Understanding shared decision-making experience among vulnerable population: Focus group with food bank clients

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Abstract

Introduction: Shared decision-making (SDM) is a critical component of delivering patient-centered care. Members of vulnerable populations may play a passive role in clinical decision-making; therefore, understanding their prior decision-making experiences is a key step to engaging them in SDM. *Objective:* To understand the previous healthcare experiences and current expectations of vulnerable populations on clinical decision-making regarding therapeutic options. *Methods:* Clients of a local food bank were recruited to participate in focus groups. Participants were asked to share prior health decision experiences, explain difficulties they faced when making a therapeutic decision, describe features of previous satisfactory decision-making processes, share factors under consideration when choosing between treatment options, and suggest tools that would help them to communicate with healthcare providers. We used the inductive content analysis to interpret data gathered from the focus groups. *Results:* Twenty-six food bank clients participated in four focus groups. All participants lived in areas of socioeconomic disadvantage. Four themes emerged: prior negative clinical decision-making experience with providers, patients preparing to engage in SDM, challenges encountered during the decision-making process, and patients' expectations of decision aids. Participants also reported they were unable to discuss therapeutic options at the time of decision-making. They also expressed financial concerns and the need for sufficiently detailed information to evaluate risks. *Conclusion:* Our findings suggest the necessity of developing decision aids that would improve the engagement of vulnerable populations in the SDM process, including consideration of affordability, use of patient-friendly language, and incorporation of drug–drug and drug–food interactions information.

Introduction

Shared decision-making (SDM) – an approach to healthcare in which patients engage with their healthcare providers and other members of the healthcare team in the medical decision-making process – has gained increasing attention from a growing emphasis on patient-centered care [1,2]. To achieve optimal decisions for patient care, providers must consider the values, goals, and preferences of patients [3]. Throughout the illness continuum, patients have opportunities to be involved in decision-making, ranging from self-care to pharmacotherapy to invasive treatment options. Many studies have demonstrated that patients' active involvement in the decision-making process can improve their knowledge and reduce anxiety, which not only is associated with improving healthcare outcomes but also may ultimately reduce unwarranted variation in care and costs [4–7].

To initiate effective SDM, patients must possess adequate levels of health literacy and enough knowledge to understand the essential trade-offs between available options to make an informed choice [8]. For these reasons, SDM tends to benefit patients who are educated, able to actively seek information, and advocate for their needs [7,9,10]. As a corollary, SDM may inadvertently exclude those who are vulnerable, defined as the disadvantaged subsegment of the community with limited life options (e.g., financial, educational, housing) [11,12] because they are more likely to play a passive role in their healthcare [10,13]. As such, vulnerable patients not only disproportionately suffer from increased disease burden but also may lack access to healthcare [13,14]. The combination of poor health and lower health literacy suggests that individuals from vulnerable populations facing multiple or complex medical decisions may frequently not be well equipped to make these decisions [15]. Facilitating SDM may be particularly important in this context.

Decision aids – tools that provide information on the pros and cons of various potential therapeutic options – offer one approach for increasing engagement with SDM [16]. Researchers have emphasized the need to include potential stakeholders and communities who can potentially benefit from decision aids throughout the process of decision aid design [17]. Indeed, a review of studies reveals improved adherence for decisions aids when those tools reflect the preferences and needs of users [18]. Although SDM can be beneficial to vulnerable populations [10,19,20], few decision aids are developed with input from members of those populations. Furthermore, patients' previous experience with SDM can influence their future decision-making behaviors [21–23]. Therefore, to leverage the promise of SDM for members of vulnerable populations, their experiences with and expectations of providers must be understood by members of the healthcare team when making medical decisions.

Thus, the goal of this study was to understand the previous healthcare experiences and current expectations of vulnerable populations with respect to clinical decision-making regarding therapeutic options.

Materials and Methods

Participants

We used purposive sampling to recruit participants from a local food bank in Western Pennsylvania (i.e., the North Oakland neighborhood of Pittsburgh) that provides healthy food to a low-income urban population facing hunger crises. Because food banks typically are located in the neighborhoods of highest need to reach vulnerable populations, they are a logical and accessible place to contact members of the population [24]. As such, flyers were posted to recruit clients of the aforementioned food bank. Any adult aged 21 years and older who had not participated in clinical trials conducted by a large local health system (UPMC) was eligible to participate. This study was part of a large initiative to design patient-centered infographics related to medication efficacy; therefore, we excluded people who were participating in related clinical trials to minimize confounding bias. Due to both limited resources for translation, and the predominance of English in the Pittsburgh population, those who could not speak or understand English were excluded.

