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Dumping the information bucket: A qualitative study of clinicians caring for patients with early stage non-small cell lung cancer

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ABSTRACT

Objective: To evaluate the quality of patient-clinician communication and shared decision making (SDM) when two disparate treatments for early stage non-small cell lung cancer (NSCLC) are discussed.

Methods: We conducted a qualitative study to evaluate the experiences of 20 clinicians caring for patients with clinical Stage I NSCLC prior to treatment, focusing on communication practices. We used directed content analysis and a patient-centered communication theoretical model to guide understanding of communication strategies.

Results: All clinicians expressed the importance of providing information, especially for mitigating patient worry, despite recognition that patients recall only a small amount of the information given. When patients expressed distress, clinicians exhibited empathy but preferred to provide more information in order to address patient concerns. Most clinicians reported practicing SDM, however, they also reported not clearly eliciting patient preferences and values, a key part of SDM.

Conclusion: Communication with patients about treatment options for early stage NSCLC primary includes information giving. We found that only a few communication domains associated with SDM occurred regularly, and SDM may not be necessary in this clinical context.

Practice implications: Clinicians may need to incorporate nurse navigators or more written materials for effectively discussing potentially equivalent treatment options with their patients.

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1. Introduction

Surgical resection for early stage non-small cell lung cancer (NSCLC) is currently considered the most appropriate treatment [1,2], and stereotactic body radiotherapy (SBRT) is reserved for patients who decline or cannot safely tolerate surgery [3,4]. These treatments have not been directly compared in high quality studies but SBRT may be associated with similar, or even better, oncologic outcomes [5–11]. There are also no high quality comparative

quality of life (QOL) data, but SBRT likely results in less decreased QOL measures than surgical resection [12] [13].

It is unknown how clinicians discuss these uncertainties about the likely oncologic and QOL outcomes, and how they discuss these competing goals when making treatment decisions with their patients. However, clinicians seem to be recommending SBRT more frequently [14]. Providing accurate information about these concepts through a process of shared decision making (SDM) is recommended by many organizations [15–18]. High quality communication is associated with improvement in several patient-centered and clinical outcomes [19–22], although results are mixed in some clinical settings [23,24]. Accordingly, clinicians who care for patients with early stage NSCLC are faced with considering how, and with whom, they discuss these two treatment options, [12]. Since the clinical evidence regarding treatment will remain indeterminate for the foreseeable future,

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¹ See Appendix A.

communication surrounding this uncertainty and decision making remains central to providing high quality patient-centered care.

The current analysis is part of a larger mixed-methods study to study the association of patient-clinician communication with patient-centered outcomes. Our previous work found that patients were satisfied with their lung cancer care, despite reporting little knowledge about risks or other treatment options. Patients also described a lack of SDM and did not recall providers directly eliciting distress [25]. We wanted to understand how clinicians communicate with patients with early stage NSCLC about treatment decisions and this potentially distressful process.

2. Methods

We included clinicians from seven medical centers in the Pacific Northwest: the VA Portland Health Care System (VAPORHCS); Oregon Health & Science University (OHSU), an employee-based academic, quaternary health center; Legacy Health, a private nonprofit, tertiary health organization incorporating both private-practice and employed physicians; Providence Health & Services, a majority employee-based not-for-profit organization; PeaceHealth, a not-for-profit health care system with private-practice and employed physicians; Tuality Healthcare, a not-for-profit community-based health care system with both employed and community physicians; and Kaiser Permanente, a nonprofit employee-based health plan organization. We enrolled providers who care for patients with suspected or confirmed Stage I NSCLC and were being considered for curative treatment. The Joint Internal Review Board (IRB) of the VAPORHCS and OHSU (#10340), the Providence (#15-031A), and Legacy IRBs, approved this study. All participants completed written informed consent. We completed recruitment after 20 participants as we had reached saturation at each study site [26,27], based on the level of contribution of new knowledge gleaned from the analysis [28,29]. We conducted 2–4 interviews at each site to include at least one radiation oncologist, one surgeon, and one pulmonologist (if applicable). Often sites only had one or two of each provider type. We conducted approximately 45-min interviews in a private space

at the provider’s location during non-clinical time. Participants were not compensated and all except one provider who was approached agreed to be in the study.

