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How Does Decision Complexity Affect Shared Decision Making? An Analysis of Patient-Provider Antiretroviral Initiation Dialogue

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Abstract

Objectives—This study analyzed patient-provider dialogue regarding **anti-retroviral therapy (ART)** initiation, assessing the degree to which shared decision making (SDM) occurred.

Methods—We analyzed 24 audio-recorded dialogues between **14** HIV providers and their patients regarding ART initiation. We coded transcribed dialogues for **seven** SDM elements. We stratified dialogues into **three** levels of decision complexity (basic, intermediate, complex) based on patient CD4 counts and evaluated SDM criteria fulfillment at each level of decision complexity.

Results—There were **five** basic, **twelve** intermediate, and **seven** complex decisions in our sample. While only **two** met the defined criteria for SDM, the mean number of SDM elements present increased with each level of decision complexity. Discussion of the clinical issue requiring the decision occurred most frequently (88%), while discussion of pros/cons (13%), patient's understanding (21%), and decision alternatives (29%) occurred least frequently.

Conclusion/Practice Implications—While few dialogues met the defined SDM criteria, providers are having conversations that respond to decision complexity. Clinicians should be aware that discussion of pros/cons, alternatives, and uncertainties are frequently skipped, even

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when these elements are clearly relevant, as in complex decisions. In addition, rhetorical questions to assess patient preferences and understanding are insufficient to fully engage patients in SDM.

Keywords

Shared decision making; patient-provider communication; antiretroviral initiation; HIV/AIDS

“It is no doubt that you cannot get from *is* to *ought*. But you ought to know what *is* is before you say what *ought* ought to be” [1].

INTRODUCTION

Involving patients in treatment decisions, called “shared decision making” (SDM), has become a popular topic of research in the healthcare community; even the United States Affordable Care Act includes a provision to increase implementation of SDM. While there is broad agreement on a few points – that SDM involves patient-provider dialogue about treatment options, is not currently utilized sufficiently, and should be encouraged - there remains significant variation in the specific criteria used to define SDM in clinical practice [2].

There are, roughly speaking, two bodies of research regarding SDM. First are studies that use conversation or discourse analysis approaches to conduct in-depth analyses of patient-provider dialogue. These studies have helped characterize the components of SDM and identify specific interactional phenomena and strategies used by providers to enable SDM [3–7]. A second body of research has aimed to identify the components that *should* be included in SDM and developed tools to allow researchers to measure SDM in recorded dialogues [8–11]. However, there has not been a lot of work done in the “middle” – research that aims to operationalize the coding schemes, applying them to dialogues and critically evaluating the results with an aim toward determining what insights the coding schemes provide as well as where they may fall short.

SDM is particularly important in the case of **antiretroviral (ART)** initiation as adherence to therapy requires strong patient commitment. As stated by the Panel on Antiretroviral Guidelines convened by the Department of Health and Human Services, “individualizing treatment with patient involvement in decision making is the cornerstone of treatment planning and therapeutic success” [12]. However, no studies have directly observed patient-provider dialogue regarding ART initiation and the nature of these conversations is therefore not known. The vast majority (> 70%) of patients living with HIV (PLWH) report that they desire involvement in healthcare decisions [13–16]. However, provider communication style and content has been found to remain the same regardless of patient role preferences, suggesting that providers do not tailor conversations to patients’ desired level of involvement [16]. Some evidence exists that SDM may help increase ART adherence by enhancing patient commitment [17]. In addition, studies have found that many of the benefits of SDM - such as increased patient self-efficacy, confidence in their treatment regimen, understanding the importance of adherence, presence of readiness, and perception of positive provider-patient relationship - all also increase ART adherence [18,19].

While SDM is recommended for all healthcare decisions, its importance increases as uncertainty about the clinical appropriateness of a given treatment increases. For ART, certainty about the appropriateness of initiating treatment is higher with lower CD4 counts, and vice versa. That is, when a patient's CD4 count is below guideline-recommended thresholds for ART initiation, the decision is more straightforward from a strictly clinical perspective, whereas for higher CD4 counts, the decision is more complex. Complex decisions, where treatment benefits are less certain, call for more thorough SDM, since such decisions are considered more "preference-sensitive." This discussion becomes even more complex when ART is initiated for the purpose of preventing transmission to others.

