



Show me the roads and give me a road map: Development of a patient conversation tool to improve lung cancer treatment decision-making

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ABSTRACT

Objective: Evidence-based decision support resources do not exist for persons with lung cancer. We sought to develop and refine a treatment decision support, or conversation tool, to improve shared decision-making (SDM).

Methods: We conducted a multi-site study among patients with stage I-IV non-small cell lung cancer (NSCLC) who completed or had ongoing lung cancer treatment using semi-structured, cognitive qualitative interviews to assess participant understanding of content. We used an integrated approach of deductive and inductive thematic analysis.

Results: Twenty-seven patients with NSCLC participated. Participants with prior cancer experiences or those with family members with prior cancer experiences reported better preparedness for cancer treatment decision-making. All participants agreed the conversation tool would be helpful to clarify their thinking about values, comparisons, and goals of treatment, and to help patients communicate more effectively with their clinicians.

Conclusion: Participants reported that the tool may empower them with confidence and agency to actively participate in cancer treatment SDM. The conversation tool was acceptable, comprehensible, and usable. Next steps will test effectiveness on patient-centered and decisional outcomes.

Innovation: A personalized conversation tool using consequence tables and core SDM components is novel in that it can encourage a tailored, conversational dynamic and includes patient-centered values along with traditional decisional outcomes.

1. Introduction

Recent advances in treatment have improved lung cancer survival. These include surgical techniques [1,2], radiation modalities [3], chemotherapy regimens [4,5], integrated palliative care [6], and targeted therapies [7,8], along with the implementation of lung cancer screening [9]. These advances are expected to offer a broader range of treatment options to more patients, while simultaneously increasing the complexity of treatment decisions for patients and clinicians alike. Lung cancer treatment decision-making also requires that patients and their clinicians consider the substantial trade-offs between potential benefits (e.g., increased survival) and harms (e.g., reduced quality of life [QOL]). Patients with lung cancer consistently report QOL as most important [10,11], however, most clinical trials focus on survival which does not correlate well with QOL [12]. Given the potential meaningful

trade-offs, patients may weigh these benefits and harms differently based on their own values and preferences. Therefore, it is important to fully engage patients in the treatment decision-making process.

Patients with cancer want to be informed about their diagnoses, treatment procedures, and goals of treatment, and the majority seek active decision-making roles [13,14]. Unfortunately, many patients report poor quality communication during clinical encounters and less involvement in decision-making than they desire [15-17]. Shared decision-making (SDM) is a process intended to align treatments with patients' values and preferences, and as a result, has the potential to improve patients' experiences, quality of care, and reduce health disparities [18-21]. Support for SDM has grown exponentially in recent years spurred by health policy and patient advocacy [18,22-25]. SDM can be promoted through the use of decision aids, which have been shown to enhance patient knowledge while

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creating more realistic outcome expectations; reduce decisional conflict, distress, depression and uncertainty; and improve physician–patient communication and patient QOL, compared with no decision aid [26]. Patient decision aids are a means of helping people make informed choices about healthcare decisions [27] and a specific type of decision aid, called a conversation tool, is designed to support collaborative conversations between patients and clinicians [28–29]. Despite availability of decision aids for a variety of conditions, rigorously studied evidence-based decision aids are not available to assist with treatment decision-making for patients with advanced lung cancer [26,30–32].

Patients with lung cancer face high stakes; critical treatment decisions that may have lasting effects on their QOL and survival. Given the paucity of evidence-based resources to help patients with lung cancer engage in high-quality SDM with their clinicians, we sought to 1) assess patients' decision-making needs and better understand their experiences in communication with clinicians while engaging in lung cancer treatment decision-making and 2) elicit feedback on the design of a lung cancer treatment conversation tool intended to improve patient-clinician communication and promote SDM. We felt that the patient experience findings inform the study aim of developing a tool that addresses the preferences for decision-making, abilities, and impacts of those experiences on future decisions. Hearing the stories of patients contributes to an overall understanding of what is needed from a conversation tool because we are able to examine why patients make certain suggestions and how to refine the tool based on their lived experiences.