Study Design

We conducted four focus group interview sessions between May and July 2017. Recruitment was discontinued when we reached data saturation. A single faculty-level facilitator with training and experience in qualitative methods conducted the focus groups for this study. Each focus group lasted 1 h and consisted of semistructured, open-ended questions about how participants made decisions about their medical care during clinical encounters. Because the interviews were semi-structured, participants were allowed to guide the direction of the interviews to share their opinions [25,26]. To ensure the consistency of the interview, a general topic guide with central questions was provided. During these focus groups, participants were asked to (1) share previous SDM experiences about treatment, (2) explain difficulties when making a therapeutic decision with providers, (3) describe any prior experiences that contributed to a satisfactory decision-making process, (4) share factors under consideration when choosing between treatment options, and (5) suggest tools that would best help them

to understand information (e.g., booklets, Internet resources, and video) and communicate with their providers. We used probes to encourage elaboration and further discussion of participants' initial responses. The study protocol was approved by the University of Pittsburgh, Human Resource Protection Office, Institutional Review Board (IRB reference number: PRO16040555). All participants provided verbal informed consent and received a $25.00 prepaid card following the completion of focus groups.

Area Deprivation Index (ADI)

Based on participant zip codes, we calculated the area deprivation index (ADI) of their neighborhood as a proxy measure for socioeconomic status to reflect patient-level social risk factors [27]. The ADI score is "the ranking of neighborhoods by socioeconomic status disadvantage in a region of interest (e.g., at the state or national level)" [27]. The ranking was determined based on the US Census indicators comprising income, education, employment, poverty, and housing quality [27]. The ADI score includes the state and national rankings of neighborhoods: the state ranking feature index scores from 0 to 10 and the national ranking ranges from 0 to 100. A higher ADI score indicates more deprived areas at both the state and national level.

Data Analysis

Focus groups were audiotaped with permission, and all recorded focus groups were transcribed by a third-party vendor who was not part of the study team. After each of the four focus groups, two team members (i.e., YL and KM) held a debriefing session to discuss themes that emerged during each focus group and modified the focus group protocol for subsequent focus groups, if needed. When the team agreed that no new information was found during a given focus group, this constituted data saturation (i.e., no new theme had emerged from participant responses), and we ceased recruitment. We used inductive content analysis to categorize the transcribed verbal data based on emerging themes rather than previously specified hypotheses [28–30]. Three coders (i.e., YL, TB, and FG) independently analyzed the transcribed data to identify categories through the process as follows: first, we identified meaning units as key words, phrases, or paragraphs regarding SDM experiences. Then, we grouped these meaning units which expressed similar concepts into categories and labeled them. The three coders held a meeting to verify the identified categories and compare findings to ensure consistency. Any discrepancies in the results were resolved through a discussion between the coders until agreement was reached.

Results

A total of 26 individuals participated in the four focus groups. Sixty-five percent of the participants ($n = 17$) were female and their mean age was 55 years (SD = 12). The state and national ADI scores of the participants' neighborhoods were 9.6 (SD = 0.8) and 91.2 (SD = 7.7), respectively, which indicate that our participants lived in areas of marked socioeconomic disadvantage. We identified the following themes in the focus group data: (1) prior negative clinical decision-making experience with providers; (2) patients preparing to engage in SDM; (3) challenges encountered during the decision-making process; and (4) patients' expectations of decision aids (Table 1).

Table 1. *Additional quotes from focus groups regarding their shared decision-making (SDM) experiences*

