Medical Shared Decision Making with a Virtual Agent

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ABSTRACT

Shared decision making (SDM) is a process in which patients and clinicians work together to make medical decisions based on clinical evidence that balances risks and expected outcomes with patient preferences and values. SDM has been advocated as the ideal model for patient decision-making in healthcare. However, SDM is rarely used in practice due, in part, to limited availability of healthcare professionals trained in these techniques. In this work, we describe the design of a virtual decision coach to help women participate in SDM about prenatal testing for Down syndrome. In a quasi-experimental evaluation study, participants demonstrated significant increases in knowledge, high levels of satisfaction with their final decision and low levels of decisional conflict and regret, indicating that virtual agents can effectively perform in the role of decision coach and facilitate the implementation of SDM.

CCS CONCEPTS

• **Human-centered computing → Human computer interaction**

KEYWORDS

Conversational agents, shared decision making, prenatal testing.

1 INTRODUCTION

There are often multiple options available for screening, diagnosis, and treatment of medical conditions. However, patients are infrequently informed of these options or given the tools they need to make an informed decision based on their personal values and preferences. To address these shortcomings, researchers in health communication and medical decision making have developed techniques for "shared decision making" (SDM), which

has been defined as "an approach where clinicians and patients make decisions together using the best available evidence" [1]. However, the majority of research to date in SDM involves the use of simple text-based tools for a health provider to use in eliciting patient preferences and describing medical options to care. Few automated systems have been developed, and these primarily use conventional media to walk patients through a specific decision problem, without the value elicitation, empathy, and alliance-building that an ideal human healthcare provider would use.

In this work, we describe a virtual agent that simulates a healthcare provider in conducting a shared decision-making conversation with a patient. Although the methods we develop are general, our initial task domain is the selection of prenatal screening options by expectant mothers. There are currently four standard options for prenatal testing, each with their own benefits and risks, and the best choice for a given woman will be based on her unique values, preferences, and medical and personal situation. In the rest of this paper we review work on SDM, patient decision aids, and virtual agents as health counselors, present the design of our initial SDM virtual agent, and discuss the results from a preliminary evaluation study.

2 RELATED WORK

2.1 Shared Decision Making (SDM)

SDM has been increasingly advocated as the ideal model for medical decision making, and particularly for preference-sensitive decisions in which more than one medically acceptable option exists and the best choice is strongly subject to the influence of patient values and preferences [2-4]. Research has shown that SDM helps improve patient participation in medical decision making [5]. Research has also shown that SDM helps improve quality of care and reduce medical costs [6].

2.2 Decision Support Techniques

Several decision support techniques have been developed to facilitate SDM. The most recognizable technique is patient decision aids (PtDAs), which are tools designed to help patients participate in SDM by providing standard information on available options as well as associated outcomes, and implicitly helping patient determine their values for outcomes of options [7]. PtDAs have been shown to be effective in increasing patient knowledge and improving accuracy of risk perceptions, decreasing decisional conflict, and promoting active participation in decision making [7-9]. However, most

currently available PtDAs are text-based forms accompanied by instructions and/or training for health professionals. In addition, they do not assist in integrating patient values and preferences with information about the benefits and risks of options to arrive at a best choice. A few researchers have also looked at decision coaching, in which a trained health professional coaches patients via face-to-face consultations or over the phone, emails, or internet to help them access the medical evidence, clarify their values and preferences, develop skills in deliberating the options, and becomes more involved in SDM [10]. Research indicates that decision coaching has a similar impact as PtDAs on increasing patient knowledge and decreasing decisional conflicts, whereas coaching tends to provide additional benefits on clarifying patient values and improving their decision-making experience [11].

2.3 Virtual Agents in Health Counseling

A number of virtual agents have been developed to provide health education and counselling, many of which have been evaluated in formal studies and shown to be effective [12, 13]. In a study evaluating a virtual agent to help explain discharge information, patients indicated that they preferred receiving their discharge information from the virtual agent, compared to the human nurses, because they could spend as much time as they needed to review the information, and could ask questions without feeling embarrassed [14]. Virtual agents have also been proven to be effective in communicating complex health information to patients with low or inadequate health literacy [15]. Of particular relevance to our work is the work by Robertson et al., which describes a virtual agent as a decision coach to help patients make a treatment decision on prostate cancer in a shared decision-making context [16]. However, this work has focused on the visual design of the virtual character, and the evaluation was only based on an example walk-through of a low-fidelity prototype instead of interactions with a fully working system.

