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Thoracic surgeon and patient focus groups on decision-making in early-stage lung cancer surgery

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Aim: To investigate medical decision-making from the thoracic surgeons' and patients' perspectives in early-stage lung cancer. **Patients & methods:** We conducted one focus group with thoracic surgeons (n = 15) and one with a group of early-stage lung cancer patients treated with surgery (n = 7). Focus groups were recorded, transcribed and coded for themes. **Results:** For surgeons, surgical procedure choice was a primary concern, followed by the surgical treatment plan decision-making process. Survivors focused primarily on the physical and mental health-related postsurgical burden for which they felt they were not well prepared and placed less emphasis on surgical decision-making. **Conclusion:** As early-stage lung cancer mortality rates are improving, surgeons and patients can prioritize surgical approaches and post-surgical care that enhance quality of life.

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In the USA, lung cancer remains the second highest in incidence [1] of all cancer types, and the first in mortality. Specifically, non-small-cell lung cancer (NSCLC) remains a leading cause of death in the USA with 5-year survival rates of 21% [2] and accounted for an estimated 26.8% of all cancer deaths in 2015 [3]. Despite the low 5-year survival rate for NSCLC, survival has been steadily improving since 1975 [1], mostly because of early detection and improved treatment options; this translates into a continually growing long-term survivor population that is often underrepresented in quality of life (QoL) and decision-making literature [4,5]. Survivors of lung cancer face unique challenges during their recovery, including both physical attributes, such as pain, fatigue and lower physical health-related QoL (HRQoL) due to the invasive nature of treatment [4,6,7], as well as lower mental HRQoL, often experiencing stigma, shame as well as resulting anxiety and depression [8–11]. These outcomes are exacerbated by the comparatively small number of support groups specific to lung cancer, when compared with other cancers, such as breast or prostate [12]. These issues are also compounded by the fact that, as with other cancers, there is often discordance between physician and patient interpretation of symptom burden [13], and there have been very few studies that assess the role of provider communication in the NSCLC survivor community [14,15].

In part due to approximately 75% of lung cancer cases being smoking-related [16], and common public perception that smoking is a modifiable lifestyle factor [17], stigma, self-blame, shame and regret are extremely common in lung cancer survivors [8–10]. Research suggests that greater negative reactions are seen when there is a perception

of controllable factors, for example, smoking habits in cancer occurrence [18]. One study found that 48% of lung cancer survivors reported experiencing perceived stigma by their medical providers [19]; this experience of stigma is also linked with survivor feelings of regret [8,20] in several studies, particularly in those survivors who were never-smokers [8,21]. Qualitative studies have also found concordant results, with lung cancer survivors noting that "there are still people that believe that it's [lung cancer] self-inflicted to people who smoke" [9], and "they don't get the funding other cancers get and probably that's because we feel that it's our fault" [10].

These experiences of self-blame and stigma, coupled with physical limitations following treatment for NSCLC can lead to significant decreases in both physical and mental HRQoL, which are already low among cancer survivors [22]. Surgery is often the treatment used most frequently in NSCLC, which enhances survival of patients; however, surgery can lead to a significant reduction in functioning, such as decreased forced expiratory volume in the first second of expiration (FEV₁), increased fatigue, increased pain (particularly neuropathic) and decreased overall health and vitality [4,6,7,23–25]. Certain demographic and psychosocial factors have also been found to be associated with physical HRQoL measures in survivors, such as white race, older age and depressed mood [25].

Mental HRQoL has been found to be significantly reduced in the NSCLC survivor population, compared with the overall cancer survivor population, with at least 40% reporting psychological distress [26]. Several studies have also shown that when compared with the general population, lung cancer patients had significantly reduced general mental HRQoL scores, with younger age, presence of physical co-morbidities and lower levels of education being shown to be significantly associated with this trend [7–11,16,18,23]. High rates of anxiety and depression have been assessed in lung cancer survivors [27,28], with one study showing postoperative depression rates significantly increased over preoperative rates, with significant relationships with age ≥ 65 years, residual pain, employment status and dyspnea [11].

Given that both physical and mental HRQoL status has been shown to differ not only between surgical techniques, (e.g., video-assisted thoracoscopic surgery [VATS] vs thoracotomy; lobectomy vs wedge resection) [4,11,29–33] but also between number and type of chemotherapy [24] regimens, it is becoming increasingly important to include patients in medical decisions which will directly impact their post-treatment well-being. This becomes more critical when considering there is often a lack of consistency in treatment decisions across different institutions [34].