Themes	Representative quotes
Prior negative clinical decision-making experience with providers	"They don't want to listen to me." "Some of them don't really listen. They tell you how they feel and what they think is best for you and I don't agree with that." "They want to give it [medicine] to you because the pharmaceutical companies are pushing it." "My knee … It's like my ortho is making money … I'm buying his house. You know what I mean? He's buying a house with my money, you know?"
Patients preparing to engage in SDM	"But you have to be an informed patient. You're supposed to find out for yourself you have to be informed about it. You well, before you go to the doctors then basically you know what you're going for. Before you go back to the doctors, well this is what I do, I get on the computer or do stuff with doctors in my family." "Like I myself recently had blood work done and the doctor called me back and told me, you know, the results of the blood test. But I thought about it afterwards but I had more questions, and I called him back and asked … and I went online." "A couple years ago when I had my gallbladder removed, I actually went online. The internet is great, I actually went online and saw the actual procedure, so this way it kind of calmed my nerves knowing what was going to happen to me, and it helped me out a lot." "I have this paper that I give every doctor, that I show when I go in, to alleviate, the fact that I'm allergic to it, what I can take and what I can't take, and it saves a lot of time and a lot of pressure on me and the doctor." "Like she said, a lot of people don't have [Internet] access." "You have to realize that that the internet to some people is a bill." "Everyone doesn't have computers, so you still have to give little pamphlets." "The doctor's offices is a good place [to access to pamphlets]." "Lots will be riding on the bus to go to our doctor's appointment and then that could, you know, you're thinking about your medications [and questions]."
Challenges encountered during the decision-making process	"It [using laymen's terms] makes them [patients] know what you're talking about." "Because you've got older people, older people are not in the internet. Like me, I'm not in the Internet. I'd rather read my stuff." "The pamphlet that I did look at, no I don't really completely understand it. So I think they need to put it a little bit more in layman's terms instead of doctors terms, for say. And they need more [information], so I can know more."
Patients' expectations of decision aids	"You could probably get a little bit more info or a little bit more detail." "The [hospital name] gives you papers instead. They tell you almost about every drug interaction that you take with." "You just put the foods there that are at risk and not only, you get what I mean? The foods that would act. … Put the alcohol, the grape juice, all of it." "(I want to know) What is this going to do to me? Am I allowed to this with food? Is it going to mess with my kidneys, is it going to do this, is it going to do that?"

Prior Negative Clinical Decision-Making Experience with Providers

Participants generally described their previous experiences in making decisions with providers as negative. They expressed concerns that providers do not listen to patients and do not consider patients' needs, values, and/or preferences while making therapeutic decisions. For example, one of the participants said *"I know my symptoms better than the doctor. When I would take my insulin or my pill, my whole body goes through a different change. … And I start shaking, break out in a sweat. And I'd be trying to tell the doctors my symptoms, and they won't listen to me. Five years ago, I passed out on the street. My whole body shut down. I couldn't move, couldn't do anything…. I've been trying to tell them all along, something's wrong with me, something's wrong with me. And they never did listen. Until I almost died."* Similarly, another participant said *"Why they don't listen to patients? Because they're up here, and the patient is down there. They're educated and we're not."*

In addition, participants revealed that they were frustrated due to providers' indifference toward patients' current needs. For example, one participant said *"I have educated myself on the medication, because I have an illness that a lot of doctors aren't aware of. … Sometimes the patient has to be their advocate. And it's tough. I had a doctor, when I tried to tell them about what I had, he put his hand up. … you go to these doctors for help, and then you come out devastated, frustrated, because they're telling you they really don't care."*

Moreover, participants said they are unable to discuss their therapeutic options at the time of decision-making because providers have very limited time with patients. A participant said *"I think the doctors should have, when he writes the script, if you are in his office, and you are getting the stuff right there, he should be able to tell you and take the time. They want to get you out. They are not going to take the time to sit there and explain everything."* Similarly, another participant said *"Drug interact this, this and that, they (doctors) don't have the time to explain."*

Participants also described being confused by providers' use of medical jargon and other vocabulary that patients could barely understand while discussing their treatment options. For example, a participant revealed that *"A lot of times doctors and nurses don't talk in the layman's terms."* Another participant described that *"I don't really completely understand it. So I think they need to put it a little bit more in layman's terms instead of doctors terms."*

Furthermore, some participants perceived that providers made decisions based on financial considerations rather than respecting patients' values and needs. One of the participants said *"I started to think that it's all about money now. The more procedures you get, the more they get paid. It's not about your health, you know, your well-being. These doctors are about getting paid."* Another participant also added *"Exactly, it is all about money now, it is not about your well being, it is all about the money. That is sad. It is sad."*

Patients Preparing to Engage in SDM

Regardless of previous negative experiences, participants were willing to participate in the decision-making process. They believed that patients should be informed about their health, as reflected in this participant quote *"This is your health, you know so you should always ask."* Participants described preparing for doctors visits. For example, one participant told us *"What I find best for me I find out what's going on with me then I get me a notebook and I write down some stuff, and then when I go see the doctor he tell me what it is, I write down some more stuff and that gives me something to ask questions so I remember what to talk about."*

Several participants responded that they sought health information regarding their diseases or medications on the Internet before visiting providers to formulate questions for discussion. For example, a participant described the following: *"WebMD, I always go on that. If I get some kind of medication, I make sure that I look it up, see what it is, because I always like to know what kind of side effects, what to expect."* Participants also reported that they used online search engines to find information on diseases, medications, or other therapies that they wanted to learn more about. One of the participants mentioned *"The internet. They write it up there for you, whatever you want to know, you can look it right up on Google . . . . Absolutely, Google really got some stuff going on."* Moreover, participants noted that they looked up information on suggested procedures, if needed, before making a final decision.

