethical standard.

In conclusion, while the replacement of human bioethicists by AI models in decision making on assisted suicide requests remains distant and undesirable, we stand at the threshold of a collaborative and augmented future, where a hybrid approach presents an effective collaboration of AI models and human bioethicists. By leveraging the strengths of both, this approach ensures efficiency, accuracy, and a deeper understanding of complex ethical dilemmas, reflecting the recognition that while AI models can enhance the decision-making process, the invaluable expertise and ethical judgment of human bioethicists remain irreplaceable.

AI models, when carefully applied to the analysis and categorization of assisted suicide case reports, have significant potential to aid decision-making in this complex and sensitive field. They can enrich bioethical and legal discussions, impacting ethical practices, research, and the field of legal tech.

In conclusion, this approach promises to offer support and insights for bioethicists and legal professionals, leading to more informed and comprehensive decisions in the complex realm of ethical and legal deliberations related to assisted suicide.

Data availability statement

The code used for data collection and the resulting data are available via this study's repository (Spitale and Schneider, 2023). It can be found here <https://osf.io/7zgmj/>.

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Investigating shared decision-making during the use of a digital health tool for physical activity planning in cardiac rehabilitation

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Background: Shared decision making (SDM) between healthcare professionals and persons with CVD can have a positive impact on motivation, adherence, or sustainability regarding long-term goals and integration of cardiovascular disease (CVD) rehabilitation in the everyday lives of persons with CVD. SDM can foster the transition between regular heart-healthy activity at rehabilitation facilities and more independent activity at home, but it is often challenging to implement SDM given limited time and resources, e.g., in the daily practice of rehabilitation. Digital tools can help but must be appropriately tailored for situated use and user needs.

Objective: We aimed to (1) describe in how far SDM is manifested in the situated context when using a digital tool developed by our group, and, based on that, (2) reflect on how digital health tools can be designed to facilitate and improve the SDM process.

Methods: In the context of a field study, we investigated how SDM is already naturally applied and manifested when using a digital tool for joint physical activity planning in cardiac rehabilitation in clinical practice. In a two-week qualitative study, we collected data on expectations, experiences and interactions during the use of a digital health tool by seven persons with CVD and five healthcare professionals. Data was collected by means of observations, interviews, questionnaires and a self-reported diary, and analysed with a particular focus on episodes related to SDM.

Results: We found that SDM was manifested in the situated context to limited extent. For example, we identified high improvement potential for more structured goal-setting and more explicit consideration of preferences and routines. Based on mapping our findings to temporal phases where SDM can be adopted, we highlight implications for design to further support SDM in clinical practice. We consider this as “SDM supportive design in digital health apps,” suggesting for example step-by-step guidance to be used during the actual consultation.

Conclusion: This study contributes to further understanding and integration of SDM in digital health tools with a focus on rehabilitation, to empower and support both persons with CVD and healthcare professionals.

KEYWORDS

mHealth, mobile health, digital health, shared decision-making, cardiac rehabilitation, physical activity, exercise planning, behaviour change

1 Introduction

Insufficient physical activity (PA) is a major global public health problem (1). Regular PA (2, 3) is associated with many positive effects on health (4) and therefore an important measure in prevention and rehabilitation of chronic diseases (5).

A major challenge with regard to regular PA is sustainable behaviour change on an individual level (6, 7). Digital health interventions can offer valuable support with regard to adherence, motivation and sustainability (8–11). However, engagement with novel digital tools, such as health apps, does not occur in isolation; but often it is healthcare professionals who introduce persons with CVD to digital tools and encourage their use. In this context, digital tools may provide an additional valuable contribution to the communication between healthcare professionals and persons with CVD, by informing and facilitating this interaction (12).

Patients are increasingly seen as active partners in the management of their healthcare (13). This is reflected, for example, in the increasing prevalence of Shared Decision-Making (SDM) in clinical encounters, denoting “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (14). Integrating SDM in digital tools to empower persons with CVD, support self-efficacy, and promote long-term behaviour change could offer new potential as shown for example by Bonneux et al. (15, 16), Reese et al. (17) and Cao et al. (18). Although some initial research has explored this topic (19), more research is needed about how digital health tools could support SDM. In particular, more detailed information is needed regarding where within the process of SDM for PA in rehabilitation additional (digital) support could be beneficial.

In the context of promoting sustainable PA for persons with CVD with cardiovascular disease (CVD), we have developed a digital tool (aktivplan) that supports healthcare professionals and persons with CVD to jointly plan and document a regular heart-healthy PA schedule (20). In this paper, we analyse the application of this tool in practice and discuss how it could be adapted to further support SDM. Specifically, we aimed to (1) describe in how far SDM is manifested in the situated context when using the digital tool, and, based on that, (2) reflect on how digital health tools can be designed to facilitate and improve the SDM process.

With our work, we contribute design recommendations for SDM in digital health tools that could be beneficial to persons with CVD and healthcare professionals in the field of CVD prevention and rehabilitation. Beyond that, our insights provide a starting point for better SDM integration in digital health tools for prevention and rehabilitation in general.

2 Methods

2.1 Study design

Patients and healthcare professionals conducted PA consultation sessions at which an exercise training plan was discussed and agreed

upon. We used a mixed-methods research design collecting data based on the following materials and measures:

2.1.1 Non-participant observation with a focus on SDM

The Observing Patient Involvement in Decision Making (OPTION, (21)) and Rochester Participatory Decision-Making (RPAD, (22)) rating scales were used to conduct non-participant observations with a focus on SDM. These scales provide key statements on observable behavior that promotes SDM. The observer reviewed video recordings of all PA consultation sessions and rated each item according to the extent to which a certain behavior was demonstrated in each session.

2.1.2 Semi-structured interviews

Semi-structured interviews were conducted separately with with persons with CVD and healthcare professionals. The interview guides were developed in an iterative process: Initial interview questions were suggested by the study lead, then discussed and refined within a 1-hour workshop setting with three other experts in digital health, and finally piloted with representatives of the participant groups in order to ensure comprehensibility and adequate duration.

Two semi-structured interviews were conducted with each person with CVD. The first interview was conducted immediately after the PA consultation session. The interview guide included eight questions focusing on expectations and previous experiences regarding digital health tools and exercise training; expectations about the upcoming use of aktivplan; and the perception of the rapport with the healthcare professional and alignment of the exercise training plan with their personal preferences. The second interview was conducted after the 14-day usage phase of the aktivplan app. This interview guide consisted of eight questions with a focus on retrospective reflections about aktivplan, i.e., experiences and potential issues when using the aktivplan app in everyday life, suggestions for improvement, and the feeling of being connected to the healthcare professional via the aktivplan app.

One semi-structured interview was conducted with each healthcare professional shortly after the PA consultation session. The interview guide included seven questions covering healthcare professionals' expectations, experiences, and possible difficulties when using a digital tool for planning exercise training in the context of CVD rehabilitation.

2.1.3 Diary

A pen and paper diary was designed to collect daily self-reported data from persons with CVD. The study lead conducted a 90-min workshop with three experts in digital health to formulate potential diary questions. A first version of the diary was then developed, discussed further, and finalised in consultation with the digital health experts. A diary was chosen for data collection to obtain continuous insights over a 14-day period about technology interaction and other aspects of use. The main topics addressed were usage (frequency), usability, user experience and acceptance of the aktivplan app, relationship with the healthcare professional (mediated by aktivplan), as well as planning and documentation of training activities via

aktivplan. The diary was designed to be filled in daily. Each day, three to five questions were provided in relation to participants' training activities and prototype usage experience, mixing quantitative questions (e.g., indicating daily motivation for exercise training on a Likert-scale) and qualitative open-ended questions (e.g., describing one's favourite experience with the app). Completing the diary could take approximately between five and 15 min per day, depending on how thoroughly open-ended questions were answered.

2.2 Participants

Participants of the study involved both CVD rehabilitation persons with CVD and healthcare professionals.

2.2.1 Persons with CVD

We recruited current patients of a rehabilitation facility in Salzburg, Austria. To be included in the study, participants had to be 18 years and older and affected by CVD with current or previous participation in medical exercise therapy, i.e., persons with CVD in cardiac rehabilitation. For details on inclusion and exclusion criteria see [Supplementary Data](#).

2.2.2 Healthcare professionals

We recruited healthcare professionals including doctors and training therapists who regularly plan and monitor exercise training of persons with CVD.

2.3 aktivplan app

The app used in the study represents a planning tool for heart-healthy PA, which is used by healthcare professionals together with their patients. In contrast to common health apps, users of

aktivplan are persons with CVD, and it was a deliberate design decision to incorporate healthcare professionals in the app and in its intended use (e.g., by having meetings with healthcare professionals in a clinical setting or by representing patient's allocated healthcare professionals in the app).

The development of the aktivplan app was conceived as an explorative and iterative, user-centered design process involving healthcare professionals, persons with CVD and researchers (23, 24, 20). As shown in [Figure 1](#), its main functions for persons with CVD include a calendar with an exercise training plan, which is established together with a healthcare professional and entered into the app by the healthcare professional; an overview of active minutes per week, indicating the progress of the current week, as well as a list of personal goals set together with the healthcare professional; an overview of active minutes per month showing the monthly progress; videos with workouts that can be performed at home; and a functionality to export and document the progress for healthcare professionals or health insurances. Overall, aktivplan is a tool that allows healthcare professionals and their patients to jointly set up, monitor, and regularly review a personalized heart-healthy PA plan. Patients are involved and guided by healthcare professionals in selecting exercises and activities they enjoy and defining personally meaningful goals. Through the app interface (intended for patients), patients can conveniently access their plan on a calendar, log, adjust or add activities, review their performance, and access a library of resources such as exercise videos. At follow-up appointments with their healthcare professional, patients can review their documented performance and discuss the plan going forward. The aktivplan app is intended to support a longer-term one-to-one relationship between a healthcare professional and patients. Healthcare professionals access a separate version of the app (web interface) and are supported in providing personalized exercise prescription as well as ongoing review and optimization of their patients' performance. The exercise

