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## ‘They leave at least believing they had a part in the discussion’: Understanding decision aid use and patient–clinician decision-making through qualitative research

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### Abstract

**Objective**—This study explores how patient decision aids (DAs) for antihyperglycemic agents and statins, designed for use during clinical consultations, are embedded into practice, examining how patients and clinicians understand and experience DAs in primary care visits.

**Methods**—We conducted semistructured in-depth interviews with patients ( $n = 22$ ) and primary care clinicians ( $n = 19$ ), and videorecorded consultations ( $n = 44$ ). Two researchers coded all transcripts. Inductive analyses guided by grounded theory led to the identification of themes. Video and interview data were compared and organized by themes.

**Results**—DAs used during consultations became flexible artifacts, incorporated into existing decision making roles for clinicians (experts, authority figures, persuaders, advisors) and patients (drivers of healthcare, learners, partners). DAs were applied to different decision making steps (deliberation, bargaining, convincing, case assessment), and introduced into an existing knowledge context (participants’ literacy regarding shared decision-making (SDM) and DAs).

**Conclusion**—DAs’ flexible use during consultations effectively provided space for discussion, even when SDM was not achieved. DAs can be used within *any* decision-making model.

**Practice implications**—Clinician training in DA use and SDM practice may be needed to facilitate DA implementation and promote more ideal-type forms of sharing in decision making.

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#### Conflict of interest

The authors declare no actual or potential conflict of interest.

## Keywords

Shared decision making; Decision aids; Provider–patient communication

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## 1. Introduction

There is a growing practice and policy impetus toward patient-centered models of care that incorporate patients' goals and preferences into medical decision making [1–4]. Compared to paternalistic models in which doctors unilaterally make decisions [5], or “interpretative”/“clinician-as-best-agent” models, in which clinicians make decisions taking expressed patients' preferences into account [6], participatory approaches respect patient preferences, and promote patient–clinician partnerships and patient involvement in making decisions in concordance with their clinician [7].

Clinicians, however, may not be as able as they think in promoting patient participation [8]; rather, a gap exists between what clinicians *think* they do to enable patient engagement and what they actually *do* [3,9]. Efforts to promote informed patient decision making (a model in which patients drive the decision making process), on the other hand, might leave patients in an inadequate position to make decisions: patients may either receive too little information to take part in decision making, or too little clinician input to have confidence in their choices [10].

Shared decision making (SDM) stands in contrast to both ‘paternalistic’ decision making and informed patient decisions [5,11,12] as a strategy to foster patient centeredness. In the ideal SDM model, patients and clinicians share knowledge about options, deliberate jointly about their advantages and disadvantages, and consensually arrive at a clinically prudent decision concordant with patient preferences. At least one recent review suggests that most patients prefer this approach [13], although SDM is not clearly defined in the literature, nor used in a consistent manner [14]. For the present paper, we take SDM to mean that at least two parties (clinicians and patients) take steps to participate in the process of decision making by sharing information and ultimately agreeing (including agreeing to disagree) [11,12,15]. We recognize that actual clinical practice will offer a range of behaviors that, while participatory, vary from the ideal SDM paradigm [16]. While some degree of sharing might occur in paternalistic and informed patient decision-making models [17], SDM may act as a potential bulwark against clinician dominance or unguided patient decisions, and as an attribute of strong clinician-patient partnerships.

One approach to involving patients as partners in decision making, is the use of patient decision aids (DAs). These are visual tools (e.g. pamphlets, cards, videos, websites, apps) designed to present the advantages and disadvantages associated with available treatment options. Here, their goal is to present patients and clinicians with this information and thus empower them to deliberate about these options from their personal viewpoints, improving the odds that decisions will reflect both the best available research evidence and patients' informed values and preferences [18,19]. Generally, DAs are recommended for situations where a range of treatment options are clinically advisable, including doing nothing [3,16,20]. DAs for medication decisions have been shown to increase patient knowledge and satisfaction, decrease decisional conflict, and allow patients to alter treatment choices [21–26].

However, clinicians who attempt to involve patients in decision making may face dilemmas. For example, SDM may introduce conflict when patients prefer an option that is not funded by the health care system or payer [16,27]. Also, SDM may be experienced as a very

different kind of interaction than clinicians and patients are used to. Here, SDM requires both parties to participate [6], with patients participating to the extent they desire. Therefore, patients could autonomously decide to defer to their clinicians in the understanding that there is a “right choice” and that their clinician is best equipped to identify it [28], as described in clinician-as-best-agent models [6]. Therefore, when patients defer or do not participate, DA use will not guarantee ideal forms of SDM even if clinicians use DAs as intended. This “myth of empowerment” is common to patient-centered approaches [8]. From a practical standpoint, there is virtually no evidence of how DAs are functionally worked into real-life primary care practice, limiting our knowledge of how DAs are routinely understood in that setting.

### 1.1. Research aims

The present study is based on interviews with patients with type 2 diabetes and their clinicians and videotaped clinical encounters. The research aims were: (1) assessing how medication choice DAs for antihyperglycemic agents and statins are embedded into practice and (2) understanding how patients and clinicians understand and experience the work of using medication choice DAs in primary care visits.