However, not all participants had access to the Internet, and some did not know how to navigate it to find the best information. Some participants said that they either do not have the Internet access at home or do not know how to search for information online. Because of these challenges, these participants preferred to have access to pamphlets in public spaces or health provider offices, rather than seeking information on the Internet. For example, a participant suggested *"You never know what to type in to search for it. Just distribute it [health information] everywhere. Libraries. Wherever. Even in stores, restaurants."* Moreover, as an alternative to seeking health and treatment-related information on the Internet or written materials, several participants revealed that they asked friends about their treatment options. For example, one of the participants said *"I talk to my friends. They give me good ideas about medication."*

Some participants stated that they used monitoring devices to keep track of their health symptoms and brought the results back to providers to aid in making decisions. *"I have a glucose machine meter for blood and then I have a, like I said it just goes around your wrist and when I go to the doctor I have my blood pressure checked. Then later at home I check it again with that thing to make sure it's right."* Another participant said that he listed his own medication history to discuss with providers. As such, this participant said *"I have this paper that I give every doctor, that I show when I go in, to alleviate, the fact that I'm allergic to it, what I can take and what I can't take, and it saves a lot of time and a lot of pressure on me and*

the doctor because then he doesn't have to look it up on the computer."

Patient Challenges Encountered During the Decision-Making Process

While seeking information, participants identified insufficient literacy as a challenge to acquire the information necessary to communicate with providers and make therapeutic decisions. They explained that some participants were illiterate or had too low level of literacy to understand information on printed materials, such as medication pamphlets. A participant said *"Lot of people, if you haven't been around medical terminology and all that stuff, they're not going to understand that."* Participants like this one preferred to have a number to call and speak with a healthcare professional. For example, another participant said *"Because you have some people that don't know how to read. A 1-800 number would be really good. A 1-800 number where they could actually call and talk to somebody."*

Several participants said that current prescription pamphlets are difficult to understand due to small fonts, numerous specialized medical terms, and jargon. A participant said *"The thing is it is that small, and who is going to sit there and read it?"* They believed that these pamphlets were not designed for patients. Participants suggested *"Those pamphlets. Speak in layman's terms. Use words that people can understand. No doctor language."*

Participants also noted that elderly patients may have an additional burden during SDM due to increased difficulty in understanding or recalling pertinent information. One of the participants expressed this notion in this way: *"Lot of seniors take medication and they just take it they don't know what they're taking. Or why, or how it's going to help them."* Moreover, because of aging and the progression of chronic diseases, patients may not be capable of advocating for themselves and need to be accompanied by someone who acts as an agent for medical decision-making. For example, another participant told us *"I notice is that a lot of elderly people need someone there to ask questions. . . . Lot of seniors don't know what to ask and what to say. That's why we need someone with us if we're not able to convey as far as what we need to know what's going on."* Furthermore, some participants expressed that members of older populations may not know how to access information on the Internet.

Additionally, our participants revealed that they face socioeconomic challenges that limit their ability to partake in SDM. One of these socioeconomic issues was that they were unable to afford all possible options that providers offered. One of the participants said *"Being on low income we can't afford [certain options]. They already know this. We're poor."*

Patients' Expectations of Decision Aids

Participants reported that they need more detailed information on their medication options from their providers. These participants desired information about how their medication might interact with other medication and, particularly, specific foods. One of the participants shared the following observation: *"Some of these things you're eating vegetables that's going to be good for them, it could be harmful for them. . . . let people know if their potassium level was high, don't eat potatoes, don't eat tomatoes. People don't know that and they'll eat tomatoes."* Another participant also mentioned the need for detailed information on a specific food: *"They say grapefruit juice is supposed to be good for you, but it was acting with her other medication."*

Additionally, patients reported that pamphlets or educational materials did not provide enough relevant information. One of participants responded *"They [pamphlets] should tell you if it is a new med, what the stuff is, the interactions and different things is."* Another participant noted *"The pamphlet that I did look at, no I don't really completely understand it. And they need more [information], so I can know more."*

Several participants suggested that education materials or medical pamphlets need to prioritize information for patients: *"I think that they should have like a small area, something in where they have a small area of the things that's most, most important because there's so much going on. Like the paper that's attached to your medication, I don't think that they had the stuff that's really important."* Another participant suggested *"Put in a red [lettering] on important things. These are the major things that you should watch out for."* Moreover, participants pointed out that contents should be easily noticeable and understandable at the time patients read them. For example, one participant said *"You want them to be able to understand them when they look at it. Being able to automatically know what it is."*

Discussion

The results of our study demonstrate that the members of the vulnerable populations that participated in our focus groups have had negative decision-making experiences with providers; nevertheless, these individuals still are willing to take an active role in the SDM process. Moreover, they identified additional challenges they face when communicating with providers to make therapeutic decisions. For example, our participants identified the Internet as their main resource for seeking health-related information. However, because members of vulnerable populations may not be able to afford access to the Internet or know how to use it, our participants noted that non-digital information located in easy-to-find spaces remains important for supporting health decisions. Overall, our participants described the typical amount of information provided by providers on therapeutic options as inadequate.