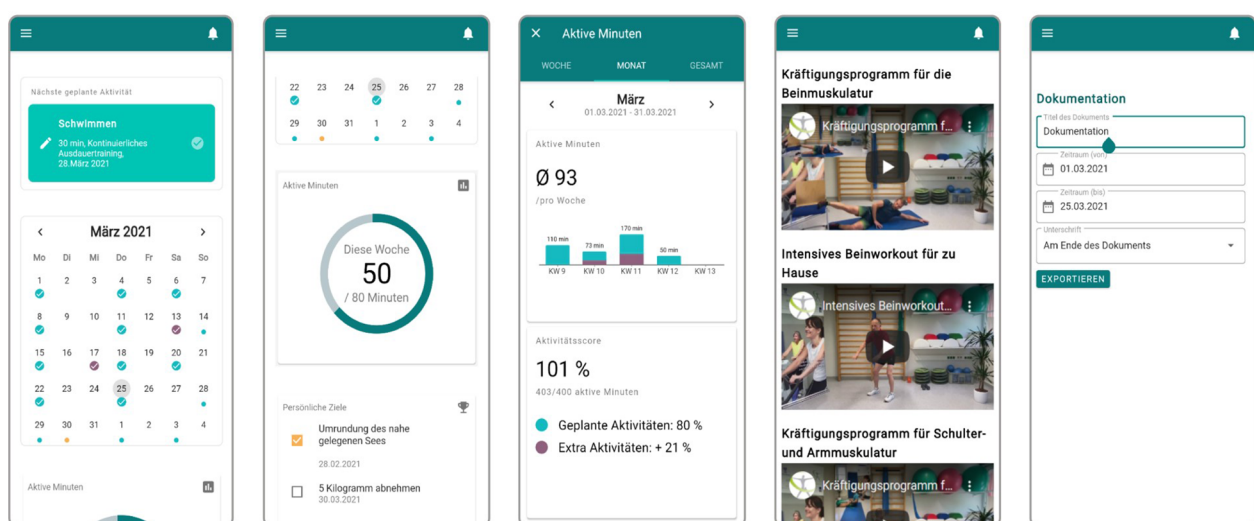


FIGURE 1

Main functionalities of aktivplan: (1) calendar with training plan, (2) overview of active minutes per week and personal goals, (3) monthly overview of active minutes, (4) videos with workouts, (5) export and documentation functionality.

training plan is entered into the app by the healthcare professional. Through the web interface, healthcare professionals can conveniently view the patients' activity logs. Activity logs can be exported and printed, to be filed in medical records, to provide documentation to health insurances, and to be used for joint review and further planning with patients at follow-up appointments. Direct communication between healthcare professionals and patients is not supported via the tool; rather, it is suggested that the exercise training plan should be reviewed periodically in follow-up consultation sessions, and that intermittent communication takes place using the healthcare professionals preferred and available channels such as email or telephone.

2.4 Study set-up & procedure

All seven PA consultation sessions and interviews took place in a quiet and comfortable atmosphere (see [Figure 2](#)) at the affiliated rehabilitation facility during May and July 2021. The sessions and interviews lasted between 45 and 90 min each and were video- and/or audio-recorded based on prior informed consent. Before the start of data collection, healthcare professionals received a 30-min introductory session about the aktivplan app and its basic functionalities, including brief guidance on how to use the app during the PA consultation session. Healthcare professionals were provided with a two-page print-out that visualised the most important steps when using the app to establish an exercise training plan. Additionally, the overall aim of the study was explained, and the healthcare professionals had an opportunity to ask questions.

Regarding the study procedure, we distinguished between the introductory phase, the usage phase and the final phase.

The main aim of the **introductory phase** was to conduct the PA consultation session between healthcare professional and person with CVD, and to provide the aktivplan app to the person with CVD. First, the researcher informed the person with CVD about the study and obtained their consent. Then, the PA

consultation session took place, aiming to establish an individual exercise training plan for the person with CVD for the forthcoming weeks. Healthcare professionals were instructed to base this on data from the person's exercise capacity assessment (ergometry) as well as their individual preferences and routines. The planning was to be conducted by using the provided aktivplan tool on the healthcare professional's desktop computer. Healthcare professionals explained the app and informed about data usage via the app; discussed routines and preferences with regard to PA with the person with CVD; and defined PA goals and an exercise training plan which were documented in the app. Healthcare professionals then asked the person with CVD to carry out their exercise training plan during the following two weeks. After the PA consultation session, the researcher interviewed the person with CVD, focusing on expectations and previous experiences regarding digital health tools and exercise training. Finally, the researcher helped the person with CVD to register and download the aktivplan app to ensure that everything was working properly before starting with the usage phase. After that, the researcher interviewed the healthcare professional regarding expectations, experiences and possible difficulties when using a digital tool for planning exercise training in the context of CVD rehabilitation (see [Section 2.1.2](#)).

The **usage phase** was dedicated to app usage in daily life over a time-span of 14 days by persons with CVD. During this time, the person was asked to use the aktivplan app to perform, track and document their exercise training as planned with the healthcare professional in the PA consultation session. Frequency and types of training activities had been individually determined, depending on the person's fitness level and state of health (as judged by the healthcare professional). In addition to using the app, the person with CVD was asked to complete a pen and paper diary ([Figure 3](#)) with questions about their physical activities, and impressions and usage experiences with the app ([Section 2.1.3](#)).

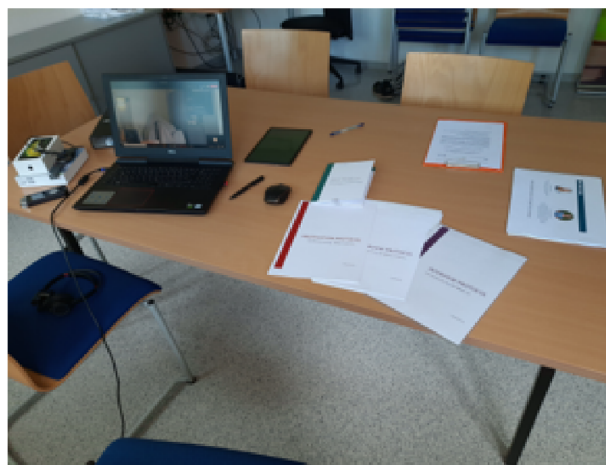


FIGURE 2

Room where the PA consultation session took place (left); room where interviews and observations were conducted (right).

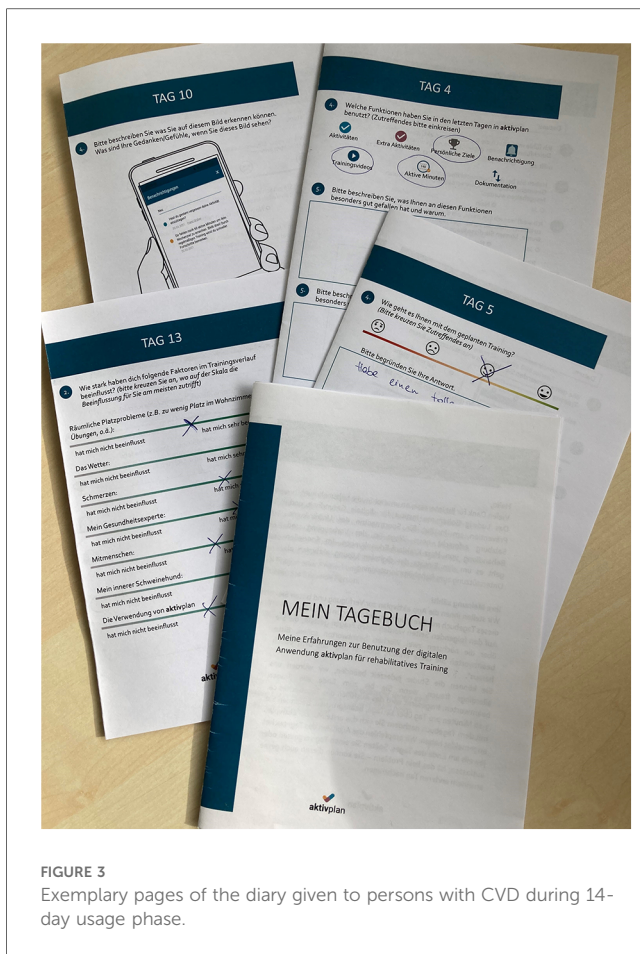


FIGURE 3
Exemplary pages of the diary given to persons with CVD during 14-day usage phase.

In the **final phase**, after 14 days of usage of the aktivplan app, the researcher conducted a final interview with the person with CVD. This interview focused on the person's experiences and potential issues when using the aktivplan app in everyday life as well as suggestions for improvement (Section 2.1.2).

2.5 Data analysis

Audio and video data was transcribed by using a free version of the software Express Scribe Transcription. Data from the diaries was transferred to an Excel file by the researcher. Diaries were completed well, i.e., there were no significant omissions, but there were variations in how detailed open-ended questions had been answered. For analysing the data, we used thematic analysis (25). This analysis approach is used to organize qualitative data sets by identifying different themes within the collected data. For our purpose, we aimed to structure and describe the collected data by revealing the prevalent themes regarding SDM in the context of establishing a PA plan with support of a digital tool. In a first step, we selected relevant data with regard to our research question, i.e., in how far SDM is manifested in the situated context when using a digital tool. Then, we assigned initial codes to the data and searched for themes based on the codes. We identified the following themes concerning the process of SDM in

a tool-supported activity planning process: (1) Relations between persons with CVD, healthcare professionals and the digital tool, (2) Language as a strong influence, (3) Planning and goal setting, (4) Expectations before actual use. These themes are described in detail in Section 3.3.

3 Results

In this section, we describe participants demographics, results of the SDM rating scales and insights based on the thematic analysis.

3.1 Participants demographics

A total of seven male persons with CVD took part in the study. All of them were enrolled in a cardiac rehabilitation programme at the affiliated rehabilitation facility. Our sample consisted of males only as there was only one woman training at the affiliated rehabilitation facility who would have fulfilled the inclusion criteria (as opposed to 23 males) at that point in time. Participants' age ranged from 65 to 83, with a mean age of 71 ($M = 70, 71$; $SD = 6, 18$). Their educational background was mixed, with two participants holding a university degree, three having completed secondary school, and two having completed mandatory school. All of the participants regularly attended the affiliated facility for their rehabilitation training, which means they already knew the structures and the healthcare professionals. Patients' experience of cardiac rehabilitation (i.e., the time since the first cardiac event) ranged from six months to ten years, with a mean value of six years ($M = 6, 35$; $SD = 3, 64$). With regard to previous experience with technology usage, three participants indicated that they were experienced in using apps, while four reported that they did not use apps in their everyday life, i.e., they were not experienced in the use of apps. Most of the participants already used digital support for training ($n = 5$; smartwatch, pedometer, fitness app on mobile phone). All participants were from Austria and lived in Salzburg at the time the study was conducted.

