

Patients' Perceptions and Experiences of Shared Decision-Making in Primary HIV Care Clinics



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Shared decision-making (SDM) is considered best practice in health care. Prior studies have explored attitudes and barriers/facilitators to SDM, with few specific to HIV care. We interviewed 53 patients in HIV primary care clinics in California to understand the factors and situations that may promote or hinder engagement in SDM. Studies in other populations have found that patients' knowledge about their diseases and their trust in providers facilitated SDM. We found these features to be more nuanced for HIV. Perceptions of personal agency, knowledge about one's disease, and trust in provider were factors that could work for or against SDM. Overall, we found that participants described few experiences of SDM, especially among those with no comorbidities. Opportunities for SDM in routine HIV care (e.g., determining antiretroviral therapy) may arise infrequently because of treatment advances. These findings yield considerations for adapting SDM to fit the context of HIV care.

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During shared decision-making (SDM), patients share their preferences and concerns about an approaching health care decision, and providers offer information about risks and benefits so that both parties can collaboratively determine a course of action (Charles, Gafni, & Whelan, 1999; Elwyn et al., 2010). SDM, a widely recognized indicator of patient-centered care (Barry & Edgman-Levitan, 2012; Ferrer & Gill, 2013; Institute of Medicine, 2001), improves patient-provider communication, health knowledge, risk perceptions, and confidence in a decision (Stacey et al., 2014). It works well in cases with multiple, viable choices and different risks and benefits associated with each (Barry & Edgman-Levitan, 2012; Lee & Emanuel, 2013).

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While SDM has been well characterized for decisions related to diagnostic testing or elective surgery, less has been written about its use in general practice where decisions may be less explicit. Murray, Charles, and Gafni (2006) have suggested that SDM principles could be incorporated into general practice because decisions need to be made in every clinical encounter, such as determining which issues to address first. Health care policy changes are also promoting expanded use of SDM. The Affordable Care Act has encouraged SDM implementation (Patient Protection and Affordable Care Act of 2010), and one accrediting agency for patient-centered medical homes (PCMH) added SDM into its standards (National Committee for Quality Assurance [NCQA], 2014). In order to earn NCQA accreditation, practices must demonstrate use of (a) shared decision-making aids, (b) incorporate SDM into patient self-management efforts, and (c) identify patient-specific education resources and provide them to more than 10% of patients. Other PCMH ideals are broadly consistent with SDM, such as collaboratively developed care plans and the overarching ideal of patient-centered care. Many primary care clinics have implemented or are currently transitioning to a PCMH model based on the strategy's potential to coordinate care for complex conditions and lower costs (Friedman et al., 2014). With these policy changes, SDM may become more prevalent beyond acute or specialty care. The outstanding questions are whether and how to best incorporate the practice of SDM into routine primary care encounters when decisions are not clear-cut.

SDM offers potential benefit for the management of HIV primary care. Patients are encouraged to attend at least two HIV care visits annually (Health Resources and Services Administration, 2013). Clinicians monitor the disease through laboratory results and patients receive advice on treatment options and adherence strategies. SDM may reduce health disparities (Durand et al., 2014), an important consideration for HIV, which continues to disproportionately affect individuals from marginalized communities (Centers for Disease Control and Prevention, 2015). To date, the little research on SDM in the context of HIV care has suggested that the idea is well accepted by patients (Deber, Kraetschmer, Urowitz, & Sharpe, 2007; Kumar

et al., 2010), and those who indicate a preference to share decisions maintain better adherence to treatment than those who prefer to make decisions alone (Beach, Duggan, & Moore, 2007).

What remains needed is a description of how SDM operates in HIV care encounters. This type of care sometimes involves the management of complicated comorbidities (American Academy of HIV Medicine, n.d.); and patients, on average, have lower literacy levels (Palumbo, 2015) and experience multiple barriers to seeking care (Rumptz et al., 2007), which may complicate the process of engaging them in medical decision-making. Our research was inspired by important questions raised by Ferrer and Gill (2013) on expanding SDM to general care and the considerations that would need to be taken when applying SDM to diverse populations. The following questions guided our research: What does SDM look like in the context of safety-net HIV care, and what are the barriers and facilitators to SDM in this setting? In this paper, we describe patient experiences in HIV primary care, focusing on factors that shape participation in medical decision-making and highlighting situations unique to this care setting that may warrant tailoring of the traditional SDM approach.