SDM requires both the active engagement of patients and extensive communication with providers to determine the best treatment option [31]. However, vulnerable populations may experience a power imbalance in the patient–provider relationship, which results in them being less likely to share their thoughts and concerns [32]. In addition, they may defer to providers for decision-making when they feel that providers do not value their experience and concerns [32–34]. Consistent with our result, the literature demonstrates that vulnerable populations often believe that they are not knowledgeable enough to make a cogent decision, and, therefore, unable to advocate for themselves [32–34].

Some of our participants revealed that they mistrusted their providers and suspected that they were making decisions for financial or insurance benefits, rather than making decisions for their best interest. It is possible that this lack of trust in clinical decision-making may be due to a fear of exclusion from the decision-making process and other psychological factors not currently understood. We assert that patients can establish rapport with providers when the patient–provider relationship is valued and trusted. This suggests that SDM may be a pathway toward improved decision-making among vulnerable populations.

Some challenges that our participants reported were consistent with those of non-vulnerable populations, such as insufficient time during office visits to ask all the relevant questions, a lack of understanding of medical terms written in education materials, a lack of medical knowledge, a limited ability to prepare questions in advance of the visit, and limited options for asking additional questions after the appointment [35–38]. These factors can impede communication between patients and providers. Indeed, some of our participants had the impression that providers were not listening to them or validating their concerns. Because of these limitations, some of our participants preferred to seek information elsewhere (e.g., friends and pharmacists), which caused a breakdown in rapport with the provider and prevented active patient engagement in SDM. This is consistent with findings in the previous literature that reveal that patients tend to ask those with whom they have easy access their questions about healthcare [39-41]. While not all communication challenges outlined by our participants are unique to vulnerable populations, a focus on overcoming these challenges may help to empower vulnerable populations by providing them access to information, educating them to advocate for themselves, and guiding them to make decisions that reflect their concerns and values.

Our participants suggested that the challenges of clinical decision-making were exacerbated by their socioeconomic status. Due to limited financial resources, members of vulnerable populations may find that they are unable to choose an optimal treatment approach. Furthermore, many studies has described how poor communication between patients with low income and their healthcare providers and limit SDM [42–44].

The Internet has become a key resource – not only for our vulnerable participants but also for the general population living in the USA – to seek and access health-related information. Studies have shown that at least 70% of US adults have sought health-related information on the Internet [45]. Although our sample drew upon the Internet as a major resource, some participants also noted being unable to afford Internet service or devices (i.e., computer or mobile phone) to access the information they seek. An ample body of literature demonstrates that disparities in social structures contribute to the digital divide – the gap between people who have access and people who do not have access to the Internet [46,47]. As such, some patients prefer to have a pamphlet or paper-based materials to review information about their therapeutic options, as some of our participants suggested. Having printed materials in their daily living environment (e.g., bus stops) would help disseminate important medical information. To increase the engagement of vulnerable populations in SDM and enhance their ability to communicate with providers, we need to consider the digital divide when developing decision aids and provide these aids in both online and traditional formats (e.g., flyers).

However, access to information does not guarantee that people can understand and utilize health information for making sound decisions about their treatment options, including medications. Relevant prior studies indicate that the majority of patients seeking health information on the Internet felt unqualified to determine the quality, veracity, and relevance of the information presented [48–50]. Indeed, our participants revealed that information on the Internet used too many medical terms and did not consider the literacy level of various audiences who may be accessing the material. These findings are consistent with studies reported in the literature about patients with low health literacy levels [15,51]. Although we did not assess the health literacy level of participants, several studies showed associations between socioeconomic status and health literacy, specifically that vulnerable populations tend to exhibit lower health literacy levels than do the general public [52–54]. As such, those who provide care in

medically vulnerable areas should consider the health literacy level of patients when developing information regarding potential treatments or procedures. Including patients in the material development process can improve the design of health information and engage patients in the decision-making process.

