



A qualitative study of interactions with oncologists among patients with advanced lung cancer

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Received: 25 February 2022 / Accepted: 27 July 2022

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Abstract

Introduction To support the care of lung cancer patients, oncologists have needed to stay current on treatment advancements and build relationships with a new group of survivors in an era where lung cancer survivorship has been re-defined. The objectives of the study were to (1) understand the perspectives of advanced lung cancer patients whose tumors have oncogenic alterations about their care experiences with their oncologist(s) and (2) describe the perceptions of advanced lung cancer patients about seeking second opinions and navigating care decisions.

Methods In this qualitative study, patients with advanced lung cancer ($n = 25$) on targeted therapies were interviewed to discuss their ongoing experience with their oncologists. We used deductive and inductive qualitative approaches in the coding of the data. We organized the data using the self-determination framework.

Results Patients described both positive and negative aspects of their care as related to autonomy, provider competency, and connectedness. Patients sought second opinions for three primary reasons: expertise, authoritative advice, and access to clinical trial opportunities. When there is disagreement in the treatment plan between the primary oncologist and the specialist, there can be confusion and tension, and patients have to make difficult choices about their path forward.

Conclusions Patients value interactions that support their autonomy, demonstrate the competency of their providers, and foster connectedness. To ensure that patients receive quality and goal-concordant care, developing decision aids and education materials that help patients negotiate recommendations from two providers is an area that deserves further attention.

Keywords Lung cancer · Survivorship · Patient-doctor relationship · Expert opinion

Introduction

The landscape, management, and treatment of lung cancer has shifted in the last 20 years. [1] Biomarker testing and targeted therapies have become routine care for a large subset of late-stage non-small cell lung cancer (NSCLC), leading

to substantial mortality improvements [2, 3]. Prior to use of targeted therapy, fewer than 10% of metastatic lung cancer patients survived longer than five years [3]. Median survival rates for patients with lung cancer characterized by one of the more common oncogenic drivers extended to a few years with some oncogenes [3]. The most common driver mutations are KRAS and EGFR, but there are approximately 9 other key driver mutations with much lower frequency [4]. Treatment development has been rapid and in 2021 alone, there were 4 new targeted therapies approved by the FDA [5]. To support the care of lung cancer patients, oncologists have needed to stay current on treatment advances and build relationships with a new group of survivors in an era where lung cancer survivorship was being re-defined. Patient-centered care and shared-decision-making are the cornerstones of oncology care in this new era of precision medicine. [6]

As treatment advancements push new standards of care (SOC), and the need for specialized knowledge, patients encounter multiple healthcare providers in various settings

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that challenges the continuity and coordination of care [6]. This is especially true in the serial referral model of lung cancer care, which is different from multidisciplinary care [7]. Providers may have differing views of optimal care due to scientific and clinical uncertainty in lung cancer [8]. This can be especially challenging for patients when seeking second opinions to help inform treatment decision-making. The patient's expectation of treatment success may change during the course of treatment, such as not only living longer but also improvement of quality of life and achievement of personal goals [9]. Equally important is the incorporation of a patient's prognostic awareness of their disease. There is often a mismatch between a patient's treatment expectations and their oncologist's expectations [10]. Ongoing patient-provider communication can help to inform patient-centered treatment modifications especially when a patient is at a new treatment decision point, when the cancer recurs or progresses. [9]

Patients and their loved ones continuously balance hopes for improvement with end-of-life concerns [11, 12]. Patients with advanced disease seek both positive and negative information with hopeful statements integrated into the information [13, 14]. Patients with lung cancer have described building confidence and faith in their oncologists through a relationship based on trust, good communication, continuity, the provision of information, and a sense of their providers caring for them as individuals. [12]

Given the complex and dynamic nature of survivorship care in this population, the objectives of this study were to (1) understand the perspectives of advanced lung cancer patients with oncogenic alterations about their care experiences with their oncologist(s), and (2) identify the perceptions of advanced lung cancer patients on seeking second opinions and navigating care decisions.

Material and methods

Study design

This is a qualitative study of the care experiences of patients with advanced lung cancer in the USA. The principal investigator (MA) conducted a longitudinal qualitative study with advanced lung cancer patients on targeted therapies to explore their experiences and how patients coped with their illness. This secondary, cross-sectional analysis using data from the 1-year follow-up interviews focused specifically on their ongoing care experience with their oncologists. Details of the original cohort have been described in previous publications [11, 15, 16]. The University of Washington Institutional Review Board approved the study (STUDY00005438).