Our study takes place in the context of HIV care and is informed by the work of Braddock and colleagues who developed a set of **seven** criteria for SDM through extensive review of the bioethics literature [11,20]. Our primary study aims were three-fold. First, we aimed to assess the frequency of SDM utilization in **ART initiation** discussions. Second, we wanted to describe the dialogue providers use to facilitate patient involvement in this decision. Finally, we aimed to assess how clinical certainty (or decision complexity) affects ART initiation dialogue and the presence of SDM. Our overall goal was to provide a nuanced view of SDM and how it is affected by decision complexity. Additionally, we sought to understand the outcomes of ART decision making as a function of patient preferences, provider preferences, and decision complexity.

METHODS

Study Design, Subjects, and Setting

The data for this study were collected as part of the Enhancing Communication in HIV Outcomes (ECHO) Study, which was conducted **in the years 2006-2007** in four cities: Baltimore, New York, Portland, and Detroit. The study included 45 providers and 434 PLWH. Providers were physicians, nurses, and physician assistants who provide primary care for PLWH. Patients were HIV-positive, 18 years of age or older and English-speaking. Visits between patients and providers were audio-recorded and transcribed verbatim by a professional transcription company. Additional details about the ECHO study are available in previous publications [21–24].

Sample Selection

From the ECHO study, we selected all transcripts in which discussion of ART initiation occurred. ART initiation dialogue was identified using the Generalized Medical Interaction Analysis System (GMIAS), which applies a topic and speech act code to every utterance made by the patient and provider. ART initiation is a standing topic code within the GMIAS system and includes dialogue about **initiating** ART with patients who had never been on ART, as well as those who had been on ART in the past but had been off of medication for a prolonged period of time. Each transcript was then reviewed by a member of the research team (MM) and all ART initiation related dialogue was abstracted. Because some dialogue contained only one or two utterances (usually deferring the issue to the future), we eliminated those transcripts and focused only on dialogues where the decision was actively discussed during that visit ('substantive' dialogues).

Data Analysis

We applied content analysis to the dialogue with a focus on understanding how SDM occurred between patients and providers.

Dialogue Coding—We coded all dialogues based on the SDM criteria developed by Braddock and colleagues, which includes **seven** elements [11]:

1. Discussion of the patient's role in the decision making process
2. Discussion of the clinical issue driving the need for a decision
3. Discussion of alternative options
4. Discussion of pros and cons of the alternatives
5. Discussion of uncertainties involved in the decision
6. Assessment of the patient's understanding of the information discussed
7. Elicitation of the patient's preference

After reviewing several SDM coding methodologies, we decided to use the Braddock model due to it being descriptive (items are present or absent), as opposed to normative (judging how *well* providers utilize the methods). We initially aimed to code each SDM element dichotomously as either 'fulfilled' or 'unfulfilled' (as prescribed by Braddock et al.). However, upon initiating coding, we felt that this binary coding was not appropriate for the two criteria *assessing patient understanding* and *eliciting patient preference*. While Braddock and colleagues counted passive assessment of patient understanding (e.g. "*Does that makes sense?*") and patient preference (e.g. "*Okay?*") as fulfillment of these respective criteria, we deemed these passive statements to be insufficient, as in practice they serve more as rhetorical statements than actual questions requiring answers from the patient. Thus, in these cases we coded the element as being 'partially fulfilled'. Full fulfillment necessitated a direct question requiring more than a perfunctory patient response. Second, for these same two criteria, we counted "assessment of patient understanding" as fulfilled if patients spontaneously demonstrated understanding (even if the provider didn't ask) and "elicitation of patient preference" as fulfilled if patients offered their preference unprompted by the provider. The rationale for this latter change was that, if patients offered this information unprompted, providers did not need to actively elicit it. These exceptions were agreed upon by two investigators (MCB and WC) who reviewed all of the data and met repeatedly to discuss the coding system in relation to the actual dialogue.