We also found that patients want to have more information from decision aids and providers regarding their therapeutic options. Currently, information is mostly provided on the benefits and risks among possible therapeutic options. Our participants insisted that they want to learn more about the potential for interactions with other medicines and foods. This finding is consistent with other studies. For example, Arcia et al. demonstrate that the Latino population living in the medically vulnerable area of northern Manhattan in New York City requested more detailed information on health-related issues [55]. These participants received information about their current blood pressure level and what it meant, but they wanted to know more about the consequences of their blood pressure level. In a similar study, Benetoli et al. showed that one of the most popular questions consumers asked of a medicine information service on Facebook was related to drug interactions [56]. However, current platforms or resources providing drug interaction information are targeted at healthcare professionals, not consumers – particularly those with a low literacy level [57,58]. Our study suggests the salient need to develop resources providing drug interaction information to patients, so that they can utilize that information in their decision-making process.

From the challenges that our participants identified in the SDM process, providers must consider practical strategies towards improving vulnerable individuals' engagement, including communicating in an empathetic manner, using language that can be understood by individuals with lower levels of literacy, and the importance of explicitly addressing the costs of different treatments. Furthermore, individuals must be adequately educated about the risk of potential medications with consideration of drug–drug and drug–food interactions. Resources that can provide additional information, such as online and paper-based tools, are essential complements to clinical conversations. In the future, we may consider utilizing telemedicine or patient portal options that facilitate advanced knowledge or follow-up questions.

More studies are needed for evidence-based changes in SDM that specifically include vulnerable populations. Additional qualitative interviews or surveys should consider recruiting participants from broader community organizations and use simpler language to limit sampling bias and non-response bias. Moreover, few randomized controlled trials or quasi-experimental studies have tested the effects of SDM interventions among vulnerable populations. We can consider conducting experimental studies to decide the appropriate amount of information for vulnerable populations to support SDM. Considering the challenges identified in this study, researchers need to conduct more RCTs with decision aids and patient–provider communication strategies in vulnerable populations to understand how they may affect clinical outcomes.

Limitations

Because we recruited participants from a single local food bank, we need to be cautious about applying our findings to the general population. In addition, we cannot assume that our participants possessed a low level of literacy because we did not measure their levels

of literacy; however, the association of socioeconomic status and literacy level is supported in the literature [50–52]. Moreover, we did not collect any personal or demographic information (e.g., ethnicity, race, income, and education level) to characterize our participants. Nevertheless, we did record ADI, which reflects a combination of these factors to estimate the degree of deprivation without spending time asking several questions.

Conclusion

Although SDM has been widely encouraged in the US healthcare system, members of vulnerable populations still perceive that they are not fully engaged in the decision-making process with their healthcare providers. We have identified how individuals with lower socioeconomic status have been engaged in clinical decision-making and what they perceive as requirements to make better decisions about various therapeutic options. In general, prior clinical decision-making experiences have been negative among members of our sample. Yet, our participants reported an interest in actively engaging in SDM and described similar challenges as have other samples, such as limited time during office visits to ask all the relevant questions. These limitations can be exacerbated due to financial difficulties and other factors such as limited literacy that may be over-represented in vulnerable populations. Our study suggests that developing decision aids that reflect the needs of vulnerable populations, including consideration of affordability, use of patient-friendly language, and incorporation of drug–drug and drug–food interactions information, would improve their engagement in the SDM process.

References

1. **Barry MJ, Edgman-Levitan S**. Shared decision making—The pinnacle of patient-centered care. *New England Journal of Medicine* 2012; **366**(9): 780–781.

2. **Elwyn G**, *et al.* Shared decision making: a model for clinical practice. *Journal of General Internal Medicine* 2012; **27**(10): 1361–1367.

3. **Allen LA**, *et al.* Decision making in advanced heart failure: a scientific statement from the American Heart Association. *Circulation.* 2012; **125**(15): 1928–1952.

4. **Simmons M, Hetrick S, Jorm A**. Shared decision-making: benefits, barriers and current opportunities for application. *Australas Psychiatry.* 2010; **18**(5): 394–397.

5. **Oshima Lee E, Emanuel EJ**. Shared decision making to improve care and reduce costs. *New England Journal of Medicine* 2013; **368**(1): 6–8.

6. **Edwards A, Elwyn G**. Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision. *Health Expectations* 2006; **9**(4): 307–320.

7. **Stacey D**, *et al.* Decision aids for people facing health treatment or screening decisions. *Cochrane Database of Systematic Reviews* 2017; **4**: CD001431.

8. **Kim SP**, *et al.* Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Investigation* 2001; **19**(7): 684–691.

