

Running Title: Patients' preferences and involvement in SDM

**Factors influencing patients' preferences and perceived involvement in shared decision making in mental health care**

Johanne Eliacin<sup>1,3,4</sup>, Michelle P. Salyers<sup>2,3,4</sup>, Marina Kukla<sup>1,3,4</sup>, and Marianne S. Matthias<sup>1,2,5</sup>

<sup>1</sup>Department of Veterans Affairs, Veterans Health Administration, Health Services Research and Development, Center for Health Information and Communication, Richard L. Roudebush VA Medical Center, Indianapolis, IN, USA, <sup>2</sup>Regenstrief Institute, Inc., Indianapolis, IN, USA, <sup>3</sup>ACT Center of Indiana, Indianapolis, IN, USA, <sup>4</sup>Department of Psychology and <sup>5</sup>Department of Communication Studies, Indiana University-Purdue University, Indianapolis, IN, USA

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**Abstract:**

*Background:* Although research has suggested that patients desire to participate in shared decision making, recent studies show that most patients take a passive role in their treatment decisions. The discrepancy between patients' expressed desire and actual behaviors underscores the need to better understand how patients perceive shared decision making and what factors influence their participation.

*Aims:* To investigate patients' preferences and appraisals of their involvement in treatment decisions.

*Methods:* Fifty-four qualitative interviews were conducted with veterans receiving outpatient mental health care at a U.S. Veterans Affairs Medical Center. Interviews were analyzed using thematic analysis.

*Results:* Participants outlined several factors that influence their preferences and involvement in treatment decisions. These include the patient-provider relationship, fear of being judged, perceived inadequacy, and a history of substance abuse.

*Conclusion:* Patients' preferences and willingness to engage in shared decision-making fluctuate over time and are context dependent. A better understanding of these factors and a strong patient-provider relationship will facilitate better measurement and implementation of shared decision-making.

**Keywords:** Shared decision-making, patient's preferences and participation, veterans, mental health

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Over the last decade, numerous studies and policies have focused on treatment decision models aimed at improving patient-provider communication, including shared decision making (SDM). SDM involves collaborative partnership between patients and providers who are both considered experts and are expected to participate in deliberation about treatment decisions (Charles, Gafni, & Whelan, 1997). Studies in various clinical settings have found that patients prefer SDM (Adams, Drake, & Wolford, 2007; Betingier, Kissling, & Hamann, 2014; Goossensen, Ziilstra & Koopmanschap, 2007; Hamann, Cohen, Leucht, Busch, & Kissling, 2005; Hill & Laugharne, 2005; Matthias, Salyers, Rollins, & Frankel, 2012a).

However, emerging studies examining actual patient behaviors reveal most patients play a passive role in decision-making (De Las Cuevas, Penate, Perestelo-Perez, & Serrano-Aguilar; Mahone et al., 2011; Protheroe, Brooks, Chew-Graham, Gardner, & Rogers, 2013; Tariman, Berry, Cochrane, Doorenbos, & Schepp, 2010). These studies suggest factors other than patient preference might influence participation in treatment decision-making. Some studies attributed providers' reluctance to relinquish power as a factor that reduces SDM (Entwistle, Prior, Skea, & Francis; Goss et al., 2008). Others suggested the severity of illness (Mahone, et al., 2011; Shepherd, Tattersall, & Butow, 2008), and that individual characteristics of providers and patients, such as gender, age, and education also complicate patients' participation in treatment decisions (Galesic & Garcia-Retamero, 2011; McCabe, Khanom, Bailey, & Priebe, 2013; Uldry, Schäfer, Saadi, Rousson, & Demartines, 2013). Numerous factors influence SDM, and patients' preferences alone do not ensure shared decision-making. Yet, little is known about patients' perspectives on factors that facilitate or hinder their involvement in treatment decisions (Joseph-Williams, Elwyn, & Edwards, 2013). More studies are needed to better understand the

complexity of SDM, and what influences patients' participation in this model of decision-making.

Such understanding is important to address patient-level barriers and to facilitate implementation of SDM in mental health care. While some studies have examined SDM in outpatient mental health settings (Adams, Drake, & Wolford, 2007; De Las Cuevas, Penate, Perestelo-Perez, & Serrano-Aguilar, 2013; Fukui et al., 2014), few have explored patients' appraisals of how treatment decisions are made in mental health. To better understand patient-level factors that might influence participation in SDM we examined patients' perceptions of treatment decision-making with mental health providers.

