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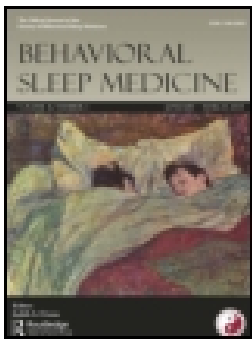
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Patient-Provider Communication With Older Adults About Sleep Apnea Diagnosis and Treatment

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Patient–provider communication impacts adherence to therapy. We explored older adults’ communication with their providers, preferences for communication, and views on communication attributes and decision aid characteristics, by conducting four focus groups. Several participants reported they had received insufficient information about their sleep apnea diagnosis and treatment options. Most participants felt that it would be helpful to have treatment information tailored to their needs, including information on the negative impact of treatment on comfort and

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convenience and disclosure about common barriers to adherence. Participants provided desired characteristics for a decision aid, including their preferred delivery method, content, and format. These findings have implications for how to design useful decision aids for older adults with newly diagnosed sleep apnea.

BACKGROUND

Sleep apnea (SA) is prevalent among older adults, and positive airway pressure (PAP) therapy is the most commonly prescribed therapy for it. Alternative therapies include oral appliances, surgical procedures, and nasal expiratory positive airway pressure. Although some patients are successfully treated with these therapies, many reject treatment entirely or have limited adherence due to physical (e.g., discomfort), psychosocial (e.g., lack of perceived need), or financial barriers (e.g., out-of-pocket costs; Sawyer et al., 2011). When patients reject or do not adhere to treatment, they often receive no treatment, which is associated with sleep disturbance, daytime symptoms, and for some, increased cardiovascular morbidity and mortality (Martinez-Garcia et al., 2012). Several studies have examined technological, psychosocial, pharmacological, educational, and multidimensional strategies to improve acceptance and adherence to SA therapy (Aloia et al., 2001; Lettieri et al., 2009; Sawyer et al., 2011; Smith, Daus, Clements, Werkowitch, & Whitman, 2009; Sparrow, Aloia, Demolles, & Gottlieb, 2010). Most of these strategies have focused on ways to improve adherence to PAP after the decision to prescribe PAP therapy has been made (Golay et al., 2006; Meurice et al., 2007).

Characteristics of the patient–provider relationship can influence adherence to therapies (Gallagher & Levinson, 2004). Provider explanations about a medical diagnosis or treatment are associated with favorable outcomes (Orth, Stiles, Scherwitz, Hennrikus, & Vallbona, 1987). Communication that elicits patient treatment preferences and goals of care and involves patients in selecting their therapy can promote adherence to therapy and improve patient satisfaction (Smith et al., 1998; Weiland et al., 2012). Engaging patients in discussions about treatment may be particularly helpful when the set of treatment options includes a mixture of favorable and unfavorable attributes, as is the case for SA. Therefore, increasing the quality of patient–provider communication may be especially useful for SA patients.

Communication in the setting of a consultative specialty visit, which is the typical type of visit for SA, can be challenging. Most patients presenting with SA are meeting their sleep clinic providers for the first time, so the patient has not had an opportunity to discuss care goals with the provider (Collins et al., 2009). Sleep providers can learn about a patient’s goals of care by reviewing medical records and talking with the patient during the visit, but a number of factors may limit the amount and type of information exchanged about the consequences of untreated SA and the risks and benefits of available SA treatment options. These factors include visit length and setting as well as patients’ and providers’ sociodemographics, attitudes regarding patients’ rights to medical information, role expectations, preferences for communication and decision making, and use of strategies to control the encounter such as changing topics, interrupting, and ignoring questions (Beisecker, 1990; Beisecker & Beisecker, 1990). Communication tools could facilitate discussions about goals of care and treatment options.