Prior qualitative inquiries of DA use have focused on patient satisfaction or quantifying specific behaviors of clinicians and patients during DA encounters [29,30]. Qualitatively studying the work of using DAs in primary care offers the potential to understand the experiential importance of these tools in real-world environments and their utility for patients and clinicians engaged in long-term relationships to manage a chronic disease. Hence, this study seeks to elucidate the “*how*” factors that influence everyday chronic disease management and decision making, and to examine the existing gap or “mismatch” [16] that persists between idealized decision-making models and the messiness of clinical realities.

## 2. Methods

This study is part of a larger cluster-randomized trial assessing the routine embedding of two patient DAs for diabetes care in 10 rural and small urban primary care practices in the Midwestern United States. Methods for the trial included surveys, interviews, and videography across three study arms: paper-based decision aids for anti-hyperglycemic agents, computer-based and paper-based decision aids for statins, and a control without DAs. These are described elsewhere [31].

This paper describes the qualitative study of clinician and patient experiences and interactions. We did not specify a hypothesis concerning the impact of DAs; rather, we intended to inductively identify and understand how DAs are embedded into primary care. We used normalization process theory (NPT) as a guiding framework to develop the study instruments. NPT focuses on the implementation, integration, and workability of complex interventions in healthcare [32,33], and has recently been extended to analyze patient and physician experiences of illness [34,35].

### 2.1. Sample and data

DAs were implemented during regularly scheduled outpatient clinic appointments. Clinicians had minimal per-protocol training in the use of DAs, and the DAs used in this trial allowed for great variability in the ways clinicians used them. Data sources included video recordings of the clinical encounter and post-encounter in-depth interviews. Study procedures took place from July 2010 until November 2011.

## 2.2. Participants

Patient participants were predominantly white, non-Hispanic men and women, 40 years and older with diverse income levels (Table 1). All received a \$25 check. For this paper, we will hereafter refer to patient participants as “patients.” Clinician participants were primary care clinicians (e.g., family practice physicians and advanced practice nurses). Most clinicians were men (83%); 7% reported previous DA training and 20% reported previous DA use. Clinicians reported a median of two encounters (range = 1–6) with trial patients in which they used a DA (Table 1). Clinicians and patients provided written informed consent. The Institutional Review Boards of the Mayo Clinic and Olmsted Medical Center approved study procedures.

## 2.3. Data collection

We developed semistructured interview guides based on literature review and expert consensus using NPT [33,36]. Patient interview guides consisted of questions assessing patients’ diabetes history, perception of diabetes, and, in the DA group, recall and understanding of DAs. Clinician interview guides consisted of questions assessing previous knowledge of SDM or training with DAs, patient management styles, and their implementation of the DA (Table 2). Interview guides were pilot-tested and refined before use. KT and AJ conducted and recorded all interviews. Patient and clinician interviews lasted a mean of 31 min (range = 15–57) and 33 min (range = 33–59), respectively. The time between the index visit and patient interviews was often very long (median = 46 days, range = 7–208, vs. planned goal of interviews within 42 days of the visit), which may have shaped how patients recalled DAs in medication discussions. Interviewers reviewed interview transcripts for accuracy. Patient/clinician encounters ( $n = 44$ ) in which both parties consented were also video-recorded and transcribed, with a mean recording length of 16 min (range = 3–40). Study personnel typically switched on video recorders in the exam room, then left the room; recording equipment was either switched off by clinicians (either after medication discussions but before routine physical health checks, or after the visit) or by study personnel after the visit was complete.

## 2.4. Data analysis

All interview transcripts were coded independently by two researchers with an inductive analysis approach guided by grounded theory [37–39]. A qualitative analysis team (DF, PF, AJ, MO, JR, JS, NS, KT) studied all transcripts in full before reducing the data for coding to identify units of general meaning, units of relevant meaning, and creating categories and themes. Nvivo 9.0 [40] was used to facilitate analysis. Researchers watched all videos, for comparison and linking of patterns to themes identified in interview data, then identified common themes for video and interview results.

We implemented the following safeguards against bias: (a) a multidisciplinary research team participated in each stage of data collection and analysis; (b) the interviewers recorded impressions sheets following each interview; (c) analysis team members discussed these and other data sources; and (d) all transcripts were coded independently by two researchers, with discrepancies discussed until consensus was reached, and a final code list was used for paired coding of all transcripts and for the generation of themes.

## 3. Results

We found that DAs were introduced into a complex array of ongoing patient-clinician relationships and norms. Clinicians and patients used, understood, and experienced DAs and decision making in different ways depending on their perspectives, experiences, and social

and clinical contexts, which we outline in two overarching themes: (1) roles in decision making and DA Use and (2) DA use in the decision making context.

### 3.1. Roles in decision making and DA use

In the interviews, participants consistently defined how they understood existing roles in decision making – i.e., their understandings of the typical actions and approaches in making medication decisions. Almost all participants across study arms identified multiple roles when describing decision-making and, for DA groups specifically, when reflecting on DA use. Across study groups, we identified four roles commonly attributed to clinicians (expert; authority figure; persuader; and advisor) and three commonly defined for patients (drivers of their care; learners; and partners), shown as subthemes in Table 3.