9. **Coulter A, Collins A** *Making Shared Decision Making a Reality: No Decision About me Without Me.* London: Thg King's Fund. 2011.

10. **Durand MA**, *et al.* Do interventions designed to support shared decision-making reduce health inequalities? A systematic review and meta-analysis. *PloS One* 2014; **9**(4): e94670.

11. **Shivayogi P**. Vulnerable population and methods for their safeguard. *Perspectives in Clinical Research* 2013; **4**(1): 53.

12. **Mechanic D, Tanner J**. Vulnerable people, groups, and populations: societal view. *Health Affairs (Millwood)* 2007; **26**(5): 1220–1230.

13. **Say R, Murtagh M, Thomson R**. Patients' preference for involvement in medical decision making: a narrative review. *Patient Education and Counseling* 2006; **60**(2): 102–114.

14. **Curtis AJ, Lee WA**. Spatial patterns of diabetes related health problems for vulnerable populations in Los Angeles. *International Journal of Health Geographics* 2010; **9**(1): 43.

15. **Muscat DM**, *et al.* Can adults with low literacy understand shared decision making questions? A qualitative investigation. *Patient Education and Counseling* 2016; **99**(11): 1796–1802.

16. **Woolf SH**, *et al.* Promoting informed choice: transforming health care to dispense knowledge for decision making. *Annals of Internal Medicine* 2005; **143**(4): 293–300

17. **Witteman HO**, *et al.* User-centered design and the development of patient decision aids: protocol for a systematic review. *Systematic Reviews* 2015; **4**(1): 11.

18. **Wiesner M, Pfeifer D**. Health recommender systems: concepts, requirements, technical basics and challenges. *International Journal of Environmental Research and Public Health* 2014; **11**(3): 2580–2607.

19. **Bonevski B**, *et al.* Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. *BMC Medical Research Methodology* 2014; **14**: 1–29.

20. **Durand MA**, *et al.* 'Much clearer with pictures': using community-based participatory research to design and test a Picture Option Grid for underserved patients with breast cancer. *BMJ Open* 2016; **6**(2): e010008.

21. **Robinson A, Thomson R**. Variability in patient preferences for participating in medical decision making: implication for the use of decision support tools. *BMJ Quality & Safety* 2001; **10**(Suppl 1): i34–i38.

22. **Suarez-Almazor ME**, *et al.* A qualitative analysis of decision-making for total knee replacement in patients with osteoarthritis. *Journal of Clinical Rheumatology: Practical Reports on Rheumatic & Musculoskeletal Diseases* 2010; **16**(4): 158.

23. **Washington K, Shacklady C**. Patients' experience of shared decision making using an online patient decision aid for osteoarthritis of the knee – a service evaluation. *Musculoskeletal Care* 2015; **13**(2): 116–126.

24. **Seligman HK**, *et al.* A pilot food bank intervention featuring diabetes-appropriate food improved glycemic control among clients in three states. *Health Affairs.* 2015; **34**(11): 1956–1963.

25. **Kvale S** (1996). *InterViews: An introduction to qualitative research interviewing.* London: Sage.

26. **Smith J** (1995). Semi-structured interviewing and qualitative analysis. In: Smith JA, Harre R, Van Langenhove L, eds. *Rethinking Methods in Psychology.* London: Sage.

27. **Knighton AJ**, *et al.* Introduction of an area deprivation index measuring patient socioeconomic status in an integrated health system: implications for population health. *eGEMs* 2016; **4**(3): 1238.

28. **Hsieh HF, Shannon SE**. Three approaches to qualitative content analysis. *Qualitative Health Research* 2005; **15**(9): 1277–1288.

29. **Elo S, Kyngäs H**. The qualitative content analysis process. *Journal of Advanced Nursing* 2008; **62**: 107–115.

30. **Moretti F**, *et al.* A standardized approach to qualitative content analysis of focus group discussions from different countries. *Patient Education and Counseling* 2011; **82**(3): 420–428.

31. **Thompson AG**. The meaning of patient involvement and participation in health care consultations: a taxonomy. *Social Science & Medicine* 2007; **64**(6): 1297–1310.

32. **Polaris JJ, Katz JN**. "Appropriate" diagnostic testing: supporting diagnostics with evidence-based medicine and shared decision making. *BMC Research Notes* 2014; **7**(1): 922.

33. **Palmer NR**, *et al.* Racial and ethnic differences in prostate cancer survivors' perceived engagement in treatment decision-making. *Journal of Racial and Ethnic Health Disparities* 2018; **5**(6): 1273–1283.

34. **Joseph-Williams N**, *et al.* Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education and Counseling* 2014; **94**(3): 291–309.