Patient decision aids are defined by the International Patient Decision Aid Standards Collaboration as “tools designed to help people participate in decision making about health

care options” (International Patient Decision Aid Standards [IPDAS] Collaboration, 2012). Decision aids can facilitate dialogue about disease and treatments, increase patient knowledge about treatment options, increase the accuracy of patients’ risk perceptions about treatments, and improve patient-provider communication (Stacey et al., 2014). Most decision aids, which may be presented in formats such as videos, pamphlets, or Web-based literature, include sections that specifically address the risks and benefits of treatment options (IPDAS, 2012). Decision aids that include a values clarification component increase the proportion of patients achieving decisions that are informed and consistent with their values and goals of care (Stacey et al., 2014). These decision aid effects may be particularly beneficial for individuals with multiple complex medical and psychiatric comorbidities, who may be forced to make more risk-benefit tradeoffs (e.g., a patient with upper extremity paralysis who needs help setting up PAP nightly may trade off independence for a reduction in daytime sleepiness associated with PAP). A decision aid for adults with SA developed by researchers in Europe provides information on disease prevalence, risk factors, SA effects on daily life, and effects of different SA treatments (Pelletier-Fleury, Gafni, Krucien, & Fleury, 2012). There are no known studies that have examined the patient-provider relationship as a determinant of SA treatment acceptance and adherence among older adults, a group more likely to have multiple complex medical and psychiatric comorbidities. In addition, older adults have been slower to adopt consumer health technologies and mobile devices than younger generations (LeRouge, Van, Seale, & Wright, 2014). No decision aids with content specifically tailored to an older adult population (e.g., SA treatment effects among adults ≥ 65 years) are available.

The purpose of this study was to describe (a) older adult patients’ perceptions of communication about SA occurring in encounters with sleep center staff and (b) older adult patients’ beliefs, attitudes, and preferences for patient-provider communication styles and decision making regarding SA treatment. We also sought to explore older adult patients’ desired characteristics for a tool (i.e., patient decision aid) for improving communication about SA and SA treatment options.

METHODS

Study Participants and Recruitment

We conducted four focus groups of patients from two health systems (Department of Veterans Affairs [VA] and academic) in Los Angeles in April and May 2014. Both health systems have comprehensive sleep centers and offer the most common SA treatments (i.e., PAP, oral appliances, surgery). At both health systems, patients met individually with their physician, and patient education on SA was provided during the visits. Within the VA, respiratory therapists provided patients education about PAP equipment during one-on-one visits. In the academic health care system, information about PAP equipment was provided by durable medical equipment companies, whose education formats ranged from one-on-one to group visits. Although some of the providers have dual affiliations with the VA and the academic health system, the overwhelming majority of the physicians were providing care in only one of the health care systems.

Recruitment posters and flyers were displayed in patient waiting areas at both health systems asking those interested to call our research center. A trained research staff member described the study and screened the patient for eligibility. Patients were eligible if they were 65 years or older,

had been diagnosed with SA on a sleep study, and had not been told by a physician that they have dementia. The VA Greater Los Angeles Healthcare System and University of California at Los Angeles (UCLA) Health System institutional review boards approved the study (VA #2013-091198; UCLA #13-001132). Verbal consent was obtained at the time of the focus groups. Study participants were financially compensated for participation.

Theoretical Framework

The Theory of Planned Behavior (TPB; Aizen, 1985) served as the overarching framework for the overall research study, which aims to develop a patient decision aid related to SA treatment. The research study began with the focus groups described in this paper. According to this framework, attitudes, subjective norms (e.g., referent beliefs about what behaviors others expect), and perceived behavioral control (e.g., perception of personal influences on the behavior and perceived difficulties performing the behavior) influence intention to use SA therapy, which in turn affects adherence to therapy. Adherence affects health outcomes. This framework was used to develop the focus group discussion guide.