As evident in Table 3, these roles were not mutually exclusive and did not characterize particular types of persons, but rather captured the typical behaviors and positions in decision-making processes with or without DAs. Patients overwhelmingly described the *clinician as expert*, highlighting reliance on clinicians' knowledge and expertise, with DAs viewed as secondary – an “irrelevant” presentational format or within clinicians' typical “line of expertise.” For clinicians, “explaining” DAs or “teaching” represented further extensions of expertise. Some participants saw the *clinician as an authority figure* who would tell patients “what to do.” This was especially true for elderly patients, and those with structural constraints (e.g., job-related or financial challenges), who often ascribed to a view of the “clinician-as-best-agent,” whose knowledge, advice, and decisions they sought out and trusted. Clinicians described this as a tendency among (especially older) patients “who wanted to be told,” and performed the authority figure role with a heightened sense of “maternal” responsibility. Some clinicians discussed tendencies toward paternalistic decision-making, but most also underlined that decision making was not simple. Presenting treatment options was not enough for patients who wanted more guidance, and many clinicians ultimately felt responsible for their patients' decisions (as in *authority figure* or *persuader* roles). Patients who relied on clinician decisions (even after DA use) did not necessarily feel uninformed or disempowered: they emphasized training and knowledge, viewing medication decisions as the clinician's “line of expertise.”

Patients also described the *clinician as an advisor* who “points [them] down in the direction.” Clinicians partially echoed this; many felt it was their duty to lay out the options and issues associated with each medication, acting as informed guides responding to patients' values. Related tasks included teaching, counseling, listening, comforting, or easing anxiety. Here, DAs served as tools that visually displayed “options.”

However, participants sometimes described actively dominant clinicians as *persuaders*, who said various things to move patients toward a preferred choice. Clinicians explained, as in the “authority figure” role, that it was their responsibility (and ability) to “steer” or “push” patients toward the “right” choice (based on their view of guidelines or potential treatment success) – as frequently observed in encounter videos. Clinicians stated that DAs made it “easy” to “lead” patients toward a “best choice.”

Patients' described roles in decision making often suggested active involvement. Both patients and clinicians highlighted an ideal-type role of *patients as drivers of their care*, with responsibility and engagement in diabetes self-care and decision making. DAs sometimes served to support patients' choices by showing they “don't have to” start a medication. For clinicians, this patient role was viewed as critical for treatment adherence. Patients highlighted their responsibility for their health and the work they performed to live a normal life. A related role was *patients as learners*. While some patients described specific tasks (e.g. keeping spreadsheets”) and portrayed DAs as showing “options,” clinicians often

described pragmatic benefits, such as informed patients being able to make better decisions. Finally, some participants described *patients as partners* in decision making who wanted to have a choice and be part of the conversation, with clinicians functioning as experts or coaches to keep them on track. Here, some clinicians highlighted that patients should ideally be seen as partners, saying they would respect patient's choices (which might differ from their own). DAs were viewed as helpful to "get the patient on board." Sometimes, patients actively weighed information (in DAs or otherwise) and "chose myself," but partnering also resulted in "trying" less intense regimens before adding a medication. Some encounter videos showed back-and-forth conversation, information sharing, and learning, but at the point of a decision, patients often asked, and clinicians often offered, their opinion of the best treatment option.

### 3.2. DA use in the decision making context

DAs were experienced and mobilized according to the decision making context in which they were used, including the *decision making steps* participants engaged in and the *knowledge context* determined by patient and clinician understandings of DAs (Table 4 shows subthemes and examples).

Participants described seven decision making steps that occurred, singly or in combination, during a given decision making process, namely: education/information exchange, clarifying preferences, deliberation, engagement, bargaining, convincing, and case assessment.

Both patients and clinicians explained how DAs helped them to exchange information and communicate about options. Clinicians noted that DAs helped them to present information and educate patients, "giving some control of that information flow back to the patient" in a manner befitting an expert or advisor role, while patients felt they were given information about issues with certain medications such as cost or weight gain that otherwise might not have been addressed. Both groups underlined *clarifying preferences* as an important step. This potentially created space for patients to act in the partner role, as some patients said they felt that their "desires" were taken "into account" and some clinicians mentioned that DAs allowed patients to "start the conversation." Video observations also showed both parties engaging in discussions about options, values, and preferences before deciding on a medication. Clinicians highlighted that DAs "prompted more questions," helped patients ask "better questions," or otherwise improved *deliberation* about diabetes medications by involving patients as learners and partners. One clinician said, "they leave at least believing that they had a part in the discussion." Some patients had similar views, stressing that they felt that DAs were "expanding the subject matter." Both groups alluded to *bargaining*; patients frequently described "holding off" or "waiting" before starting a new medication, and clinicians sometimes acquiesced, reasoning that patients needed to believe in what they were doing to improve buy-in.

However, while many clinicians said that patients "should decide," some contradicted themselves by mentioning a step of *convincing* (in their role as *persuaders*), conceptualizing DAs as a tool that "[means] business" and "helped people accept the idea that [one needed] to add more medication" – even a medication they had been resisting (e.g. insulin). In video observations, this convincing behavior was especially apparent in consultations when clinicians described health risks, downplayed difficulties, or used overt statements to convey their preferred choice.