Methods

Overview

Our analysis is part of a mixed-method evaluation of PCMH demonstration projects. The *Mark Etzel Patient-Centered Medical Home Initiative* was funded by the California HIV/AIDS Research Program to study the implementation and effectiveness of PCMH components in safety-net HIV care settings. Five demonstration sites implemented projects that aligned with the PCMH model and addressed the unique needs of their patient populations. The University of California, San Francisco, served as the cross-site evaluation center. Demonstration sites had flexibility in what they implemented, and were not required to include all PCMH components. As such, there was no explicit expectation that they focus on SDM, but the relevance of SDM to the PCMH model made it a natural area for investigation.

Interview Domains

In this study, we focused on our qualitative interviews with patients across the demonstration projects ($n = 53$). We interviewed at least 10 individuals in each demonstration project. Interview domains relevant to our analysis included patients' relationships with their providers and clinical staff, management of HIV or other medical care, and decision-making preferences and examples. Sample questions from the interview guide include: *When you have a question or a problem related to your health, how do you handle it? Could you give me an example of when you've done this, and describe how it went? What is your role in managing your health?* Phenomenology was the underlying philosophical approach to our qualitative inquiry (Creswell, 2013). We sought to understand the worldview of our research participants through their lived experiences; specifically, we sought to explore the phenomenon of what it means to be a patient living with HIV in a care setting that is striving to become a PCMH.

Recruitment

Eligible individuals were: (a) at least 18 years of age, (b) fluent in English, and (c) receiving HIV clinical services at a project site. One demonstration site required that participants be ages 50 years or older because its project specifically worked with that population.

Typically, providers or clinical staff referred patients to the study. One site preferred that we recruit patients from waiting rooms used exclusively for those with HIV care appointments. Once patients were identified, interviewers described the study, verified eligibility, and obtained informed consent.

Interviewer Team

Our team consisted of a group of four interviewers. All interviewers had received qualitative interview training and had experience conducting in-depth, semi-structured interviews. A cultural anthropologist with more than 15 years of experience conducting interviews with people living with HIV led the team of interviewers.

Interview Procedures

We conducted semi-structured interviews in private clinic spaces. Interviews lasted 45 minutes on average, and participants received a \$40 gift card as compensation. We used an interview guide; however, each interviewer was encouraged to add clarifying questions or modify inquiries when needed. All interviews were recorded with the participant's consent and transcribed verbatim after redacting identifying information. Interviewers obtained verbal informed consent and documented the receipt of consent on a tracking sheet. Consent was obtained verbally, instead of in writing, so that participants would not be required to disclose their names, thereby preserving anonymity. The principal risk of the study would be potential harm resulting from a breach of confidentiality. All names used in this manuscript are pseudonyms. The University of California San Francisco Institutional Review Board reviewed and approved all procedures.

Analysis

Three qualitative analysts who were part of the interview team conducted the analysis. First, we read a subset of interviews as a group to develop codes to be applied to the transcripts. We used both a priori codes and those that emerged during analysis, generating a total of 36 codes. The a priori codes came directly from domains or particular questions in our interview guide, such as the code "role in health care decisions" to capture participant responses to that question in our guide. Our a priori codes related to the decision-making domain (e.g., active, passive, or shared decision-making) came from terminology and conceptualizations presented in published literature on patient and provider decision-making preferences (Kumar et al., 2010). At least two researchers then coded each interview. When coding disagreements arose, researchers met to come to consensus. We entered coded transcripts into Dedoose (Version 6.1.18; SocioCultural Research Consultants, 2015) to facilitate data management, and then conducted a Framework Analysis (Ritchie & Spencer, 1994) to organize the data and identify themes.

Results

Demographics and Overview

Most participants were male (66%, $n = 35$), with an average age of 48 years (range: 30-65). More than half had completed at least some college. A majority identified as Latino (34%, $n = 18$) or Black/African American (32%, $n = 17$). See [Table 1](#) for complete demographics.