Focus Group Sessions

The focus group sessions contained a mix of patients from both sites and were held in conference rooms at the VA. At the beginning of each session, participants completed a questionnaire asking for information about their SA treatment and demographic information. The focus groups were conducted by an experienced focus group moderator with content expertise in sleep medicine (JLM). Focus groups were conducted using a detailed guide of open-ended questions and covered three core issues: (a) types of patient-provider discourse that occurred when the patients first learned of their SA diagnoses, (b) preferences on discourse about SA diagnosis and treatment, including information the patients wish they had known about SA when they were first diagnosed with SA, and (c) perspectives on patient decision aids in the context of SA treatment (see Table 1). Participants were shown examples of patient decision aids developed for other medical conditions. Patient decision aid formats shown included paper, video, and online interactive content. The sessions lasted 90 min and were audio-recorded. After each session, the research staff (JLM, CHF, CT) discussed major themes that arose during the session and new understandings about the domains that emerged.

Focus Group Data Analysis

The audio-recordings were transcribed and subsequently reviewed by two team members (CHF, KJ) to identify major themes and to develop an initial coding tree (NVivo 10). During the development of the initial coding tree, coders were blinded to the codes of the other coder. The team (CHF, KJ, CT, JLM) discussed the coding tree during a group meeting and, based upon this discussion, made modifications to the coding tree. Then, each transcript was read by two team members independently (CHF, KJ, and/or CT) and manually coded for instances of each code. The coding tree was iteratively revised as each transcript was coded until the coding tree was finalized. Differences in coding were discussed with a third team member and resolved by consensus. The baseline and final coding trees are presented in Figure 1. Throughout data analysis, we acknowledged the need to safeguard against preconceived ideas derived from

TABLE 1
Focus Group Discussion Guide

-
1. Now I'd like you to think back to when you first learned that you have sleep apnea. Visualize yourself back in the room at a doctor's office, on the telephone, or wherever it was that you learned that you have sleep apnea.
 - What type of conversation, if any, did you have with your provider about your diagnosis?
 - What did your health care provider talk with you about in terms of the options available for dealing with this new diagnosis, sleep apnea?
 - What was your impression of the interaction?
 - What roles did family and friends play in these interactions and decisions?
 - Ideally, what information would you have wanted to be conveyed about your new diagnosis?
 2. I'd like you to think back to the weeks or months following your initial diagnoses with sleep apnea. Some of you may have started a treatment for sleep apnea, while others might not have. Tell me about what you did? How did that go?
 - For those of you who received medical equipment like CPAP or a dental device, how did you feel about the treatment when you first received your equipment?
 - Being diagnosed with a new medical condition and having to use new equipment (like CPAP or a dental device) can impact the people around you too. How did the other people in your household—or other people in your life—react to your CPAP or a dental device?
 - What makes using sleep apnea equipment regularly easy? Difficult?
 - What did you think would change once you started using CPAP or a dental device?
 - Now that you have some experience with it, can you think of anything that you would have wanted to know before you got started with treatment?
 3. We're developing an information tool to help patients understand the different options available to people with sleep apnea. The initial version will be a pen and paper version. It will contain pictures and text about the risks and benefits of different options. Questions within the tool will encourage patients to carefully consider whether each option matches their own personal health care goals. The tool is not meant to be a substitute for discussions with health care providers. Rather, it is a tool to encourage patients and health care providers to make informed decisions about health care, working together.

What are your thoughts on a sleep apnea information tool like the one I just described?

 - How might it be used?
 - What are your thoughts about a tool like this for obstructive sleep apnea?
 - We're conducting today's session to help us develop an information tool for older adults with newly diagnosed sleep apnea. I'd like to get your opinion on a few different approaches [provide examples].
-

clinical experience. To limit this risk, a team member who did not have prior direct clinical experience with patients with SA observed all of the focus groups, helped develop the coding tree, and coded the transcripts. We openly discussed whether the coding tree represented the key themes of the focus group discussions and whether the quotes selected for the manuscript are representative of the focus group content.

We examined frequencies of items from the questionnaires distributed to focus group participants. Those data were analyzed using Stata/SE13.1 (StatCorp LP, College Station, Texas).