Additionally, criteria 3 and 4, *discussion of alternative options* and *discussion of pros and cons of alternatives*, required further discussion to characterize dialogue that fulfilled these criteria. We turned to the basic principles behind SDM: to provide the necessary information for patients to participate in healthcare decisions and to encourage their involvement in decision making. Given this basic principle, we determined that the following elements were needed to fulfill these criteria:

Criterion 3 - discussion of alternative options: must explicitly state either that not **initiating** or waiting to **initiate ART** is an option

Criterion 4 - discussion of pros and cons: must include at least one statement that supports each of the two decision options (e.g. fulfilled if mention: *both* benefit of option 1 *and* downside of option 1 OR benefits of both options OR downsides of both options. Not fulfilled if just state benefit of option 1 and downside of option 2 because these both support option 1.)

Once the coding criteria were agreed upon, one investigator (WC) coded all of the data and a second investigator (MCB) double-coded a randomly selected subset of 20% of the dialogues. The inter-coder agreement was 86% (kappa 0.70). Any coding discrepancies were discussed and mutually agreed upon.

Determination of Decision Complexity—Using two of Braddock et al.’s criteria regarding decision complexity (medical consensus and nature of outcome), we deemed ART initiation decisions to be “basic” for patients with CD4 counts ≤ 200 cells/mm³, “intermediate” for CD4 counts 201-350 cells/mm³, and “complex” for CD4 counts > 350 cells/mm³ [11]. These **cut-offs** were based on the recommendations published by the World Health Organization (WHO) and the U.S. Department of Health and Human Services during the time period in which these visits occurred (2006-2007) [25]. At the time, these guidelines recommended ART for all patients with CD4 counts ≤ 200 cells/mm³. For those with CD4 counts 201-350 cells/mm³, they recommended that patients be offered ART but did not strongly suggest that ART was necessary in all cases. Finally, they recommended that therapy be deferred for patients with CD4 counts > 350 cells/mm³, unless there was another compelling reason to **initiate** [25,26].

SDM Criteria Fulfillment—Whether a dialogue met criteria for SDM depended on the complexity of the decision being made. In accordance with the Braddock coding system, basic decisions qualified as fulfilling SDM if they met criterion 2 (*discussion of the clinical issue*) plus either criterion 1 (*discussion of patient’s role*) or criterion 7 (*assessment of patient’s preference*). In addition to the criteria for basic decisions, intermediate decisions also required fulfillment of criterion 3 (*discussion of alternatives*), criterion 4 (*discussion of pros and cons*), and criterion 6 (*assessment of patient’s understanding*). Finally, complex decisions required fulfillment of all seven criteria [11].

Determination of Patient Preferences, Provider Preferences, and Decision Outcomes—We determined the degree to which patients wanted to initiate ART and the degree to which providers wanted to prescribe ART by reviewing the transcript for statements that indicated each party’s preference. We coded preferences as: wanting to initiate ART, not wanting to initiate ART, and ambivalent about the decision based on the dialogue because we felt that these preferences might relate to how providers and patients discussed, and made, the decision.

For each encounter, we also noted the “outcome” of the discussion (e.g. decision to **initiate** ART, ongoing discussion, no decision) based on whether a clear decision was reached within the dialogue. We evaluated the number of each outcome by decision complexity and by patient and provider preferences for ART initiation.

RESULTS

Provider and Patient Characteristics

Of the 434 patients in the parent study, 100 were not on ART (21%) and of those, dialogue regarding ART initiation was present between 24 patients and their providers. The 24 patients were seen by 14 providers of whom **seven** (50%) were female, 10 (71%) were physicians, and 11 (79%) were white, with mean age of 45 years (range 30-64). Of the 24 patients, the mean age was 43 years (range 30-59). Fourteen (61%) were female and 16 (70%) were African American. Seventeen patients (74%) had known their provider for more than one year, and five of these patients had known their provider for more than five years. Five patients had CD4 counts ≤ 200 cells/mm³, **twelve** had CD4 counts between 201 and 350 cells/mm³, and **seven** had CD4 counts > 350 cells/mm³. **As judged from the dialogue, ten** patients had taken ART in the past, while 14 had never been on ART.