SEG (qualitative research analyst) and/or CGS (pulmonologist) interviewed the clinicians and we digitally recorded and transcribed the interviews. Neither researcher practices surgery or radiation oncology. We used a patient-centered communication (PCC) theoretical model emphasizing five domains to guide our understanding of the communication strategies [30], but the flexibility of the interview guide (Supplementary Appendix A) allowed other themes to emerge. While the PCC model includes five domains (Fig. 1 [19]), we focused on the following three: information exchange; patient as person (consideration of patients’ feelings, preferences, and values); and sharing power and responsibility (shared decision making) [19]. The PCC theoretical model incorporates multiple indirect methods of communication [19] to evaluate influence on patient-centered outcomes. Therefore, by using this framework, we evaluated how and if clinicians incorporate each domain into practice, and what barriers or facilitators are involved in the communication process. Each clinician was identified by a randomly assigned letter not related to his or her name and a letter following a hyphen for the type of provider (N=thoracic oncology Nurse; P=Pulmonologist; S=Surgeon; R= Radiation Oncologist).

2.1. Analysis

We used directed content analysis [26,31], which uses existing theory to first identify key concepts as initial coding categories before defining them operationally. First, SEG and CGS reviewed together three completed transcripts to develop a codebook. Following discussions about the codebook, we then independently coded an additional three transcripts. Collaboratively, we refined the codebook, reviewed, coded, and discussed discrepancies in the original transcripts. SEG independently reviewed and coded the remaining transcripts, with CGS separately reviewing and coding three randomly selected transcripts to ensure consistency. We used ATLAS.ti 7.1.7 (ATLAS.ti GmbH, Berlin, Germany) for analysis.

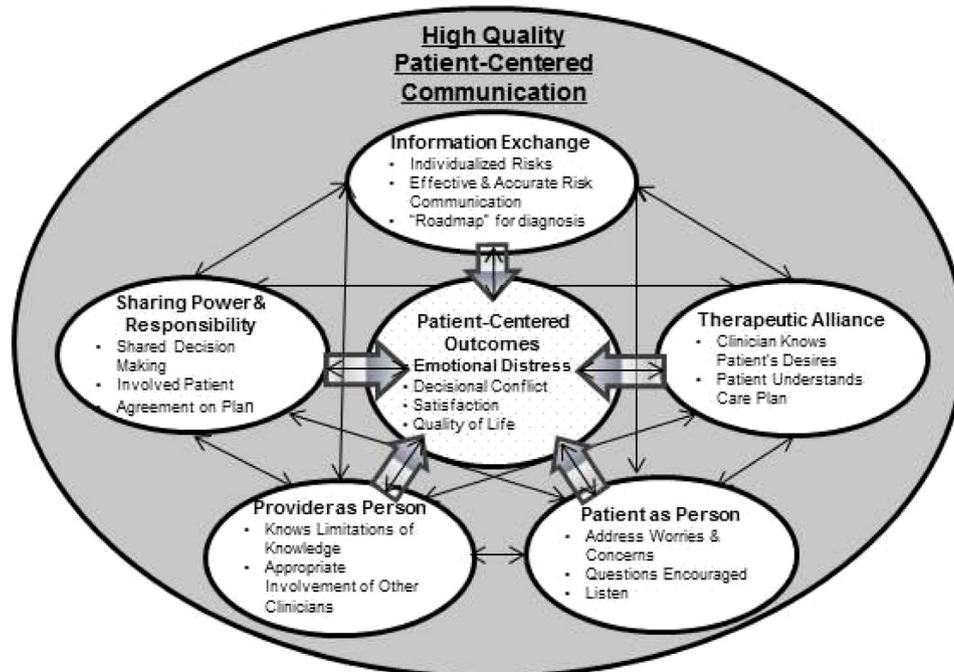


Fig. 1. Patient-Centered Communication Model.

3. Results

Our sample included eight radiation oncologists, seven thoracic surgeons, four pulmonologists, and one thoracic oncology clinic nurse. Table 1 presents self-reported demographic characteristics. We did not find substantially different themes or responses based on where the participant provided care or specialty.

3.1. Information exchange

3.1.1. Importance of information

All clinicians expressed the importance of providing information (Box 1). Clinicians felt their primary job was to provide information to their patients and the more information that was provided, the higher perceived quality of care. Clinician O-R said, “I

Table 1
Cohort characteristics.

Characteristic	Measure n = 20
Age (yr), mean (SD)	47 (6)
Female, n (%)	3 (15%)
Race/ethnicity, n (%)	
White	9 (45%)
Asian/Pacific Islander	9 (45%)
Other	2 (10%)
Provider type	
Pulmonologist	4 (20%)
Thoracic Surgeon	7 (35%)
Radiation Oncologist	8 (40%)
Other	1 (5%)
Health Care System Type by clinician (n = 20)	
Employee-based	12 (60%)
Both employee-based and private practice	8 (40%)
Years of practice, mean (SD)	12 (9)
Years of practice at current site, mean (SD)	10 (8)