2. Methods

In accordance with International Patient Decision Aid Standards (IPDAS) that describe a systematic approach for decision aid development, we conducted a multi-site cognitive interview study from January 2020 through October 2021 to assess the acceptability and usability of a conversation tool to be used among any stage non-small cell lung cancer (NSCLC) treatment discussions. Patients from the VA Portland Health Care System (VAPORHCS) and Oregon Health & Science University (OHSU) were recruited from ambulatory lung cancer clinics. We conducted weekly electronic health record review to determine eligibility. Patients were eligible to participate if they had received treatment for stage I–IV NSCLC in 2016 or later or were currently receiving treatment. We included patients between ages 18 and 99 who were English-speaking. For eligible patients, study staff contacted their treating clinicians to confirm eligibility and request permission to contact the patient. If patients agreed to participate, they were consented via a phone script and scheduled for a virtual interview (IRB# 4529/20688). Participants were assessed for health literacy and numeracy using three validated instruments: Single Item Literacy Scale (SILS), three-item Subjective Numeracy Scale (SNS), and the Numeracy Understanding in Medical Instruments – Short form (S-NUMI) [33–35].

2.1. Conversation tool

In accordance with IPDAS, we developed a low-literacy conversation tool designed to support the patient–clinician dyad during lung cancer treatment decision-making. *Our conversation tool is meant to be a first step, promoting a conversation with the medical team while incorporating all core components of SDM models: (i) creating choice awareness, ii) values clarification [11] and iii) discussing options and preferences" [36–41]. We intend the tool to be completed prior to a clinical encounter and printed out with space for written questions and comments in preparation for the discussion with a clinician.*

The conversation tool was based on literature reviews and expert opinions initially. All patient suggestions were considered, but more weight was given to suggestions made by more than one participant. We also revised the tool in an iterative process throughout based on input from a patient advisory group, lung cancer clinicians and researchers; and patients with any stage NSCLC during the ongoing cognitive interviews. The version was revised approximately every five interviews, and herein we describe the finalized version. The conversation tool included six sub-sections. Participants

were asked to give their impressions and recommendations for each section rather than complete the conversation tool themselves. The first section, "Education," gave a brief explanation of available lung cancer treatments; surgery, radiation, chemotherapy, targeted and immunotherapy, and palliative care. The second section, "Values," presented ten value statements previously developed that are associated with QOL or survival related to lung cancer along with a Likert scale for users to rate the importance of each value [11]. The third section, "Weighted Values," included six sets of pairwise comparisons of the values from the previous section using established methods [41]. The fourth section, "Goals," provided two sets of goals to choose from related to either survival or QOL using a previously developed question stem [42–43]. In the fifth section, "Treatment Choice Awareness," participants were asked to answer two free response questions which prompted users to consider that choice exists in lung cancer treatment decision-making. The sixth, "Treatment Comparisons," compared benefits and risks of available treatments in NSCLC in a consequence table format [44–46]. See Fig. 1 for a text version portion of the conversation tool.

2.2. Interviews

One of two investigators (DRS, a pulmonary and critical care physician, or ALT, a trained research coordinator) conducted the semi-structured interviews via WebEx video using an interview guide that allowed for other questions to emerge (Supplement). Interviewers used probing questions to elicit more information when necessary. Each interview lasted between 13 and 49 minutes. The interviewer presented the conversation tool to the participant one section at a time. In each section, participants were encouraged to verbalize their thoughts and opinions about the presentation and the conversation tool material. After the interviewer reviewed all sections of the tool, participants rated their ability to use and understand the tool using a Likert scale from 1 (hard to use) to 5 (easy to use). Interviews were transcribed and verified for accuracy by two study team members, with identifiers removed. Participants are identified herein by an anonymous number and their stage of lung cancer.