A total of five healthcare professionals participated in the study, all working at the affiliated rehabilitation facility. Three of the participants were sports scientists by profession, one was conducting an internship (sports scientist in training), and one was a physician by profession. They were aged between 21 and 41 years, with a mean age of 34 years ($M = 33, 80$; $SD = 8, 87$).

3.2 SDM ratings via OPTION & RPAD

The mean score of OPTION was 17 ($SD = 7, 26$; 12 items ranging from 0–4; maximum possible score = 48, with higher scores indicating greater level of SDM). The mean score of RPAD was 5,3 ($SD = 1, 44$; 9 items ranging from 0–1; maximum possible score = 9, with higher scores indicating greater level of SDM). These mean scores indicate that the shared decision level of the dialogue could still be improved.

3.3 Aspects of SDM with a digital health tool

In the following, we point out how the use of a digital health tool for PA planning can be related to SDM. We identified the following themes around the process of SDM in a tool-supported activity planning process: (1) Relations between persons with CVD, healthcare professionals and the digital tool, (2) Language as a strong influence, (3) Planning and goal setting, (4) Expectations before actual use. Based on these themes, we describe different aspects that show the manifestation of SDM when using the aktivplan app.

3.3.1 Relations between persons with CVD, healthcare professionals and the digital tool: interactional aspects

Before introducing the aktivplan app to the healthcare professionals and persons with CVD, the normal routine for conducting rehabilitation was to perform an exercise capacity assessment (ergometry) at the beginning of the rehabilitation. After the assessment, the healthcare professional and the person with CVD sat together. The healthcare professional discussed results and implications from the assessment with the person with CVD, and suggested which activities to perform at home. Depending on the healthcare professional, there was more or less emphasis on SDM. Then, by providing the aktivplan tool to the healthcare professional, a technical device was involved in this consultation situation. This device was used actively by most healthcare professionals as a **means for visually supporting the conversation**. Observational data showed that four out of five healthcare professionals explicitly used the computer monitor to explain functionalities of the app, in particular to show what the calendar overview looks like. The fifth healthcare professional did not use the computer monitor but explained the functionalities of the app in a verbal-descriptive way without demonstration (healthcare professionals could choose how they wished to explain the app to the person with CVD, i.e., there was no instruction given). For example, HP2 indicated: “Right, now we have the training sessions on Tuesday and Thursday in the calendar [points to monitor]. And on Sunday we have added a 45-min walk.”

Involving a technical device in a counseling process was also related to **technical flaws and challenges**, e.g., one professional (HP3) said “...I have now created a user profile for you here on the computer,” thereby rotating the monitor towards the person with CVD and causing a malfunction by that (display vanishes). In general, the situation of sitting together in a room, i.e., the shared physical presence of both person with CVD and healthcare professional, was experienced positively by the persons with CVD. The spatial arrangement of sitting together in front of a computer screen and deciding about the exercise training plan can be understood as a physical manifestation of sharing. Watching along on the computer screen was associated with being interesting, having a **learning effect and conveying transparency**. For example, P4 indicated: “It is important to watch the screen, you have the feeling that it is transparent.” Persons with CVD further stated that **interacting with**

healthcare professionals provided support and control and was **perceived as motivating**. This was considered important for positive health behaviour change. P5 formulated this as follows: “I needed the medical side, because otherwise I wouldn’t have done it. Because I rely on it completely...and then I want to stick to that.” Similarly, P3 pointed out: “Personally, it took me about three months to change my diet and the physiotherapist helped me tremendously. So for me, it was just the luck of having the physiotherapist and the family doctor.” Personal relationships, in particular with healthcare professionals, turned out to be crucial for individuals’ motivation. In addition, healthcare professionals positively influenced health behaviour change of persons with CVD through knowledge provision and support.

3.3.2 Language as a strong influence: conversational aspects

An important aspect in SDM was the use of appropriate language to emphasize that a joint decision would be made. The example of HP5’s introductory words nicely showed the **targeted involvement of persons with CVD through the use of appropriate language**: “We will then go through the data protection, where you then agree and then I would ask questions about your sports history, what you are currently doing, what you have done in the past. And then I would develop a plan together with you, which you can then also see on your mobile phone, for the next four weeks. Is that ok for you?” (HP5). Regarding such an involvement via language, the use of the word “we” by healthcare professionals was found to be regularly used, e.g., “So now we’re going to plan this” (HP4); “...we look at where we are [at the moment] and then the goal where we want to go” (HP3). Overall, four out of five healthcare professionals used the key word “we” multiple times. Related to that, the term “together” emerged in the conversations of two healthcare professionals. The **provision of support and assistance** by healthcare professionals was acknowledged by persons with CVD and can be interpreted as a manifestation of SDM. Patients positively mentioned having a point of contact for questions and the feeling that someone is there in case of insecurities or problems during their rehabilitation. Four out of five healthcare professionals explicitly stated that persons with CVD could ask any questions and offered their support. All participants asked questions during the process of establishing a training plan. Many of these dealt with the question of how to use the app at home (on their mobile phone), which data had to be entered and where, or what counted as a so-called extra-activity. SDM was addressed in the conversation via the language used as well as by actively offering assistance. However, none of the healthcare professionals explicitly mentioned the adoption of a SDM approach directly towards the persons with CVD. With regard to the usage of the app after the PA consultation session, persons with CVD often mentioned that monitoring and insight of healthcare professionals into their activities was desired as this enabled **control and support**, providing them a **feeling of safety and togetherness** (not being alone). For example, P5 stated “For me it’s very important, I think it’s really good when I know that there’s a medical side that pays attention, that’s there for me. I

feel safer there.” Knowing that there was a future appointment with the healthcare professional further motivated the persons with CVD as a goal to work towards.

3.3.3 Planning and goal-setting: decisional aspects

After data from the person with CVD (e.g., weight, height, maximal heart rate) was entered into the app and agreement on data usage and voluntary participation was given, the healthcare professional could freely decide about the further procedure. This should include the explanation of the app and its functionalities, the definition of the goals, and the creation of an exercise training plan. This part tended to be rather unstructured in the sense that every healthcare professional acted differently (e.g., some defined goals before the training plan and vice versa). For example, one healthcare professional did not explicitly mention the goal of the app. The other healthcare professionals mentioned the goals but did this in different ways, using terms such as “support,” “visualise data,” “planning,” “monitoring,” and “individual training.” Although there was a sequence of steps suggested by the provided materials, this was not necessarily adopted. The **lack of routine when working with the digital tool** was for example expressed in the following statement: “*Ah, I just have to follow these guidelines a bit so that I don’t forget anything*” (HP4).

Within the process of creating a training plan, talking about **routines and habits of persons with CVD** was important. Considering preferences and everyday routines of persons with CVD was a source of motivation for individuals and should be part of PA planning. PA was the topic most prominently addressed with regard to already established activity routines and preferences for specific sports. Hereby, going for a walk - with the dog, the partner or peers from cardiac rehabilitation - was the activity mentioned most often by persons with CVD. Next to that, football, hiking, and cycling were popular activities. In this context, persons with CVD often indicated **influences on their activity level**. In particular, pain and weather played a crucial role when it came to conducting a targeted activity. For example, P3 mentioned weather as a determinant of chosen activities: “*It’s relatively weather dependent [how active I am]...It’s more when the cycling season is over - November, December - that I do walking again, but when the weather is like this I prefer cycling.*” Similarly, P5 stated: “*My weekly schedule strongly adheres to the weather, whether I’m exercising alone or in a group.*”

P7 referred to pain as an inhibitor of activity: “*Yes, the time would be there and I had to put the brakes on because the pain in my back was so bad that I couldn’t do the exercises and then of course I didn’t do them. As it is now, I could certainly do certain exercises.*” Overall, we found that current habits and sports activities of persons with CVD were discussed, however, general preferences and potential new sport activities were only marginally addressed or not addressed at all by the healthcare professionals.

When planning activities, healthcare professionals entered activities from the rehabilitation facility and activities already regularly performed by the persons with CVD into the app. The process of establishing a training plan required most of the

conversation time between healthcare professional and person with CVD. Hereby we found a clear lead of healthcare professionals, having the longest talk time by far and persons with CVD being rather passive, having their main task in answering questions (e.g., regarding preferred days for planned activities or their pulse). Details of this process varied individually, meaning that some healthcare professionals asked persons with CVD much more than others. Participants experienced the process of planning the exercise training plan as positive. In particular, **integrating personal interests and social context in the training plan** motivated persons with CVD. The following statement illustrates the importance of (considering) the individual’s social context: “*My wife and I push each other... Have you already done that, I’m going to train now or let’s go for a walk. That is our community, we are already [active] together. We have been married for 60 years*” (P1). According to the persons with CVD, they mostly appreciated that the training plan was established together and tailored to their interests. Vice versa, not considering personal interests of persons with CVD was counterproductive as could be seen in the statement of P5, who indicated that he would change the plan afterwards as his interests with family were not considered.

Regarding the goals which were set for the persons with CVD, some healthcare professionals mentioned that they did not actively consider goals so far, but perceived **goals as motivation and incentive** for conducting activities. When it came to goal-setting by means of the app (dedicated functionality), we found that this was done differently by the healthcare professionals. Particularly, the definition and realisation of “goal” was diverse amongst healthcare professionals. Specifically, four healthcare professionals deliberately drew on personal interests and formulated goals based on before mentioned interests of persons with CVD. For example, based on the before stated interests and preferences, HP3 suggested the following: “*...we could set a target in the next few weeks with a 45 km bike ride*” (HP3). Goals were actively requested only by three of the five HPs. This could also related to the fact that persons with CVD sometimes had already formulated goals for themselves, e.g., P5 indicated that his goal was it to climb a specific mountain, to go all the way up there. He further pointed out: “*The goal is I want to go up and now I’m going up to half time and if I’m doing well then I’m going up. Thanks for the structure.*” In general, participants appreciated to have (more or less) individually set goals. However, two persons with CVD were sceptical about the feasibility of the set goals. The **perceived feasibility of a goal** was found to be crucial for an individual’s motivation to conduct the planned exercises and stick to the training plan, implying that unrealistic goals may have a negative influence on the individual’s adherence.