Participant ID	Importance of Information
J-R	I mean how could more information be harmful to them?
B-S	The common questions usually relate to prognosis and long-term outcome. I guess they would ask, “Well which one’s better? Should I have surgery or should I have radiation therapy?” And then I just give them the data . . . And then I am probably going into more detail about lung cancer and the treatment than what they want to know or need to know. But I think it really helps them.
S-P	I think if you sit with them and discuss the pros and cons . . . they might not remember the intricacies of each decision making, but the larger [picture] they get.
D-S	Uncertainty I never tell people with cancer that they’re cured or cancer free or anything like that. Even after 5 years I’m like, ‘well that’s great but you just have to keep watching it.’
M-S	I don’t [talk about survival]. And the reason for that is I don’t always know how to frame it in the context of a patient’s health.
E-S	I mean we always say there is always uncertainty and that’s why you have the option of watching this . . . Because we don’t have a diagnosis. Alternative Treatments
D-S	When I talk with the patient I tell them the options . . . I usually have them see both the surgeon and the radiation oncologist.
P-R	I mean its like should someone who’s not a candidate for chemotherapy have to meet with a medical oncologist to talk about chemotherapy? If it’s not an option it’s not an option.
R-R	I guess since I believe it makes sense to treat and the toxicity is not that high and the benefit of the treatment is so high, I might not be necessarily the right person to discuss that [surgery] since I believe it’s the right treatment, I benefit from them choosing this treatment, so I do think that for these patients the best person to discuss might be a pulmonologist or a primary care physician. It might not necessarily be me. Risk/Benefit
D-S	The morbidity risk for lobectomy in low risk patients with VATS lobectomy is about 15%. So that’s what I quote them. And with thoracotomy it was usually quarter to 30 to 40%. And pneumonectomy is also 40 to 50%. So that’s what I tell them.
O-R	I usually try to use terms that are not insultingly stupid but something they can relate to.
R-R	The population that I serve for lung cancer I find that the patients are not driven to ask very detailed questions and look for studies and read the articles themselves. Maybe patients without these diseases, breast cancer patients might be a little bit more driven and a little bit more sophisticated to actually shop around, you know, get down to the data analysis. But lung cancer patients tend to typically be a different population of patients here.
K-P	And I’m happy knowing that they felt like they had it explained to them, and they felt like they had the information that they needed to make a decision at that point in time. Whether they remember all that information or not might be a different matter.

Participant ID	Distress Management
K-P	So I think you need to kind of figure out what their understanding really is. And I think through understanding their fears get addressed.
S-P	[When asked how they manage distress] It’s more of just giving them information. Trust
T-S	I think that’s why a lot of the meeting is saying, ‘I’m dealing with you straightforwardly, I’m dealing with you honestly, I’m telling you as much as I possibly can while making it interpretable, but it’s clear I really know what I’m talking about.’ So I think that the main point of that meeting is the trust that’s engendered of it.
M-S	And some of the data is good, some of it’s bad, and it can be overwhelming for people to kind of wade through that. It’s overwhelming for us as practitioners to go through all the information that’s out there! So you can’t expect a lay person to necessarily be able to wade through all the data . . . there has to be a certain amount of trust between whoever is taking care of the patient and the patient. Preferences and Values
B-S	And if I can sense they’re a little hesitant about it then I tell them, “Is there somebody else you’d like to talk to? You know, do you want to talk to somebody in radiation therapy about other treatments?” And then the other thing I would say is like, “Well why don’t you go home and think about it?”

Table 1 (Continued)