Study population

Twenty-five study participants who met the following inclusion criteria participated in follow-up interviews: (1) metastatic or advanced non-small cell lung cancer with one oncogenic alteration (EGFR, ALK, or ROS1); (2) considered healthy physically and psychologically to participate; (3) English proficiency; and (4) receiving medical care in the USA. Patients were identified using purposive sampling from oncogene-specific online lung cancer support groups: the EGFR Resisters, the ALK-Positive Facebook Group, and the ROS1ders. The first phase of the study included 40 participants with a median age of 48 (range 30–75). Twelve of the participants were male, and 28 were female. Interviews occurred after a median of 19.5 months (range 3–152) of diagnosis. Among those, 25 survived and/or were available to participate in the follow-up interviews. Detailed methods are included in previous publications. [11, 15, 16]

Study procedures

The principal investigator (MA) conducted participant interviews by phone, videoconference, and in-person, based on participant location and preference. Most interviews were conducted by phone. After obtaining verbal consent, the principal investigator conducted the follow-up interviews between September 2019 and April 2020, one year after the first interviews. The interviews were digitally recorded and transcribed verbatim. During follow-up interviews, participants were asked to share about continuous care processes and experiences with their healthcare team (Table 1). Participants received a \$50 gift card for study participation.

Analysis

We used NVIVO 11 (QSR International) to store and manage the de-identified interview transcript data [17]. The coders (MA and CW) met via videoconference on a weekly basis to jointly code the data from October 2020 to June of 2021. The study team conducted deductive and inductive qualitative approaches following standard processes of coding outlined by Carspecken [18]. After coding all of the interview excerpts related to care experiences with oncologists, they identified emerging themes and further organized them using the self-determination framework [19]. For each category or topic area of the framework (e.g., patient autonomy), codes were included to depict aspects of care patients appreciated and did not

Table 1 Interview prompts

- Opening Questions And General Follow Up Prompts
 - o I would like to hear about your experience with your oncologist, share about the interactions and what stood out. Give some reflections
 - o Tell me about that
 - o Share with me some reflection about your experience, generally
 - o Share about some of the interactions with your oncologist
 - o Give me an example of an interaction that stood out
 - o What takes place during the visit?
 - o Can you share about the conversations when you started the second opinion and before that?
 - o How are the interactions with the consulting oncologist?
 - o Tell me about what happens during those visits to your own oncologist?
 - o Did you notice anything in the conversation that this that made you concerned?
- Specific Follow Up Prompts
 - o Can you share an example about..?
 - o Can you give an example of where they are more thorough?
 - o Can you give me more information about specific things?
 - o Can you share a reflection on this incident?
 - o Tell me more. What made you think so?
 - o What are some of the questions that you have for him?
 - o Tell me about the difference, from your experience, between a general Oncologist and a Lung Specialist Oncologist
 - o Share with me about your "role."
 - o Share an example about these. You've talked about difficult decisions
 - o You used the word direct medical care. Share with me more about that
 - o You said they'll let you direct the medical care. How's that?
 - o You made a decision to change your oncologist. Share the story of that and your reflection on it
 - o How was participating in the trial introduced to you? What was told to you about it?

appreciate. They continued this process until there were no new themes identified. For experiences with second opinions, we expounded reasons for seeking expert opinions and aspects of care they liked or disliked. We also explored how they navigated care when discordance or congruency occurred.

We shared our preliminary study findings with five study participants, and members of the lung cancer community as a form of member checking. The authors incorporated respective feedback and suggestions in the final revision. The principal investigator is an advanced lung cancer survivor and practicing primary care physician with expertise in qualitative health research. CW is a licensed social work clinician and researcher with a focus in adolescent and young adult oncology. MS is a cancer disparity researcher. She was a caregiver of her beloved husband who died of lung cancer. The lived experience related to cancer by MA and MS shaped their motivation to push for optimizing patient care and bring forth patient voice. CB is a thoracic oncologist and lung cancer researcher. EMJ and UPR are researchers and lung cancer patient advocates, both working for LUNGeVity Foundation.