In *case assessment*, each party evaluated the need for a medication change. Patients understood their situation as having few remaining options: one said she had "felt it [...] coming, so [she decided to] just bite the bullet and do it [start insulin]." Some clinicians noted that the evidence presented on the statin DA seemed to go against the guidelines.



These clinicians preferred not to use statin DAs with certain patients, but differed on whether this meant high-risk patients (who might choose an option against guidelines), versus “people that could go either way” (who might see little benefit in adding a medication). Some clinicians also explained that, for certain patients in this trial, no decision was needed, making the DA-related discussion educational or even hypothetical. Case assessment also was apparent in videos when patients had made up their minds before the visit and resisted starting any more medications, no matter what the clinician might say.

DAs were introduced into a specific kind of *knowledge context* based on participants’ understandings of SDM and DAs, which in turn influenced how DAs were implemented, used, and experienced by both groups. It is not surprising that patients, based on their lay status, generally had little notion of how they should be involved in SDM in a setting marked by clear power differentials, with the doctor representing an authority figure and expert. Clinicians had varied understandings about how the concept of SDM could be implemented in real-life consultations, with or without DAs, wondering, “how much sort of help [they] should be giving” patients. This was amplified by widely varied attitudes regarding DAs and SDM among all participants. Most patients had no or only a vague memory of a DA: some remembered it as a pamphlet or brochure akin to other health education literature. In addition, many patients were noncommittal or neutral about DA utility, feeling as if it made no difference in decision making. Many clinicians, while saying they generally “liked” the DAs for design and utility and believing they did not add more time to the consultation, also said using them felt “awkward,” or “unprepared.” Though clinicians often felt that they had a good understanding of the DAs themselves, they felt unprepared to “present the tool to the patient,” and they did not have enough practice to “get familiar with” a DA before implementing it. Most clinicians used the DA only once or twice, due to slow enrollment in the trial. Patients who lauded a DA for enriching their medication discussion conversations often had worked with clinicians with a greater track record in DA use.

## 4. Discussion and conclusions

### 4.1. Discussion

This study used data from interviews and video-recorded clinical encounters to examine how patients and primary care clinicians used, experienced, and understood medication DAs. Despite previous work stating that DAs may help promote shared decision making (SDM) to introduce choice, clarify options, and support deliberation [41], our results show that DAs became *flexible artifacts* with variable uses, which embodied patients’ and clinicians’ existing roles in decision making. This connection with existing roles suggests that, rather than serving as vehicles for needed *culture change* and *redefining* decision making roles [3], DAs operated as vehicles for *situational variations within cultural continuity*. Consequently, as flexible artifacts, DAs designed for the clinical encounter [42] could support any model of decision making on the spectrum from paternalistic to shared or informed decision making depending on the aim of the clinician and on patient preferences [43].

Our study has three main findings. First, DAs designed for clinician delivery during face-to-face consultations served as flexible artifacts with varying social uses and were incorporated into existing decision making roles for both clinicians (as expert, authority figure, persuader, and advisor), and patients (as drivers of healthcare, learners, and partners). The interplay of roles served as part of the social context surrounding DA use.

Second, DAs, as flexible artifacts, were applied to different *decision making steps* (education/information, clarifying values, deliberation, engagement, bargaining, convincing,

and case assessment). These steps reflected the interplay of existing roles and shaped the embedding and experience of DAs in decision making. DAs did create a potential space for discussion, even in face of the time constraints of clinical encounters. Presumably, for the purposes of creating true partnerships and shared decisions, this discussion space would occur at several steps of a collaborative process. However, here, DA use within this discussion space took multiple forms (including convincing and bargaining) not necessarily intended for DAs.

Third, DAs were introduced into a context comprised of participants' knowledge and literacy regarding SDM and DAs, which influenced the DAs' embedding and use within decision making. While patients' lay status precluded familiarity with SDM concepts, clinicians demonstrated varied understandings of and comfort with SDM in theory and practice. Likewise, participants had varied understandings of the DAs, what they did, and how they should be used. Some clinicians simply chose not to use DAs, or, more boldly, they used the DA as a convincing tool. Equally important, some clinicians expressed mistrust in the science presented on the DA (particularly the statin DA), and uneasiness with presenting information to patients with which they did not agree.

Our results support work indicating that implementing DAs into clinical practice is not straightforward, but rather is shaped by ongoing chronic disease management and dynamic social processes [36], but also extend that work by showing that flexible uses of DAs allowed clinicians to use DAs in multiple ways, including approaches not conventionally seen within ideal forms of SDM [44]. Paternalistic behavior and convincing may have served to uphold the cultural continuity of a 'traditional' doctor-patient relationship (with clinicians as experts and authority figures), while responding to patients' preferences to "tell them what to do." Further research is needed to examine if the appropriation of DAs as convincing tools in clinical encounters is more widespread.