Participant ID	Distress Management
F-S	So I always end saying, “Well what questions or concerns do you have?” And we spend that time talking about other treatment options, things to look for, how we’ll keep an eye on them, and if it turns out not to be early stage disease. It gives them more time. It’s not so much fact finding any more. It’s more addressing their concerns, which I think is a big advantage.
R-R	I usually ask them how do they feel, what’s on their mind . . .
Participant ID	Recommendations and Suggestions
M-S	It’s probably best for them to talk to both providers and then decide what they want to do. I think it’s ok to have the pulmonologist direct that again. But again, I think a lot of it is about informed consent.
Q-S	They make the final decision. I mean if I feel strongly about something based on like their lymph nodes or something like that, then I might push them one way or the other. But I hear what they say.
R-R	For my patients with lung cancer since there is no alternative with surgery, since there is only treatment or no treatment I still make it very clear that it’s their decision and that I don’t want them to make the decision today in front of me, that I want them to go home, talk to someone else, talk to their primary care physicians, talk to their family, and sort of make up their minds at home. And I think that by doing this I kind of make it clear to them that . . . I’m not signing them up as we’re talking, but I’m there to discuss issues with them and for them to make the decision at home. I think that in medicine . . . its decision sharing, it’s not decision making.
K-P	If somebody has terrible lungs . . . and they look like they have early stage lung cancer, shared decision making is around to treat or not to treat. It’s not really about how to treat.
A-N	You have to have the team. You have to have the physician buy-in.
D-S	And often I ask them to bring somebody with them so that there’s somebody else there who can hear the conversation, and then if they are a high risk patient we’ll often meet them a second time and go over it again. I mean we do a pretty good job of follow-up but I think we could always be better . . . The other thing, like I said, is we’ve gotta discover a cure for lung cancer.
F-S	A lot of times, [I say] ‘blah blah blah,’ and the patient only hears like ‘cancer,’ and ‘death,’ and they forget a lot. So I think [written materials] would be helpful.
G-R	I think to make patients more aware of the SBRT options, even for operable patients . . . I would love to have a follow-up clinic . . . To see and to learn about complications. So I think having some kind of a systematic way of following . . . learning about each other’s modalities through doing follow-up clinics would be really helpful.
R-R	There should be a multidisciplinary clinic where patients with early stage disease come to the room and they see a surgeon and radiation oncologist at the same time in the same room, not one after the other but together, and talk about the different treatment options.
J-R	To some extent the right person who could be kind of a neutral person to talk about both the effects . . . having a multidisciplinary clinic with a pulmonologist, surgeon, and radiation oncologist, seeing the patients . . . making a collective decision along with the patient so that they can, in one go, get all the information about different modalities and to understand their disease, and the physicians can talk among themselves about what would be the most appropriate course of action for the patient, would be the ideal way to go.
K-P	I think that particularly the patients with ongoing treatment or more advanced cancers, or cancers that are symptomatic, there should be more of a partnership between palliative care and the other treating oncologists to give people both the time and attention, and kind of a bigger bag of tricks, to help them. So I think I would want a little bit more of a dedicated partner in palliative care. And I also would like to see social work to be able to be more of a part of the clinic because there’s a lot of logistics.

try to inform them as much as possible . . . I tell them the word ‘doctor,’ literally means, ‘teacher.’” Almost all clinicians described attempting to provide tailored information on a consistent basis, mostly in relation to tumor or treatment characteristics as opposed to patient-specific values, preferences, or comorbidities. Clinicians consistently indicated the need to tailor information to the patient’s level of understanding. For instance, Clinician T-S said, “I’ll tailor it, and if it’s somebody that is not sophisticated I won’t use percentages.”

3.1.2. Uncertainty

Clinicians reported they were often uncertain how to frame treatment goals since it is challenging to predict an individual outcome for each patient. Thirteen clinicians said they use the word “cure” when talking to patients about treatment, but five of those said they always use qualifiers like “potential,” “try,” or “intent” to cure. A few clinicians explicitly said they do not use that word. When asked why, Clinician I-R replied, “I’m an oncologist. We’re told you never use that word . . . for lung cancer, patients are never cured.” The uncertainty about treatment was often underscored by the lack of an adequate randomized control trial and clinicians noted the importance of informing their patients about that gap. Much uncertainty also surrounded the cancer diagnosis, especially for those patients who are treated with SBRT without a pathologic diagnosis of cancer (Box 1). Clinician E-S described, “Every time I say cancer or lung cancer I’ll say, ‘If this is

cancer then this is what we’ll do.’ It’s that word in there that tells them we don’t know what it is.”

3.1.3. Alternate treatments

Thirteen clinicians believed that all patients, regardless of their ability to safely tolerate surgery, should hear about both SBRT and surgery. Only two (one pulmonologist and one radiation oncologist) said that patients who are ineligible for surgery should not hear about both options since an operation is not available (Box 1). The remaining five were unsure, citing the lack of evidence and/or having concerns about the balance of presentation. In response to the question if all patients should hear both options, Clinician T-S said, “It depends on the medical environment . . . I feel like we give a balanced presentation but when it’s not done by the other collaborative members, then why would you plug [patients] in?” Several clinicians described instances when other clinicians had not accurately presented the risks and benefits of a treatment they did not perform. All clinicians provided as much information as needed about their specialty’s treatment, but the majority noted they either tried not to speak about other treatment options, or only gave general information.

Although most clinicians reported patients should hear about all treatment options, they also reported that only a minority of patients at their institution actually do hear about both options, with a couple stating only SBRT patients hear about both. Nonetheless, every clinician said it was important to discuss the

Box 1. Information Exchange.