3.3.4 Expectations before actual use: anticipatory aspects

Patients’ expectations towards a digital tool for PA planning were mainly related to the aspect of being **supported to regularly perform exercise**. For example, persons with CVD expected to (begin and) stick to being active by **having a structure** and plan which they have to follow. Those who had

previously been active hoped to get back into former activity patterns. Further, a calendar with planned activities represented a **feedback mechanism** which mirrored and explicitly represented the performed behavior. For example, P1 states: “Yes I think so [that the app is helpful]...so that you have a mirror in front of you.” Similarly, P4 stated that entering and looking up activities provided better control of oneself: “Yes, probably [the app is helpful], because you should really enter something and look it up, and thus you control yourself even better.” This structure which was provided by experts also concerns **realistic goal-setting**, i.e., having more realistic training goals (compared to those which are defined by oneself): “[I expect from aktivplan] that you really keep to the training goals, because often you are a bit too optimistic yourself” (P3). We also found **concerns regarding app usage** before the launch. This initial scepticism in persons with CVD was mainly due to a lack of skills in using digital applications. Some mentioned that this is difficult to change/learn when older. They also reported fear of being overwhelmed, as a lot of information was expected to be processed at the beginning for them. Further, one participant was afraid that using the app would mean a lot of effort for him: “[In the app I] have to choose what I do and that’s a certain amount of work” (P3). Within the present study, the **importance of the enrolment and introduction process** of the app was expected to be significant. Persons with CVD indicated that getting started is important for motivation to continue using the app. The first contact was considered to be crucial, e.g., the registration process and the activation of the account. From the persons with CVD side, there was the expectation that there was information and guidance on what to do and how to proceed with the app. **Motivation** was another issue regularly mentioned with regard to expectations of the app. One source of motivation was the on-site training at the rehabilitation facility. This was linked to training without fear, training in a group with other persons with CVD, and under expert supervision (P2). The expectation that activities can be viewed by healthcare professionals was considered as another source of motivation (i.e., by having the feeling of being controlled). Besides supervision and training together with other persons with CVD, another source of motivation was attributed to pursuing personal interests (walking with the dog, hiking to see nature).

When interviewing health experts about their expectations and attitudes towards the app, the app was seen as a **connection between healthcare professionals and persons with CVD**, providing them the opportunity to guide and stimulate persons with CVD not only at the rehabilitation facility but also in their everyday life: “They go home and do things, they know they should exercise and so on. And so I intervene directly and say ok, what does your everyday life look like, when would you have time to do something and I can give him my guidance, my instructions for why don’t you take a look at this, I can give him ideas where he might say, ok, I wouldn’t have thought of that idea” (HP2). Such a bridging function seems to be of particular value as this integrates the “home,” i.e., the everyday life of persons with CVD. This was not the case before, meaning that activities at home were not actively considered in the planning of exercise

training. Thus, it was seen as a new approach compared to the “traditional” rehabilitation practice at the facility. In the words of HP1: “...but what he did at home, we don’t look at that. And I think that would be a starting point with gadgets...It’s a different approach.... monitoring allows checking [the activities of person with CVD] and also keeping them motivated.” Healthcare professionals expected the app to be **patient-oriented, intuitive and simple**. It should actively involve persons with CVD and provide a **concretisation and specification of training activities** to them, and promote a more detailed discussion with persons with CVD. This was expected to lead to a more sustainable training and better outcome (i.e., physical performance) at the end. It was further expected to give healthcare professionals **insight into the performed activities** of the persons with CVD. Checking later what the person with CVD had done and actively dealing with activity from the person was thought to be an important part of the app usage. In relation to that, data protection issues were expected to be handled by the tool.

4 Discussion

4.1 SDM supportive design in digital health apps

In our study, we identified four aspects concerning the process of SDM in a tool-supported PA planning process which should be considered when integrating SDM in digital health tools: (1) interactional aspects of SDM, dealing with relations between patients, healthcare professionals and the digital tool; (2) conversational aspects, emphasising the influence of language when a digital tool is part of the SDM process; (3) decisional aspects, focusing on the process of planning and goal-setting supported by a digital tool; and (4) anticipatory aspects, putting emphasis on the expectations before actual use of a digital tool in relation to its users and their relationship (i.e., the relationship between a healthcare professional and a person with CVD). Additionally, data from the OPTION and RPAD scales demonstrated potential for further improvement regarding the content and quality of the SDM dialogue, and interview and observational data highlighted the need for more structured goal-setting and more explicit consideration of preferences and routines.

Based on observed processes, expectations, and feedback regarding SDM, we formulate implications for design. In particular, we suggest how digital tools can support SDM. Our suggestions are based on the use case of planning PA for persons with CVD; however, we assume that they can also be useful on a more general level. As we consider SDM as a cyclical activity in relation to chronic diseases, we mapped our findings to temporal phases when SDM can be adopted. **Table 1** provides an overview on how SDM can be better integrated in digital health apps.

In the first phase, i.e., before the actual PA consultation session, SDM is intended to prepare both the person with CVD and the healthcare professional for the upcoming encounter. According to Carmona et al. (26), this phase is about reflecting on what matters

TABLE 1 Overview on SDM supportive design in digital health apps.

When <i>point in time regarding consultation</i>	What <i>actions that can be taken</i>	Why <i>purpose regarding SDM</i>	How <i>digital implementation of actions</i>
Before PA consultation session	Provide information	Preparation	Dedicated platform for patients providing information sources
	Trigger reflection		Dedicated platform for patients eliciting routines, habits and preferences
	Provide data		Dedicated data base/platform for health professionals where (already) available data from patients is accessible
During PA consultation session	Create collaborative atmosphere	Decision making	Step-by-step guidance (“digital stepper”)
	Check knowledge and inform		
	Discuss data		
	Set goals		
	Define exercise plan		
	Inform about next encounter		
After PA consultation session	Offer resources	Long-term adherence	Activity monitoring
	Ensure contact person		Reminder messages
	Offer additional support		Time plan (further appointments)
			Online resources

to them, what they hope will happen as a result of the discussion, and what questions they would like to ask. In line with the description above, our data pointed out the importance of addressing concerns and expectations of persons with CVD to optimally prepare them and avoid false assumptions. Expectations that persons with CVD have before getting to know the app are important to consider, so that negative associations, doubts and fears can be intercepted beforehand by adequate preparation and information. Based on our findings, we suggest three thematic blocks. To optimally prepare persons with CVD, we suggest (1) information provision (e.g., about SDM, CVD or digital tools) as well as (2) reflection triggering (e.g., about routines, habits and preferences). To optimally prepare healthcare professionals, we suggest (3) data provision (e.g., patient data such as personal data or health data from clinical assessments, data collected from wearables, or data regarding the preferences and habits of persons with CVD. These blocks could be provided and elicited on a dedicated platform for persons with CVD (e.g., a website). Similarly, a dedicated data base/platform for healthcare professionals could give them the opportunity to optimally prepare for the upcoming consultation and could further provide some time-saving.

In the second phase, i.e., during the PA consultation session, decisions should be made. With regard to our use case, these decisions should result in set goals and an exercise training plan. In our study, we found a strong need for more structured guidance for healthcare professionals. Based on previous work of Carmona et al. (26) and Elwyn et al. (27), aligned with results from our use case investigation, we suggest that the following issues should be addressed in a face-to-face appointment in which PA planning takes place: (1) create a collaborative atmosphere to make sure that persons with CVD or service users understand that they can participate as much as they want and feel encouraged, (2) check knowledge and inform about the digital tool, data usage and privacy issues, (3) discuss recorded data (e.g. from clinical assessments or activity records) to show where the person with CVD can actively contribute/improve, (4)

set goals and provide good goal-setting support, (5) define an exercise training plan as a basis for long-term PA, and (6) inform about the next encounter and the time in-between to provide guidance on how to go on (in case of questions, changes, ...). To use the potential of digital tools and provide structured guidance within the SDM process, we suggest to implement a step-by-step guidance (“stepper”). This stepper guides the healthcare professional throughout the conversation and assures that all parts are discussed. The stepper is thought to provide a rough overview which can be “zoomed in” on two levels: when clicking on a dedicated item, a more detailed description is provided (level one); by clicking a second time on a dedicated item, examples on how to phrase a specific aspect of the conversation are provided (level two). This should offer healthcare professionals flexible support in remembering and articulating key statements that are essential for a communication style that facilitates SDM.

In the third phase, i.e., after the PA consultation session, emphasizing follow up meetings is important (especially in the case of chronic diseases) with regard to long-term adherence. Based on previous work (e.g., (26, 27)) as well as our own insights, we suggest to take the following actions: (1) Offer people resources to help them understand what was discussed and agreed, (2) ensure that information provided after discussions includes details of who to contact for any further questions, (3) offer additional support to people who are likely to need extra help to engage in SDM. Our results showed the importance of tracking activities (i.e., by automated or manual reporting). This induces a feeling of being monitored in persons with CVD and in turn motivates them to be active, and at the same time provides valuable information to the healthcare professionals. Further, communication channels play a crucial role in order to make the SDM “sustainable.” Providing means of communication and prospects of further consultations are therefore considered important factors towards persons’ with CVD adherence. As more (physical) meetings increase the

adherence but are often not realistic due to the high time effort for healthcare professionals, a good balance should be found here. Besides, alternative communication channels could be implemented. For example, an automated reminder message (e.g., reminding about a planned activity) with a picture of the associated healthcare professional could be thought of as low-effort compensation. Finally, the provision of online information material can be beneficial for long-term adherence.