Results

Twenty-five total participants participated in the follow-up interviews. Interviews lasted 60–75 min. Table 2 presents participants' characteristics. Table 3 presents the

Table 2 Participant demographics

Demographic	Mean (range)/ number of participants
Age	51.64 (30–75)
Gender	
Male	7
Female	18
Stage at diagnosis (same as current stage)	
IIIA-B	4
IV	4
Race	
White	23
Asian	2
Ethnicity	
Non-Hispanic	24
Hispanic	1
Education	
Some college	2
College	15
Masters	5
Doctorate (MD or PhD)	3
Insurance	
Medicaid	2
Medicare	3
Private	20

Table 3 Organization of study findings

Navigating care with primary oncologists
Supporting patient autonomy
Expertise in the field
Relating to patients and lung cancer community
Navigating second opinions
Reasons to seek a second opinion
Attributes patients appreciate in the consulting oncologist
Patient's concerns
Negotiating the relationship between two providers

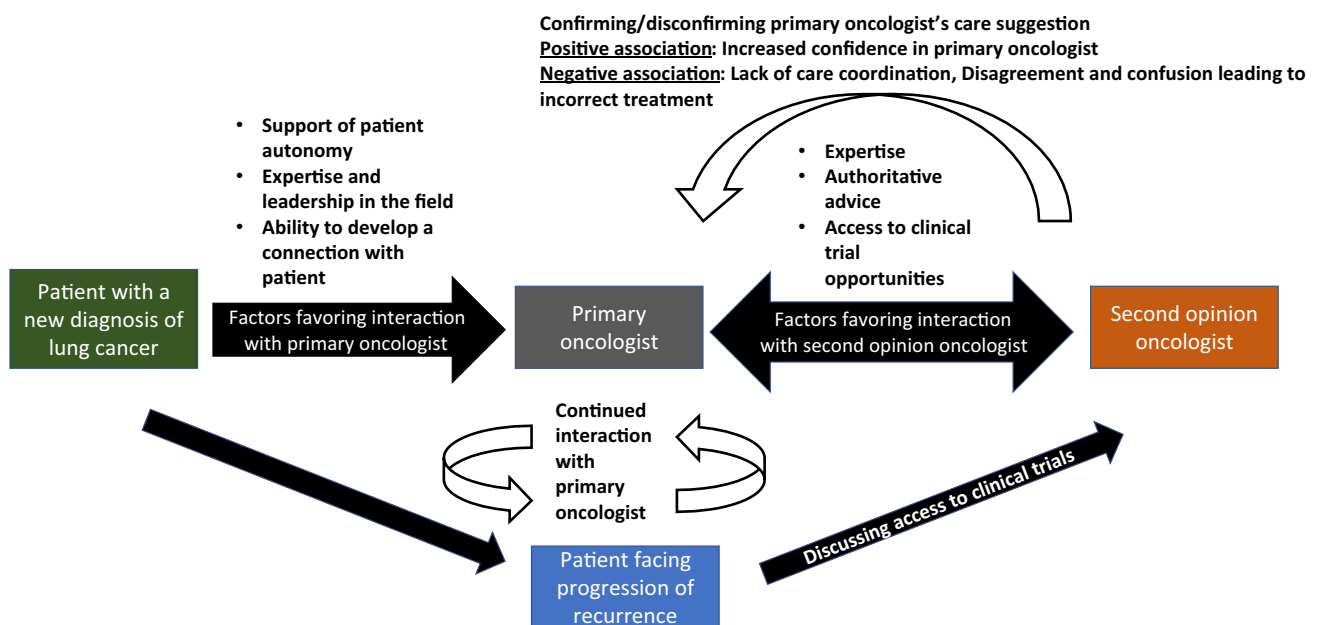
organization of our study findings. We organized our findings starting with the perspectives of advanced lung cancer patients with oncogenic alterations about their experiences with their oncologist, including the positive and negative aspects in each area (supporting patient autonomy, expertise in the field, and relating to patients and lung cancer community). Then we described why advanced lung cancer patients seek second opinions, what the experience is like, and how they navigate tensions as they occur between their primary oncologist and specialists (Fig. 1). Our interviews reveal that different factors drive patients to seek second opinions. Furthermore, navigating discussions with a primary and second opinion oncologist are somewhat dynamic in nature, where patients may expect interaction between their primary and second opinion oncologist especially during specialized treatment options such as clinical trials. This dynamism is more obvious in the journey of patients whose

cancers have progressed or recurred. Specific themes about navigating care with a primary oncologist and second opinions are described below.

Navigating care with primary oncologists

Regarding supporting patient autonomy, participants appreciated when the oncologist gave the patient a “voice” and provided rationale that helped the person choose among options. One participant describes, “I had brought a couple articles that I had pulled off the Facebook groups of different trial medications and drugs...I take them in to show them. And I really appreciate her response because she takes them, she reads them, she listens to me, and makes me feel like I have a voice.” (2006). On the other hand, they did not appreciate perceiving the oncologist as dismissive, not being provided with sufficient explanations, or viewing the oncologist as unilaterally making decisions. As one person describes, “Sometimes you had to pull information out of her. I think she's more the type that kind of wants you to just be the patient and let her take care of you. And she doesn't necessarily explain things.” (1015) Some participants also described resistance from their oncologist to discuss uncertainties (e.g., treatment options if the common treatment protocol stops working).