SDM Dialogue Characteristics

Prevalence of criteria fulfillment, and where applicable, partial fulfillment, are shown in [Table 1](#), and examples of each SDM element are shown in [Table 2](#). As shown in [Table 1](#), discussion of the clinical issue driving the decision occurred most frequently ($n = 21$) while discussion of pros and cons ($n = 3$), assessment of patient's understanding ($n = 5$), and discussion of decision alternatives ($n = 7$) occurred least frequently. The provider only actively assessed patient understanding in **one** case while in **four** additional cases patients offered evidence of their understanding unprompted by the provider. Among the remaining 19 dialogues, 10 were coded as "partially fulfilled," representing dialogues in which the provider made a perfunctory gesture to ascertain the patient's understanding by rhetorically asking "Okay?" or "Does that make sense?" Rates of fulfillment for *elicitation of patient preference* were higher with 15 fully fulfilling this criteria, though active preference elicitation only occurred in **five** dialogues; in the other 10 patients offered their preferences unprompted.

SDM and Decision Complexity

On average, 2.8 SDM criteria were fulfilled per dialogue, with basic decisions fulfilling a mean of 1.2 criteria, intermediate decisions a mean of 2.5 criteria, and complex decisions a mean of 4.6 criteria ([Table 3](#)). As shown in [Figure 1](#), rates of fulfillment of each individual criterion increased with each increase in decision complexity. Only **two** of the dialogues fully met criteria for SDM as defined by Braddock et al., both of them basic decisions ([Table 3](#)). None of the intermediate or complex decisions, which required more SDM criteria to be met to be considered fulfilled, reached the standards prescribed by Braddock and colleagues. Furthermore, of the 19 intermediate and complex decisions, only ten met criteria for even "basic" decisions.

SDM and Patient/Provider Preferences for ART Initiation

Half of the providers were ambivalent or undecided and half clearly expressed a desire for the patient to **initiate** ART. Among the patients, **seven** did not want ART, **eight** were ambivalent or undecided, **five** expressed a desire to **initiate** ART, and in **four** cases the

patient's preference was not determinable because the provider dominated the discussion. Patients and providers agreed on their desire to initiate ART in 11 cases and disagreed in 13 cases. There was only one case in which the patient seemed to have a stronger preference to **initiate** ART than the provider.

As shown in [Table 4](#), more criteria were fulfilled when the provider was ambivalent about initiating ART (mean 3.8 criteria) than when the provider felt more strongly about the need to initiate ART (mean 1.8 criteria). Similarly, when the patient wanted to initiate ART, the dialogue fulfilled a mean of **two** criteria, when they were ambivalent a mean of 3.8 criteria, and when they did not want ART a mean of 3.4 criteria.

Decision Outcomes

Two categories of decision outcomes were present: in **seven** dialogues a decision was made to **initiate** ART and in 13 a decision was made to defer a final decision on ART initiation until sometime in the future. In the remaining **four** discussions the conversation was so dominated by the provider with little to no participation by the patient that it was not possible to determine a discussion outcome ([Table 5](#)). Notably, ART was initiated in all cases when patients desired it, but in less than half of cases when providers desired it. As expected, ART initiation tended to be deferred more with higher CD4 counts (i.e., less clinical certainty about the appropriateness of treatment).