4.2 Challenges & opportunities

Although SDM is getting increasingly established in clinical practice, the application of SDM can still be improved. As stated in the introduction, SDM bears potential for empowering persons with CVD and supporting long-term behaviour change (16–18). A systematic attempt to bring together SDM and behaviour change was made by Bonneux et al. (15). In our digital tool we found the stated principles to be integrated. However, as seen in the present study, issues such as goals, habits and preferences are often discussed on a general level. Here, improvements towards a more structured process could be beneficial, guiding the conversation towards a more detailed and individual level. Based on our data, we see the most pressing issues to be tackled as follows: We made the observation that **goals** are defined very differently and in an unstructured way. From the viewpoint of a person with CVD, perceived feasibility of a goal was found to be crucial for the motivation to conduct the planned exercises and stick to the training plan. This corresponds to Rutjes et al. (12), highlighting the importance of specific and achievable goals to stay motivated and increase self-efficacy. To improve and structure the process of goal-setting, we suggest a digital step-by-step guide as described in [Section 4.1](#). In addition to goals, **preferences and routines** need explicit consideration. This is in line with Rutjes et al., who points out that “the more specific and tailored the advice, the more likely clients are to adhere to it” (12, p. 5). To come to individually optimized decisions - in our case personalized training plans - we suggest a dedicated platform which supports persons with CVD to reflect on preferences and routines before the actual PA consultation session takes place ([Section 4.1](#)). Finally, **time efforts** are crucial for healthcare professionals. To reduce time effort, we suggest to collect data about the person with CVD (e.g., personal or health related data, preferences and routines) before the actual PA consultation session and provide it to the healthcare professional (so that elicitation during the session is not necessary any more and the healthcare professional can prepare in an optimal way).

We further argue that successful and sustainable SDM has to be implemented on an organisational level. To be successfully and sustainably implemented in clinical practice, SDM has to be seen not only on a micro-perspective but also from a macro-perspective. In our study, healthcare professionals pointed out the demand of acknowledging and supporting SDM on an organisational level. For example, a potential shift of healthcare professionals' time resources as well as onboarding and learning how to use a digital device for establishing a shared decision has to be considered (from higher level management). This is in line

with Carmona et al. (26), who states that SDM is more likely to become standard practice in organisations when it is led from the highest levels of the organisation.

Overall, we argue that digital tools hold great potential for facilitating and shortening processes and thus offer invaluable opportunities for supporting SDM in clinical practice. For example, step-by-step guidance and in-situ phrasing examples, visualizations of progress and goals, and adequate preparation of persons with CVD and healthcare professionals can be effective means for that.

5 Conclusion

As Elwyn et al. stated, “*new systems will be required to appropriately reward truly patient centered practice*” (27, p. 1366). Such a practice centered on SDM is thought to foster sustainable adherence to physical exercise (18) and thus helps to bridge the gap between on-site and remote exercise training in cardiac rehabilitation (16). In the context of a field study, we investigated how SDM was already applied and manifested when using a digital tool for heart-healthy PA planning in clinical practice. Based on that, we have identified when additional support would be beneficial within the process of striving for a shared decision and have pointed out the potential of digital tools that can be used to better support SDM.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Ethics Commission of the state of Salzburg (“Ethikkommission Land Salzburg”). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DW: Conceptualization, Data curation, Investigation, Methodology, Writing – original draft, Writing – review & editing. JuN: Conceptualization, Methodology, Formal Analysis, Investigation, Validation, Writing – original draft. E-MS: Methodology, Software, Writing – review & editing. IH: Data curation, Investigation, Writing – review & editing. BM: Investigation, Writing – review & editing. AE: Investigation, Writing – review & editing. MS: Investigation, Writing – review & editing. BR: Investigation, Writing – review & editing. MN: Investigation, Writing – review & editing. JoN: Funding acquisition, Investigation, Writing – review & editing. JDS: Writing – review & editing. STK: Conceptualization, Data curation, Funding

acquisition, Methodology, Investigation, Project administration, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Targeting behavioral factors with digital health and shared decision-making to promote cardiac rehabilitation—a narrative review

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Cardiac rehabilitation (CR) represents an important steppingstone for many cardiac patients into a more heart-healthy lifestyle to prevent premature death and improve quality of life years. However, CR is underutilized worldwide. In order to support the development of targeted digital health interventions, this narrative review (I) provides understandings of factors influencing CR utilization from a behavioral perspective, (II) discusses the potential of digital health technologies (DHTs) to address barriers and reinforce facilitators to CR, and (III) outlines how DHTs could incorporate shared decision-making to support CR utilization. A narrative search of reviews in Web of Science and PubMed was conducted to summarize evidence on factors influencing CR utilization. The factors were grouped according to the *Behaviour Change Wheel*. Patients' *Capability* for participating in CR is influenced by their disease knowledge, awareness of the benefits of CR, information received, and interactions with healthcare professionals (HCP). The *Opportunity* to attend CR is impacted by healthcare system factors such as referral processes and HCPs' awareness, as well as personal resources including logistical challenges and comorbidities. Patients' *Motivation* to engage in CR is affected by emotions, factors such as gender, age, self-perception of fitness and control over the cardiac condition, as well as peer comparisons. Based on behavioral factors, this review identified intervention functions that could support an increase of CR uptake: Future DHTs aiming to support CR utilization may benefit from incorporating information for patients and HCP education, enabling disease management and collaboration along the patient pathway, and enhancing social support from relatives and peers. To conclude, considerations are made how future innovations could incorporate such functions.

KEYWORDS

secondary prevention, behavior change, patient transition, cardiovascular disease, patient-centered

1 Introduction

Cardiovascular diseases (CVDs) are a group of disorders of the heart and blood vessels, commonly causing heart attacks or strokes. CVD are the leading cause of death and are responsible for approximately 32% of all deaths globally (1). They are primarily caused by behavioral risk factors, for example, unhealthy diet, tobacco use, obesity, physical inactivity,

and harmful use of alcohol (1). In addition to surgery and medication, cardiac rehabilitation (CR) is crucial for the secondary prevention of CVDs, i.e., preventing the occurrence of further acute cardiovascular events, reducing the risk of premature death and improving health-related quality of life. With its multi-faceted program centered around supervised exercise therapy, CR represents a steppingstone for many patients into a more heart-healthy lifestyle. Moreover, patients attend educational sessions, learning about blood pressure management, lipid and glycemic targets, heart-healthy nutrition, and tobacco cessation, and they receive psychological support (2). Throughout their secondary prevention pathway, patients' self-management capabilities are of great importance.

The positive effects of CR, namely a better heart health and function, less need for medication, the adoption of healthy behaviors, and a lower risk of cardiac mortality have been multiply confirmed (3). Therefore, the American Heart Association and the European Society for Cardiology recommend CR with the highest classification possible (4, 5). Nevertheless, evidence shows that CR is underutilized worldwide (6). The term *CR utilization* comprises four aspects (7). Firstly, the patient's referral to CR, which is usually conducted in hospitals. Secondly, the patient's enrolment in the CR program. Thirdly, the adherence rate as indicated by the proportion of sessions completed out of those prescribed. Finally, the reassessment after the CR intervention after program completion (7).

Previous research has shown that the reasons for CR underutilization comprise of an interplay of barriers addressing different stages of the patient pathway (6). Patient information and communication between healthcare professionals (HCPs) and patients were identified as fundamental factors for patients' acceptance of medical advice (8). For example, HCPs recommendation to participate in CR positively influences patients' motivation to participate. Although the barriers to CR have been thoroughly investigated, with the first publications dating back to 1992 (9), there is a lack of standardized reporting.

Frameworks such as the *Behaviour Change Wheel* (BCW) (10) can provide structure, guidance, and a systematic approach for developing and implementing (digital) interventions. Moreover, such frameworks help to deconstruct complex healthcare system-related challenges and support researchers and developers in creating targeted solutions. In cardiac care, frameworks focusing on behavioral factors have the potential to support the understanding of barriers and facilitators to patients' CR pathways. They could serve as a roadmap considering stakeholders' preferences, underlying needs, and social context. The insights could then build the basis for developing digital interventions reinforcing a targeted behavior, for example, the uptake of CR.

1.1 Shared decision-making on the patients' pathway to CR

Shared decision-making (SDM) is a collaborative decision process incorporating current medical evidence and patients' personal preferences regarding their medical treatment. The approach focuses on patient-centered care and ethical perceptions of individuals' self-determination. Patients are considered

stakeholders who are actively involved in the medical decision process while HCPs educate them about their options in layperson's terms. Treatment decisions are made jointly between patients and HCPs. Therefore, a trusting interpersonal relationship between HCPs and patients is necessary (11, 12).

Related work describes medical SDM in multiple models and frameworks (12). For example, Elwyn et al. (11) provide a three-step model as guidance on how SDM can be accomplished in routine clinical care: At first, a *choice talk* represents a planning step and aims to make the patients aware that reasonable treatment options exist. HCPs emphasize the importance of respecting preferences and inform the patients about making a decision. By checking patients' reactions, HCPs elicit to what extent patients want to be involved in the decision-making process. Next, HCPs list options including their harms and benefits according to patients' knowledge base. This *option talk* aims to provide decision support. Finally, a *decision talk* clarifies patients' questions and preferences, and moves towards a decision. HCPs close the discussion by offering to review the decision. The described steps can be iterated as often as necessary to ensure patients are clear about the options and can articulate their preferences and needs.

In cardiac care, related work indicates that patients' values and preferences for decision-making might change along their care pathway. Burton et al. (13) researched patients undergoing elective cardiac surgery and found that only 40% wanted to be involved in their treatment decisions. However, they also found that perceived involvement in decisions led to higher confidence regarding the decision (13). This finding aligns with evidence showing that cardiac patients who participate in SDM have a better understanding of the risks and benefits of treatment options (14). Bente et al. (15) investigated values of CVD patients facing lifestyle and behavior change. They found that patients wanted to be involved in decision making and expressed interest to oversee their health and treatment progress. Patients also preferred personalized care, considering their individual needs and preferences (15).

A structured SDM approach, including personalized patient education, may enhance awareness among patients about the option of CR. It can also address individual considerations influencing patients' decision to participate in CR. Enhancing patients' awareness and understanding of their condition and the role of CR can contribute to informed decisions regarding CR participation.

1.2 Digital health technologies supporting CR utilization

Digital health technologies (DHTs) can support the use of CR programs, e.g., by facilitating care processes and increasing patients' understanding of their condition. Technologies could also engage patients as proactive stakeholders beyond their time with HCPs. This includes educating them about treatment options and facilitating SDM.

In order to enhance CR uptake on the healthcare system level, related work describes automated rehabilitation referrals based on data from electronic medical records (16–19). However, such solutions fall short when it comes to considering patients on an

individual level. As hospitalization time decreases due to highly condensed workflows and workforce shortages, the time for discussing follow-up care and educating patients about secondary prevention in the acute setting is limited (20). At this point, digital decision aids could take effect (21, 22). Through imparting knowledge and eliciting medical treatment options, they have the potential to enable and prepare patients for SDM with the HCPs. On the continuing care pathway, text message reminders and activity monitoring may support cardiac medication and rehabilitation adherence (23, 24).