2.3. Data analysis

We used Atlas.ti 9.0 (Atlas.ti GmbH, Berlin, Germany) to organize and support analysis. We used an integrated approach of deductive and inductive thematic analysis to interpret interview data. We began with deductive rapid analysis to develop an initial understanding of the interviews [46]. SEG, a social scientist with expertise in health services research, created transcript summaries after review of the first 3 transcripts, organized by aspects of usability and acceptability: usability (barriers participants encounter to engaging with the tool), acceptability (intention to use), comprehensibility (perceived and reported understanding of the tool), content (what may be missing or extraneous information), and other suggestions [47–48]. SEG and DRS reviewed five additional transcripts and discussed findings to come to agreement and consensus. SEG created summaries from the remainder. During this process we also created a codebook to identify patterns and further emergent themes through thematic analysis. SEG and DRS coded the same 8 transcripts and SEG coded the remainder independently after acceptable agreement was reached. We did not perform member checking; however we did discuss findings throughout amongst the study team. We created matrices of transcript summaries to organize qualitative findings and allow for further thematic analysis across domains and participants. We performed secondary comparative analyses with patients grouped by lung cancer stage and year of diagnosis.

The Flesch Reading Ease score for this tool was 77.3 and the Flesch-Kincaid Grade Level was 5.3, calculated with Microsoft Word [49–50].

3. Results

We interviewed 27 participants (11 from the VA and 16 from OHSU) with stage I–IV NSCLC. Fourteen participants (52%) were stage I. (Table 1) Most participants had average literacy and numeracy.

1. EDUCATION

Lung cancer starts in the lungs, but can spread to other parts of your body such as your liver or bones. The stage of lung cancer (from stage 1 through stage 4) is based on where the cancer is in your body.

Based on the stage of cancer and your other medical illnesses, your clinicians may discuss 1 or more of the following therapies with you:

WHAT IS SURGERY?	WHAT IS RADIATION?
The lungs are made up of different parts called lobes. During surgery, a lobe or part of the lobe that contains the cancer is removed.	Radiation therapy uses high-energy rays to kill the cancer cells. Multiple treatments are often needed.
WHAT IS CHEMOTHERAPY?	WHAT IS PALLIATIVE CARE?
A combination of medications taken through a vein (with an IV) or by mouth that are used to kill the cancer cells.	Medical care that focuses on improving quality of life by treating symptoms such as pain or shortness of breath.

2. VALUES

VALUES	Not Important 0	1	2	3	4	Most Important 5
Being able to remain in my current living situation or home	0	1	2	3	4	5
Additional years of life	0	1	2	3	4	5
Being able to take care of myself	0	1	2	3	4	5
Minimizing the chance the lung cancer returns	0	1	2	3	4	5
Staying away from regular visits to doctors/hospitals	0	1	2	3	4	5

Fig. 1. Text of two conversation tool sections: Education and Values Clarification.

We first report our findings regarding patients’ experiences of being diagnosed and treated with lung cancer, and then we report perceptions and evaluations of the conversation tool. There were no differences in responses based on year of cancer diagnosis, and only one difference (described below) was found based on lung cancer stage. There were three main themes related to patients’ experience being diagnosed and treated for NSCLC: Ability to make initial decisions, values and preferences, and impact of experience on future health decision-making. Additional illustrative quotes are found in Tables 2 and 3.

3.1. Patient experience

3.1.1. Ability to make initial decisions

Most participants expressed surprise about their lung cancer diagnosis with some fear of the unknown. One participant said what many expressed, “If it’s your first time dealing with cancer, it’s scary” (Participant 13- IIIa). Others said, “Everything about cancer is scary in the beginning” (Participant 2- IV) (and Table 2 quote 1) and “When I was told I had cancer, it was kind of like somebody punching me right in the forehead. I kind of woke up.” (Participant 16- I)

A few patients had previous cancers or other serious health experiences and felt they could just “deal with what [the disease] presents”

regarding treatments and not “dwell” (Participant 25- I) on the diagnosis. Most participants expressed that making decisions about treatment was largely positive and perceived as not difficult, chiefly because they expressed feeling like there was not really a treatment decision to be made since they felt they “only had one option” (Participant 27- IIIb). One participant said:

“I had all sorts of people there and we discussed the possibility of surgery which was ruled out... I was given the choices and I was given recommendations on the choices. So I really didn’t have to do a lot of deciding... it was pretty well laid out for me.” (Participant 8- III)

Sometimes reasons for feeling that there was only one option came from clinicians’ recommendations, or sometimes from patients’ internal values and preferences guiding treatment (quotes 2-5):

“I wanted... radiation and so the decision was easy. I wasn’t about to want surgery or chemo because of my age.” (Participant 1- I)

For others, decisions were more difficult. As one participant expressed concerning continuing chemotherapy:

“... it’s just more medicine on top of more medicine and you feel bad. But you don’t know what else to do and so you think oh, I’ve gotta do this. Cause this is all they’re offering. And I think, you need the chance to step back and say, do I want to do all that?” (Participant 13- IIIa)

Table 1
Demographics.

Characteristic	N = 27
Institution	
OHSU	16 (59%)
VA	11 (41%)
Age in years, mean (SD)	71 (8.4)
Sex	
Male	15 (56%)
Race/ Ethnicity	
White/Non-Hispanic	27 (100%)
Treatment Initiation Year	
2014-2016	5 (19%)
2017-2019	13 (48%)
2020-2021	9 (33%)
AJCC –TNM ^a Staging	
I	14 (52%)
II	2 (7%)
III	5 (19%)
IV	6 (22%)
Histology	
Adenocarcinoma	18 (67%)
Squamous Cell Carcinoma	3 (11%)
Unknown	6 (22%)
Treatment ^b	
Surgery	14
Radiation	11
Chemotherapy	10
Does anyone help you make medical decisions?	
Yes	13 (48%)
No	10 (37%)
If yes, who? ^b	
Children	6
Partner	5
Sibling	2
Other	1
Health Literacy	
Below Average	-
Average	12 (44%)
Above Average	11 (41%)
Missing	4 (14%)
Numeracy ^c	
0	2 (7%)
1	7 (26%)
2	9 (33%)
3	5 (19%)

Note. Values are N (%) unless noted. Percentages may not equal 100 due to missing data. Institution – Treatment characteristics based on EHR review.

^a AJCC-TNM = American Joint Committee on Cancer-Tumor Node Metastasis

^b Treatment categories are not exclusive.

^c Scores ranged from zero to three with zero being no correct answers and three being all correct answers.

Participants reported that decisions were more difficult during the second treatment of an initial diagnosis, or when presented with options for different treatments (e.g., surgery or radiation for early stage) without a clear recommendation from their clinician. Importantly, many participants expressed satisfaction with their clinician’s communication about their treatment option(s) (quote 6), although some felt like they lacked guidance. One participant said:

“The only thing I got out of [the clinical encounter] was [to] think of this as a football game and your oncologist is your quarterback. Well, my first oncologist wasn’t a very good quarterback... he coulda been my coach or something. I needed to have more explanation when I was first diagnosed.” (Participant 12- Ib)

3.1.2. Values and preferences

Participants discussed their values and preferences as being at the forefront of their minds during their decision-making process, especially when faced with treatment decisions considered to have equipoise. They discussed values and preferences mostly spontaneously without prompts, highlighting the importance of communication with their care team about their preferences. One participant said:

Table 2
Patient experiences selected quotes.