DISCUSSION

The low level of SDM that occurred in our sample is consistent with previous findings [10,27]. However, while very few (<10%) dialogues about ART initiation fully met criteria for SDM, the extent to which providers engaged in SDM increased with increasing decision complexity. In fact, not only did the mean number of criteria met increase with decision complexity, the frequency of *each* individual criterion increased. If we simply look at SDM criteria fulfillment as an 'all or nothing' phenomenon, then our study has pessimistic findings. However, a nuanced analysis reveals that many providers in our sample are having conversations that respond to the particularities of individual patients. This is consistent with prior studies showing significant intra-provider variability in fulfillment of SDM criteria; providers engage in different amounts of SDM with different patients [10].

Interestingly, fulfillment of the **seven** SDM criteria was higher across the board in our sample than in Braddock et al.'s original research [11], especially when one considers that these conversations represent just one snapshot in the relationship between each provider and patient. Even considering that some of the SDM elements may have been addressed in other visits, and even with the more stringent coding rubric we applied, there was a higher rate of fulfillment of every criterion. Most notably, while in Braddock et al.'s study discussion of the patient's role occurred in only 5.9% of discussions, in our study this was 7-fold higher at 42%. Similarly, discussion of uncertainties was more than 6-fold higher at 38% compared to 4.1%, and assessment of patient understanding was 7-fold higher at 21% compared to 1.5% [11]. The higher levels of SDM in our sample may be related to several factors. First, since its emergence HIV has been a focus of grassroots activism and patient empowerment that continues to influence the HIV/AIDS community today [28,29]. This

patient empowerment may translate into more activated patients who are more engaged in treatment decisions. Secondly, PLWH tend to have more frequent encounters and may have a longer-term relationship with their provider than primary care patients who may only see their provider once a year, perhaps leading to greater mutual respect, understanding, and more SDM. A third factor is the reality that partnering with the patient is of extreme importance when initiating ART because it requires such strong patient buy-in for the treatment to be successful due to the risks of viral resistance with inconsistent adherence [30,31]. Finally, Braddock et al. conducted their study in 1993 whereas our study took place in 2006-2007. During these 10+ years, SDM has become increasingly recognized as an important component of the doctor-patient relationship and is increasingly taught in medical schools and residency, perhaps contributing to higher levels of SDM in the later sample.

Our study found less SDM (particularly less discussion of treatment risks, alternatives and uncertainties) when providers wanted to prescribe, or seemed to think it was in the patient's best interest to take, ART. This may represent the providers attempting to persuade patients by not focusing on the downsides of or alternatives to treatment. Previous studies have found that providers often choose what information to give patients based on what they believe to be "necessary" and choose to withhold information that may lead the patient to make what the provider believes to be a sub-optimal choice [32,33]. From an ethical perspective, providers may need to be more cognizant of their inclination to avoid discussion of risks and alternatives so as not to omit information that is important for an informed discussion with the patient. In other cases, if a patient's resistance is rooted in hyperawareness of the risks, providers may focus on the benefits to realign a patient's perceptions of ART. Although some might consider this a deficit in SDM, it probably represents an emotional investment and concern on the part of the provider for the patient's well-being. This suggests that clinical equipoise may not always be necessary for the practice of SDM. Situations where patients refuse to **initiate** clinically appropriate treatment ($CD4 \leq 200$ cells/mm³) may require a different focus: the provider's role may be to elicit patients' concerns and values so as to better understand their preferences. As has been argued previously in a study that looked at SDM in cases of pediatric viral tonsillitis where parents desired antibiotics, one of the roles of SDM may be to create space for the exchange of information, preferences, and values to facilitate effective and appropriate clinical practice [34].

From the perspective of methods to measure the quality of SDM in dialogues, this research is novel in two ways. First, in contrast to previous research that analyzes different types of decisions, all of the decisions in our sample were the same (whether or not to initiate ART). We then stratified this one decision type into basic, intermediate, and complex decisions based on the patient's clinical condition. Second, we modified the dichotomous coding scheme (fulfilled vs. unfulfilled) to include more nuance. While Braddock et al. counted any attempt at assessing patient understanding and preference as fulfilling these criteria, we felt that passive statements such as "*Okay?*" or "*Make sense?*" did not fulfill the spirit of SDM. To truly fulfill these domains, we feel that providers need to actively elicit patient preference and understanding through questions such as "*how do you feel about that?*" or by having the patient repeat back important information to ensure comprehension with an approach that takes the responsibility for understanding onto the provider herself (e.g. "just so that I can

make sure I was clear...”). In addition, we chose to include spontaneous statements of preference or understanding by the patient, even if not prompted by the provider, as fulfilling that SDM element. In these cases, we did not feel that it would be appropriate to penalize providers for not eliciting this information as the patient gave them the necessary information.