Informants described a range of preferences and experiences in health care decision-making. Some preferred to make most decisions themselves, others preferred to make decisions jointly with providers, and still others preferred to be less involved in the decision-making process. Most participants did not fit uniquely into one of the groups because their behaviors fluctuated depending upon context.

SDM worked well in situations when (a) there were decisions to be made, (b) each option presented meaningful differences, and (c) patients were primed by provider discussions to take a role in decision-making. Perceptions of personal agency and trust in a provider could work for or against SDM, though greater agency and trust usually encouraged SDM. In the following sections, we explore how these factors facilitated SDM or created situations in which SDM was either not warranted or did not serve the patient well. We have assigned pseudonyms for our participants.

Table 1. Interview Participant Demographics ($N = 53$)

	<i>N</i>	<i>%</i>
Race		
African American	17	32.1
Asian Pacific Islander	2	3.8
Hispanic/Latino	18	34.0
White/Non-Hispanic	12	22.6
Other	4	7.5
Gender		
Men	35	66.0
Women	13	24.5
Male-to-female transgender	5	9.4
Education		
Less than a high school degree	8	15.1
High school degree/GED	10	18.9
Some college/Associate's degree	31	58.5
Bachelor's degree or higher	4	7.5

Note. GED = graduate equivalency degree.

Factors That Promote or Hinder SDM

Salient and viable differences between options. Differences in the potential outcomes and/or processes associated with each option needed to be meaningful for patients to facilitate engagement in a health care decision. Daniel, a 39-year-old, Latino man, captured this requirement in the quote below, where he described a hypothetical situation of choosing between options that conveyed insignificant differences to him. In the excerpt from which the quote was drawn, Daniel was talking about frustrations with placing decision-making responsibility on patients without sufficient guidance: "If I were just told, okay, you have let's say Atripla, Truvada, or Isentress, choose. Well, one is pink, one is blue, and the other one is orange. So I'm like—today I'm in the mood of pink."

In contrast, Mark, a 50-year-old, White man, described a situation that facilitated his engagement in decision-making. His HIV was well managed and his main concern was feeling cold due to neuropathy. He had taken medications to mitigate symptoms and did not feel complete relief, so he experimented with other solutions. He discovered that wearing polyurethane knee sleeves kept his legs warm. Mark wanted to know that his provider supported the decision, so he discussed the knee-sleeve strategy with her and gained her endorsement.

Not surprisingly, SDM only worked when there were two or more viable options available. Diego (62-year-old, African American/Latino man) was taking a medication he believed caused brittle nails; however, he felt that he had no choice but to continue treatment because it was the only medication he had taken that lowered his viral load to undetectable levels.

Interviewer: You're feeling like you want to get rid of at least one of those pills.

Diego: Yeah, at least one or two, or at least the one that's having my fingers so ugly.

Interviewer: Does [your provider] know that that's what you're so concerned about?

Diego: I told her, yeah, but then she said, "Which one do you prefer, to have your nails

like this or to be healthy?” That was [the] option. I mean, yes, I’m healthy, but I’m not happy. That’s what it is. I’m healthy but I’m not happy.

Diego’s dilemma highlighted a scenario in which the provider technically gave him options, but clearly disfavored one of the choices. While the communication strategy was effective in keeping Diego on anti-retroviral medications, it also appeared to exacerbate his discontent by drawing attention to the limited options and giving him a false sense of choice.

Comorbidities or current health status. We found that having concurrent health conditions tended to heighten patients’ vigilance about their health, and may have led to more engagement in decision-making. Jill, a 43-year-old, Asian-Pacific Islander woman who was living with HIV, diabetes, high cholesterol, high blood pressure, painful fibroids, and limited mobility, asked her provider for a hysterectomy to minimize ovarian cancer risks. She was concerned about her family history of ovarian cancer and the ongoing pain due to fibroids. While asking for the hysterectomy was not an example of SDM per se, it led to an SDM encounter about whether or not to have the procedure.

Opportunities to make medical decisions arose infrequently for patients who were fairly healthy or whose health conditions were stable. Miguel, a 50-year-old, Latino man, could not recall any instances of decision-making. With no major health issues, he said that he only attended routine appointments and described himself as an “easy patient.”