## **Methods**

Participants were recruited from a larger exploratory study on SDM using convenience sampling; patients were approached in the waiting room prior to their appointments. Seventy-nine patients agreed to have their appointments recorded; 54 (68%) participated in the interview portion following their appointment. Most common reasons for non-participation in the interview were lack of time and interest. Most participants were White, men, and over 40 years old (See table 1). Participants' psychiatric conditions included mood disorders, PTSD, and schizophrenia; and most (66%) had worked with the same provider for 1 to 3 years. Participants signed written consents prior to the interviews.

Research procedures were approved by the by the local institutional review board and medical center research committee. Development of the interview protocol was guided by the literature and informal conversations with providers. Interviews were conducted by 4 trained research assistants, were semi-structured, and lasted about an hour. Questions focused on the patient-provider relationship, treatment decision-making, medication adherence, and illness

management. All interviews were audio-recorded, transcribed, and imported into Atlas.ti computer program (2010), a qualitative analysis tool.

The authors analyzed the data using an inductive thematic approach (Braun and Clarke, 2006; Patton, 1990), which involved identifying and comparing common emergent themes across transcripts. All 4 authors participated in the data analysis process to provide multiple perspectives, create consensus, and facilitate validity of the analysis. We individually read several transcripts to gain a general understanding of the data. We compared responses across transcripts to identify emergent themes. We developed a list of preliminary codes by labeling segments of the documents (Miles and Huberman, 1994). We resolved inconsistencies in the coding structures through consensus. We reviewed the preliminary codes using an iterative approach in which codes were combined, eliminated, or expanded to best capture the data (Saldaña, 2009). Throughout the data analysis process, we continually returned to the data to strengthen the analytical categories and search for verification or counter evidence (Bazeley, 2013). Thematic saturation was established once no new variations of a given theme were identified, and based on evidence of repeated coding within the same category (Suter, 2012).

## **Results:**

### *Participants' preferences*

Participants reported a broad range of preferences for participation in treatment decision-making. Several preferred full engagement in decision-making and viewed it as an effective mode of communication that helps them to share information with their providers and ensure their needs are met. They described sharing information about their illness, discussing pros and cons about treatment options, and making a final decision with their providers. Some also viewed active participation in treatment as their responsibility and an important component of their recovery.

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They conveyed a sense of responsibility and empowerment in the decision making-process, as these examples illustrate:

D51: I like to be involved with the decision making of the medication that I'm taking because that gets my physician's insight and that gives me more insight. . . . It makes taking my medications more acceptable.

D71: Lots of people go through life believing that doctors and nurses are semi-omnipotent. . . . I don't necessarily agree with that philosophy. I believe that a person, whether it's for heart failure or mental health, has to take an active role in their own recovery and not just idly follow the directions of the staff.

Others also noted a preference to include friends and family members in their decision-making. They explained that relatives or friends are well-informed of their health needs and well-suited to contribute to treatment decisions. Some remarked that their spouses accompany them to mental health visits and provide valuable input about their experiences with medications.

D53: Because I spend most time with my wife, we discuss things a lot and then, when I have an appointment I discuss it with [provider] . . . . It's well thought out between my wife, me and [provider].

D65: I have a good friend; he's dealt with medicine. He said, "some of the medications you don't need because you got three different pills that are supposed to do the same thing." which makes sense. I listen to him.

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Not everyone wanted family and friends involved in their mental health decisions. For some, mental health remains a private domain. They also viewed family and friends as lacking interests, skills, and knowledge to productively contribute to decision making. One participant explained: D48: "None of my family members are medical professionals. . . . If I have an issue with my mental health, I go to the experts. In this case, it is [provider]. I trust her judgment."

### *Partial or minimal involvement in SDM*

While some participants expressed desire for full participation in treatment decision making, others preferred to leave decisions to their providers. Participants offered different explanations for this preference. Some cited providers' expertise as a reason for "leaving the decisions up to the professionals." Others focused on outcomes of decisions, noting they simply "agree with the doctors," as long as they are receiving the help they needed.

D45: She's a professional. She's supposed to know what's best for me. I have input on it but I prefer her to make the decision . . . . She went to college. I didn't.

D12: I normally will do whatever the doctor tells me. . . . It's "here's what I recommend and you will take it." That's pretty much the way it is. . . . I don't care [how treatment is decided] as long as I can get some help.

In contrast, a number of participants who had long relationships with their providers, which led to a deep trust, believed that not only were their providers capable, but they considered participants' best interests when deciding treatment. This trust led them to feel comfortable deferring decisions to their providers.