Quote #	Subject ID (Cancer Stage)	Quote
Ability to Make Decisions		
1	22 (I)	I was very reluctant to even accept that I had cancer.
2	6 (Ib)	The doctors are more knowledgeable than I am so, I listen.
3	4 (IIIb)	I would go with what [the doctors] recommend. They certainly know more than I do.
4	22 (I)	[Different treatments] was never presented to me as options I should look at until they knew. But they [could not get a biopsy].
5	13 (IIIa)	Some people may choose to do something even though the side effects are really difficult, they may choose to do it where you may choose not to do it. So those side effects may matter more to one person than to another.
6	14 (IV)	[The doctors] were really good. They took the time to sit and talk to my wife and I. They showed us the pictures. They gave us a complete list of here are the options, here’s what happens and so on. So we felt like we were able to make a decision based on the best facts known at the time.
Values and preferences		
7	3 (Ib)	I wanna be able to take care of myself. And if I get additional years I will say I’m a lucky person.
8	1 (I)	There’s no way I’d do everything I could to live longer.
9	14 (IV)	It’s important to me to take care of myself and with the help of my wife I’ve been able to do so. The additional years of life, that’s something you can’t worry about. Either it’s there or it’s not. You can walk outside and step in front of a truck.
10	23 (I)	If I’m gonna live longer I’ll spend the extra year in a hospital bed if you can guarantee I’m gonna live longer.
11	8 (III)	I’ve got stage III lung cancer. But I’m not paying for anything. And I’m getting the best treatment in the world.
12	11 (Ia)	[Prior radiation for] prostate cancer, it kicked me in the butt.
13	8 (III)	And so we’re familiar with all the treatments that people have gone through, and it wasn’t a happy situation with many of them... we were more afraid of chemo than anything else.
14	15 (IV)	My mother... having been through radiation and chemo, and just having heard about it from other people, I knew it would probably be rough, but it was more important to me to get rid of the cancer even if I ended up in the hospital for a little bit.
15	6 (Ib)	To me, chemo kills you. Sorry to say that, but I mean I think I would rather enjoy life until the end instead of doing the chemo if that makes any sense.
Future decision-making		
16	1 (I)	It’s up to each individual what their choice is and what they would like to do. Whether they want to hang in there and be uncomfortable and miserable or just let it go
17	22 (I)	The questions are still out there. And I think we rely on the information given to us from our medical providers, family, so I think it’s true. I mean I don’t know, you’re the doctors. What do the doctors say? There probably are doctors who say the best treatment for you is. <u>But I think it’s coming to realize is that it is a very personal choice for the patient.</u>
18	9 (IV)	...it’s kind of like somebody opens the door, it’s just a black hole, so to speak. There’s no lights. And then they start turning the lights on slowly, explaining to you what the treatment entails. The side effects that may occur, and the possibility of success or failure. And as it lightens up I think you’re more in shellshock than thinking about dissecting that information to any degree.
19	2 (IV)	But so many people are like doctors are gods. And they’re too afraid to speak up or they have this kinda different perspectives on the medical field and I think it’s important for people to know that their doctor is their partner in this.

“[the doctors] could not say one or the other [treatment] would be better than the other to me. I asked each one of them why would you use the other person’s method instead of yours? And they kinda gave me a reason why... And I chose radiation vs. surgery because I’m too active.” (Participant 11- Ia)

Most, but not all, participants prioritized quality over quantity of life – specifically the ability to take care of themselves and stay in their own home. One participant said, *“I’d rather be self-sufficient about everything I try to do.”* (Participant 18- Ia and quotes 7-9). Whereas the minority expressed, *“the most important [value] was the additional years of life,”*

Table 3
Conversation tool selected quotes.

Acceptability		
20	15 (IV)	[The conversation tool] gives you a choice. I think it puts some of the power back in your hands. It gives you the feeling that you're powerful enough to make choices in the medicine that you choose to take or the route you choose to take.
21	23 (I)	I mean it gives you a lot more information and that's the big thing, right? Getting the information.
22	5 (IV)	... when you're first diagnosed, this is gonna be really good so far. I'm really quite pleased.
23	12 (Ib)	I needed to have more explanation when I was first diagnosed. And [the conversation tool] sounds like really something very good that... focuses in on what's available, what the options are, and what you can do and what you can't do.
24	13 (IIIa)	It gives the person a chance to look at [the tool] and then... state whatever fears they may have and any questions they may have.
Content		
25	23 (I)	[I like that the tool shows] me the charts and the differences between each therapy that you could get. And just letting you know how it could affect you... after the initial process of removing the cancer and what can happen afterwards.
26	25 (I)	Well this puts more information in front of you than the way I've seen it presented in the past. So I think this is good. A little scary perhaps, but good.
27	16 (I)	For me, this is really a good education in the early stages. Because I had to learn a lot of this stuff going along by myself.
Comprehensibility & Usability		
28	9 (IV)	I think you've mastered the transition from Latin to English so I think you're good. [re: medical jargon]
29	15 (IV)	I think you've really got words that everybody understands and so I think it's pretty good.
30	15 (IV)	... if you have this in your hand and you can go home and you can go okay, I can read now, I can maybe understand what the doctor said... you need more ways of understanding.
g	5 (IV)	I think it's understandable, it's giving me an idea of where things are and where things are going and so here's what's important to me.
H	3 (Ib)	It's written where people can understand it and they can understand what their doctor's talking about.