RESULTS

Description of Participants

Of the thirty-five patients (86% male) who participated (Table 2), 77% had only used PAP, while 20% had tried more than one type of SA therapy (Table 3). Eighty-eight percent of participants had been treated for at least one year. Half of the participants reported using

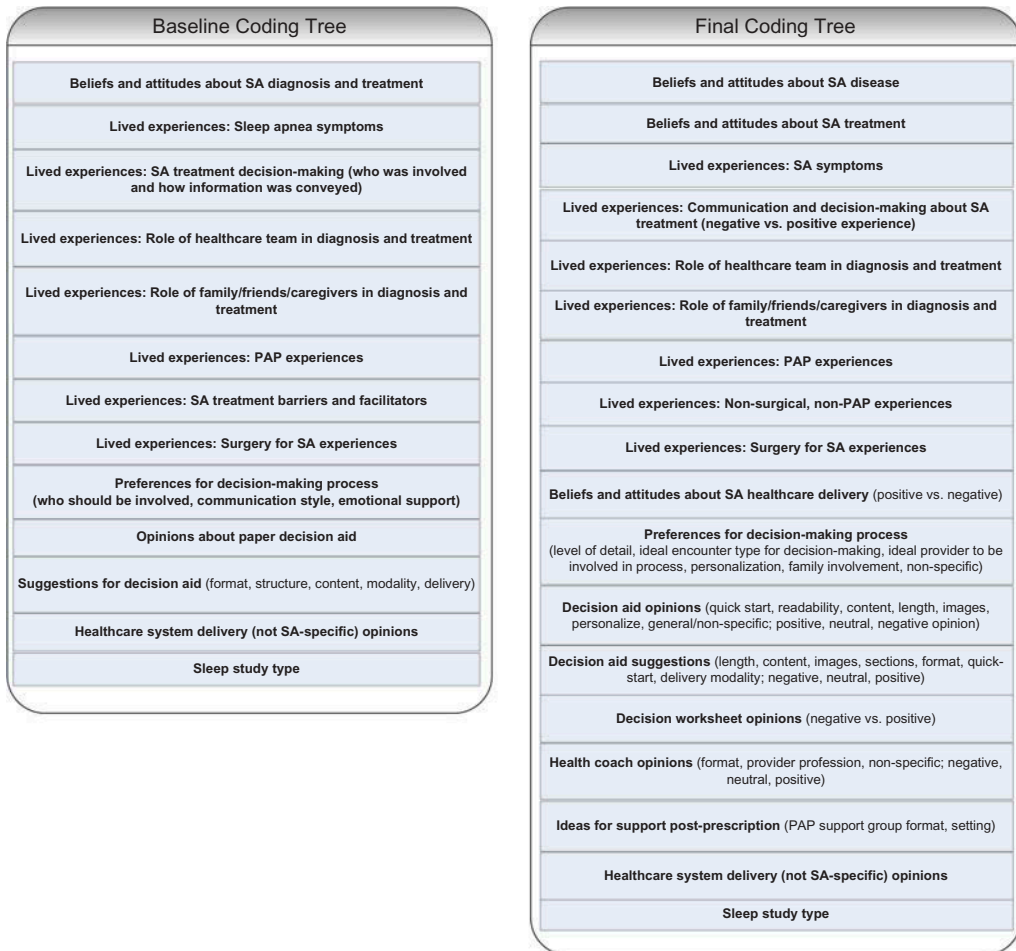


FIGURE 1 Baseline and final coding trees (SA = sleep apnea, PAP = positive airway pressure).

their SA therapy nightly (Table 3). During the focus groups, participants discussed symptoms that were typical of SA (e.g., apneic episodes, excessive daytime sleepiness, nighttime awakenings, snoring, fatigue, and motor vehicle crashes) and described well-known mechanical barriers to SA therapy. Because most patients had used PAP only, the majority of comments were related to comfort and convenience barriers to the use of PAP. However, some patients who had tried oral appliances or surgery also described anatomical barriers to fitting oral appliances or undergoing surgery.