2.4 Summary of Related Work

Many researchers have studied SDM and decision support technologies such as PtDAs and decision coaching. Research indicates more benefits associated with decision coaching compared to PtDAs. However, there are barriers to implementing decision coaching in clinical practice by human healthcare providers, including lack of time, lack of knowledge and skills, and insufficient training for decision coaching. Past studies have demonstrated that virtual agents are capable of providing health counselling and can have a positive impact on patient satisfaction and health outcomes. Thus, virtual agents could represent a promising alternative to the provision of decision coaching by human healthcare providers.

3 DESIGN OF VIRTUAL DECISION COACH

The idea of using virtual agents to support SDM is inspired by the Decision Coach-Mediated SDM Framework developed by Stacey et al [10]. Unlike other frameworks in which SDM is built upon the traditional patient-clinician dyad [2], this conceptual framework includes the role of decision coach to facilitate SDM. According to this framework, the decision coach is mainly responsible for (a) assessing patients' uncertainty about a medical decision, and their deficits in knowledge, value clarity and support, (b) providing decision support by facilitating access to evidence-based information, clarifying values, building skills in deliberation and accessing support, (c) monitoring the progress of decision making, and (d) facilitating the implementation of patient decision. This role presents a perfect opportunity for virtual agents to participate and intervene in SDM.

In our work, we designed a virtual agent that performs in the role of a decision coach to help women make decisions regarding prenatal testing for Down syndrome. The agent provides guidance and support throughout the decision-making process. Our goal is to help women achieve an informed decision and be satisfied and comfortable working with the agent in this role.

3.1 Virtual Decision Coach

The virtual decision coach is a 3D embodied conversational agent (Fig. 1). The agent talks using synthetic speech and displays a range of conversational nonverbal behaviors, including facial expressions, eyebrow raises, head nods, posture shifts, and various hand gestures. Conversational nonverbal behavior is generated for each agent utterance using BEAT [17] and animated in synchrony with the agent's speech. Participants interact with the virtual coach using a menu of utterances options that are updated after each conversational turn.

3.2 Decision Coaching Conversation

The design of the decision coaching conversation is based on the SDM Model developed by Elwyn et al [18], which translates the conceptualization of SDM into a practical model that can be used to guide how to do shared decision making in clinical practice. This model describes SDM as a step-wise process: (Step 1) choice talk, which refers to "the step of making sure the patients know that reasonable options are available"; (Step 2) option talk, which refers to "providing more detailed information about options"; and (Step 3) decision talk, which refers to "supporting the work of considering preferences and deciding what is best". Following this model, we designed the decision coaching conversation to cover the following primary topics.

Topic 1: Greeting and Alliance-building. The virtual coach begins the session by establishing rapport and therapeutic alliance [19] with the patient through social chat and empathy.

Topic 2: Health Education. The virtual coach continues by ensuring the patient is fully informed of the health problem they are facing and the options available to them to address the problem, and to motivate the patient to participate in shared decision making. In our prototype, the agent first talks about Down syndrome and the risk factors associated with Down syndrome, followed by a brief discussion about why shared decision making for prenatal testing is important in this context. The agent then discusses prenatal testing in general and the testing options available for Down syndrome in particular.
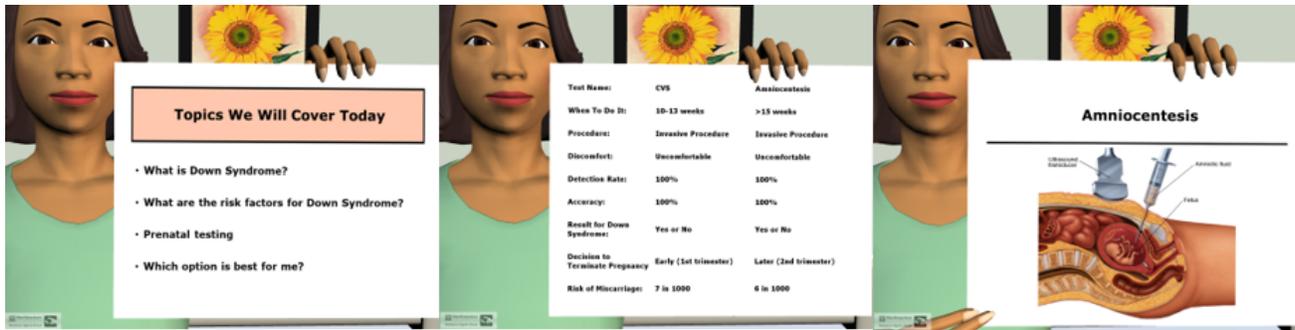
Figure 1: Examples of Virtual Decision Coach Using Various Visual Props

The virtual coach uses text props to provide outlines of the topics under discussion and side-by-side table to allow users to compare between different testing options. The coach also uses stadium charts and images to help explain risk concepts and provide additional information for complex medical procedures. Deictic gestures are used to refer to these props during the agent's conversation with a patient [20].