Participant ID	Importance of Information
J-R	I mean how could more information be harmful to them?
B-S	The common questions usually relate to prognosis and long-term outcome. I guess they would ask, "Well which one's better? Should I have surgery or should I have radiation therapy?" And then I just give them the data . . . And then I am probably going into more detail about lung cancer and the treatment than what they want to know or need to know. But I think it really helps them.
S-P	I think if you sit with them and discuss the pros and cons . . . they might not remember the intricacies of each decision making, but the larger [picture] they get. Uncertainty
D-S	I never tell people with cancer that they're cured or cancer free or anything like that. Even after 5 years I'm like, 'well that's great but you just have to keep watching it.'
M-S	I don't [talk about survival]. And the reason for that is I don't always know how to frame it in the context of a patient's health.
E-S	I mean we always say there is always uncertainty and that's why you have the option of watching this . . . Because we don't have a diagnosis. Alternative Treatments
D-S	When I talk with the patient I tell them the options . . . I usually have them see both the surgeon and the radiation oncologist.
P-R	I mean its like should someone who's not a candidate for chemotherapy have to meet with a medical oncologist to talk about chemotherapy? If it's not an option it's not an option.
R-R	I guess since I believe it makes sense to treat and the toxicity is not that high and the benefit of the treatment is so high, I might not be necessarily the right person to discuss that [surgery] since I believe it's the right treatment, I benefit from them choosing this treatment, so I do think that for these patients the best person to discuss might be a pulmonologist or a primary care physician. It might not necessarily be me. Risk/Benefit
D-S	The morbidity risk for lobectomy in low risk patients with VATS lobectomy is about 15%. So that's what I quote them. And with thoracotomy it was usually quarter to 30 to 40%. And pneumonectomy is also 40 to 50%. So that's what I tell them.
O-R	I usually try to use terms that are not insultingly stupid but something they can relate to.
R-R	The population that I serve for lung cancer I find that the patients are not driven to ask very detailed questions and look for studies and read the articles themselves. Maybe patients without these diseases, breast cancer patients might be a little bit more driven and a little bit more sophisticated to actually shop around, you know, get down to the data analysis. But lung cancer patients tend to typically be a different population of patients here.
K-P	And I'm happy knowing that they felt like they had it explained to them, and they felt like they had the information that they needed to make a decision at that point in time. Whether they remember all that information or not might be a different matter.
T-S	This line can be deleted.

lack of randomized control data to directly compare the two treatments. Only one said every patient at her/his institution consistently sees both types of specialists. Some were unsure what was discussed upstream from their contact. When asked if patients hear both options a radiation oncologist (G-R) expressed, "I only see the ones that get referred to me!" Pulmonologists were often mentioned as the most appropriate clinician to discuss both options since they have the least bias, however specialists were still wary of how other specialties present a different specialty's treatment.

3.1.4. Risks and benefits

Clinicians consistently reported they described risks in more detail than benefits, often divided into acute versus chronic effects. A slight majority used numbers most or all of the time, while others reported using numbers to varying degrees. There was uncertainty from a few clinicians regarding how to tailor numbers to their specific patients. For instance, B-S said, "If you go online these are the published risks and death and morbidity, but really it's very individualized you know? Cause in their mind, 'well you told me 5 to 7%, well if it happens to me it's 100%.'" Clinicians reported that

patient questions mostly centered on logistics, prognosis, and survival as opposed to risks or benefits. Clinician I-R said, "I think they don't know what questions to ask . . . I think that they're probably a little bit overwhelmed too."

Although all clinicians noted that providing information was of utmost importance, they also agreed that patients probably did not remember much of what they heard (Box 1). "What you're doing is you're taking an information bucket and just dumping it on them," said T-S, when describing the initial clinical visits with patients. Clinicians recognized this lack of remembering information was a problem but did not report using strategies to improve knowledge retention. For instance, Clinician O-R said, "But what do you do? You can't wait until they could take a quiz and pass."

3.2. Patient as person

3.2.1. Distress management

The great majority agreed patients seemed scared, concentrated on cure as the top priority, and did not ask many questions. When asked what strategies were used to mitigate distress Clinician M-S said what many reported, "I think the main thing is

Box 2. Patient as Person.

Participant ID	Distress Management
K-P	So I think you need to kind of figure out what their understanding really is. And I think through understanding their fears get addressed.
S-P	[When asked how they manage distress] It's more of just giving them information.
T-S	Trust I think that's why a lot of the meeting is saying, 'I'm dealing with you straightforwardly, I'm dealing with you honestly, I'm telling you as much as I possibly can while making it interpretable, but it's clear I really know what I'm talking about.' So I think that the main point of that meeting is the trust that's engendered of it.
M-S	And some of the data is good, some of it's bad, and it can be overwhelming for people to kind of wade through that. It's overwhelming for us as practitioners to go through all the information that's out there! So you can't expect a lay person to necessarily be able to wade through all the data . . . there has to be a certain amount of trust between whoever is taking care of the patient and the patient.
B-S	Preferences and Values And if I can sense they're a little hesitant about it then I tell them, "Is there somebody else you'd like to talk to? You know, do you want to talk to somebody in radiation therapy about other treatments?" And then the other thing I would say is like, "Well why don't you go home and think about it? Please insert closing quotation marks at the end of this sentence.
F-S	So I always end saying, "Well what questions or concerns do you have?" And we spend that time talking about other treatment options, things to look for, how we'll keep an eye on them, and if it turns out not to be early stage disease. It gives them more time. It's not so much fact finding any more. It's more addressing their concerns, which I think is a big advantage.
R-R	I usually ask them how do they feel, what's on their mind . . .