Description of Communication Between Patients and Health Care Providers

Communication about the causes of SA and the risks of living with SA ranged from very negative to very positive. Participant responses indicated a desire to have more information

TABLE 2
Participant Demographic (N = 35)

<i>Variable</i>	<i>Frequency (%)</i>
Gender	Male 30 (86%)
	Female 5 (14%)
Age	65–69 years 23 (66%)
	70–74 years 7 (20%)
	75 years or older 5 (14%)
Education	Less than high school 2 (6%)
	High school or equivalent 3 (9%)
	Vocational/technical school (2-year) 4 (11%)
	Some college 14 (40%)
	Bachelor’s degree 8 (23%)
	Master’s degree 3 (9%)
	Doctoral degree 1 (3%)
Ethnicity/Ethnicity	White 20 (57%)
	Black 4 (11%)
	Hispanic 8 (23%)
	More than 1 race/ethnicity 1 (3%)
	Missing 10 (29%)

Note. Participant demographics were similar across the focus groups, so data from the four focus groups were pooled together.

TABLE 3
Participant Treatment Characteristics (N = 35)

<i>Variable</i>	<i>Frequency (%)</i>
Sleep apnea therapy	
Positive airway pressure only	27 (77%)
Oral appliance only	1 (3%)
Positive airway pressure and oral appliance	5 (14%)
Positive airway pressure and nasal expiratory positive airway pressure	2 (6%)
Treatment duration	
< 1 year	3 (9%)
1–5 years	11 (31%)
5–10 years	8 (23%)
> 10 years	12 (34%)
Don’t know	1 (3%)
Self-report therapy use (past 30 days)	
Every night	18 (51%)
Most nights	7 (20%)
Some nights	5 (14%)
No nights	5 (14%)

when receiving the diagnosis for the first time, including an explanation of the implications of having an SA diagnosis, the risks of not adhering to therapy, and how to use the PAP device.

1. Positive experiences: Some participants clearly remembered receiving their diagnosis of SA or discussing the risks of untreated SA, even in cases diagnosed more than one year ago. In some cases, the patient was simply told that she or he had an SA diagnosis, but in other cases, a description of SA and the risks of untreated SA were conveyed:
 - “[The doctor] said ‘I want to explain to you what we’ve found in the tests that you took home.’ He says, ‘You have sleep apnea.’”
 - “You definitely have sleep apnea. And I said, ‘Why do you say that?’ He said, ‘Because I ran this test on you all night. And your heart [*sic*] stopped at least 80 times in the first hour. And one of these times, without some kind of help, you’re going to fade away.”
2. Negative experiences: Other participants recalled that very little information was provided, and communication about SA and the risks of untreated SA prior to being given a PAP device was limited:
 - “They just checked me over and sent me home.”
 - “I went to my doctor, explained to him I was having problems sleeping. They sent me here for the test. My doctor got back to me and brought me back out here. Just told me that I have sleep apnea and to come pick up the machine. And I picked it up.”

Similarly, communication about the available treatment options and the risks and benefits of SA treatments also varied.

1. Positive experiences: In these discussions, providers informed patients about the reason for using or not using a particular therapy and acknowledged that more than one option was available:
 - “They said it was better for your heart and things like that.”
 - “Then he laid out the different options I had. Surgery, which he did not recommend because he says it usually doesn’t work. He talked about the CPAP machine. And then a dental thing. And told me the main reason of using such a tool is besides not sleeping well, he explained that it affects your heart. You could have a . . . heart attack, because you’re putting a lot of stress on your heart because you’re not breathing.”
2. Negative experiences: These discussions were characterized by a lack of exchange of information about treatment options in general and about second- and third-line options:
 - “I was told CPAP or nothing.”
 - “I asked if there was any other treatment. The only thing they said was a CPAP machine and different masks. That’s it.”
 - “They gave the CPAP, and that was my only option. But that’s not true. There’s many, many options.”