While shared decision-making (SDM) in NSCLC has become increasingly important in recent years, with two guideline-specific courses of treatment for NSCLC: surgery and stereotactic ablative radiotherapy [35], studies have demonstrated its relevance to lung cancer patients for many years [36]. Studies have shown that patients want to take an active role in information gathering, as well as the opportunity to express their opinion. In a factor analysis, 'guidance by the physician' was found to be most important to patients, whereas 'active role of patient in treatment decision-making' was reported to be least important [36]. However, recent studies have shown that many physicians neglect to provide both treatment options to patients, instead favoring those which they found to be most effective, which limits the applicability of SDM [37,38]. Similarly, a recent study found that physicians and patients with NSCLC rarely/seldom practice many components of SDM [39].

The current study uses qualitative methods to better understand thoracic surgeons' and early-stage lung cancer surgical patients' perspectives on surgical decision-making and the impact of surgery on QoL issues.

Methods

Participants

Fifteen thoracic surgeons from the USA ($n = 12$) and from outside the USA ($n = 3$), who were attending an international meeting on lung cancer screening and agreed to stay after the meeting to participate in the focus group after being asked by the meeting organizer (C Henschke). The surgeon group consisted of two females and 13 males. Convenience sampling was used as these 15 were the surgeons who attended the meeting and were able to stay the extra time to participate in the focus group.

The patient focus group participants were seven adults who were diagnosed and surgically treated for early-stage lung cancer, and were participating in a meeting at the Lung Cancer Alliance. Eligible meeting attendees (early-stage lung cancer patients who had undergone surgery) were asked via email or phone by one of the meeting organizers (S Ross) if they would like to attend approximately 2 months prior to the meeting. Those who said yes were mailed a letter explaining the purpose of the study and what participation in the focus group would entail. Patient participants were six females and one male, their surgery was performed 1–12 years before the focus group (most of them were treated 5-years before), five were ex-smokers and no participants currently smoked. Six patients had

lobectomies, one had a wedge resection; all surgeries were conducted in major medical centers on the east coast. Participants were compensated for their time with a gift card.

Thoracic surgeons' focus group

This focus group was held in December 2014, and was facilitated by an experienced qualitative researcher (RM Schwartz). The purpose of the group discussion was to assess how thoracic surgeons make diagnostic decisions in early-stage lung cancer cases, to assess if and how they present diagnostic options to their patients, and if and how they adjust the decision-making process based on different patient characteristics or clinical situations.

To guide the focus group discussion, a semistructured discussion interview guide was used, which was developed by the authors of this paper and generally focused on understanding factors affecting surgical decision-making in early-stage lung cancer cases. The focus group, which lasted approximately 75 min was conducted in a private conference room and was audio-recorded. All participants signed consent to be recorded.

Early-stage lung cancer surgical patients' focus group

The patient focus group was held in a private meeting room during the Washington DC at the Lung Cancer Alliance meeting, as part of their routine educational programs. The discussion guide was developed by the authors of this manuscript (RM Schwartz, E Taioli, R Flores, C Henschke, TN Taylor), with input from the Lung Cancer Alliance (S Ross). The focus group lasted approximately 90 min, was audio-recorded after having obtained written consent from the participants.

Both focus groups were facilitated by one of the authors of the manuscript (RM Schwartz) with an additional author as cofacilitator/notetaker (E Taioli, SM Kerath).

Data analysis

Audio files were professionally transcribed verbatim. Transcripts were analyzed in two stages. First, a qualitative researcher (TN Taylor) manually coded transcripts for major themes and wrote an evolving qualitative memo with extended annotated interview excerpts to help coauthors verify examples and themes. Given the manageable size of the data, we chose not to use qualitative analysis software. The other authors reviewed and provided feedback on the multiple versions of the memo. After reviewing each coded theme, another qualitative researcher (K Gorbenko) revised the qualitative memo-linking categories and subcategories to each other. Our research team regularly conferred to discuss varying interpretations of the content and meaning of participants' responses for several months until consensus was reached. Quotes from participants are reported to support our findings. Ellipses mark where quotes were edited for clarity and square brackets indicate new content.

Human subjects protection

De-identified data were analyzed after the collection and transcription. The project was deemed exempt by the Mount Sinai Medical Center Institutional Review Board.

Results

We report results from 15 thoracic surgeons and seven adults diagnosed and surgically treated for early-stage lung cancer. Analyses yielded results in four categories discussed below that roughly follow the treatment timeline: choice of appropriate surgical procedure (surgeon participants), presurgery discussion between physicians and patients (surgeon and patient participants), patients' postsurgery and long-term experience (patient participants).

Surgeons' perspectives

In the surgeon focus group, two main themes emerged: surgical decision-making and presenting information to the patient. **Box 1** shows surgeon quotes representative of each of these themes.