Despite the promising potential of DHTs in supporting cardiac patients, they face criticism. One significant drawback is the limited quality of health technologies, which hinders their full impact in practice. Decision aids, for example, might be easily accessible online. However, their overall content quality is criticized as low, and some aids may not be suitable for groups with low literacy (25). This limitation can undermine the efficacy of supporting SDM, creating a potential digital divide in access to crucial information and guidance. Moreover, HCPs' concerns regarding the effectiveness and perceived workload associated with digital technologies hamper their implementation in practice (26). Consequently, the long-term evaluation of DHTs' effectiveness in improving patient outcomes and CR utilization remains an ongoing challenge. Research gaps persist in understanding the impact of DHTs on patient engagement, behavior change, and long-term health outcomes. The healthcare landscape is dynamic, and the rapid evolution of digital technologies introduces new challenges and opportunities that require continuous evaluation and adaptation. Technologies supporting medication adherence and rehabilitation show promise in the shorter term. More research is needed to assess their long-term effectiveness and ability to promote sustained behavioral change in patients.

2 Objectives

This narrative review aims to deepen the understanding of factors influencing CR utilization and the role of SDM in potential digital solutions. Using the BCW (10) as an underlying theory, we map factors influencing CR utilization to the behavior domains. We also highlight intervention functions for future health innovations designed for increasing CR utilization. We discuss how available DHTs already incorporate such functions to address barriers and reinforce facilitators to CR. We also outline how future DHTs might be designed and the role of SDM in this context.

In summary, our review (I) provides understandings of factors influencing CR utilization from a behavioral perspective, (II) discusses the potential of DHTs as solutions to address barriers and reinforce facilitators to CR uptake and (III) outlines how DHTs incorporate SDM to support CR utilization.

3 Methods

A narrative review was chosen as it allows a reflective analysis of the current evidence about factors influencing CR utilization. It

also emphasizes the interpretation and the proposal of new ideas and concepts (27), and we make use of this by speculating on future healthcare innovations.

This review follows the *Scale for the Assessment of Narrative Review Articles* (28) to support research integrity and improve the standard of non-systematic reviews. It also follows the hermeneutic approach for literature reviews (29).

3.1 Literature search and inclusion process

In order to identify literature describing barriers and facilitators for CR, German and English review articles were searched in PubMed and Web of Science (Core Collection) databases. *Barrier*, *cardiac rehabilitation*, and *utilization* were defined as keywords. Keywords were combined in search strings with synonyms and Boolean operators for each database. An additional keyword search was conducted in Google Scholar (Supplementary Material 1).

Inclusion and exclusion criteria were defined regarding publication date, language, publication and article type, topic, region, and population (Table 1). Data regarding the studies' characteristics were extracted from full texts with data charting sheets (Supplementary Material 2). The PRISMA flowchart depicts the literature inclusion process (Figure 1). We identified 153 reviews describing factors influencing CR utilization. After exclusion of duplicates, 146 studies were screened for title and abstract. Nine studies were selected for full-text review and included for qualitative data synthesis.

The included studies were published between 2012 and 2021. Six studies (30–35) were systematic reviews of quantitative research, two (8, 36) were systematic reviews of qualitative research, and one (37) was a scoping review. Eight studies (8, 30–33, 35–37) investigated the utilization aspects (referral, enrolment, adherence, completion), and one (34) the patients' engagement with physical activity. With regards to structuring the factors that influence CR utilization, two studies (32, 33) used a socio-ecological health model, and six (8, 30, 31, 34–36) used healthcare-related categories, such as the patient, provider and system level. One study (37) described the factors narratively without any given structure. Table 2 gives an overview of the study characteristics.

3.2 Mapping factors influencing CR utilization to the BCW

The factors influencing CR utilization were mapped according to the BCW (10). The wheel can be considered a framework for understanding or targeting a specific behavior. It supports the design and implementation of evidence-based interventions by linking them to human behavior and therefore also lends itself for guiding retrospective analyses to these ends.

The BCW-hub includes the COM-B *Model of Behaviour*, where *Capability*, *Opportunity*, and *Motivation* influence each other and generate human behavior. The COM-B is encircled by the

TABLE 1 Inclusion and exclusion criteria.

Criteria	Inclusion	Exclusion
Publication date	2012–2023	
Language	<ul style="list-style-type: none">• German• English	
Publication type	Research articles	Letters, Editorials, Abstracts
Article type	<ul style="list-style-type: none">• Systematic reviews• Scoping reviews• Narrative reviews	
Topic-related	<ul style="list-style-type: none">• Cardiology• Cardiac rehabilitation	<ul style="list-style-type: none">• Other medical fields• Medication• Burden• Frailty• Risk factors
Country/region		<ul style="list-style-type: none">• Reviews focusing exclusively on low-resource settings• Reviews focusing exclusively on African, Asian or North American contexts
Population	<ul style="list-style-type: none">• Adults (+19 years)• Cardiac conditions and related co-morbidities	<ul style="list-style-type: none">• Children• People with dementia, cancer or stroke

Theoretical Domains Framework (TDF). This framework aids in identifying influences on HCPs’ behavior in implementing

evidence-based care and studying the behavior of patient populations. The TDF in turn is based on 33 theories of behavior and behavior change, including the theory of planned behavior, social cognitive theory, and self-determination theory (38). These theories were deconstructed and simplified into 14 domains, such as *Knowledge, Beliefs about Capabilities, and Memory, Attention and Decision Processes* (39). The factors defined by the COM-B and the TDF can be tackled by nine *Intervention Functions*, i.e., activities aiming to influence a targeted behavior. These activities are, for example, *Education, Enablement, Persuasion, and Environmental Restructuring*. The *Intervention Functions* are encircled by seven policy categories, such as *Guidelines and Legislation*, not considered in this review.

The TDF was used to group factors according to specific behaviors that could hinder or lead to CR utilization. The final domains, according to the BCW, were summarized qualitatively.

4 Factors influencing CR utilization

Figure 2 provides an overview of the factors that influence CR use. In the following, we present the factors influencing CR utilization according to the BCW domains (10).

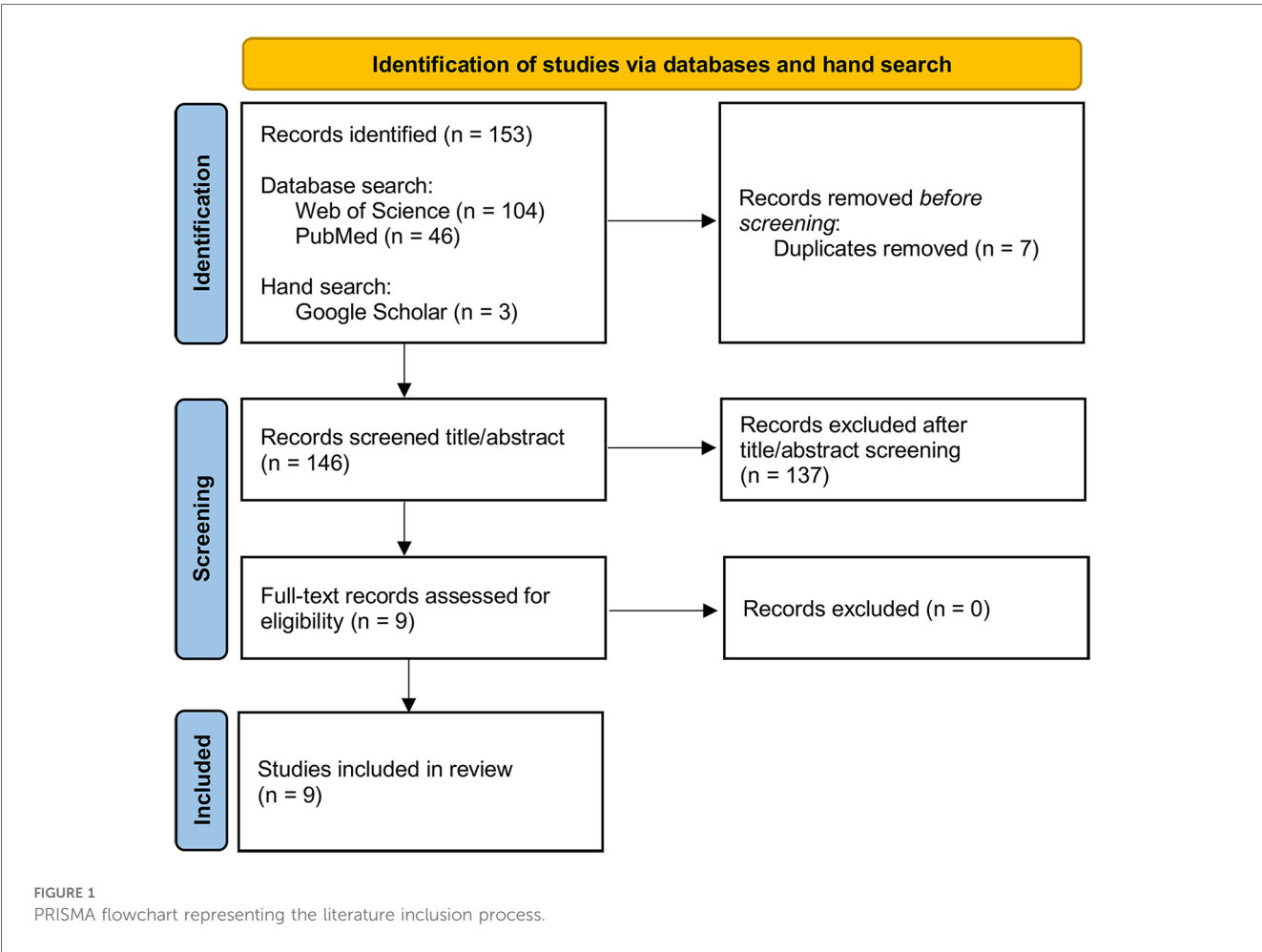
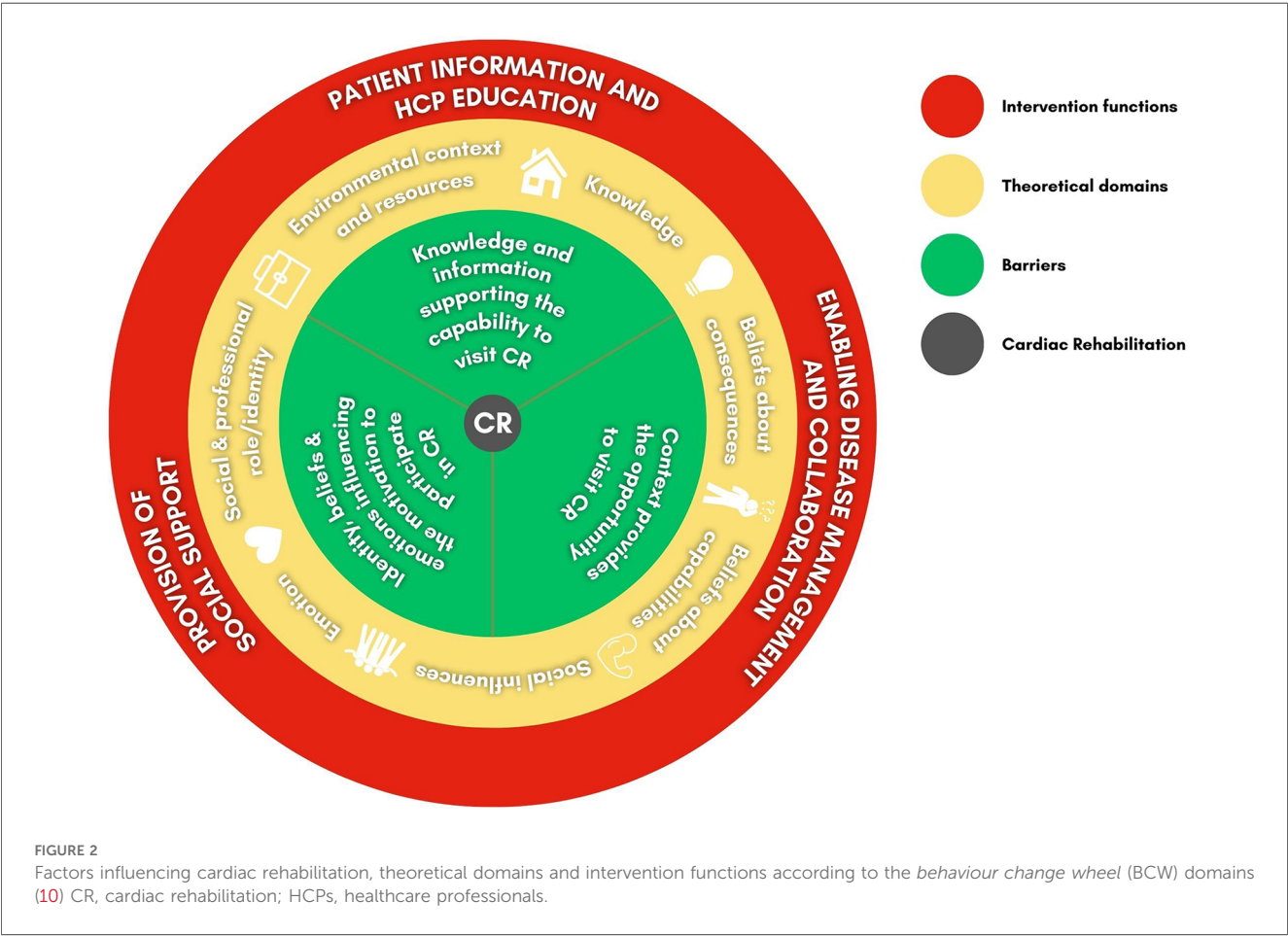