Participants' Beliefs, Attitudes, and Preferences for Patient-Provider Communication and Decision Making

Some participants believed that they should be provided with more information about their diagnosis and treatment to make them more knowledgeable, which in turn could provide them with more power over their condition and make the decision-making process a joint effort.

- “We need to know in detail.”
- “Knowledge is power. When you know something, you’re able to handle it better and make better decisions. And you feel less anxious and nervous about things if you understand.”
- “I just think it’s a joint effort.”

However, some participants’ attitudes reflected skepticism that physicians would provide more details about SA diagnosis and treatment due to time constraints, physician tactics to limit their question asking, and lack of consideration of their overall health concerns.

- “The doctors don’t have time.”
- “Most doctors will say, okay, this is it. Here’s your paper, sign here.”
- “They don’t take into consideration, nor do they look into your medical records to find out what is the real problem.”

Participants expressed their expectations and preferences for patient-provider communication in the context of SA diagnosis and treatment.

1. Provide more details: The vast majority felt that more details would be helpful.
 - “I’d like to have the doctor explain to me the diagnosis, not just from saying, well, you have this and this is to happen. No, tell me how, what and when and what I can do to take care of it.”
 - “I want options. At least I’ll know if this is not working, there’s someplace else to go, instead of giving up for an extended period of time.”
2. Fully disclose the common barriers to treatment: Several participants wanted health care providers to be up front about barriers to therapy and to provide anticipatory guidance about the therapies and about alternative therapies.
 - “This problem here is the sales pitch. Initially, it’s oh, oh, wow, I’m totally sold on the CPAP as my treatment. Then, wait, I realize I’ve got to wear this mask? Where was the mask in the sales pitch? The providers are not truthful up front.”
 - “You should not hide the negatives. You’re up front, maybe right from the beginning.”
3. Tailor the information: Participants expressed a desire for information about treatment options to be specifically tailored to each patient’s needs and communicated with a personal touch. They also wanted to know which option is recommended for their particular situation:
 - “Some people have personal issues with claustrophobia (or other conditions that may be a barrier). You need to address that.”
 - “It should be a personal interaction.”
 - “I just want the health care professional that’s going to have learned all this stuff. When they tell me this is what will work for you, I’m going to say okay. If this is what

it's going to be, this is what it'll be. And if it doesn't work, then I tell them this isn't working. Then I figure it's their place to come up with the next step.

Participants' Perspectives About Decision Aids

Participants provided a variety of perspectives about their level of interest in an SA decision aid. Most participants expressed interest in an SA decision aid. They felt that information provided about SA and treatment options to newly diagnosed patients could help patients communicate with providers about their disease and treatment options. However, a few participants felt that they could obtain information through existing sources on the Internet or that the sleep center provider should already be providing the information without the use of a decision aid.

- “A lot of people, they don't understand what's going on. That's why you think they don't ask questions and get to the bottom of it.”
- “Wish I would've had this decision aid at the beginning.”
- “It seems to me that what you're suggesting—this information about SA— just Google it.”
- “Why can't the person that's talking to you—the doctor—give you all this information, without making another step of people that have to go through all this?”
- “A technician could take time to explain.”

Participants described the types of decision aid characteristics that would make a decision aid useful. As shown in Table 4, these characteristics align with the participants' communication preferences, beliefs, and attitudes described above.

- Content describing OSA and treatment options: Participants agreed that they would like to see a list of the treatment options and relevant questions that might be discussed with a provider. Not only did they want a description of the options, they also wanted information about what might happen if the SA is left untreated.
 - “Do a FAQ, because that would be efficient. The same questions everybody's going to ask in the beginning.”
 - “What does it do to your body if you don't use this? Because a lot of people don't know that.”
- Content describing common barriers to treatment:

TABLE 4
Crosswalk: Communication Preferences—Decision Aid Characteristics

<i>Communication Preferences</i>	<i>Decision Aid Characteristics</i>
Provide details of diagnoses, treatment options, risks of failing to adhere to treatments.	Content: List and provide details of treatment options. Describe risks of untreated sleep apnea.
Disclose common barriers to treatment.	Provide information about the most common barriers to treatment.
Tailor information.	Provide both general information about sleep apnea as well as patient-specific information.
Provide a variety of delivery methods.	(1) Modality: ranged from patient-patient communication to accessing decision aid through a DVD/Internet at home. *(2) Format: Short in length, summary sheet, illustrations and images.