**4.1.1. Study limitations**—The study has several limitations. Some medical visits were not videorecorded reducing the number of videographic observations and the number of patients eligible for interviews. In the trial, patient recruitment was slow, such that most clinicians used DAs with only one or two patients (resulting in limited experience with DAs) and influencing recruitment for the qualitative study (as not all recruited patients agreed to the interview). Also, the patient sample offered limited ethnic diversity. Finally, not all patients in the DA arms were good candidates for treatment choice discussions; in some cases, the DA was used to perform a hypothetical discussion "for the camera." These uses contradicted the study protocol in which clinicians were asked not to use the DAs if their use was not pertinent and may have affected patient and clinician perception of the value of embedding the DA in clinical practice.

## 4.2. Conclusion

Overall, our analysis of interviews with patients and clinicians and videotaped encounters provides primary care practitioners and researchers with an in-depth understanding of participants' experiences with medication DAs in real-life consultations. Our study shows that DAs designed for face-to-face clinical consultations may "create a conversation" [45] around medication options, while providing opportunities for different degrees of sharing during the decision making encounter [17]. Uses of DAs as flexible tools suggest that DAs may assist clinicians and patients in achieving more discussion in decision making, even if ideal paradigms of SDM are not achieved. As outlined in the Salzburg statement on SDM, the implementation of SDM with or without DAs will need a culture change among professionals, institutions, and patients [3]. Similarly, our study results suggest that there is a long way to go to achieve SDM in practice through DA use, thus confirming existing



discrepancies [16] between the ideal of SDM and the relative paucity of SDM in practice [46]. Our study results can inform future research on clinician-patient communication and decision making.

### 4.3. Practice implications

Clinician training may be needed to facilitate DA implementation to promote a culture change in decision making.

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**Table 1**

## Participant characteristics.

<b>Demographics</b>	<b>Number (%)</b>
<b>Patient characteristics (n=22)</b>	
<i>Age (years) [mean: 57 years]</i>	
18–39	3 (14%)
40–65	14 (64%)
>65	5 (22%)
<i>Female gender</i>	3 (14%)
<i>Race</i>	
White	22 (100%)
<i>Marital status</i>	
Single	3 (14%)
Married	15 (68%)
Separated/divorced/widowed	4 (18%)
<i>Education</i>	
High school graduate or GED	6 (27%)
Some College or vocational school	10(46%)
College graduate or higher	6 (27%)
<i>Employment status</i>	
Employed	15 (73%)
Disabled	2(9%)
Retired	3 (14%)
Unknown	1(4%)
<i>Income (US\$)</i>	
<20,000	2(9%)
20,000–60,000	9 (41%)
60,000–100,000	5 (23%)
> 100,000	6 (27%)
<i>Study arm</i>	
Usual care	9 (41%)
DA intervention	13 (59%)
<i>Number of years with diabetes</i>	
<5 years	9 (41%)
5–9.9 years	5 (23%)
> or =10 years	8 (36%)
<b>Clinician characteristics (n= 19)</b>	
<i>Female gender</i>	4 (21%)
<i>Previous DA use</i>	
Yes	3(16%)
No	12 (63%)
Unknown	4 (21%)

<b>Demographics</b>	<b>Number (%)</b>
<i>DA use outside trial</i>	
Yes	5 (26%)
No	11(57%)
Unknown	3(17%)

**Table 2**

Interview sample questions.

Domain	Patient Interviews	Clinician Interviews
Sense-making work	<ul style="list-style-type: none"> <li>• What have you heard about the idea of using educational handouts to make decisions about choosing a new medication?</li> <li>• At your last visit, you and your clinician discussed the possibility of adding a new medication. What do you remember about the different medications, their pros and cons?</li> <li>• Did you decide to take/not take a new medication? Did you participate in the decision to the extent that you wanted? How so?</li> </ul>	<ul style="list-style-type: none"> <li>• How do you approach decision-making with patients?</li> <li>• What have you heard about the idea of using decision aids in medical practice?</li> <li>• What did you do to prepare to use the decisions aids, if anything?</li> <li>• Can you tell me about your experience of using the decision aid with your patients for this study?</li> </ul>
Relationship work	<ul style="list-style-type: none"> <li>• Would you say that using the diabetes cards affected your relationship with your clinician? If so, how? Explain.</li> </ul>	<ul style="list-style-type: none"> <li>• Would you say that using decision aids affected your relationship with your patients? If so, how?</li> <li>• How did using decision aids influence the ways in which you communicate with patients?</li> <li>• How confident did you feel about using the decision aids with your patients? What helped you/hindered your confidence using decision aids?</li> </ul>
Enactment work	<ul style="list-style-type: none"> <li>• Did you tell family members/friends about the DA you used with your doctor to discuss diabetes medications/statins?</li> <li>• Did you bring the DA printout home and discuss with family or friends?</li> </ul>	<ul style="list-style-type: none"> <li>• How did the decision aids fit into your patient management style? Explain.</li> <li>• Did you recommend using decision aids to colleagues? Why? Why not?</li> <li>• If DA were to become part of routine practice, what protocols/ policies would you like to see?</li> </ul>
Appraisal	<ul style="list-style-type: none"> <li>• What do you remember about using the DA? What did you like about it/dislike?</li> <li>• Did using the DA helped you decide about adding on a new medication/changing your medication? Explain.</li> <li>• What did you think about the presentation of the DA? Was it straightforward/easy to understand/difficult? Explain.</li> <li>• What could have been better when you and your clinician used this tool during your visit?</li> </ul>	<ul style="list-style-type: none"> <li>• Do you feel the decision aids helped you to accomplish your goals with your patients?</li> <li>• Did it hinder you in your practice?</li> <li>• How do you think the patients felt about having a decision aid?</li> <li>• What role would you say did the decision aids played to help patients decide about medication use (if any)?</li> <li>• What would you do differently if you were to use decision aids with these patients again?</li> </ul>

DA, decision aid.