Topic 3: Values Clarification. The agent then helps patients clarify their personal values and preferences related to prenatal testing by leading them through a value clarification exercise. In this exercise, patients are asked to rank order a list of attributes (e.g. detection rate, risk of miscarriage), by personal importance when it comes to making a decision regarding prenatal testing. The responses are then used to generate a preference list of testing options tailored to these personal priorities.

Topic 4: Decision Making. Finally, the agent assists women in making a final decision regarding prenatal testing. The agent first makes a recommendation based on the values and preference information collected previously and the SMARTER decision analysis algorithm [21], and then asks patients how they feel about the option. Women can either accept the recommended option or choose a different one.

Patient decision making based on preference information is supported using Multi-Criteria Decision Analysis (MCDA) [22]. MCDA is a general term for several analytical approaches concerned with structuring and solving decision problems involving multiple criteria, which are defined as the measures of performance by which the options are judged [23]. The algorithm used in this work is specifically based on the value measurement approaches in MCDA, which seek to associate each option with a real number (or 'value') so that the options can be compared and ranked to generate the best choice [23]. Such approaches involve two essential steps: (a) weighting, which captures the priorities or preferences between criteria, and (b) scoring, which capture priorities or preferences within a criterion [23]. They can then be combined and used to calculate the relative values of options. The SMARTER algorithm uses criteria relative ranks as weights and physical measure relevant to each criterion as scores, and follows an additive model to calculate each option's overall value [21].

$$\text{Option Value} = \sum_{n=1}^{N} w_n s_n \qquad (1)$$

where N are the indexes of the evaluative criteria, W_n are the weights, one for each evaluative criterion (summing to 1), and S_n are the scores, one for each evaluative criterion.

In our work, the weights are patients' ranked priorities of the option attributes (e.g. detection rate, risk of miscarriage), and the scores are normalized physical measures of each option's attributes (e.g. 0.99 detection rate for Amniocentesis).

4 PILOT EVALUATION STUDY

To evaluate the acceptance and efficacy of the virtual decision coach, we conducted a quasi-experimental study in which participants interacted with the agent in a single counselling session, with measures collected prior to and immediately after the session. The study was approved by the Institutional Review Board at our University and participants were compensated for their time.

4.1 Participants

To be eligible for the study, participants had to be female, at least 21 years old, able to speak and read English, and have not had a child before but interested in having children in the future.

4.2 Procedures

After being consented, participants completed baseline questionnaires, had their health literacy and numeracy assessed, and completed a knowledge test on prenatal testing. Participants were then asked to interact with the virtual decision coach for approximately 30 minutes. Immediately after the interaction, the same knowledge test was administered again, as well as questionnaires measuring how they felt about their decision, and their attitudes towards the decision-making experience and the virtual coach. At the end of the study, a semi-structured interview was conducted to ask participants about their overall impression of the experience, which was audiotaped for subsequent analysis.

4.3   Measures

In addition to sociodemographic measures, we collected the following self-report measures prior to (T0) and immediately after interacting with the virtual coach (T1).

- Health Locus of Control was assessed at T0 using the Multidimensional Health Locus of Control Scale [24], to evaluate the belief of an individual in who or what has control over their health. The scale has 18 statements of which 6 items indicating strong beliefs in internal control by oneself, 6 items indicating strong beliefs in external control by powerful others, and 6 items indicating strong beliefs in external control by chance.

- Preferred Role in Decision Making was assessed at T0 using the Control Preference Scale [25]. The scale consists of five cards, each portraying a different role in medical decision making using a cartoon and a statement. These roles range from the individual making the decision (an active role), the individual making the decision jointly with a physician (a shared role), to the physician making the decision (a passive role).

- Health Literacy (HL) was assessed at T0 using the Rapid Estimate of Adult Literacy in Medicine (REALM) instrument [26].