Surgical decision-making

Although most surgeons in the focus group mentioned reviewing the literature for new trends, recommendations and evidence from clinical trials, they also revealed that they made their surgical decisions based on the virtue of their training, practice and clinical experience. One surgeon, for example, explained that even if her patient had received different recommendations from another surgeon, she "would have to go by what [she] knows is right by virtue of [her] training and practice regardless of what the other consultants are saying." Our respondents noted that

Box 1. Surgeons' perspectives: representative quotes.**Surgical decision-making**

- "If they had seen another surgeon and he said something different than I would, I would have to go by what I know is right by virtue of my training and practice regardless of what the other consultants are saying."
- "...if another surgeon had said that thing is perfectly okay... I wouldn't say that the other surgeon's wrong, I'd just say it wouldn't be what my choice would be for myself."
- "...sometimes these are lesions that have been followed through for 3 or 4 years... and have slowly enlarged over that period of time... I also take that into account when we have a clearly, very innocuous natural history but yet, it's has kind of gotten to the threshold of doing surgery."
- "I would favor the sublobar resections especially in the non-smokers and with the caveat... that down the line it could be something in the same chest or in the collateral lung and when you burn your bridges with a total lobectomy and then the pulmonary functions start to progress with time then you've got what's the next step type of thing."
- "I prefer to do an open resection because... I think that there is more benefit in parenchymal sparing and less distortion of the underlying lung than a difference in the incision."
- "...we have data. that suggests you can follow completely non-solid lesions essentially forever and many of them will never do anything for 10, 12, 15 years."
- "I have never decided to do a case one way or another based on reimbursement."
- "I think [reimbursement is] actually a very significant and concerning factor and I think it's a limitation of screening and screening policy is the unintended consequences of hungry surgeons... that want to do a case."
- "But that's the reality of a fee for service based system... if you think, globally and socially, there is no way that it's not a big part of decision-making when you've got the ambiguous lesion."

Presenting information to the patient

- "You tell the patient that you're going to go in there with the idea that in your heart of hearts you're giving them a good cancer operation and that you're not going to short change them and you may make a decision, hey this doesn't look like it's going to line up for a VATS, it's better as an open or maybe it should be a lobe, so I think that some of that you're going to even make on your feet."
- "...give them time to see what they want to do, them and their family. Then I would try to accommodate them as much as I can within what I take to be my safety field of the two or three options."
- "...if I'm going to do a lobectomy and I'm certain of it, I'll tell them that you'll probably be in the hospital about 3 or 4 days. If it's a sublobar resection, you may be out in about 36 to 48 hours."
- "...they are almost always concerned about what are the immediate hospitalization and recovery quality of life to get back to work or life aspects."
- "I've been burned because I've told a patient not to have surgery who should not have had surgery. It was a lesion and it was stable for 7 years, and [she] went to an institution in town, had surgery, was told it was cancer and... threatened to sue me for [not operating]."
- "I'm still going to tell patients they don't need surgery if they don't need surgery."
- "I use the word cancer... but... then add my impression that it looks like a well behaved cancer and I will give them very clear information that we are increasingly knowledgeable about cancers that they'll never die from..."

when they found themselves disagreeing with another surgeon the patient had seen, they would refrain from telling the patient the other surgeon was 'wrong', emphasizing that they would choose a different treatment or surgery option for themselves. Most participants described particular criteria to help them assess if surgery was appropriate. These criteria included the size of the nodule mass, location of the nodule mass and nodule characteristics (i.e., part solid, pure ground-glass opacity or solid).

Our focus group discussion highlighted the existing debate in the field regarding the best management of nonsolid and solid lesions. While many surgeons reported opting for the gold standard lobectomy, others were open to using a sublobar resection in a solid lesion less than 2 cm. One participant pointed out that agreeing on a nodule size that should be regarded as a cutoff for sublobar resection was difficult: "Where's the transition though, is it 1.2, 1.5? 1.6 [cm]?[...] You get a radiographic 1.7 centimeter tumor, you do a sublobar resection and it comes out to 2.1 centimeters." The majority of our respondents, though not all, agreed that the standard of care was a lobectomy as they believed it to be the safest choice for reducing the chance of recurrence. Some, however, preferred open or minimally-invasive surgery. For example, one respondent favored sublobar resections in nonsmokers to keep 'the next step' options open in case there is a recurrence at a later point. Another surgeon told us he preferred to perform an open surgery when performing a sublobar resection, but VATS for lobectomy or segmentectomy because "with VATS... you can't palpate to the same degree, the deep margins of parenchyma." He believed that sparing large sections of lung tissue and creating less distortion of the lung architecture was more important than the size of

the surgical cut. Respondents reported using a segmentectomy and/or wedge resection less often and considered pneumonectomy a last resort.