This study has several limitations. First, our sample size was limited and did not allow us to draw statistical conclusions regarding our findings. However, we believe that the patterns we observed are important preliminary findings for future study. In addition, as we note above, these conversations represent a snapshot in a long-term relationship between the patient and provider. Conversations about ART initiation often occur over time and sometimes with multiple providers. Similarly, our study includes mostly patients who are actively engaged in medical care, with a long-term relationship with their provider. Discussions of ART initiation may therefore appear different among patients less engaged in HIV care. Finally, audio-recording the visits may have affected provider-patient communication. However, previous studies have suggested that recording medical encounters does not have a significant effect on patient or provider behavior [35–37].

Conclusion

Overall, we are encouraged by the results of this analysis. If we look solely at how many dialogues met the set criteria for SDM, the conclusion would be very pessimistic. A more nuanced assessment of the results, however, reveals that providers are in fact having conversations that respond to decision complexity. There is wisdom in what providers do in practice, and we feel that assessing these dialogues provides valuable insights into the complexities of SDM. It is no longer enough to say ‘clinicians are doing SDM or not doing SDM.’ We should evaluate what clinicians are doing, analyze why they might do it that way, and decide what is most important to improve.

Practice Implications

Our findings suggest two specific areas of improvement to increase the quality of SDM among practicing clinicians. First, practicing clinicians should be aware that the most often dropped elements of SDM are discussion of risks and benefits, alternatives, and uncertainties, even when these elements are clearly relevant, as in medically complex decisions. This is especially important when the physician feels strongly about a given decision outcome, as physicians are most likely to skip these SDM elements when they have a strong preference for one option. In addition, rhetorical questions to assess patient understanding and preference may be insufficient to fully engage patients in decision making, and providers should be conscious of actively empowering patients to vocalize their thoughts and opinions. For research purposes, we may want to rethink what a model for shared decision making looks like for patients refusing beneficial medical treatment (“basic decisions”). In these cases, SDM may not be the appropriate lens by which to view the quality of dialogue.

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Highlights

- Few dialogues met criteria for shared decision making (SDM)
- Frequency of *each* SDM criterion increased with increasing decision complexity
- Discussion of pros/cons, alternatives, and uncertainties are frequently absent
- Less SDM occurs when the provider or patient has a strong preference **for** a given option
- Passively assessing patient preference/understanding is insufficient for SDM

Figure 1.
Percentage of Dialogues Fulfilling SDM Criteria by Decision Complexity

Table 1

Frequency of Clinician Shared Decision Making Criteria Fulfillment

	Criterion fulfilled		Criterion not fulfilled	
	Provider actively discusses	Patient offers unprompted	Passive/perfunctory fulfillment	No attempt at fulfillment
Patient's role	10	-	-	14
Clinical issue	21	-	-	3
Alternatives	7	-	-	17
Pros and cons	3	-	-	21
Uncertainties	9	-	-	15
Patient understanding	1	4	10	9
Patient preference	5	10	5	4