- “A page that says you’re home, you’re frustrated, and you’ve stopped using the machine: a reinforcement.”
- “If you have dry mouth, this should be addressed. If you develop dry mouth, these are our suggestions and recommendations.”
- Content tailored to individual needs:
 - “I think what’s more valuable are questions that you might be discussing with your doctor, like, I’m claustrophobic.”
 - “Part of this book should be general for everybody. But then also a section should be separate just for the individual and his issues.”
- Delivery modality: The participants provided a range of recommendations on the method for delivering a decision aid. Some suggested an in-person group format that would include patients who already have SA and could share their experiences with newly diagnosed patients, whereas others wanted to access the decision aid and worksheet at home through a DVD or the Internet.
 - “Why not have a group where we can discuss sleep apnea?”
 - “If you are going to have a discussion with brand-new people, then it would be very important to have one or two or however many you think who are already using it, to help with the explanation and share their experiences.”
 - “Well, can you also make it available so somebody can punch it in their computer and read it?”
 - “Just give them a CD.”
 - “One program on a website would save a whole lot.”
 - “I would much rather have a video than paper and pencil.”
- Format (i.e., length, visual appearance, readability): Many participants expressed a preference for a decision aid that is short in length and felt that a summary sheet (e.g., a quick start guide) would be helpful. They felt that a format that would enable them to quickly choose just the sections relevant to them would be helpful. Illustrations and images were suggested.
 - “Lots of illustrations.”
 - “A lot of people don’t read anymore at all, you know.”

DISCUSSION

We found that patients’ perceptions of communication about SA with their sleep providers ranged widely. We also found that older patients desire information about the risks of untreated SA disease when they are initially diagnosed, their treatment options (not just the first-line option), and the most common barriers to treatment. Study participants expressed an interest in a patient decision aid for improving communication about SA and SA treatments and offered suggestions for making the patient decision useful and easy to use.

For many participants, the exchange of information about their SA diagnosis consisted of brief, declarative statements (“you’ve got sleep apnea”), while others received a description about the physiological effects of the SA diagnosis (e.g., number of apneas per hour) and risks of untreated SA (e.g., death). Of note, these comments reflect participants’ perceptions of the

discussion about their SA diagnosis rather than actual recordings of the discussion that occurred. Communication about the availability of treatment options varied. Many discussions were framed as if PAP were the only treatment option for SA, which led one patient who rejected his PAP to forego any treatment for an extended period, because he was not aware that other options were available and therefore did not follow up with his provider. Our results suggest that some patients are not informed consumers of their sleep apnea treatment, which has important ethical and quality-of-care implications that deserve attention. The American Academy of Sleep Medicine's clinical guidelines for the long-term care of SA therapy state that "the patient should be an active participant in the decision on treatment type and taught to contribute to the management of his or her own disease" (Epstein et al., 2009, p. 268). In contrast, other participants described a discussion that included a set of choices (i.e., PAP plus other treatment options). For some participants, the discussion about treatment options was personalized, factoring in the individual's other health care issues and personal preferences. However, in other cases, the discussion felt like a "one size fits all" approach. Our findings are similar to reports from studies of other conditions, which suggest a lack of involvement in the decision-making process for some patients. For example, a study involving decision making in physical therapy found that shared decision making was not common, although patients expressed a preference for this approach (Dierckx, Deveugele, Roosen, & Devisch, 2013).