Table 3

## Theme 1: Roles in decision making and decision aid use.

Theme	Subtheme	Patient interview quotes	Clinician interview quotes	Video observations
Clinician Roles	Clinician as expert	P34: "Yes [it was the] first time ever [that we talked about a statin and used a DAJ. [... J To be real honest, the only thing I was interested in was what my medical professional had to say, and how it was presented was irrelevant."	C14: [Regarding effectiveness as shown on the diabetes DAJ: "They would look at this and say, 'Well, none of these drugs really work.' One or two percent, but, you know, you sort of have to explain what that means in relationship to their hemoglobin A1c.	Diabetes DA Case 1: Clinician quickly reads off current lab results and provides patient with a lot of information about what medications do, their side effects, which lab numbers are good or not, and revisits old lab results. The patient occasionally asks questions but mostly listens.
		P41: "I had not heard about [medication DAs J but you know [...] I am not up to date on all that stuff anyway, I rely on the doctor. I figure that's his line of expertise."	C08: "I do see it as my role [...] to teach them and allow them to make the best decision on their own [...] But the other side of it, as a physician, you're [...] responsible for them even if they make bad choices."	
	Clinician as authority figure	PI 62: "[...] I think of [my clinician's] concern and I want to please him. I mean I got to please myself. It's nice to have him acknowledge 'Hey, I'm seeing less of you these days,' you know."	C06: "I would say a good majority of the patients just say 'You're the doctor, just tell me what you want.'" C08: "I think there is a bit of feeling of maternal responsibility [...] This is going to sound really bad, but in spite of their resistance to something, you know, you have a responsibility of pushing them."	Control Case 2: Clinician recommends increasing the dosage of the current medication: "You shouldn't really notice anything... you double up that dose... take two a.m. and p.m." There is no discussion around what other options exist to help reduce blood sugar. No options are presented.
Clinician as advisor	Clinician as advisor	P48: "[My clinician] never really tells me what to do, but [...] he points me down in the direction and we discuss it."	C08: "I think they all look to be given advice."	Diabetes DA Case 3: Clinician gives patient a card to look at and says insulin is an option. Patient says she does not want shots. Clinician talks about cost, routine, side effects, and low blood sugar risk. He says: "Which ones put you at risk of going too low?" But for "(medication name) is kind of what I'm aiming for, [low blood sugar] not an issue."
		P49: "Based on my results [my doctor] said: 'I don't recommend any changes. Keep on doing the same thing you're doing. It's working for you.' [...] He's really good about that. He's more like a coach."	C07: "If I have a strong feeling one way or the other, that they ought to do one thing or another [...] I might tell them 'I really think you should do this, but this is up to you.'"	
Clinician as persuader	Clinician as persuader	P34: "And it depends on, you know, if someone said, 'Do you want to go on [medication name]?' I would have said, 'No,' but my doctor laid it out in such a way that when he finished talking, I knew there was no choice. I was just going to go on a diet, and he said, 'No, you need to do this,' and he explained why so I did it."	C17: "It was easy to direct patients with the cards, [...] and it was easy to lead a patient down a path that agreed with what you thought might be their best choice."	Statin DA Case 4: Clinician uses statin DA to explain the patient's MI risk. He says: "Medicine is cheap. If it were me, I would take a statin" and statins are "well respected" and "very commonly used." She does not ask about patient preferences. Patient agrees to start a statin.
		Patient roles	Patients as drivers of their care	P52: "I'm a hundred percent responsible, number one. Two, the only other person that really has an interest in me [...] is my wife [...] and then my doctor is the sounding board."

Theme	Subtheme	Patient interview quotes	Clinician interview quotes	Video observations
				[medication] has helped. Clinician then reviews statin DA. Patient notes that losing weight will help prevent an MI too, and doesn't want a statin: "You know if I come back here three months from now and the tests look different, then you know, but I [...] don't want to start down these pill roads."
	Patients as learners	P48: "I have a spreadsheet that I keep track of all my [...] blood results and everything. [...] I try and track my weight. I always jot down my blood pressure and my pulse, and I keep track of the blood tests."	C13: "With diabetes we're trying to get their A1c's to a certain target and their LDL to a certain target and some patients buy into that. You know, the engineer who comes in with three colored pens and the graphs laid out in a spread sheet. They get the numbers and they're excited about that."	Control Case 6: Patient has lost weight. Clinician praises her and asks what she did. Patient says she watches carbohydrates. Clinician mentions that while A1c is lower, it is not low enough to stop her medication. Patient says she intends to continue exercise and hopes to then drop one of her 3 medications. Clinician says that it is possible.
	Patients as partners	P048: "We concluded this time let's give the diet and exercise a crack, let's give the weight loss, let's try some weight loss until we start messing with that. And [the clinician] talked, and he said 'You know, there's a lot of different options still.'"	C07: "Those DAs [...] are helpful a lot of times... So, if you can get the patient on board with what you're doing, it's always helpful [...], you get more cooperation."	Diabetes DA Case 7: Clinician suggests beginning a medication; he fans out [DAJ cards at arm's length from patient and asks which card they should look at. Patient has no preference. Clinician takes A1c card: "I don't think an oral medication [is] going to do the job," and suggests insulin. He uses cost card, says some oral medications are "awfully darned expensive." Patient does not want to do "the shot thing," and asks about side effects. They discuss, and agree to try an oral medication before insulin.