Table 2

Examples of Shared Decision Making Dialogue

1. Discussion/ acknowledgment of the patient's role in the decision	<p><i>D: Remember, it's always your choice. But my gut feeling, and I'll run it by [name] again, too, is that I'd like to do labs again in a few more months, we'll do your genotype then too. If your viral load is still this high-</i></p> <p><i>P: Mhm.</i></p> <p><i>D: I would probably say it's worth taking medications. P: Mhm.</i></p> <p><i>D: If your viral load was only running around 100,000, you know, I'd feel okay but 600,000 still makes me not happy-</i></p>
	<p><i>D: Like you said, your weight is up, you are making good food choices, you are making good life choices.</i></p> <p><i>P: Mhmm</i></p> <p><i>D: Do you think that this is something you are ready to do?</i></p> <p><i>P: Uh, as long as there is a medication that I'm sure it's not, I'm going to get supplements I can work with, I mean, because I can't take that feeling.</i></p> <p><i>D: Okay, um so what we can do is we can work together to figure out what the best medicines are for you</i></p> <p><i>P: ok</i></p>
	<p><i>D: Now, I can appreciate what you are saying that you are not ready now ok?</i></p> <p><i>P: ok</i></p> <p><i>D: but what I want to do is I want you to continue to make all the good strides in your life to make you ready for medicine.</i></p> <p><i>P: I can, I can try it.</i></p>
2. Discussion of the clinical issue driving the need for a decision	<p><i>D: So the T cells are inching their way down.</i></p> <p><i>P: mhm</i></p> <p><i>D: And this time, remember they had gone, they were in the 300s, even dipped into the high 200s?</i></p> <p><i>P: Mhm.</i></p> <p><i>D: Then basically stay there. Just barely over 300, we were talking about starting the meds, and you wanted to see what they were doing. Well they went down a little lower again this time.</i></p> <p><i>P: Mhm.</i></p> <p><i>D: So you're definitely somebody that I would recommend treating the HIV at this point, cuz those T cells are in the level where people can get sick, although usually not seriously sick, like deathly sick, at this level.</i></p> <p><i>P: mhm</i></p> <p><i>D: But this is where trouble starts to brew. And also if you wait too long, until they're low enough that you can really get sick, sometimes you can't get 'em up as strong as you could if you started a little earlier.</i></p> <p><i>P: Mhm.</i></p>
3. Discussion of alternative choices	<p><i>D: Some people don't have many.</i></p> <p><i>P: Okay.</i></p> <p><i>D: You have two options --</i></p> <p><i>P: Okay.</i></p> <p><i>D: Which is good.</i></p> <p><i>P: Okay, all right.</i></p> <p><i>D: You could say, "I want to try the needle, I don't want to wait," that's fine, we can do that.</i></p> <p><i>Or, "I don't want to try the needle because I just don't think I want to do this needle for more than a year, and I might need to, so can we just follow my blood work as we have been doing, and if my blood work stays at a certain level, then I can wait until --</i></p>
4. Discussion of pros and cons of alternatives	<p><i>D: Um, I'll tell you though, what the benefit of that will be. Okay, the benefit of starting you on medications now is that your numbers, um assuming that you do respond to them, okay</i></p> <p><i>P: mhm</i></p> <p><i>D: and that uh, you tolerate them okay and are able to take them. Your numbers should get better</i></p> <p><i>P: mhm</i></p> <p><i>D: T cells should go higher.</i></p> <p><i>P: ok</i></p> <p><i>D: virus should come down.</i></p> <p><i>P: ok</i></p> <p><i>D: You may not feel any different.</i></p> <p><i>P: Okay.</i></p> <p><i>D: Okay, I'm going to be honest with you, because I don't think a lot of your symptoms are necessarily from the HIV. You may not feel any better.</i></p>

P: ok

D: **You may have side effects from the medications, okay?** They are usually mild, but some people have more significant side effects than others

5. Discussion of uncertainties

D: Right? However you aren't following that pattern, which is a weird thing, you know-
P: Yeah.

D: Is that your T cells have steadily gone up in spite of you having a high viral load. So you know, it's one of those things where it's just kind of like, you're not symptomatic, right? You're not feeling bad. Your T cells aren't in any risk range of you being at risk for getting an opportunistic infection or anything like that. So I don't feel compelled to say, Gee, you know, I really feel like you need to go on medicines--

P: mhm

D: right? Because you're not symptomatic and your immune system numbers are strong. However on the flip side I don't like seeing, you know, your viral load that high just in general, right?