We elicited the types of content that patients want when they receive their SA diagnosis. Patients want information about the effects of untreated SA presented to them at the time of diagnosis. There was a general consensus that patients should be informed by their health care providers about the availability of different treatment options, not just the first-line option. These results are similar to those reported from a population-based survey of preferences for decision making, in which 96% of respondents indicated a preference to be offered choices and to be asked for their opinions (Levinson, Kao, Kuby, & Thisted, 2005). Information to promote self-management and troubleshooting of SA device-associated problems was also considered important to many study participants to help them with their daily decisions about whether or not to use their therapy. Our results suggest that patients also want to know if the treatment modality will be optimal for their specific situation.

This study supports the development of strategies to improve communication about SA and its therapies. Our findings are similar to those reported by Goff and colleagues, who conducted in-depth interviews with patients to explore patients' beliefs and preferences about medications to uncover factors that contribute to medication adherence (Goff, Mazor, Meterko, Dodd, & Sabin, 2008). They found that patients wanted to know their medication options and understand the risks and benefits of each option and that lack of communication decreased confidence in a physician's recommendations. Our results are also similar to those found by Lau and colleagues, who studied medication adherence among older women with osteoporosis. They identified information exchange and relationships with health care providers as key factors that influence adherence to therapy (Lau et al., 2008). Prior studies have found empirical evidence supporting a link between communication and adherence. A meta-analysis of empirical studies on physician's communication and patient adherence found that poor communication is associated with a 19% higher risk of nonadherence and that training physicians in communication skills results in a 1.62 higher odds of patient adherence compared with no training (Zolnierek & Dimatteo, 2009). A tool that improves communication between older patients and their sleep health care providers has the potential to influence patients' knowledge and attitudes toward SA treatments and

acceptance and adherence to SA therapy, although a recent Cochrane Database Review on decision aids found that the effects of decision aids on adherence are inconclusive (Stacey et al., 2014). Since studies suggest that adherence levels are determined early in the course of SA treatment (Weaver & Grunstein, 2008), a strategy implemented at the time of diagnosis is ideal. Participants voiced a desire for information about SA treatment options relevant to their conditions and were receptive to a patient decision aid or health promotion tool. A decision aid specific to older adults that offers SA information that is derived from studies that included older adults, who often have comorbid conditions, may be needed. Participants differed in preferences when discussing the format for delivering this tool. Some felt that a face-to-face, group format would be an efficient delivery method, while others felt that online or DVD formats that could be accessed at home would be better. Many participants were skeptical that their physicians would be able to provide sufficient information about the different treatment options during a typical clinic visit.

The main limitation of this study is that the participants were recruited using convenience sampling from only two different health care systems (both located in the same city) and most participants were male. This sampling strategy may have resulted in omission of extreme or deviant perspectives on the topic, thereby limiting generalizability of the findings. Another limitation is that we did not directly observe or record patient-provider encounters. Patient recall may differ from actual patient-provider encounters. Studies suggest that patients often recall only a fraction of the content discussed with their provider (Flocke & Stange, 2004). The length of time that elapsed between the focus groups and the initial discussion about diagnosis and treatment, which was probably > 10 years for one third of participants, may have further reduced patient recall. However, even if patients did receive information about treatment options, the discussion and content were not memorable. We did not perform validation checks with participants or field experts. This qualitative study's sample size was not sufficient for quantitatively estimating the frequencies of the different types of patient-provider communication patterns or the number of patients who prefer certain types of decision-making styles; and due to the qualitative design, the study did not include standardized measures of patient-provider communication. Finally, some participants described health care system and payer issues they encountered, but because the focus group discussions emphasized the discourse between the patient and provider, these comments were too limited to analyze; future studies should explore the impact of insurance and other structural issues.

In conclusion, we explored the ways in which the diagnosis of SA was communicated with patients and the types of information patients received about treatment options. We learned that many patients received little information about their diagnosis and were not informed about alternative treatment options. Participants were enthusiastic about a patient decision aid, which would provide information about SA and treatment options. These findings suggest that a decision aid could improve patient-provider communication about SA treatments and help older adults with SA make decisions about their care that would be better informed and participatory in nature.

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