- Numeracy was assessed at T0 using a validated measure [27]. The 11-item objective numeracy scale evaluates individuals' understanding of risk concepts and their ability to solve basic probability problems.

- Knowledge about prenatal testing was assessed at T0 and T1 using a knowledge scale that consisted of 12 true/false/don't know statements. The scale was based on a knowledge measure developed and validated to evaluate a web-based decision aid on decision making regarding prenatal testing [28]. The content of the original measure was based on a generic list of domains considered to be essential to informed decision making in prenatal screening for Down syndrome [29, 30].

- Decisional Conflict was assessed at T1 using the Decisional Conflict Scale [31] to evaluate individuals' uncertainty in making their decision on prenatal testing. Possible scores range from 0 to 100, with higher scores indicating higher level of Decisional Conflict.

- Decisional Regret was assessed at T1 using the Decision Regret Scale [32] to evaluate individuals' distress or remorse after making their decision. Possible scores range from 0 to 100, with higher scores indicating higher level of Decision Regret.

- Decision Satisfaction was assessed at T1 using the Satisfaction with Decision Scale [33] to evaluate individuals' satisfaction with their decision. Possible scores range from 1 to 5, with 1 indicating not satisfied at all and 5 indicating very satisfied.

- Attitudes towards the Decision-Making Experience was assessed at T1 using 4 single-item questions on a 7-point scale (Table 2).

- Attitudes towards the Virtual Decision Coach was assessed at T1 using 5 single-item questions on a 7-point scale (Table 2).

5   RESULTS

We recruited a total of 13 participants, of whom 12 participants successfully completed the study and are included in the analysis. The demographics and personal characteristics of the participants are shown in Table 1.

Table 1: Participant Sociodemographics

Participant Characteristics (N=12)	Descriptive Statistics
Age, mean (SD)	24 (1.5)
Ethnicity, n (%)	
Asian or Pacific Islander	9 (75)
White	3 (25)
Marital Status, n (%)	
Single	11 (92)
Married	1 (8)
Education, n (%)	
Some College	3 (25)
College Graduate and Higher	9 (75)
Health locus of control, n (%)	
Internal control	11 (92)
External control by chance	1 (8)
Control preference, n (%)	
Active Role	7 (58)
Shared Role	2 (17)
Passive Role	3 (25)
Health literacy, n (%)	
Adequate	9 (75)
Inadequate	3 (25)
Numeracy (0-11), mean (SD)	10.3 (1.1)

5.1   Quantitative Results

Overall, participants were satisfied with their decisions and the decision-making experience. Eight participants chose the option recommended by the virtual agent based on the decision analysis algorithm and chose it as their final choice for prenatal testing.

5.1.1   Knowledge of Prenatal Testing. There was a significant increase in participant's knowledge score after using the agent-based decision aid (M=11.17, SD=0.83) compared to before (M= 3.58, SD = 1.62), paired t (11) = 13, p<.01.

5.1.2   Decisional Conflict. Participants reported low decisional conflict (M=19.79, SD=8.89) after talking to the agent, and their scores were significantly lower than a 'neutral' score of 50 (One Sample t-test, p<.01).

5.1.3   Decision Regret. Participants reported low decisional regret (M=20.83, SD=10.41) after the interaction, and their scores were significantly lower than a 'neutral' score of 50 (One-Sample Wilcoxon Signed Rank Test, p<.01).

5.1.4   Satisfaction with Decision. Participants reported high satisfaction (M=4.19, SD=0.45) with the decision they made with the virtual coach, and their scores were significantly higher than a

'neutral' score of 3 (One-Sample Wilcoxon Signed Rank Test, p<.01).

5.1.5   Attitudes towards the Decision Making Process. Participants felt they received slightly more information than they wanted. However, they perceived low pressure about making the decision, with their scores significantly lower than a 'neutral score' of 3 (One-Sample Wilcoxon Signed Rank Test, p<.01). They were highly satisfied with the decision-making process and reported that they were very likely to adhere to their chosen prenatal testing option in the future, both significantly higher than a 'neutral score' of 3 (One-Sample Wilcoxon Signed Rank Test, p<.01). (See Table 2.)

5.1.6.   Attitudes towards Virtual Decision Coach. Participants were very satisfied with the virtual agent. They also liked the agent, trusted the agent, found the agent to be knowledgeable, and expressed a desire to make future decisions with the agent. One-sample Wilcoxon signed rank test demonstrated all ratings were significantly higher than a 'neutral' score of 3 (p<.01). (See Table 2.)