just making sure that they have their questions answered. I think a lot of anxiety is just because of the unknown." Another said, ". . . of course I try to be as informative as possible because I believe that information is key. That's my way of solving the problem, is give more information" (S-P). Overall, all clinicians used information exchange as the primary method for mitigating distress (Box 2).

Several clinicians reported a wide variety of patient reactions ranging from afraid, nervous, and anxious, to ". . . patients who are just like, 'You bet doc, whatever! Remove my lung? Sure!'" (Clinician C-R). Reactions dictated how much information was given in many cases. Trust arose as a key component of the patient-clinician relationship, which when established, was perceived to lessen a patients' worry. Having a strong collaborative team helped establish trust because patients could feel that it's not only one

clinician giving input into the situation. Giving accurate information was also mentioned as a way to establish trust since, "Patients understand that bad things can happen during big surgery and are rarely angry about it as long as they're dealt with honestly . . . and there's really good communication patterns" (T-S). When discussing reasons why patients feel satisfied despite not remembering much information this same clinician explained it's "the apparent honesty, the demeanor of the physician, and the time put into it." A small number of clinicians spontaneously reported that trust is a key component of care, and when asked, all agreed it was.

3.2.2. Preferences and values

Clinicians reported they did not explicitly discuss patient preferences and values. They only rarely discussed individual

Box 3. Shared Decision Making.

Participant ID	
M-S	It's probably best for them to talk to both providers and then decide what they want to do. I think it's ok to have the pulmonologist direct that again. But again, I think a lot of it is about informed consent.
Q-S	They make the final decision. I mean if I feel strongly about something based on like their lymph nodes or something like that, then I might push them one way or the other. But I hear what they say.
R-R	For my patients with lung cancer since there is no alternative with surgery, since there is only treatment or no treatment I still make it very clear that it's their decision and that I don't want them to make the decision today in front of me, that I want them to go home, talk to someone else, talk to their primary care physicians, talk to their family, and sort of make up their minds at home. And I think that by doing this I kind of make it clear to them that . . . I'm not signing them up as we're talking, but I'm there to discuss issues with them and for them to make the decision at home. I think that in medicine . . . its decision sharing, it's not decision making.
K-P	If somebody has terrible lungs . . . and they look like they have early stage lung cancer, shared decision making is around to treat or not to treat. It's not really about how to treat.

patient’s perceptions regarding how they weighed the relative risks or benefits or the subjective functional outcomes, even though they did often leave time for questions or patient comments. Clinician B-S described attempting to provide, “a subjective measure of what I think their new lung function’s gonna be . . . just so that when they come back to us for surveillance and they’re maybe a little bit more winded, or can’t do what they originally did a long time ago, they at least understand and are aware.” Even in situations like this where the clinician did discuss subjective factors, clear elicitation of patient preferences was not articulated. Some clinicians described discussing the patient preference for treatment vs no treatment, but again, values and subjective factors were rarely taken into account.

3.3. Shared decision making

3.3.1. Who makes the decision?

All clinicians said the ultimate decision on treatment was up to the patient after presentation of the information and options, meaning the patient always had the option to refuse (Box 3). Interestingly however, many commented about decisions made prior to their consult. This was especially true for radiation oncologists; several said they let the patient make the decision despite the feeling that the decision had already been made based on the fact the patient was not referred to surgery. The only options for these patients were SBRT or no treatment, since surgery had been removed as an option. For instance, C-R said, “I guess the ultimate cop out as a radiation oncologist is that we tend to be kind of tertiary providers, that we’re not involved in that decision process.” Eight clinicians said pulmonologists make the decision, mainly due to referral patterns, six said it was all up to the patient and the remainder said surgeons made the decision. Of those six

however, about half said they would “push” or “steer” the patient “in one way or the other,” while the remainder would not. Clinician O-R said, “I guess I’m kind of a car salesman in a way.” Whereas Clinician C-R stated the opposing view saying, “please let us not sell things, you know?”