Trust in the provider. We interviewed many patients who had been living with HIV for more than 10 years and had used the same clinic and/or provider for care throughout that time. Trust was built over the course of this long relationship and many of these patients saw their clinic as lifesaving. In the quote below, David (39-year-old, Latino man) provided a classic example of SDM while emphasizing the role that trust in his provider had played in contributing to his health status. For some patients, the trajectory of their relationships with providers was unique because they had lived with HIV prior to the advent of antiretroviral therapies. They had faced imminent

decline in health and were “saved” once treatments became available. Having gone through such intense health issues together could not be overlooked when considering how SDM played out in these relationships.

Interviewer: Thinking about making decisions about your health, what role is yours and what role is your doctor’s? How do you figure that out?

David: I know with my doctor, in particular, he doesn’t tell me, you have to do this or you have to do that. He gives me both options and lets me see the weight of it and decide it on my own. And he’ll tell me the facts of it before I start getting into like where I hear things and—he’ll break it down to where—we’ll work on a compromise. I put my trust in these doctors, because I know, one, I wouldn’t be here, and I know that whatever they’re doing, they’re keeping me alive, and that they actually care.

Trust could also have the opposite impact on SDM, however. Another participant described why he trusted his provider to make decisions for him. Anthony, a 53-year-old, African American man said, “She’s knowledgeable about what I need, and sometimes it’s not always what I want, but then she’s knowledgeable and I just listen and follow the advice.” Even if he disagreed with his provider’s recommendations, he felt that she was better equipped to make the decision.

Perceptions of agency. Regardless of how engaged participants wanted to be in decisions, there was overwhelming sentiment that they and their providers acted as a team. Eddie, a 30-year-old, African American man, for instance, preferred to turn decisions over to his physician, yet he still felt that he worked in partnership with his care team. He said that his physician and nurse “partner together with me and my health.”

Occasionally, there were participants who believed that they had limited autonomy. Robert, a 41-year-old, Latino man remarked, “The only thing is, [providers] give you an option, but at the same time, they want to do what they want to do.” Yet most

participants felt that they had the final say (“it all boils down to my decision”), or that they ultimately were in charge, despite the variation we noted in decision-making preferences and behaviors.

Perception of their own knowledge often factored into the level of autonomy patients assumed while making decisions. Unlike Anthony, who saw his provider as knowledgeable and therefore felt compelled to follow her advice, John (61-year-old, White man) said that he would find his own solutions and disregard his provider’s advice if he did not like the proposed treatment plan. When asked to specify how he sought answers to health questions, John responded:

The Internet. Just like [my provider] does. I ask him a question and he doesn’t know, he searches it and he Googles it—the same database I do. I’m a lot more focused on my own issues than I can expect anybody else to be, including my physician. And a lot of subjects, I’m way ahead of him. He says, “Oh, well, I’ll look into that,” and I go, “You don’t have to, I already know.”

John felt that he was often as knowledgeable as his provider, if not more so, because he knew his own body and could consult the same resources as the provider.

Attitudes about decision-making roles. Some patients wanted directive advice, which seemed at odds with the principles of SDM. James (63-year-old, White man) told a story of not wanting to initiate medications to control cholesterol and blood pressure in order to minimize daily pill burden. It was the urging of a friend, not his provider, that successfully convinced him otherwise:

I didn’t want to go on either one, but [my friend] would say, “What’s wrong? You want to live or you want to die!” See, I don’t think [my doctor] can say that to me, but [friend] she’ll grab me and slap me or say, “Shut up and take your medicine!”

We cannot assume from this quote that James would do poorly in an SDM encounter, but his example does show the limitations of a collaborative approach for people who respond better to direct orders than gentle guidance. However, attitudes about

SDM can be changed through discussions between patients and providers, helping to clarify roles and expectations for those who are skeptical. Daniel, a 39-year-old, Latino man, explained that SDM initially made him uncomfortable: “I think it’s so strange, because [providers] are trained, or they should have been trained to decide for you.” The expectation that he would participate in a decision was substantially different than his prior experiences receiving care in Mexico. The excerpt below illustrates how he negotiated getting what he wanted from his provider—direct advice on “what will be the best thing?” They clarified the kind of information they needed from each other in order to make the best decision.