Presenting information to the patient

During the focus group, the surgeons discussed particular tactics and strategies for talking to their patients about the diagnosis and the surgical treatment plan and why they used those particular presentation tactics. Overall, surgeons tried to educate their patients on existing options without overwhelming them with too much information. Several surgeons reported explaining to patients why they thought a particular approach would be best in their situation. Our respondents also told us that sometimes they would consciously relay less information until they were able to confirm the diagnosis. They believed this approach would help alleviate patient anxiety.

Some surgeons reported giving patients time to process the information about their diagnosis. After explaining to patients their surgical and treatment options, the surgeons preferred to "give them [and their family] time to see what they want[ed] to do." One surgeon explained, "I would try to accommodate them as much as I can within. . . [the] safety field of the two or three options that they might take." However, our respondents often emphasized that the choice of the specific surgical and treatment option lay with the physician. For example, even when presenting multiple surgery options to patients in order to maximize patients' knowledge of the various options, surgeons sometimes were aware that only one of those options is preferable and, in these cases, would try to guide the patient toward that option by explaining why it is the most preferable. If the patient continued to want a different option, if the surgeon was not comfortable with that option, she/he might suggest that the patient get a second opinion. One surgeon reported mentioning both lobectomy as the standard of care and sublobar resection as a viable option for a particular patient. According to this surgeon, she could not remember a patient ever saying they wanted having a whole lobe removed instead of a sublobar resection.

Our surgeon respondents emphasized the importance of educating patients about the uncertainty of surgical decision-making. The surgeons wanted their patients to understand that they were unable to provide a definitive surgical decision until the operation was in progress and they could visually assess the situation. For example, one surgeon reported explaining to her patients that decisions were often made during the surgery: "you may make a decision, hey this doesn't look like it's going to line up for a VATS, it's better as an open or maybe it should be a lobe." Another surgeon similarly noted, "I present to the patient the fact that. . . we strongly feel this is a cancer and. . . it's up to me and at the time of surgery to decide what is the best for that particular patient. . . I usually will tell the patient. . . it would be a lobectomy, maximum, and then it could be. . . a VATS." Our respondents believed that presenting all the potential scenarios that may have to change during the surgery was necessary to prepare the patient for the surgery.

Our respondents agreed that the presentation of the material had to be personalized for the specific clinical and social situation of each patient. For example, one surgeon gave us an example of two patients in his/her practice, "the executive from Microsoft or Boeing who ha[s] already researched it and knows as much about [lung cancer] as I do" and "a rancher from Montana who wants me to tell them what to do and doesn't want all the fuss of the details." In the former case, the surgeon told us that he would share the uncertainty about the lobar or sublobar resection. In the latter case, the surgeon compared his communicative strategy with talking to a family member: "if it was my family member this is what I would do." Surgeons also reported being aware of other patient characteristics before their conversation about the surgical and treatment options. For example, for some elderly patients, cancer risk had to be weighed against their other co-morbidities: "if we're already talking to an 84-year old, then it's even more likely that they're going to die from something else."

Depending on their assessment of how much the patient wanted to know about the surgery, our respondents reported modifying the level of detail they shared with patients. Generally, patients tended to ask questions about the length of stay in the hospital, length of recovery process and whether they would have to go through other treatments, such as radiation or chemotherapy, after the surgery. However, if the surgery was going to be invasive the surgeons acknowledged that they spent extra time to get the patients to understand the seriousness or extensiveness of the procedure. For example, one surgeon said he/she would normally "have that full conversation about. . . the oncologic uncertainties or potential benefits as well as the physiologic outcomes of a lesser versus larger resection that the patient can participate in." Another surgeon noted that even though patients may not always ask about it, "they are almost always concerned about what. . . the immediate hospitalization and recovery quality of life [would be] to get back to work or life aspects." Our respondents noted that while often concerned about the chance of

recurrence, patients seldom asked about their risk of recurrence or death during from surgery. One surgeon said his/her patients often ask about "how they will be able to breathe."

Some surgeons used a strategy of reducing the cognitive load in an already emotional conversation. One surgeon, for example, said that he preferred to avoid "go[ing] into a lot of detail about the amount of tissue because I don't think that's. . . necessary." Instead, surgeons focused on assuring their patients that they would receive the best clinical care possible: "that's the level of discussion, is that. . . you're going to give them a good cancer operation based on the best knowledge that you have."

Some respondents discussed using words deliberately, realizing that patients might have emotional reactions to some terms. For example, one surgeon admitted delaying to reveal his/her suspicions that the nodule might be advanced until confirmed, in order to avoid causing the patient unnecessary anxiety. This surgeon told us that she would share the information with the patient gradually. Initially, she/he would admit she/he did not know what the nodule was. Then, she/he would say that she/he was "becoming more concerned" and that "it could be a lung cancer." This surgeon also admitted that she sometimes tried to dispel patient worry by referring to their nodule as 'early': "I know it's wrong but I use the term "early" . . . because I think that. . . decreases the anxiety of the patient because if they hear something [is] early. . . they feel better about it."