TABLE 2 Study characteristics.

First author	Pub. year	Review design	Included studies (n)	Focus on special patient population	Cardiac rehabilitation utilization aspects	Categorization of factors
Clark (36)	2012	Qualitative systematic review of qualitative or mixed-method studies	90	Not given	Attendance	Personal/Contextual
Clark (8)	2012	Qualitative systematic review of qualitative or mixed-method studies	34	Not given	Referral	Personal/Contextual
Clark (35)	2013	Systematic review of qualitative or mixed-method studies	62	Not given	Participation	Patient/Professional/System
Ruano-Ravina (30)	2016	Systematic review of cohort/cross-sectional studies	29	Not given	Participation, adherence	Gender/Age/Accessibility to CR/ Employment status/Socioeconomic status/Comorbidities/Civil status
Supervia (31)	2017	Systematic review of interventional and cohort studies	24	Female patients	Referral, enrollment, completion	Patient/Provider/Societal/Environmental
Resurreccion (32)	2017	Systematic review of observational, interventional and qualitative studies	24	Female patients	Participation, dropout	Interpersonal/Intrapersonal/CR program/Logistical/Health system
Resurreccion (33)	2019	Systematic review of prospective cohort studies	43	Not given	Participation, dropout	Intrapersonal/Interpersonal/Clinical factors/Logistical/CR program/Health system
McHale (34)	2020	Systematic review of qualitative studies	12	Not given	Not given	Post-event communication and advice/ Expectations of exercise-based CR
Vanzella (37)	2021	Scoping review of cohort or cross-sectional studies	20	Ethnic minority groups	Referral, enrollment, completion/adherence	Not given



4.1 Knowledge and information support patient capability to utilize CR

Patients' capability to take up CR was influenced by their knowledge about their disease and considering CR as fundamental for recovery, the received information, and the communication with HCPs.

Patients' knowledge about their disease and awareness regarding the role of CR in the recovery process facilitated CR utilization (8, 31, 34–37). The phase before the CR program started was characterized by an urgent information need. Therefore, timely information about CR can be helpful (8, 35). Receiving little information caused unawareness of CR and uncertainty about program benefits (31, 32, 34).

During CR, the educational components and the opportunity to ask questions facilitated adherence, whereas lack of interaction with the HCPs was a barrier (32, 37). Receiving individual exercise advice, monitoring the recovery progress, and assessing symptoms were linked to feelings of security and safety. The supervision supported patients who perceived the risk of CVD as unpredictable, inevitable, and uncontrollable (37). In contrast, language differences resulting in communication difficulties with HCPs and a lack of understanding of written and verbal information were barriers to CR utilization (37).

4.2 Patient identities, beliefs and emotions influence their motivation to participate in CR

Personal factors, patients' self-perception, and comparisons with fellow participants influenced patients' motivation to participate in CR. Emotional barriers and a sense of control over their condition also significantly determined their willingness to take up CR.

Gender, age, and occupation were described as influential factors in patients' motivation to attend CR. For example, patients who felt too old to exercise were less likely to participate in CR. Especially in female patients, placing family obligations or occupational demands above health needs was a barrier to CR uptake (30, 33, 35, 36).

Two studies described a fitness identity (34, 36) as a relevant factor for taking up CR: Patients who had the self-perception of already being active enough or who underestimated the severity of their illness were less likely to participate (32, 34–36). Additionally, comparing oneself with other CR participants influenced adherence. Patients who perceived themselves as more fit than their CR fellows were more likely to quit CR (34).

Moreover, feelings and emotions were strongly related to CR utilization. Feeling too sick, too old, overwhelmed, and out of control were mentioned as barriers (33–35, 37). Uncertainty and anxiety about exercising and being unable to address these feelings in the native language also led to non-participation (35). Another barrier was the belief that CR would not make any difference to the current health status; thus, attendance was not considered necessary (32, 33). Negative experiences reinforced this perception

(31, 32, 34–36), such as missing social support during exercises or HCPs being too judgmental (34, 35). Irrational health beliefs, for example, the belief in being capable of managing the CVD by oneself, were seen as a barrier to CR. In contrast, a high sense of control over the heart condition was a facilitator (34, 36). Moreover, it was a facilitator for the uptake of CR when patients were aware of the health benefits and recognized CR as crucial for their recovery (34). Motivation was also reinforced by information about the aims and objectives of the CR program. The prospect of a supervised environment and HCPs supporting the setting of appropriate exertion levels and rehabilitation goals positively influenced CR uptake (34). Generally, HCPs' encouragement was essential for CR adherence (35).

4.3 Healthcare system factors and personal resources influence patients' opportunities to utilize CR

Patients' opportunities to attend CR were influenced by healthcare system factors such as ineffective CR referral processes and HCP awareness, as well as personal resources including logistical challenges and comorbidities; additionally, patients' relatives played a dual role as facilitators and inhibitors in CR utilization.

The patient's social context and healthcare system barriers were repeatedly described as influential factors in CR utilization (8, 30–37). First, the lack of CR referrals in hospitals and a constricted information flow across healthcare sectors hindered initiating the referral process (8, 30, 33, 37). Also, when HCPs were unaware of the indications and did not know that the patient was suitable for CR, this was a barrier to referral (8). Within the CR settings, programs that were unresponsive to the needs of ethnic minorities or women hindered the ongoing uptake of CR (34, 35). For example, when exercising with men was considered sinful for religious reasons, CR programs with mixed-gender classes were considered inappropriate (34).

Regarding personal resources, logistic barriers hindered the uptake of CR, such as a lack of transport possibilities, being a non-driver, and living in a rural setting with poor public transport links (30, 32, 35–37). Moreover, physical barriers were mentioned; for example, a high disease severity or recovery from surgery prevented patients from attending CR and focusing on physical activity. Besides, comorbidities, such as depression, musculoskeletal diseases, obesity, and diabetes, were related to non-attendance. Psychological factors, such as symptom-related pain or anxiety, were also described as barriers (30, 31, 33, 34, 37). Patients with fatalistic health beliefs due to religious reasons, for example, being fated to have heart disease, were less likely to participate in CR (32, 37).

The patients' families strongly influenced CR utilization (31–33, 35–37). On the one hand, relatives were described as facilitators when supporting patients in risk factor management during CR (36). On the other hand, families could also represent a barrier to CR attendance by withholding information to prevent patients from becoming distressed about their CVD (37).

5 Discussion and considerations for future innovations aiming to support CR utilization

Based on the results of the BCW analysis regarding factors influencing CR utilization, we identified seven relevant theoretical domains (10) (Figure 2). These domains are intertwined and influence patients' behavior in the context of CR utilization:

- Environmental context and resources
- Knowledge
- Beliefs about consequences
- Beliefs about capabilities
- Social influences
- Emotion
- Social and professional role/identity

In the following, we propose three intervention functions (10) that are especially important when it comes to addressing the behavioral factors stated above: *patient information and HCP education, enabling disease management and collaboration, and provision of social support for cardiac patients* (Figure 2). We discuss how future innovations could incorporate these functions and SDM to increase CR utilization. Table 3 provides an overview of evidence-based considerations for DHTs designed to support CR uptake.