Interviewer: Did you want [your provider] to make the decision for you?

Daniel: More than making the decision for me, discussing more deeply what will be for me to take medication A, then medication B, then medication C. Because at the beginning she presented, “Okay, you have three options.” And then I spoke to her and I told her, “This is [what] I think will be much better, if you explain to me what will be the best thing.” ... So she said, “Okay, for you, this will be 1, and those will be the side effects. This is 2 and those will be the side effects. And this is 3, those will be the side effects. So according to what you’re telling me and according to what you have, I think the best option that we have is this.”

Daniel engaged in SDM with his provider; she presented the options; he expressed concerns about side effects and asked for recommendations. His example also showed that there may be an implicit assumption by providers that patients want to engage in SDM.

Discussion

We found a range in decision-making preferences and behaviors among our participants, from those who preferred to make decisions without provider input to those who turned decisions over to the provider. Overall, we found few instances of SDM

described in terms of HIV care and treatment. Factors that influenced participants' perceptions of and experiences with SDM included: the choices available, current health status, satisfaction and trust in the provider, perceptions of agency, and attitudes about decision-making roles. The influence of these factors on SDM was complex, particularly in terms of agency and trust. Patient perceptions of their own health knowledge contributed to their perceptions of personal agency in the care setting. While a systematic review has demonstrated that patients who feel more knowledgeable and empowered may be more inclined to participate in SDM (Joseph-Williams, Elwyn, & Edwards, 2014), we found a few notable outliers in our sample. Some participants who described themselves as having high degrees of knowledge and agency did not seem to value a shared approach to decision making. To be clear, we do not intend to suggest that patient knowledge should be suppressed. Rather, we aim to illustrate that the impact of health knowledge on SDM is not necessarily straightforward. Patients may have high levels of perceived knowledge, but may greatly benefit from additional health literacy and education.

Trust in the provider emerged as another factor that we found to have varying impact on SDM. A trusting relationship facilitated communication, but it did not inevitably lead to a sharing of health care decisions. Trust often created an inviting environment for SDM, but there remained situations in which the provider made decisions alone because trust led the patient to feel secure following the provider's advice. A qualitative study with African American patients living with diabetes found that trust in the provider was a facilitator of SDM (Peek et al., 2009), and a study in mental health care also identified trust as a facilitator of SDM (Hamann et al., 2016). On the other hand, survey data of patients receiving treatment for cancer or fractures found low levels of trust in patients who preferred to make decisions autonomously and high levels of trust in patients who preferred to turn decisions over to their providers (Kraetschmer, Sharpe, Urowitz, & Deber, 2004). A systematic review of patient-reported barriers and facilitators of SDM in a variety of health care settings found that trust could be a barrier or a facilitator, depending on the context (Joseph-Williams et al., 2014). In our sample of patients in

HIV care settings, it appeared that higher levels of trust, as reflected in participants' interview statements, did not always lead to SDM. This may have been due to the relationships that long-term patients in HIV care settings had with their providers.

Our study's participants were patients in safety-net health care settings. In a separate analysis on the PCMH study, we found that a history of stigma had made many of these patients wary of how they would be treated in clinical settings. As a result, they looked to attentiveness from and availability of the providers as cues that they could be trusted (Steward, Koester, & Fuller, 2015). SDM potentially complicates these perceptions, particularly if it is mistakenly interpreted as the provider seeking to reduce the amount of attention s/he needs to give a patient. As we found in our analyses here, encouraging patients to participate in SDM can be facilitated by a clear discussion about roles and expectations. We recommend that providers utilize these discussions to help patients better engage with SDM and avoid the misperception that providers are forcing unwanted responsibility onto patients.

Our findings suggest that care should be taken when promoting widespread use of SDM. Informants who were not interested in participating in decision-making were not necessarily less engaged in their care. While patients can be encouraged to participate in care decisions, forcing them to do so would at times be counterproductive. In our data, patients were content with a more provider-directed approach to care when (a) there were few explicit decisions to navigate, (b) the patients needed more encouragement or guidance, or (c) when only one desirable course of action existed. Based on these findings, we recommend the following steps when considering the use of SDM: (a) establish if patients are willing to engage in SDM, (b) assess the role they want to take, and (c) respect the patients' preferences. This should be done for each decision because a patient's preferences may change over time and be influenced by situational factors, such as the number of viable choices under consideration in a decision. Finally, we call for further research to explore how best to support patients who do not want to play an active role in decision-making when the option to do so arises.