(Participant 21- II), no matter the side effects or need for staying in a skilled nursing facility following treatment (quote 10). Differences in values and preferences were influenced by the age of the participant, family support system, and their activity level prior to receipt of cancer treatment. For instance, some who were older, did not have family that could care for them, and/or were already functionally limited, and therefore, they tended to value taking care of themselves more than living longer. Cost did not seem to be a significant factor for any of the participants, but Veterans especially expressed gratitude that they did not have to factor cost into their treatment decisions (quote 11). Participants diagnosed with later stages (i.e., stage II-IV) generally reported a higher preference for additional years of life compared to those diagnosed with stage I.

In general, prior experiences with cancer provided a sense of reassurance and provided some treatment knowledge that impacted their decisions. One participant said:

"I have had several experiences with cancer and I just kinda take it as it comes and don't think too far forward because, I find that works for me." (Participant 25- I, and quote 12). Experiences of others also influenced decision-making and views of treatment, largely due to poor experiences with chemotherapy (quotes 13-15). For instance, one participant explained:

"I didn't want chemo. I've seen too many friends and relatives that just changed—ewww—ugly from the chemo treatments in order to stay alive... so [I was] relieved when I heard [I didn't need chemo]." (Participant 16- I)

When participants reflected on their own recent lung cancer treatments, even several who underwent chemotherapy expressed treatments were not as bad as they expected them to be or as they had heard from others.

3.1.3. Impact of experience on future decision-making

When talking about interactions with the health care system during treatments, participants had mostly positive comments. This positivity led

them to report little regret about their decisions. A couple of participants mentioned the trouble associated with transportation to and from appointments, or certain clinicians' lack of availability, but ultimately, even these participants felt they would have made the same treatment decision again. No matter the ease with which the decision was made, their values and preferences, or their final treatment outcome, participants made it clear that, "... *everybody should be able to make their own decisions and everybody's decision is personal*" (Participant 27- IIIb). When thinking about future health care decisions that may arise, some participants expressed that they would like to continue with the same doctors and would ask more knowledgeable questions now that they have more information (quotes 16-19).

3.2. Conversation tool

3.2.1. Acceptability

All participants reported that the conversation tool would be helpful to clarify their values and goals of treatment, to weigh pros and cons in an organized way, and to improve patient-clinician communication (Table 3 quotes 20-21). One patient commented that the tool would have, "*been helpful in discussing [treatment] with the doctors. It would have made me formulate my questions to them a little better*" (Participant 8- III). There were many expressions of feeling overwhelmed or scared when speaking with cancer doctors and they reported having appreciation for something tangible to refer to. Several participants mentioned it would be especially helpful for those newly diagnosed and/or those with options for treatment (quotes 22-23). In addition, participants expressed that each treatment decision is individual and personal, and they felt the conversation tool would help clarify that point. One participant said the tool would, "*help [other patients] make a decision because okay, [the] doctor comes out and says I think your best option is blah blah blah whatever it may be. Surgery, radiation, chemo or whatever. And based on the stage you have. But that might not wanna be what that patient would want to do.*" (Participant 18- Ia)

Other participants discussed how the conversation tool would lead to more understanding of the options and patient empowerment, saying:

"I went to the lung cancer oncologist; it was like he laid this stuff out. This is what we have, and this is what we're offering and this the only thing we have. And I was like, 'well I don't know if I want to do that.' And he just shrugged his shoulders. He said, 'well then the decision is yours. I'm not coming after you to make you do it.' So that left me feeling pretty deflated. If I had [this conversation tool] I would have had more understanding." (Participant 13- IIIa)

Another participant described the tool as showing "*the roads and giving me a kind of roadmap... if I do this, I can do that*" (Participant 12- Ib) to guide to different options that might be right for the individual (quote 24).