D59: [Provider] normally decides based on the symptoms that I tell her. . . . I feel very confident in [provider's] abilities. I do personally feel that she is looking out for my best interest. I trust her wholeheartedly.

D25: I like. . . . discussing different options with my doctor and finding out what she feels would be best for me because I trust her opinion more than my own.

Some participants chose a passive role in decision-making because they feared that a poor decision could significantly jeopardize their mental health. They reported they lack the medical knowledge or feel ill-equipped to make sound judgments about their mental health care.

D21: I know nothing about mental health... I'm nuts... I generally leave it up to my doctor...I don't disagree about nothing...I just take [Provider's] word for it.

D32: Medication-wise, I pretty much leave that up to [Provider]. I don't know a thing about [medications]...If she gives it to me, I take it...I don't make any decisions about that.

Other barriers to SDM included fear of being judged, violating patient-physician role boundaries, or possible repercussions from providers. As an extreme example, a White male shared that his fear of losing his health services led to ineffective communication with his provider. Instead of trusting (or, alternatively, being honest with) his provider, he described how he “played along” with a provider to obtain his desired outcome.



D39: One trainee wanted to do testing of anything that might cause depression ...I'd already been through many years of this... I was like why are we doing this now? ... The impression I got was, "we're gonna test to see if you really need this medication. If not, we're taking you off of it". . . . I went along with what she's saying. As we were leaving, I said, I'll make an effort and she said something like, "you definitely want to if you want to continue service." So, I'd made the decision. I was still getting my refills. I put it off and finally decided to totally ignore it, taking a chance. Ultimately, I did see a true psychiatrist and discussed it. . . . I've even brought up my fears of losing my medication.

### *Patient-provider disagreements*

Participants also acknowledged that treatment decision-making can be fraught with disagreements. Their interviews highlight the negative impacts that disagreement can have on the patient-provider relationship. They also underscore the dynamic process of SDM and patients' attempts at managing discontent with providers. Below, a participant illustrates how treatment disagreement jeopardized her relationship and ability to communicate with her provider.

D51: I disagreed about my care, going to the [substance abuse program]. . . The only reason I went is because [provider] said if I go, he would give me the medication I needed. So, I enrolled in the [program], and he didn't give me the medication. That started making me feel very uncomfortable about communicating, dealing with [providers].

Participants employed different strategies to manage disagreements. Several reported they had fired providers, often without attempting to resolve the problem. In many cases, as in the

excerpts below, participants noted that poor communication was at the center of the disagreement.

D65: I would change doctors two or three times. . . . I said [to Provider], my head's hurting and he wrote down [opioids]. I said, I'm not taking those stuff and he'd say this will help you...a lot of things would help me, too. I went to the patient advocate.

D48: Within the last year I was seen by a physician who told me that I had no issues related to PTSD and all I needed was quit smoking and my problems would be solved. I asked for a new [doctor].

Others overcame disagreement by discussing their concerns with their providers. In these cases, a strong patient-provider relationship facilitated these discussions, by encouraging patients to clarify their needs and preferences. It also cemented trust between patients and providers.

D53: One time she was going to lower my medication and I let her know that I didn't think it would be a wise idea. I explained to her why and then she concurred with my decision. After we talked it out it was better that we left it at the same dosage.

D39: At first I didn't agree with her [provider] . . . . I was having severe anxiety. . . I came in and she put me back on [anti-depressant], which I didn't say: "well, that's just the wrong thing to do!" But I thought, "what [is it] going to do?" because it hasn't had any effect on me . . . . But, I trust her judgment, so I went ahead with it. . . . I am not going to

refuse to take it as long as she believes it's going to help. She also trusts my side of it where I said I have tried it for two to three weeks and it doesn't seem to be doing me any good. . . . It did help. . . . I had my doubts, but I also thought, she's gotten me this far.

Issues of substance misuse also emerged during the interviews as a major point of tension in the patient-provider relationship and the process of decision-making. A few participants acknowledged that their history of substance use created concerns, frustration, even suspicions for providers, which in turn affected the patient-provider relationship and SDM.

D65: Since I told [Provider] I had a drug and alcohol problem some years ago...she was testing me every dayv I said, "Ma'am, you can test me 24 hours a day. I'm clean and sober." I just got tired of it . . . . She didn't like to listen.