SDM has been incorporated formally into at least one PCMH credentialing system (NCQA, 2016).

Clinics, including those that offer HIV primary care, may feel pressure to adopt SDM given the PCMH recommendations. SDM is consistent with the patient-centered ideal that is part of the PCMH model, but an emphasis on SDM as a marker of patient-centered care may be debatable. Advocating for SDM in all cases may undermine patient-centered care, as a patient-centered approach should incorporate patient preferences.

As we found, not all patients valued SDM, and meaningful opportunities for decision-making may not occur often in HIV care because of advances in treatment. Patients typically choose between medications with few appreciable differences (e.g., similar side-effect profiles) that would help patients determine a best choice. Discussing prevention strategies, such as reducing the likelihood of HIV transmission or acquisition of other STIs, may offer a more productive opportunity for SDM than discussions about treatment regimens for people who are able to take first-line therapies and have no other comorbidities to consider.

Another potential area in which to apply SDM in HIV care is in the discussion of preventive care such as flu shots and pap smears. Quality improvement efforts tend to focus on meeting benchmarks for health maintenance tasks, which are often presented to patients as procedures that need to be done, especially in HIV care where patients have suppressed immune systems. By outlining the risks and benefits of each option and engaging patients in the discussion, SDM could help patients better understand or buy into a decision to follow through on these tasks. However, when health maintenance tasks, such as annual flu shots, are informed by evidence-based guidelines that recommend receipt of the service by all people living with HIV ([National Institutes of Health, 2016](#)), it calls the role of SDM into question.

There are limitations to our findings. Patients were selected either by purposive or convenience sampling, which may have favored the recruitment of those relatively more engaged in care. The study was conducted in the context of PCMH practice changes. We also sought to explore the nuances of SDM in HIV safety-net clinics that deliver comprehensive primary care, and findings may not be generalizable to other types of care settings for this population. Another limitation was that we

only included the patient perspective on SDM. Further qualitative research could explore SDM from the perspective of HIV care providers to present a more comprehensive picture of how SDM operates in this care setting.

As our findings have demonstrated, SDM is not necessarily a reasonable goal for all aspects of HIV care. The approach works well in some situations, particularly when there are more comorbidities to manage. In routine HIV care, there is less salient decision-making to be had. Determining for whom and in what scenarios SDM is a benefit and understanding how patients receiving HIV primary care may respond to an approach like SDM will be critical in guiding implementation and preparing patients for changes that may arise. Overall, we support the conclusions made by [Charles and colleagues \(1999\)](#), who highlighted the importance of flexibility in the decision-making process for patients. A patient-centered approach needs to incorporate patient preferences. Rather than recommend SDM as the gold standard of patient care, the standard should be to assess and respect preferences around SDM.

Conclusions

Our study explored the boundaries through which SDM can operate in an HIV primary care setting and highlighted considerations for adapting SDM to fit the context of HIV care. With increased effort to incorporate SDM into the clinical encounter, it is important not to forget the importance of having flexibility to accommodate patients' varying levels of interest and comfort in decision-making. We found that opportunities for SDM in routine HIV care may arise infrequently. However, other aspects of health maintenance tasks and prevention strategies, may lend themselves well to a shared approach and build patient appreciation and comfort in the kinds of collaborative discussions related to their care.

Disclosures

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Key Considerations

- Individual and contextual factors (e.g., choices available, current health status, trust in the provider, perceptions of agency, and attitudes about decision-making roles) influenced participation in shared decision-making among a sample of patients in safety-net HIV care clinics.
- Shared decision-making may require special considerations in an HIV care setting, and we recommend flexibility to accommodate varying levels of interest/comfort in shared decision-making.
- Opportunities for shared decision-making may arise infrequently in routine HIV care management, although the approach could be applied to discussions about prevention strategies and health maintenance tasks.

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