D: That make sense? And I know, and I wish I could say you're not a clear-cut case. I wish I could say, here we are, this is what it is and here you follow the rules and you fit in this nice little, you know, column, and because you fit in column B, then we're gonna start you on, you know, and you're an individual

6. Assessment of the patient's understanding (only example of active)

P: I can, I can try it. But I'm just afraid that I'm going to miss

D: **right, and what happens when you miss doses?**

P: Doesn't that mess up the, yeah.

D: Yeah, but basically what happens when you miss doses is the virus gets smart.

P: Yeah.

D: And it becomes resistant to the medicines and the medicines don't work. And that has happened in the past

P: yeah

(passive)

D: But now, you know, lots and lots of people have taken medications, and they continue, not you know, all of them, but obviously some of them will still continue to pass on viruses that have seen medicines from their body.

P: Okay.

D: **Does that make sense?**

P: Mhm.

D: Okay.

7. Elicitation of patient's preference (active)

D: Well we'll go ahead and get your T cells, your viral load. Now we'll see what the numbers show. I must tell you, I'm a little worried this episode of shingles may be a clue that your immune system --

P: Is not --

D: Is down a little.

P: mhm

D: And I just want you to be prepared for the fact that it's possible the numbers may indicate that it's time to start on medicine for HIV.

P: Okay.

D: **If I were to recommend that to you, how would you feel about that at this point?**

P: It'll be time to go on meds and do everything

(passive)

D: So the plan is for us to start on the HIV medicine today. **Are you good with that?**

P: Yeah.

Table 3

Frequency of each SDM Element by Decision Complexity

Element	Basic (n=5)	Intermediate (n = 12)	Complex (n = 7)	All (n = 24)
Patient's role	1	5	4	10
Clinical issue	4	10	7	21
Alternatives	0	2	5	7
Pros and cons	0	1	2	3
Uncertainties	0	4	5	9
Patient understanding [*]	0	2	3	5
Patient preference [*]	2	7	6	15
Mean score	1.2	2.5	4.6	2.8
Meets SDM criteria for specific level of decision complexity	2	0	0	2
Meets SDM criteria for basic decision	2	4	6	12

^{*} For patient understanding and patient preference counting as fulfilled if provider actively elicits from patient or if patient offers

Table 4

Frequency of each SDM Element by Patient and Provider Preference

Element	Provider wants to initiate ART (n= 12)			Provider ambivalent (n=12)		
	Pt wants ART (n=4)	Pt ambivalent (n = 3)*	Pt does not want ART (n=5)	Pt wants ART (n =1)	Pt ambivalent (n= 9)*	Pt does not want ART (n= 2)
Patient's role	1	1	2	0	4	2
Clinical issue	2	3	5	1	8	2
Alternatives	0	0	1	1	4	1
Pros and cons	0	0	0	1	1	1
Uncertainties	0	0	1	1	5	2
Patient understanding	1	0	1	0	2	1
Patient preference	3	1	3	0	6	2
Mean score	1.75	1.67	2.6	4	3.3	5.5

* Include 2 instances in which patient preference was unable to be elucidated due to provider monologue

Table 5

Decision Outcomes, by Patient Preference, Provider Preference, and Clinical Certainty

	Decision to initiate ART (n=7)	Decision to defer ART initiation (n=14)	Decision uncertain (n=3)
Patient wants ART (n=5)	5 (100%)	0 (0%)	0 (0%)
Patient ambivalent (n=12)	2 (17%)	8 (66%)	2 (17%)
Patient does not want ART (n=7)	0 (0%)	6 (86%)	1 (14%)
Provider wants to initiate ART (n=12)	5 (42%)	5 (42%)	2 (16%)
Provider ambivalent (n=12)	2 (16%)	9 (76%)	1 (8%)
CD4 200 (n=5)	2 (40%)	1 (20%)	2 (40%)
CD4 201-350 (n=12)	3 (25%)	7 (58%)	2 (17%)
CD4 > 350 (n=7)	2 (29%)	5 (71%)	0 (0%)