DA, decision aid; SDM, shared decision making; LDL, low density lipoprotein; MI, myocardial infarction. A1c, hemoglobin A1c/glycosylated hemoglobin. Brackets in quotes ([...]) refer to deleted disfluencies (e.g., "um"), repetitions, or tangential phrases (for brevity); inserted text (for context/clarification); or non-verbal cues (e.g., [chuckles]).

Table 4

## Decision aid use in the decision making context.

Theme	Subtheme	Patient interview quotes	Clinician interview quotes	Video observations
Decision making steps	Education/information	P48: “[The DA] was really helpful, to know what was available, [...] daily routine, not so much the cost, [but] the weight change type thing, that one actually makes you lose weight [...] Other [medications cause] weight gain. So I thought they [...] were very helpful. It’s the first time that I had seen [the DA], and I would recommend them.”	C02: “You know one of the things that I think is a criticism of how we do our work [...] is we are telling the patients what we think they should know instead of what they think they should know. And the decision aid process gives some control of that information flow back to the patient.”	Diabetes DA Case 8: Patient has a 20-year+ history of diabetes and is maxed out on an oral medication but the A1c is fairly well controlled and clinician says no change is needed. Clinician then takes cards to educate patient and explain what options and issues there are with different medications.
	Clarifying preferences	P24: “When I first saw her, we were going to put me on insulin right away, and I expressed the fact that I really hated the idea of shooting myself with a needle. [...] She said that she would put me on [oral medication] to start me off to see if I would respond to that, and [...] if I didn’t respond, she would have to put me on insulin. [...] So she took my desires into account.”	C02: “[The DA] really allows the patient to start the conversation and choose what’s important to them. I don’t know that there’s a way of consciously doing that without an aid present in the room.”  C13: “And so trying to find out what their goals and needs are and kind of mesh what we’re talking about so they’re aware of why it helps them get to their goals.”	Diabetes DA Case 9: Clinician suggests adding insulin. Patient asks about weight loss, his biggest concern. He says: “I’m not a big medication person.” Clinician: “You know the needles are very fine. They’re barely perceptible that you’re even using them. They are very minimal as far as intrusiveness or discomfort or pain very honestly, but it does involve an injection.” He explains in terms of weight loss. After discussion, patient agrees.
	Deliberation	P16: “[Using the DA] helped cover talking points. You know, if he didn’t have these, [...] it would have been ‘Well, start insulin. We’ll talk about it after the fact.’ [...] I got the sense that it was expanding the subject matter. [...] Giving him options, giving me options.”	C06: “[The DA] prompts more questions. I think [patients] like that it’s customized to them, so they feel like I’m not speaking in general terms and really speaking right down to their level, and I think because of that, they’re a little more invested in the discussion and they ask more questions; they ask better questions. [...] Maybe if they don’t agree with me, they at least leave believing that they had a part in the discussion. [For example] with the statin tool, almost every time I use it, patients don’t take the statin. [...] And I think that’s fine.”	Diabetes DA Case 10: Clinician says patient’s current medication is maxed out and they need to look at adding another one to lower A1c. He goes over the cards and they engage in a conversation with patient asking questions and clinician explaining, then asking for preferences. They identify three issues: cost, low blood sugar, and side effects. Patient: “So, what do I do?” Clinician suggests a medication that takes care of all issues and patient agrees.
	Engagement	P30: “[My doctor] showed [the DA] to me. [...] Overall, with or without the tool, [my doctor] seemed like he was more concerned about my health.”	C09: “[The DA] gets [patients] more engaged [...] Because, if they’re trying to accomplish my goal then they’re not going to be as successful as if they’re trying to accomplish [theirs].”	Statin DA Case 11: Clinician explains MI risk reduction with the DA. Patient: “I don’t think I’d ever take a cholesterol pill.” After discussing cost and side effects, patient reaffirms decision. Clinician says it’s reasonable because her cholesterol is controlled and she is losing weight. Patient gets fired up about her diet and weight loss.
	Bargaining	P49: “[When my doctor suggested a medication], that’s when I kind of pushed back a little bit and said, ‘Wait, I didn’t know we were going to go on medication! How about	C05: “Fifty percent want to be in control, you know, saying, ‘There’s no way I’m changing my medicines now,’ and I say, ‘Okay. [...] Maybe another trip to the dietician.	Diabetes DA Case 12: Clinician uses cards to discuss A1c reduction. He later says they will increase dosage of [medication name] to two pills, twice daily. Patient says she