Faced with the conflicting obligations to provide accurate representation of facts and give their patients hope, one surgeon reported that conveying the bad news of cancer diagnosis was "a very complicated discussion depending upon where you are in the natural history of the damn thing." Describing cancer as 'the damn thing' highlights the frustration of this physician in having to balance his duties as a surgeon focused on removing the lesion with his moral imperative to provide compassionate care to the patient.

While some surgeons used terms such as 'early' to reduce unnecessary patient worry, others, by contrast, used the word 'cancer' to encourage patients to consider surgery. For example, one surgeon reported telling her patients "what I see here is a marker that you are at risk for developing an invasive cancer." Aware of the power of the term, this surgeon added that "the cancer word comes in there then, and. . . it's more of a radiological marker but that's the way I describe it to them." Overall, surgeons in our focus group admitted that they rarely used 'the "have it operated while you're well" card' because of too much uncertainty in predicting outcomes with and without surgery. For example, one surgeon stated that using this argument to convince the patient to have surgery might be effective but that surgeon felt uneasy about using it.

Patients' perspectives

Several themes emerged within our patient respondents' perspectives on their experience with lung cancer surgery. We grouped these themes analytically into three categories that correspond to the lung cancer treatment timeline (presurgery, postsurgery and long-term experience).

Presurgery decision-making

We identified two primary themes in presurgery decision-making: surgeons' opinions were of the greatest importance when deciding the appropriate treatment; patients' role in presurgery decision-making varied (Box 2).

Many of our respondents emphasized that they completely trusted their surgeon in decision-making. One participant, for example, said she chose not to pursue second opinions because she "felt [her surgeon] was pretty much the guy." Explaining what might have engendered this trust, many participants spoke about how their surgeon made them feel about their prognosis. For example, one participant described his doctor as "positive that we can get it all and it's very early," another respondent described her surgeon as "upbeat." Two respondents spoke about their surgeons being not particularly warm, but they trusted them despite these qualities: "as long as he's good at his job. . . That's all I cared about," as one participant put it.

When asked about presurgery discussions of treatment options, most participants described those discussions as 'brief', and few mentioned having to choose between more than one option. Most of the time, the surgeon told them what type of surgery they needed. Most reported that their surgeon was confident that it was cancer, with a caveat that even if it was not, it had to come out anyway. For example, one participant reported his physician explaining that the surgery would improve his breathing capacity, even if the mass were not cancer. Across our seven participants, most reported that their physician presented them with only one option. For example, when asked by a family member about first having a biopsy, one surgeon recommended against it, citing his certainty that it was cancer. Several respondents recalled having a conversation with their doctor about the uncertainty of decision-making during the operation that could require converting a VATS procedure to a thoracotomy or going

Box 2. Presurgery decision-making: representative quotes.**Surgeons dominated in presurgery decision-making**

- "But he's so positive that we can get it all and it's very early and he was right. That was six years ago."
- "No, my doctor was very upbeat. He kept saying this one is going to end well, this one is going to end well."
- "I felt reasonably comfortable with him not just with what I found out on the internet but just as a person, the eye contact, personable, he seemed to know what he was talking about."
- "Well, you know, I just decided I don't need to love him... I just need him to do this job... As long as he's good at his job... That was all that I cared about."
- "Well um, my discussion was very short. My [primary] doctor said, have the surgery, get on with your life. Call this guy, he looked up a surgeon, he gave me a phone number, he said call and have surgery, come back and see me."
- "I spoke to a surgeon and he was pretty positive... he just said it should come out no matter what it is. So I went in to surgery to have a wedge and ended up having a lobectomy. They took it out and well, it was cancer."
- "The surgeon ... just said that he could go in and take out the tumor and with the wedge and that they could save some of the upper left, which he was able to do."
- "My husband asked about doing a biopsy and the surgeon wasn't recommending that. He asked my husband, "Do you really want to put your wife through that because we're pretty sure it's cancer." So we didn't do the biopsy, we had half the left lobe removed."
- "No, he said it was a lobectomy, with a thoracotomy, that's it... You know? That's it. No choices. ... I was at NIH and that guy does it that way. That's the way he operates."