Table 2: Single-Item Outcome Ratings

Single-Item Outcome Ratings	Mean (SD)	p-value
How much information did you get? (1=Too little; 4=Just right; 7=Too much)	4.25 (0.75)	n.s.
How likely would you go with the option you prefer? (1=Extremely unlikely; 7=Extremely likely)	5.67 (0.65)	<.01
How much pressure did you feel? (1=No pressure; 7=Extreme pressure)	2.75 (1.06)	<.01
How satisfied were you with the decision-making process? (1=Not satisfied; 7=Extremely satisfied)	5.58 (0.90)	<.01
How satisfied were you with the animated character? (1=Not at all; 7=Very satisfied)	5.83 (0.83)	<.01
How much would you like to make future decisions with the animated character? (1=Not at all; 7=Very much)	5.58 (1.08)	<.01
How much do you trust the animated character? (1=Not at all; 7=Very much)	5.75 (0.87)	<.01
How much do you like the animated character? (1=Not at all; 7=Very much)	5.67 (0.98)	<.01
How knowledgeable was the animated character? (1=Not at all; 7=Very knowledgeable)	6.17 (0.39)	<.01

5.2   Qualitative Results

Interview responses were transcribed and coded for common themes. In general, participants found the virtual decision coach helpful and easy to interact with, and they felt more informed after their conversation.

When asked about the most helpful topic in the decision aid, some participants referred to "*when she described all the procedures and what happens in each of them and you know how accurate these are and what are the risks and benefits*" because it helped "*understand what each of these procedures entail*" (P5). Some found "*the part where it asked you about what you value the most and you listed your priorities down to the bottom, and kind of analyzed those for what would match*" (P12) was most helpful because it "*helped you make a decision based on your information*" (P6). Some participants expressed appreciation for the side-by-side comparison table (Fig. 1) of the testing options. For example, "*after each section, she had the two options side by side, so you can see the numbers side by side because you heard them and remembered them but visually seeing them side by side is probably most helpful*" (P9).

For participants who chose to accept the option suggested by the coach, they felt the agent's suggestion provided a reassuring feeling. For example, "*I knew I would pick a screening test, but I was not sure about which one, and her suggestion was helpful, and I feel more sure about my choice*" (P6). Also, "*I feel it [agent's suggestion] was probably reassuring because when I looked through it logically, the things that I took into account were also the things she took into account, so it came to the same result*" (P12).

Some participants chose an option other than the one the agent suggested simply because they had a preference for a particular option. For example, "*She suggested NIPT [...], but at the end of the day, I would really like to know whether my baby has Down syndrome or not [...], so I would prefer CVS*" (P11). There were also participants who preferred a different option for personal reasons. For example, "*I know I wouldn't terminate my pregnancy, so I would prefer to have no test because I do not see the benefits of knowing this statistics or risks because it may probably cause more stress, so I would not want the number*" (P10).

When asked about ideas for future improvement, some participants suggested having the option to skip over information they were not interested in. Other participants expressed a desire for more detailed information, for example, "*I want to know more about the diagnostic test [...]. The risks are very similar. I want more details about what the small difference means*" (P5). And, "*Maybe it could be a little bit more elaborate on the discomfort of the diagnostic test, like how long it is going to be and how severe, and is it going to be for everyone or just by chance*" (P8). Also, "*Maybe you can set up a section to talk about what if your baby is diagnosed with Down syndrome, and what are the options*" (P7).

6   CONCLUSION

Many researchers in health communication and medical decision-making feel that SDM can only be performed by a human healthcare provider. However, we demonstrated a virtual agent can fill this role, using best practices from the SDM literature, performed with perfect fidelity. Participants demonstrated

significant increases in knowledge, and high levels of satisfaction with their final decision and low levels of decisional conflict and regret, indicating that virtual agents can effectively perform in the role of medical decision coach.

Future work involves comparison to other decision aid media, evaluation of alternate decision analysis frameworks (such as the analytic hierarchy process [34] and discrete choice experiment [35]) and generalization of the dialogue framework so the coach can be easily adapted for a wide range of medical decision problems. Adapting the decision coach to assist patients with longitudinal sequential decision-making—in which they need to make a sequence of decisions over time [36]—represents another important direction of future research, Ultimately, a randomized clinical trial with longitudinal measures of long-term decision satisfaction, decisional regret and decisional conflict are needed to more thoroughly evaluate the approach.

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