3.3.2. Decision process

Clinicians reported providing information and guidance but that the ultimate decision on treatment was up to the patient. When asked if they performed SDM during this process, Clinician S-P replied, “I think so, because I think an honest attempt has already been made in discussing the pros and cons.” The intensity and direction of guidance, however, as well as the level of patient involvement, varied. The majority of clinicians noted the importance of a multidisciplinary setting to help guide their decisions, while only a few discussed the importance of a patient seeing both types of specialists to get a balanced presentation of each treatment so they can make a fully informed decision. Clinician L-P expressed, “I never am the [only] one to make a decision that you can’t have surgery. If there’s any question, that patient’s been presented at tumor board and there’s a discussion.”

3.4. Recommendations

The most common recommendations (Box 4) for providing high quality early stage lung cancer care were making patients aware of their options, having a care navigator embedded in clinic for easy patient accessibility, using more written materials, leaving time for questions, showing scan images, and utilizing a “neutral” clinician, like a pulmonologist, in treatment recommendation discussions. Some ideas to improve knowledge retention included asking patients what they heard or sending information prior to the visit.

Box 4. Recommendations.

Participant ID	Recommendations and Suggestions
A-N	You have to have the team. You have to have the physician buy-in.
D-S	And often I ask them to bring somebody with them so that there’s somebody else there who can hear the conversation, and then if they are a high risk patient we’ll often meet them a second time and go over it again. I mean we do a pretty good job of follow-up but I think we could always be better . . . The other thing, like I said, is we’ve gotta discover a cure for lung cancer.
F-S	A lot of times, [I say] ‘blah blah blah,’ and the patient only hears like ‘cancer,’ and ‘death,’ and they forget a lot. So I think [written materials] would be helpful.
G-R	I think to make patients more aware of the SBRT options, even for operable patients . . . I would love to have a follow-up clinic . . . To see and to learn about complications. So I think having some kind of a systematic way of following . . . learning about each other’s modalities through doing follow-up clinics would be really helpful.
R-R	There should be a multidisciplinary clinic where patients with early stage disease come to the room and they see a surgeon and radiation oncologist at the same time in the same room, not one after the other but together, and talk about the different treatment options.
J-R	To some extent the right person who could be kind of a neutral person to talk about both the effects . . . having a multidisciplinary clinic with a pulmonologist, surgeon, and radiation oncologist, seeing the patients . . . making a collective decision along with the patient so that they can, in one go, get all the information about different modalities and to understand their disease, and the physicians can talk among themselves about what would be the most appropriate course of action for the patient, would be the ideal way to go.
K-P	I think that particularly the patients with ongoing treatment or more advanced cancers, or cancers that are symptomatic, there should be more of a partnership between palliative care and the other treating oncologists to give people both the time and attention, and kind of a bigger bag of tricks, to help them. So I think I would want a little bit more of a dedicated partner in palliative care. And I also would like to see social work to be able to be more of a part of the clinic because there’s a lot of logistics.

4. Discussion and conclusion

4.1. Discussion

This is the first study to qualitatively describe the experiences of clinicians managing patients with early stage NSCLC undergoing treatment. The findings demonstrate that all clinicians value the importance of providing information, despite the recognition that patients recall only a small amount of the information given. Indeed, we have previously reported that patients do not recall much of the information provided before either surgery or SBRT but are nonetheless very satisfied with their lung cancer care [25]. When patients seemed to be distressed, clinicians responded by providing more information rather than exploring or responding to causes of distress. A majority of clinicians felt they were practicing SDM by providing guidance and information and by ultimately leaving the decision up to the patient. However, they also reported not clearly eliciting patient preferences and values, a key component of SDM.

With the United States Preventive Services Task Force recommendation for lung cancer screening [32] and the Centers for Medicare and Medicaid Services recent approval of payment [33], more patients will be diagnosed with early stage NSCLC. While patients trust their providers to give them complete and clear information [34], it is unknown if discussing both SBRT and surgery is appropriate for all patients with this disease given uncertainties of long-term survival with SBRT [11]. Nonetheless, SBRT is now increasingly offered, while rates of surgery are declining [10,14,35] and clinicians recognize the urgent need for higher level evidence that compares these two treatments even though it is no longer clear which is the “best” treatment [11,36–39].

Patients may have less treatment uncertainty if providers utilize tailored written or visual materials that provide simple instructions [40–45]. Furthermore, improving communication may improve satisfaction [46], knowledge [45], and other patient-centered outcomes [19–22]. Some clinicians reported asking patients to reiterate the discussion, an approach that has been useful in other settings by improving patient adherence, disease-specific knowledge, and self-efficacy [47,48]. Interestingly, clinicians did not recommend training to improve patient-centered communication, which may be due to perceived ineffectiveness, cost, or lack of evidence [49].