Patients' role in presurgery decision-making varied

- "Um, I tried to stay off the internet because I didn't want to terrify myself any more than I already was."
- "My friend told me not to get, she said, don't go on those discussion boards because you'll get depressed. I said, no, no, one of them is separated by a stage so if I just stay at the stage 1 discussion I'll be okay, and that's what I did."
- "I did check out the doctor [online]. I checked him out... Oh I Googled them all to death, I know where they live, I know [what] their families are like..."
- "He gave me the name of the doctor, but I said, can I shop around? Because I thought this was a huge decision, I'm not going to let the first guy ask me out. And so I started calling people I knew to find out if they had some connections. I knew someone who had had lung cancer and she gave me the name of her doctor and I scheduled a consult with him."
- "I didn't feel the need ... to go talk to someone else and get a second opinion, I felt like he was pretty much the guy."

from a limited resection to lobectomy. However, one patient reported having only one option – lobectomy – because "that's the way [this surgeon] operates." Although most participants admitted that their physician did not spend much time discussing treatment options, many consciously chose not to seek a second opinion or research their options online. One participant said she did not want to feel more terrified than she already was, and another felt overwhelmed with the abundance of information on the internet. However, some respondents were keen to learn more about their condition and treatment options. They conducted their own research online, interviewed multiple surgeons and learned to ask the right questions. Two participants also mentioned getting surgeon recommendations through other physicians they knew, and trusting their judgment.

Postsurgery issues

Three themes emerged in the discussions of the postsurgery issues. People felt unprepared for their physical experience; their emotional state; other people's reactions (Box 3). Physically, respondents pointed out a discrepancy between how they felt and how the physicians thought they should feel. The doctors relied on the spirometer to measure their patients' lung capacity postsurgery, and appeared happy to see when the measurement was not negatively impacted by the surgery. However, contrary to physicians' anticipations presurgery, participants reported pain, discomfort, low stamina or difficulty breathing "in very cold weather, walking uphill." Clinical outcomes, according to the participants, failed to capture the lived experience. Female respondents spoke about being unprepared to their inability to wear a bra. For example, one participant described wearing a scarf "to hide the fact that [she] wasn't wearing a bra." When one of the doctors complimented her on a beautiful scarf, she replied, "yeah well, it's not a fashion statement." Emotionally, participants experienced anxiety, feelings of isolation and stigma. Several participants mentioned feeling very lonely from the moment of receiving the diagnosis, which one respondent described as "fall[ing] into an abyss," to the time after surgery when they realized that the experience of

Box 3. Postsurgery issues: representative quotes.**Physical experience**

- "When he came in after the surgery, you know how they check the thing that checks your green thing that goes up and down, I've had 98% just before the surgery, I had 98% right after. [The surgeon] was so excited."
- "...he said to me, 'well you'll be sore'. And you just look around and I was like, sore? Is that the word you're going with? Really 'sore'? And he was like, 'yeah, you'll be sore' and I was like, 'okay'. That's the word he wanted to use."
- "...he said the same thing to me that you know, once you recover, you won't notice a difference and I think my lung function is the same... but I didn't feel the same at all."
- "You know, nobody told me I wouldn't be able to wear a bra... this is a woman thing but you know, nobody ever told me I wouldn't be able to wear a bra."

Emotional state (anxiety, isolation)

- "And one doctor said, you know, 'are you afraid'? And I said, 'look, I don't have pierced ears because I'm afraid to stick a needle on my ear and now you're going to open my chest, I mean I don't even, I can't even react to that."
- "... you feel damaged somehow. You feel like you don't belong with your friends, you know. You're different now."
- "This is a big thing. It happens, it's a big thing and you think about life and death and you go through this humongous surgery. But it was extremely lonely, you know. It's like well, it's like I don't really, like I'm not doing chemotherapy, I don't have all these things going on that people in the chat boards are talking about."

People's reactions (stigma and guilt)

- "We're trying to do one [support group] locally where I live, and we just can't get the people to come forward and we know they're there because there's still that stigma ... They want to keep it a secret."
- "And you see, part of that is the stigma itself that you carry yourself."
- "It's our fault and we're treated as if it's our fault."
- "When people find out I'm a cancer survivor, I don't tell them what it is. You tell them it's lung cancer and they step back, like you're contagious."
- "One of my best friends... she signed me up for hospice care."
- "You keep feeling better, and everyone seemed surprised that I looked the same. I think they think that if you have cancer, you're bald."

the disease and treatment was transformative in marking them as "damaged somehow." For one participant, being unable to return to normalcy was deeply rooted in feeling loss of control over her body.

The emotional difficulties were often exacerbated by the stigma and shame that derived from a widely held assumption that lung cancer patients were responsible for their illness because they engaged in the unhealthy practice of smoking. Participants were routinely reminded of the stigma of their condition when friends or strangers showed discomfort upon hearing about the lung cancer diagnosis. In particular, several participants reported encounters with strangers who avoided eye contact or stepped away from them after hearing about lung cancer. Some participants mentioned their friends acting on the assumption that they were going to die soon, by either changing their will or signing them up for hospice care.