35. **Melzer AC**, *et al.* What exactly is shared decision-making? A qualitative study of shared decision-making in lung cancer screening. *Journal of General Internal Medicine* 2020; **35**(2): 546–553.

36. **Wiener RS**, *et al.* Patient and clinician perspectives on shared decision-making in early adopting lung cancer screening programs: a qualitative study. *Journal of General Internal Medicine* 2018; **33**(7): 1035–1042.

37. **Schoenfeld EM**, *et al.* A Qualitative analysis of patients' perceptions of shared decision making in the emergency department: "let me know i have a choice". *Academic Emergency Medicine* 2018; **25**(7): 716–727.

38. **Hofstede SN**, *et al.* Barriers and facilitators to implement shared decision making in multidisciplinary sciatica care: a qualitative study. *Implementation Science* 2013; **8**(1): 95.

39. **Carlsson M**. Cancer patients seeking information from sources outside the health care system. *Support Care Cancer* 2000; **8**(6): 453–457.

40. **Lee CJ**, *et al.* Looking beyond the Internet: examining socioeconomic inequalities in cancer information seeking among cancer patients. *Health Communication* 2012; **27**(8): 806–817.

41. **Altizer KP**, *et al.* A qualitative analysis of how elders seek and disseminate health information. *Gerontology & Geriatrics Education* 2014; **35**(4): 337–353.

42. **Okunrintemi V**, *et al.* Association of income disparities with patient-reported healthcare experience. *Journal of General Internal Medicine* 2019; **34**(6): 884–892.

43. **Clemans-Cope L, Kenney G**. Low income parents' reports of communication problems with health care providers: effects of language and insurance. *Public Health Reports* 2007; **122**(2): 206–216.

44. **Murray E, Pollack L, White M, Lo B**. Clinical decision-making: patients' preferences and experiences. *Patient Education and Counseling* 2007; **65**(2): 189–196.

45. **Fox S, Duggan M**. Health Online 2013. *Health* 2013: 1–55.

46. **Bodie GD, Dutta MJ**. Understanding health literacy for strategic health marketing: eHealth literacy, health disparities, and the digital divide. *Health Marketing Quarterly* 2008; **25**(1–2): 175–203.

47. **Jha AK**, *et al.* Evidence of an emerging digital divide among hospitals that care for the poor. *Health Affairs* 2009; **28**(6): w1160–70.

48. **Atique S**, *et al.* Lessons learnt from a MOOC about social media for digital health literacy. In: *The Proceedings of the 38th Annual International Conference of the IEEE Engineering in Medicine and Biology Society.* Orlando (FL), August 17–20, 2016: 5636–5639.

49. **An LC, Wallner L, Kirch MA**. Online social engagement by cancer patients: a clinic-based patient survey. *JMIR Cancer* 2016; **2**(2): e10.

50. **Jacobs M, Clawson J, Mynatt ED**. A cancer journey framework: guiding the design of holistic health technology. In: *The Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare.* Cancun (Mexico), May 16–19, 2016: 114–121.

51. **Miles RC, Baird GL, Choi P, Falomo E, Dibble EH, Garg M** Readability of online patient educational materials related to breast lesions requiring surgery. *Radiology* 2019; **291**(1): 112–118.

52. **Kim SP**, *et al.* Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. *Cancer Investigation* 2001; **19**(7): 684–691.

53. **Howard DH, Sentell T, Gazmararian JA**. Impact of health literacy on socioeconomic and racial differences in health in an elderly population. *Journal of General Internal Medicine* 2006; **21**(8): 857–861.

54. **Mantwill S, Monestel-Umaña S, Schulz PJ**. The relationship between health literacy and health disparities: a systematic review. *PLoS One.* 2015; **10**(12): e0145455.

55. **Arcia A**, *et al.* Sometimes more is more: iterative participatory design of infographics for engagement of community members with varying levels of health literacy. *Journal of the American Medical Informatics Association* 2015; **23**(1): 174–183.

56. **Benetoli A, Chen TF, Spagnardi S, Beer T, Aslani P**. Provision of a medicines information service to consumers on Facebook: an Australian case study. *Journal of Medical Internet Research* 2015; **17**(11): e265.

57. **van Beusekom MM**, *et al.* Low literacy and written drug information: information-seeking, leaflet evaluation and preferences, and roles for images. *International Journal of Basic & Clinical Pharmacology* 2016; **38**(6): 1372–1379.

58. **Wolf MS**, *et al.* To err is human: patient misinterpretations of prescription drug label instructions. *Patient Education and Counseling* 2007; **67**(3): 293–300.