Theme	Subtheme	Patient interview quotes	Clinician interview quotes	Video observations
		you give me some time to see if I can take my own action? And then we agreed on a length of time working together to see if I could make an impact.”	You haven’t been there in a few years. [And then] we check [your A1c].”	does not want that much of an increase. Clinician offers two pills in the morning, one at night. They agree that is fine for now and if it does not bring A1c down, they will increase again.
	Convincing	P33: “Well, you gotta do it because you need to do it. So, if [my doctor] says I gotta have another pill, then I gotta have another pill.”	C11: “Both [patients], I’d been trying to talk into insulin for a while and they don’t want to do it. [...] It just so happens, after I used these cards, they both went on insulin.[...] I think, ‘Well that’s interesting.’ I got this other guy now that I’m trying to get on insulin. I think I [...] should probably use [the DA]. [...] Maybe I can talk him into it.”  C14: “I think [the DA] helped people accept the idea that we need to add more medication. [...] [It] helped convince people that I’m serious and I mean business, and we really are going to choose something.”	Statin DA Case 13: Clinician introduces DA, explaining the graphic shows how statins could “delay the risk of a first heart attack” in patients with diabetes. Patient, full of emotion, with hands clasped: “Right. But if I could get <i>that</i> [diabetes] under control.” She bites her lip, concentrating, and sits up in her chair. Clinician: “Yeah. If you could get your diabetes under control, your risk would reduce. However, having a heart attack is a very life-changing experience and fully disabling to many people. If they survive it.” They discuss daily routine and side effects; patient agrees to a statin.
	Case assessment	P24: “[The DA] allowed me to actually go, ‘Yeah. Well, it is an improvement [in risk of a CV event], not dramatic enough improvement that I feel it’s worth it.’ [...] I had already been opposed [to taking a statin]. [...] The tool gave me more information, [...] without the tool [my clinician] would have probably put me on a statin because I had not made any progress lowering my cholesterol.”	C18: “I think it’s with [patients] that are more borderline like the ones that I had [in the study] that really makes it hard [to use the DA [...]. And maybe that’s the right thing to do is not start them on it, I don’t know, but it seems to be at odds with the guidelines we’re supposed to follow.”  C08: “With high-risk patients [...] I don’t bother [using the DA] as much. [...] [With] people that could go either way, I think the tool is very helpful.”	Statin DA Case 14: Patient has gained weight. A1c is up. HDL is very low. Patient explains that his Dad had low HDL. They review MI risk on the DA. They discuss side effects. Doctor: “You have a miserably low HDL that isn’t going away, and I think you have a genetic predisposition to that. It’s not your fault, I think it was all set in stone before you had a say. [...] I think it’s a good idea [to start a statin]. Patient nods and agrees to start a statin.
Decision making knowledge	SDM literacy	P05: “Well, I’m usually okay letting [my doctor] decide [...]. I usually go with the thought that she knows a lot more ... and a lot better than I do, and usually just try to follow what she says.”  P34: “When I made a decision to take [medication name], I was sure I was going to take it. When I made a decision not to take the statins, I was very comfortable and sure of my decision.”	C11: “[I felt like] this is pretty awkward [...] I didn’t know honestly how much sort of help should I give them, [...] in making a decision [...] So I guess the biggest thing I thought predominantly [when showing them the DA was], ‘This is awkward.’ [...] Maybe if I had more practice and found it more helpful.”	Statin DA Case 15: DA shows 2% MI risk reduction. Patient: “At two percent, I think I’ll stay without the drug.” Clinician: “OK. Alright.” Patient, pointing to the chart: “I mean, as it is, I try to lower the amount of pills I feel I’m taking a day [...], so definitely, I don’t want to add any more.” Clinician nods. Patient: “[...] What we’re really looking at is there’s a two percent chance, and I’ll take my chances. [...] Since no one in my family has ever had heart problems.”
	DA literacy	P17: “It was the first time that [my doctor] had seen [the DA]. [...] So it was kind of a new thing for both of us. [...] Well, actually I don’t even think we did it quite right ‘cause there was three sections, I think, and we only used one of them. [...] [chuckles] We figured it out afterwards that we messed up, but, oh well.”	C01: “My learning wasn’t, when I saw the tool [...], ‘Oh, I don’t get this.’ [...] My learning was, as I use the tool, learning how to use it to accomplish the goal of why you’re using the tool in the first place.”  C19: “The part that would be helpful is to receive some	Diabetes DA Case 16: Clinician has cards ready, but says patient is in good control and has very good results so he does not need a medication change. Clinician fans out cards once, saying one could use this to decide about medications, but does not use them and puts them away. He then adjusts the prescription for the patient.

Theme	Subtheme	Patient interview quotes	Clinician interview quotes	Video observations
			guidance on what to do when that pictorial representation looks really [low risk] but it's conflicting with what you're told based on the guidelines."	

DA, decision aid; SDM, shared decision making; LDL, low density lipoprotein; HDL, high density lipoprotein; MI, myocardial infarction; A1c, hemoglobin A1c/glycosylated hemoglobin. Brackets in quotes ([...]) refer to deleted disfluencies (e.g., "um"), repetitions, or tangential phrases (for brevity); inserted text (for context/clarification); or non-verbal cues (e.g., [chuckles]).