3.2.2. Content

Overall, participants reported the conversation tool content was appropriate and was similar to what they had heard from their clinicians and experienced in their treatments. Three participants had never heard of biologics or immunotherapy. No participants stated they experienced a visit with a palliative care clinician, and only a handful had heard of or were familiar with palliative care, often erroneously described as only end of life care. The participants for whom information was new were pleased to see something that they could potentially ask their clinicians about if the need arose. Participants reported appreciating the head-to-head comparisons of different treatments in the consequence table section, and the list of possible side effects for each (quotes 25-27).

There were suggestions for additional content. For instance, a handful of participants wanted to see more information about both short- and long- term effects of treatments, including short- and long- term survival and end of life topics. A couple of participants mentioned the importance of noting mental health and optimism for optimal treatment on the conversation tool, as well as being your own advocate. As one participant said, "*[you need to] be responsible for your own wellbeing and your progress*" (Participant 2- IV). Others wanted to see offers or discussion of support groups or explanations of possible additional diagnostic testing (e.g., MRI, PET)

during the cancer work-up. One participant suggested explicitly listing the treatment option to do nothing. Suggestions were incorporated into the iterative version of the conversation tool during development.

3.2.3. Comprehensibility and usability

Overwhelmingly, 96% of participants rated the conversation high in terms of comprehension and usability (i.e., 5 out of 5 on a five-point Likert scale) and one participant (4%) rated it 4 out of 5. Most participants reported the tool was, “really good, well-described” (Participant 27- IIIb). Overall, they had no additional concerns with the language (quotes 28-30). One patient explains the language as being:

“... gentler. Seeing where cancer has gone to... where it's located in your body is different than saying it's metastasized and has spread. It's less, it's kinder.” (Participant 25- I)

Although participants did not engage with the conversation tool by themselves, they all reported they would have no issues using it independently. Despite these responses, there was a mix of opinions on whether the conversation tool would be better to send home with patients to “muddle through” (Participant 19- I) first and then discuss with clinicians, versus discussing it with clinicians before taking it home to discuss with family and think things through:

“Cause I don't know that you could just hand this to somebody and say oh by the way you have lung cancer, here are things you need to think about. Fill it out and let's talk about it. I think most people would need time to process the diagnosis so maybe you could give it to them after they'd been informed and before you meet with them the next time.” (Participant 15- IV)

4. Discussion & conclusion

4.1. Discussion

There is increasing attention toward individualized cancer care with an emphasis on SDM [51-53]. However, operationalizing patient participation in cancer treatment decision-making in routine clinical practice is challenging [54]. Currently, there is considerable room for improvement as many patients feel they are not participating, are unaware that treatment decisions need to be made, and there is discordance between what patients prefer and what their clinicians think they prefer [11,13-14]. Furthermore, only a minority of patients reported that they discussed what was ‘important to them’ with their physician before starting cancer treatment [55]. Overall, studies suggest that there is a troubling communication gap between what patients with cancer want their clinicians to know about their values and preferences, and what clinicians think they know.

As illustrated by our results, when patients had prior cancer experiences personally or with family members, they reported better preparedness for cancer treatment decision-making. This underscores the potential benefits of our conversation tool among patients without similar prior cancer experiences to help inform and guide them. Consistent with previous research in lung cancer, our findings also highlight the importance of QOL among patients when they are considering treatment trade-offs [11]. Most of our patients reported values prioritizing QOL as most important; however, we also found patients' socio-demographics, cancer stage, or current functional status may influence the balance between quality and quantity of life trade-offs when they consider treatment options. Overall, patients characterized their prior cancer treatment experiences as positive. However, with an increasing focus on high-quality communication and increased complexity of lung cancer care, patients may need more information or different approaches to communication (i.e., incorporating decision aids) to augment the brief periods of face-to-face contact they currently receive to achieve SDM.