5.1 Providing patient information and HCP education

Evidence indicated that a central intervention function should address patients' lack of knowledge about their disease and the role CR can play in their recovery. Receiving little information caused unawareness about program benefits, representing a barrier to participating in CR (8, 31, 34–37). We conclude that information about the benefits of CR and preparation regarding what to expect during the program could help reduce patients'

uncertainty about their recovery. With information emphasizing the necessity of CR to reduce the likelihood of further cardiac events, patients are prevented from developing inaccurate assumptions and beliefs regarding their benefits from CR. Further research indicates that especially unemployed women would benefit from tailored educational interventions (40).

Digital health holds great promise to provide patients with evidence-based, easily accessible educational content. Such content will help patients understand the importance of CR and the associated lifestyle changes. Related work describes DHTs incorporating educative elements and providing patient information to increase patients' knowledge regarding their condition. For example, disease-specific symptoms in electronic bookshelves, e-learning programs, or digital transcripts of the patient-HCP encounter have been implemented (41–43). Other DHTs combine educative elements with monitoring features, providing the possibility for video conferences or counseling with (virtual) HCPs (42, 44).

Kim et al. (45) developed a support tool that provides patients facing bone marrow transplants with personalized, clinically validated information about possible outcomes of treatment options. They investigated patients' preferences regarding the presentation of outcome likelihoods with survival calculators and found that sense-making regarding the health condition and emotional support was crucial for patients. In particular, they expressed a need for structured, personalized information (45). Related work shows that the need for evidence and personalized, credible information is also present in cardiac patients (23, 46). Sankaran et al. (41) demonstrated how a single DHT can address these needs. They prototyped a system through which HCPs and patients can jointly select preferred information conforming to medical guidelines, patient needs, and pathways. The information was adapted to the patient's level of knowledge for a remote CR program and chosen in an SDM process between the HCP and the patient (41).

We also found that HCPs' knowledge gaps and unawareness can be a barrier for CR referral (8). Clinical decision support has

TABLE 3 Considerations for future digital health technologies aiming to support cardiac rehabilitation utilization.

Aim	Recommendations
Providing information for patients and HCPs	<ul style="list-style-type: none">• Combine educative elements with monitoring features, enabling video conferences or counseling with (virtual) HCPs• Provide evidence-based, clear, personalized information about CR health benefits• Consider individual factors (gender, age, knowledge level, diagnosis) for personalized content• Allow HCPs and patients to jointly select preferred information in alignment with medical guidelines and patient needs• Implement decision aids to empower patients in SDM• Tailor educational content to provide timely and targeted support at critical moments during rehabilitation
Enabling disease management and collaboration	<ul style="list-style-type: none">• Provide virtual platforms for CR programs to overcome accessibility barriers by offering real-time monitoring, exercise guidance, and interaction with HCPs• Incorporate gamification features, virtual reality games and persuasive elements to virtual CR programs• Implement monitoring features and wearable devices to facilitate self-management and to increase self-efficacy• Provide real-time data for patients and HCPs, enabling timely support and intervention• Tailor support from diagnosis through CR to long-term post-rehabilitation care• Make SDM integral, allowing patients to shape their rehabilitation journey, for example through joint goal setting with their HCPs
Enhancing social support	<ul style="list-style-type: none">• Explore mobile applications that track contextual, experiential, and behavioral data to initiate co-responsibility between patients and their relatives• Establish and foster online platforms for cardiac patients to exchange personal stories and receive social support from relatives• Leverage the power of peer experiences to inform patients about the benefits of CR, for example, through peer testimonials

CR, cardiac rehabilitation; HCPs, healthcare professionals; SDM, shared decision-making.

the potential to address this barrier, for example, by raising awareness about regional services, highlighting appropriate indications, and facilitating the CR referral process. Abidi et al. (47) investigated how such a system can support family physicians in evidence-based treatment decisions. Based on current medical evidence, the system provides advice on monitoring risks and contraindications for multiple cardiac conditions. During the clinical encounter, it also provides the opportunity to note patients' preferences to facilitate SDM (47).

Decision aids within technologies potentially empower patients to engage in SDM with healthcare providers. Patients are well-informed about their options and able to actively participate in selecting treatment plans that align with their goals and values. The premise of practical use is that DHTs provide personal content tailored to individual factors, such as gender, age, level of knowledge, and diagnosis (23, 46). Interventions should also respect patients' preferences regarding their degree of involvement in SDM and tailor the support accordingly. DHTs can provide timely and targeted support to address individual patients' challenges at critical moments in their cardiac rehabilitation journey.

5.2 Enabling disease management and collaboration along the cardiac patient pathway

Limited personal resources, for example, lack of transportation possibilities, limited physical fitness due to comorbidities, and pain or anxiety, hindered patients from participating in CR (30, 32, 35–37). Therefore, a second relevant intervention function works to increase the patients' self-efficiency in managing their condition and enable collaboration with their HCPs.

Remote CR programs have gained popularity within the last few years. They represent an option to overcome accessibility barriers (48). Given the growing acceptance of telehealth as an alternative to center-based rehabilitation, CR programs may become more accessible through virtual platforms (49). Digital CR programs could offer real-time monitoring, exercise guidance, and interaction with HCPs from the patients' homes. Previous research has already highlighted how remote CR could positively affect cardiac patients' cardiorespiratory fitness (50). Future DHTs can contribute to this with gamification features and persuasive elements, impacting patients' adherence and motivation. For example, Geurts et al. (51) developed an immersive virtual reality game to motivate patients to exercise by guided cycling in a safe and enjoyable environment. Gatsios et al. (52) also suggested a combination of gamification and virtual coaching to improve adherence to home rehabilitation programs. In order to support behavior change and a sustainable healthy lifestyle, Wong et al. (53) propose a serious game with fictive scenarios to encourage patients to reflect on their values and make conscious health-related decisions. For example, patients could earn rewards or incentives for meeting specific rehabilitation milestones, making digital CR programs more engaging and enjoyable.

Furthermore, DHTs incorporating self-monitoring features can facilitate self-management and collaboration between patients, HCPs, and relatives. Salamah et al. (54) provide an example of a mobile application allowing patients with autoimmune diseases to track symptom progression, vital information, and laboratory results. Further, the integration of wearable devices could enable continuous monitoring of a patient's cardiac condition at a much more fine-grained and adequate level. These devices could provide patients and healthcare providers with real-time data, ensuring they receive timely support and intervention when needed. Innovations in outcome tracking will enable patients to monitor their progress over the long term, promoting accountability and motivation. Patients may also receive personalized recommendations based on their tracked data.

Future DHTs should prioritize the development of highly personalized care pathways that cater to individual patient needs and preferences. Pathways should also offer tailored support from the point of diagnosis through CR and long-term post-rehabilitation care. SDM will be integral, enabling patients to actively shape their recovery journey, from choosing the preferred rehabilitation program to adjusting it based on their evolving needs and preferences. Therefore, DHTs adapt their content to not only guiding patients through the decision-making process about CR participation but also providing support for emotional well-being and facilitating a sustainable lifestyle change.

Related work already demonstrated how personalized decision support could be supported by digital systems. Peleg et al. (55) introduced a personalized evidence-based decision-support system for HCPs and patients with chronic diseases. The system incorporates a module to elicit patients' preferences and psychosocial context. It provides real-time personalized recommendations combined with medical guidelines and informs the SDM process during a patient-HCP encounter (55). Regarding personalized goal-setting, Chaudhry et al. (56) developed a DHT for community-dwelling older adults with chronic multimorbidity. It supports care workers and residents in setting health goals jointly.

5.3 Enhancing social support from relatives and peers

Barriers to CR utilization showed that patients' families played a significant role as they can support or hinder patients' uptake of CR (31–33, 35–37). Peer comparisons and the perception of not fitting into the group of people who need CR were also barriers (34, 36). Cardiac patients' need for social support is in line with existing evidence (57, 58) and, hence, should be incorporated by DHTs as a third intervention function.

Related work demonstrates how social support could be enhanced digitally. Jansen et al. (59) investigated how co-responsibility between bariatric patients and relatives could be initiated by a mobile phone application comprising features to track contextual, experience and behavioral data. They found that shared routines of relationships could facilitate lifestyle change. However, patients' partners were not aware of their role and

lacked knowledge about how to support (59). Coull et al. (60) researched cardiac patients' attitudes towards physical activity and found that social support from family and friends was crucial for maintaining an active behavior. Patients valued an online platform for exchanging personal stories with peers. The feeling of helping peers by sharing experiences and knowledge was also appreciated.

Future DHTs could enhance development of virtual peer networks specifically for CR patients. These networks could offer support, motivation, and sharing of personal experiences to encourage adherence to the program. Research has demonstrated the positive impact of peer support on patients' ability to retain information, boost self-efficacy, and enhance overall well-being (58, 61). Peers can provide emotional support and help individuals navigate periods of uncertainty, for example, through testimonials sharing experiences (62). It is conceivable that upcoming innovations will incorporate such social aspects into SDM, e.g., leveraging the power of peer testimonials to inform patients about the benefits and experiences of cardiac rehabilitation. Digital health platforms could foster engagement within a community of CR patients, facilitating discussions, support, and knowledge sharing. This sense of belonging to a community can be a powerful motivator.

6 Conclusion

This review represents the first step towards a more patient-centered and need-based development for DHTs to increase CR utilization. Our synthesis of evidence provides barriers and facilitators to CR and possible digital interventions according to the BCW.

The patient's capability to attend CR is influenced by disease knowledge, awareness of the benefits of CR, and interactions with HCPs. Additionally, contextual factors such as referral processes, HCPs' awareness, and patients' resources, including logistical challenges, influence their opportunity to participate in CR. The motivation to engage in CR is affected by patients' emotions, self-perception of fitness and control over the cardiac condition, and peer comparisons. Based on this, we found that patient information, HCP education, enablement of disease management, collaboration along the patient pathway, and

enhancing social support from relatives and peers are relevant intervention functions. To conclude, we considered how future DHTs could incorporate these functions.

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Supplementary material

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