D4: Because I've used in the past, they won't give me drugs that will help me because they figure...I want to abuse it. . . I feel like whenever I talk to them about what worked for me, they look at me like "you're just wanting to get high." . . . I feel like they look at me wrong. I don't know if that's true. . . . that's the feeling I get.

## **Discussion and conclusion**

Study results highlight the complexity of patient participation in SDM. Findings suggest that patients' willingness to participate in SDM might be independent of their understanding and opinions of shared decision-making. Instead, the patient-provider relationship and situational contexts play an important role in patients' participation. Even patients who expressed positive views of SDM reported preference at times for partial or minimal involvement in SDM,

frequently citing their trust in their provider as reasons for their low level of involvement. This finding has implications for the implementation of SDM, since education of patients alone might be insufficient to facilitate full participation in this model of treatment decision-making. Chawla and Arora (2013) noted similar findings. Emphasizing the fluctuating level of patients' involvement in SDM, they cautioned against over-emphasizing the final treatment decision and encouraged inclusion of patients in the deliberation process.

This idea is further developed in Matthias et al.'s (2013) framework of SDM, which directs attention away from the moment a decision is made to emphasize the entire visit leading up to the decision point, and the patient-provider relationship. According to this framework, partnership is central to SDM, and is often forgotten in SDM studies. Our findings support the notion that SDM involves much more than the moment a decision is made, and illustrate that a strong patient-provider relationship and effective communication throughout the visit facilitate SDM and help overcome communication barriers in mental health care. For example, our findings indicate that veterans with mental illness have varying preferences for participation in treatment decision-making, might feel uncomfortable initiating involvement, are unaware of the option, or do not know how to participate in treatment decisions. This highlights the need for providers to foster trusting relationships and communicate effectively to better understand patients' desired role in decision-making and potential contributions of family and friends, especially since previous studies have shown that providers often cannot predict patients' preferences (Hamann et al., 2010).

Consistent with Matthias et al.'s (2013) emphasis on the relationship, our results illustrate that interpersonal as well as clinical issues might serve as barriers to SDM during routine outpatient mental health visits. Some participants perceived themselves as ill-equipped to be full

partners in deciding treatment plans due to lack of knowledge and the nature of their mental illness. This finding supports the “informal paradox” that Joseph-Williams et al. (2013) discussed in their systematic review of patient-reported barriers and facilitators to SDM. They explained that patients often underestimate their ability to acquire or understand “complex” clinical information as well as their ability to provide valuable information including their preferences and personal experiences. This lack of self-efficacy challenges some basic tenets of SDM, such as open information exchange and partnership. This paradox might be particularly salient among patients with mental illness, and thus renders it more crucial for mental health providers to initiate discussions about shared decision-making early on and to empower patients to engage in their own care.

This study is based on a relatively small sample of patients at a single VA mental health clinic and focused only on patients' perspectives and historical accounts, which present a limited view of patient-provider communication. However, our findings are consistent with previous studies showing that patients have varied levels of preference for SDM. More importantly, our findings help to explain why these variations occur.

Our findings emphasize that the patient-provider relationship in mental health care is longitudinal and dynamic. Consequently, communication and SDM are likely to vary over time depending on the patient's needs. A cross-sectional study cannot capture these relational dynamics, which limits our understanding of SDM in the context of patient-provider relationships that might span many years (Matthias et al., 2013; McCabe 2013). Indeed, our data suggest that during routine medication checks, some patients preferred to defer treatment decisions to their providers because they have a trusting, long-term relationship with them. Although trust in providers might lead to deferring control over treatment decisions, it is not

necessarily a barrier to SDM. Rather, over time, patients and providers might develop communication processes to meet their situational needs. Similarly, because mental health visits occur with regularity, all decisions might not require a complete SDM process. For many routine visits, decisions involve primarily review and adjustment of medication dosage, which might not require lengthy discussions. Thus, some participants noted it was appropriate to shorten the decision-making process, yet they still felt a sense of autonomy and partnership in their care. Participants' flexible uses of varied elements of shared decision-making raise additional questions about how to assess and implement shared decision-making in chronic care. Future studies should include longitudinal data to answer these questions.

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<b>Table1. Participants</b>				<b>Total</b>	
<b>AGE GROUP</b>	<b>20 - 40</b>	(0)	3 Male 0 Female	(0)	3 Male 0 Female
	<b>41 -70</b>	9 Male 1 Female	35 Male 3 Female	2 Male 1 Female	46 Male 5 Female
		<b>BLACK (10)</b>	<b>WHITE (41)</b>	<b>Other (3)</b>	<b>54</b>

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