Our respondents also mentioned people commenting on how good they looked, showing their assumption that cancer survivors had to look sick. For example, one participant told us: "[E]veryone expects me to be thin and bald, and I'm neither and people said, 'oh, you look just like yourself'." To cope with the discomfort observed in others, some respondents reported trying to avoid disclosing what type of cancer they had, so they could receive empathy and support they felt they deserved. For example, one female participant considered telling people she had breast cancer: "And then it's kind of tempting. It's like, do I let them think that? That's the pink cancer. It's a popular cancer and they'll hug you. . . They'll sympathize, right?" Participants recognized that the stigma of lung cancer is preventing those who need support from getting it. For example, one participant noted that recruiting people to join a support group was difficult because many lung cancer survivors try to keep their specific diagnosis a secret to avoid the stigma and blame. The stigma affected smokers and nonsmokers alike. One respondent, a never-smoker, felt alienated even when seeking care. She reported that the nursing staff in the intensive care unit after her surgery repeatedly asked her whether she had quit smoking.

Long-term experience & social support

The theme of social support emerged as central to the patient experience with lung cancer treatment both before and after surgery. Our respondents spoke about support from family and friends as well as strangers who have had

Box 4. Long-term experience and social support: representative quotes.

- "I never told my mom."
- "I didn't tell my sister until the day I was going in for surgery And she asked me why. . . I didn't say something and told her I didn't want to screw up anyone's holidays and there's not a darn thing you could've done to begin with. I mean, I told my best friend from work."
- "My doctor wouldn't let me go home alone, my friends had to come, or my daughter came. She would not let me be home for three, four days. . . ."
- "Nope, nobody visited me. . . . No, I didn't need it. I just needed someone to- and they had someone to. I think when you live alone it was a different thing. I think if I hadn't had friends. . . ."
- "That has been, and all of my family loves me and everybody understands, they can't understand, once you face death. . . . you have to be with people who've taken that walk and the support group was so important."
- "But it was extremely lonely, you know. It's like well, it's like I don't really, like I'm not doing chemotherapy, I don't have all these things going on that people in the chat boards are talking about."
- "Everything is a mind thing and with lung cancer, I think, it does have the stigma so if you could do a support group, it would be very beneficial and you really have to reach out to the patients. . . ."

experience with lung cancer (Box 4). Our participants were ambivalent on the subject of information disclosure while seeking support which is supported by the literature that indicates that cancer patients often have conflicting feelings of wanting to seek out support but also wanting to limit reminders of their illness [40,41]. While having a family member or friend to accompany the patient to the initial diagnosis appointment is recommended, several respondents reported not telling their close family members about their cancer until after surgery because they did not want them to worry. One participant found it comforting to bring her spouse to the initial diagnosis conversation, but noted that he was more upset and unable to process information than she was, and she had to remember all the details herself. Several respondents reported feeling very lonely in their nondisclosure. Managing logistics pre- and postsurgery often required coordinating family and friends around the time of discharge from the hospital. One participant mentioned the hospital arranging for a nurse to visit her, while others relied on friends and family. Patients may need help completing simple tasks at home after the surgery, such as making a warm meal or arranging transportation to and from appointments. Two patients mentioned that having a hospital-assigned nurse navigator was crucial in reducing their stress and anxiety around arranging their postoperative care appointments and addressing postoperative needs. Those lacking strong social and financial means to get help may be particularly vulnerable after surgery.

Several respondents noted the integral role of support groups because, they explained, only people who have gone through a similar experience could understand how they felt. However, finding the right group was a difficult task. At times, participating in a support group made our respondents uncomfortable. For example, one participant shared a story of being asked to speak about her experience as the only person who no longer had any evidence of cancer in a lung cancer support group. She felt uneasy when people congratulated her because she "didn't do anything." For this participant, recognizing she was one of a minority of lung cancer patients who was 'cured' felt isolating. Another participant reported feeling disconnected from other cancer survivors in online forums because she had not experienced chemotherapy and could not relate to that experience.

Discussion

The contrast between the surgeon and patient perspectives underscores the potentially differing priorities of the two groups. As mortality is less of an issue in early-stage lung cancer, surgeons and patients can prioritize surgical approaches and postsurgical care that enhance QoL given that the patients in the current study expressed the need for greater attention to QoL concerns. This can be accomplished in a number of ways on both the provider side and the patient side. As the patients suggested, a more thorough discussion of the postsurgical physical and mental health consequences of the surgery (and the lung cancer in general) can be important in setting patient expectations. Organizing social support prior to surgery can help maximize positive coping. Professionally moderated peer support groups in the healthcare and the community settings can mitigate the experiences of stigma and isolation described by our patient respondents. Additionally, those patients in the current study who had a nurse navigator involved in their care found the person to be extremely beneficial. Research indicates that nurse navigators are helpful in addressing patient barriers that physicians may be unable or unqualified to address [42]. Finally, cognitive behavioral

therapy and hypnosis interventions effective in other types of cancer can help reduce anxiety presurgery and control pain postsurgery for patients with early-stage lung cancer [43,44].