Compared to usual care across a variety of decisional contexts, people exposed to decision aids have a more active role in decision-making and more accurate risk perceptions, and are more knowledgeable, better informed, and clearer about their values [26]. Given the complexity and trade-offs between different treatment options, especially in lung cancer, patients frequently do not understand what decisions need to be made,

let alone how they ought to be made. Although the principles of SDM are well-established, implementation of these principles in clinical practice remains unclear and significant individual and organizational barriers exist [56-57]. Our study demonstrates promising results in terms of acceptability, comprehensibility, and usability of a conversation tool applicable among patients with NSCLC. Ultimately, our tool development process and methods may be applicable to patients with other cancer types. Next steps for the conversation tool will be to test effectiveness on patient-centered and decisional outcomes in accordance with IPDAS standards.

4.2. Innovation

Many existing decision aids exclude one or more core SDM components, although evidence-based decision support resources are unavailable for patients with lung cancer. To facilitate SDM, our conversation tool incorporates all core components of SDM models, especially focused on values clarification, which consists of discovering what really matters to patients to better align treatments with patients' goals, instead of only relying on guideline-driven care [58-59]. Despite the importance of values clarification, a recent International Patient DA Standards (IPDAS) review noted that only about 42% of DAs incorporated explicit means of measuring patients' values, even fewer studies examined the effects of this elicitation [60]. Our tool is designed to be part of the clinical encounter (i.e., just prior to) producing a written summary report for review during the encounter, which is expected to promote patient-clinician communication, a central component of SDM [61]. Another innovative aspect is that an individual's value clarification responses will be populated into the preference elicitation exercises of the tool using personalized consequence tables [62], focusing on what really matters to an individual when making treatment choices. The goal is to encourage a conversational dynamic in which evidence and options are discussed in the process of discovering what is best for a patient, in the context of their circumstances.

Our study has strengths. In addition to addressing a population that has very little decision aids available, we are also utilizing cognitive interviews as a novel technique to elicit feedback and development of the conversation tool, incorporating core components of SDM into the tool, and providing personalization through the consequences table included in the tool.

Our study also has limitations. Our conversation tool is designed for patients with newly diagnosed lung cancer; however, this stage of development was restricted to patients who had already received or were currently receiving treatment. We will conduct a pilot study and randomized controlled trial of the conversation tool as next steps. Given local hospital COVID restrictions among patients with comorbidities or those who are immunocompromised and considered high-risk for COVID-19 complications, most study visits were conducted remotely using technology potentially restricting generalizability among patients from lower socioeconomic groups. A number of studies have also shown that patient report of aspects of communication with clinicians correlate poorly with direct observation; therefore, patients' reports of their prior experiences may be subject to positive recall bias [63-66]. Although we recruited patients still receiving lung cancer treatment across all stages of NSCLC, the five-year survival rate for lung cancer is about 20% and patients with advanced stage or more significant comorbidities are likely underrepresented [51]. Finally, our study is at risk of moderator acceptance bias, in which participants may respond with what the researchers want to hear.

4.3. Conclusion

Patients with lung cancer face difficult treatment-related decisions and most feel their individual values and preferences should be an essential component of the collaborative decision-making process during discussions with their clinicians. Patients found our conversation tool was acceptable, comprehensible, and usable when discussing treatment options. Likewise, patients found our conversation tool may empower them with more confidence and agency to actively participate in cancer treatment decision-making. More research is needed to develop and test patient-clinician

decision support resources to overcome barriers to SDM among patients with cancer.

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Note

The Department of Veterans Affairs did not have a role in the conduct of the study, in the collection, management, analysis, interpretation of data, or in the preparation of the manuscript. The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs or the U.S Government.

Authorship statement

All authors have made substantial contributions to the 1) conception and design, acquisition of data, or analysis and interpretation of data; 2) have contributed to drafting the article for important intellectual content; and 3) have provided final approval of the version to be published. Sara Golden takes responsibility for the content of the manuscript, including data and analysis.

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Appendix A. Supplementary data

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