Despite research that shows increasing knowledge by itself does not decrease distress [25,50–57] clinicians prefer to provide more information when patients are distressed rather than explicitly asking about patient worries or concerns. The PCC model indicates other communication strategies may be necessary to address distress, such as eliciting personal meaning or addressing unique psychosocial concerns [19]. It is also unclear if communication alone will improve favorable communication perception since personal characteristics such as anxiety and perceived empathy also play a role in management of uncertainty [58], and there is a tenuous balance where explanation of uncertainty may lead to decreased understanding of health information [45].

Clinicians frequently reported that trust was a significant facilitator of high quality communication. Indeed, our patient interviews suggested that while patients do not remember the information they received, the process of receiving that information facilitated trust in their physician [25]. Even when patients do not get high quality care, if the clinician is likeable or trusted, patients still generally report high quality communication [59] and care satisfaction [25]. High levels of trust also lead to patients not requiring as much information from their clinician [25].

Providing accurate information and eliciting a patient's values and preferences through SDM is recommended by many organizations [15–18], and is considered by many to be an ethical imperative [60]. Notably, our prior [25] and current results suggest that patients and providers are satisfied with the process and outcome of their decisions even when SDM did not seem to occur. In other settings, the effect of SDM on patient-centered outcomes is mixed. The most consistent positive effects are seen when SDM is used for long-term decisions among patient with chronic illness [24]. In addition, SDM often improves patients' knowledge about the decision but the effect on other patient-centered outcomes is less clear [24]. This gives credence that perhaps acute treatment decisions for lung cancer are not situations in which SDM would be most effective. The balance between evidence based practices and SDM may be challenging for clinicians in different clinical settings, especially when evidence based guidelines are strongly supported [23] and SDM is not perceived to be as suitable. Nonetheless, there is evidence that using guidelines as well as a process of SDM in discussions with patients are not mutually exclusive behaviors [61]. It is therefore important to continue to study the longitudinal associations between SDM and patient-centered outcomes to determine if there are long term sequelae of not engaging in SDM for patient undergoing treatment for early stage lung cancer.

Patients may not feel that a decision is needed if options are not clearly presented [34]. Furthermore, SDM can be challenging when it is not clear how involved patients wish to be in the decision making process [25,62,63]. Accordingly, when the patient's desired and actual roles in the decision making process are concordant (e.g., a patient desires to make the decision on their own *and* that is what actually occurred), there is an association with increased quality and satisfaction with care [64]. This finding indicates that SDM itself may not necessarily be the most important factor in determining patient-centered outcomes. Conversely, even when patients indicate a preference for a more passive role, active involvement can lead to more positive clinical benefits [65]. Interestingly, clinicians in our study believed their patients were making their own treatment decisions despite often referring to decisions upstream from their consult. More research is needed to help describe where in the cancer care process decisions are best made, and who should be helping to make them. We are in the process of longitudinally evaluating these aspects of lung cancer care in patients by using both quantitative and qualitative methods

Our study has limitations. We included single interviews from clinicians from seven health care settings but the results may not be generalizable to other settings. It is possible that more interviews with the same or different clinicians may have yielded further commonalities or differences, though it was common to only have one or two providers of each type at each location. Interviewing providers outside of their clinical setting may have produced different results. Our findings from interviews with patients, however, support our current findings. We included one nurse since nurses were infrequently involved in treatment discussions. We did not directly observe patient-clinician interactions so our findings may not reflect actual practices. We did not fully address two domains of patient-centered communication since they were not included in our hypothesis and it is important to understand the other more modifiable domains before understanding these others. Our results are subject to participant recall bias, as well as moderator acceptance bias, where participants may respond with what they think the interviewer wants to hear [66]. Finally, while our results offer insights into potential communication strategies (Box 4), tools, and interventions should be tested prior to widespread dissemination.

4.2. Conclusion

Clinicians who engage in discussions about SBRT and surgery for early stage lung cancer are increasingly facing difficult challenges. These primarily relate to insufficient randomized control trial data that compare these two disparate treatments with regard to oncologic outcomes and health related QOL. A majority of clinicians believe they are practicing SDM though few elicit patient preferences and values. It may be that SDM is not necessary in this clinical context. When patients are found to be distressed, clinicians prefer to share more evidence rather than consider other potential solutions. There is a preference to focus on discussing risks, as opposed to benefits.

4.3. Practice implications

Our findings demonstrate the unmet communication needs for patients with early stage lung cancer who are increasingly offered the option of either surgery or SBRT. Clinicians noted making patients aware of their options, having a care navigator embedded in clinic for easy patient accessibility, using more written materials, among others, as the most important aspects of a high quality lung cancer care program. Clinicians provide accurate information but may need to consider asking more specifically about distress and other patient values and preferences. Health care systems and payers may need to create improved processes so patients consistently receive accurate and balanced information about these two treatment options.

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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 B. Supplementary data

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