Patient respondents in our study reported high levels of trust in the surgeon and provider team regarding decision-making around surgery type, however, thoracic surgeon respondents spoke about different approaches to coping with surgical uncertainty (e.g., relying on training, individual experience and evidence from the latest clinical trials). Developing empirically derived standardized protocols will benefit surgical decision-making. Prospective studies on early-stage lung cancer surgical patients can highlight relevant information, such as patient or tumor characteristics, to help guide surgeons' decisions. Incorporating issues related to QoL can help make surgical decision-making more patient-centered. For example, a patient with a high level of anxiety at baseline might not be a good candidate for watchful waiting. Among surgical patients, wedge resections should be preferred to lobectomies, given the potential greater negative impact that lobectomies have on physical and mental HRQoL [30,33] measures, such as pain and anxiety.

Furthermore, the literature on patient/provider expectations and goal congruence around participation in cancer clinical trials points to the importance of ensuring alignment of goals between the two groups and also the role of QoL on participation in such trials. Higher baseline QoL was associated with patients' perceptions of increased potential benefit from experimental therapy [45]. Perhaps higher baseline QoL would also translate to increased expectations of particular surgical approaches and would be associated with increased propensity to have surgery when it is one of a number of options. Further research in this area is warranted.

Future research should also focus on the impact of the various surgical options on physical and mental HRQoL. This research should be incorporated into medical education of future surgeons, so that they can be more aware of the immediate and long-term effects of surgery on their patients. An integrated team approach that includes mental health clinicians, nurse navigators and patient support staff located within thoracic surgery could be beneficial in facilitating optimal decision-making. Baseline assessment of mental health and QoL can be additional pieces of information that could inform surgical decision-making.

Our study has several limitations. The two focus groups were not representative of the whole population of early-stage lung cancer patients and thoracic surgeons. The patient participants all lived in the northeast and mid-Atlantic regions of the USA and had their surgeries in large academic medical centers on the east coast. Patients in rural, less populated areas may experience even more stigma and isolation and may require more additional social support. Most patient participants were women and therefore discussions may not adequately reflect issues experienced by male patients. Male patients with early-stage lung cancer may experience the stigma, physical and emotional difficulties after surgery differently, and may have different views of necessary social support. Furthermore, all patient participants were white. Racial and ethnic minorities and immigrants may have additional stressors including difficulties navigating the US healthcare system, lack of insurance, low health literacy and linguistic barriers [46,47]. Also, there may be recall bias among the patients given the longer lengths of time since treatment for some of the participants. It is possible that the patients do not remember the details as clearly or accurately as they would have had their surgery been more recent. The surgeon participants represented a wide range of geographic locations. They attended an academic meeting to earn required continuing education credits. This group of surgeons may be more likely than others to seek learning opportunities or participate in a focus group, though continuing education credits are required of all thoracic surgeons.

Conclusion & future perspective

In sum, issues regarding QoL and mental health are clearly important to early-stage lung cancer patients and need to be incorporated into the pre- and postsurgical discussions. Also, as personalized medicine in cancer treatment becomes increasingly likely, patients' surgical preferences in combination with additional genetic information will allow for 'personalized surgery' that varies from patient to patient. As lung cancer-related death is not likely for these patients, it is now important that a comprehensive, integrative approach to surgical treatment is utilized to maximize their short-term and long-term physical and mental HRQoL.

Executive summary

- Early detection of stage I lung cancer has resulted in decreased mortality and increased treatment options for this group of patients. This allows for potential greater discussion of treatment options between thoracic surgeons and patients.
- Survivors of lung cancer face unique challenges during their recovery, including both physical attributes, such as pain, fatigue and lower physical health-related quality of life (QoL) due to the invasive nature of treatment as well as lower mental health-related QoL, often experiencing stigma, shame as well as resulting anxiety and depression.
- Two focus groups were facilitated: one with thoracic surgeons (n = 15) and one with early-stage lung cancer surgical patients (n = 7). Focus groups were recorded, transcribed and coded for themes.
- In the surgeon focus group, two main themes emerged: surgical decision-making and presenting information to the patient.
- In the thoracic surgeon focus group, two primary themes emerged: surgeons' opinions were of the greatest importance when deciding the appropriate treatment; patients' role in presurgery decision-making varied.
- The contrast between the surgeon and patient perspectives underscores the potentially differing priorities of the two groups. As mortality is less of an issue in early-stage lung cancer, surgeons and patients can prioritize surgical approaches and postsurgical care that enhance QoL given that the patients in the current study expressed the need for greater attention to QoL concerns.

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