For expertise in the field, participants valued when their oncologists had reputation and esteem in the field. This qualification was evidenced by participating in research, using guidelines, and directing to clinical trials as needed. One participant spoke of her perception of and appreciation for

**Fig. 1** How individuals navigated the experience of having a second opinion

her oncologist stating, “I have what I consider to be one of the best cancer doctors in the world. So, I feel incredibly fortunate that I’m in such good care” (2002). But as patients grew more self-sufficient, some had concerns regarding mismanagement or what they perceived as errors and pitfalls in their care. One participant elaborates, “Some decisions that my oncologist made, now that I’m a much better advocate for myself, I question highly and I felt like some of the things she decided were terrible decisions for me” (1005). Further, as some participants sought non-traditional options (e.g., herbs, supplements, etc.) to maximize conditions of survivorship, they felt tension with oncologists who had little support for strategies outside of pharmacological approaches. One participant explained, “My oncologist is a typical traditional oncologist. She’s very dismissive,” Oh you know, this has never been proven and we don’t have clinical trials to prove it.” And I understand her concerns but I also understand that she doesn’t have anything to cure me. I have to do what I need to do to think out of the box to see if there’s something that possibly could prolong my life” (2004).

Patients appreciated an oncologist they can relate to and with whom they felt a genuine human connection. They valued the ability to access and reach the oncologist directly. They also valued when the oncologist connected with their families and their cancer community. For example, patients especially celebrated their oncologists who are working in community advocacy. Since many oncologists work within teams, connection often develops with broader team members who come to be appreciated for their efforts and support. One person described, “The smartest thing I did, which I realized I should have done sooner, was just to call her sidekick person who is lovely and makes everything happen for you” (2003). On the other hand, patients dislike it when communication breaks down and when they feel the team’s busyness delays accessing care and information. A participant describes, “They were just really busy in clinic...And I needed some answers...they didn’t get back for a while. The nurse called me and apologized for the delay that they’re just really busy...I know it’s probably because they’re busy, but I guess just hearing that doesn’t make me feel real confident” (1015).

Navigating second opinions

Reasons to seek a second opinion Patients sought second opinions for three primary reasons: expertise, authoritative advice, and access to clinical trial opportunities. Most patients sought specialists with the expertise to verify treatment decisions, as one person describes “the doctor that I’m with right now is nice, but I’m just concerned that he may not be as well informed about all the different clinical trials that are happening and the latest evolution in medicine

when it comes to lung cancer” (2001). Some patients needed authoritative advice when they disagreed with their local oncologist. Further, a few sought the specialists at research centers who have access to clinical trial opportunities.

Attributes patients appreciate in the consulting oncologist Patients appreciated the specialized care received when working with specialists, noting that in addition to their research and clinical expertise, they also fostered autonomy and feelings of relatedness. A participant expressed her opinions about her specialist, “She’s very upbeat, she keeps me in the loop, she always seems to have a plan and options and she gives me advice, but she gives me the final say in which direction I want to go.” (1014). Patients described seeing world renowned oncologists, learning about clinical trials, and receiving more thorough care. Patients discussed being supported as “captain of the ship” and being able to have conversations about what could happen down the chute as well as having more time with the specialist and being supported by their team.

Patient’s concerns Some patients noted concerns about the care they received with specialists. Some patients felt the university centers can be intimidating. They are very sterile and do not convey the homely feel of a smaller clinic. The busy specialists were not always seen, rather their assistants were the ones delivering the care. When the specialists are seen, at times, the visits were quick and succinct. One participant described his specialist, “He’s very humble but at the same time I felt a little bit more like a number in his office and I just got the sense that he was really busy. He’s very succinct” (1008). The sterility of the space and lacking the personal touch at times, some felt like a number. Worse, because of the special expertise of these providers, some left their clinical roles to work for pharmaceutical companies and that made some patients feel the loss, “Shortly after my first oncologist left, then I found out that [expert oncologist] left for another pharmaceutical company. I’ll miss having them as my doctors because I really trusted them” (1015).

Negotiating the relationship between two providers The local oncologist had often been supportive of the patients seeing a specialist and they were open to receiving recommendations. Verifying the treatment plan and receiving congruent recommendations by the specialists helped patients gain reassurance and confidence. A participant expressed this about their specialist saying, “She’s aware of the latest research and she’s also involved in it. And so just having that second opinion that reassurance I get— it gave me more confidence in my doctor” (1003). They felt enhanced trust in their local oncologists. When there is disagreement in the treatment plan between the primary oncologist and the specialist, there can be confusion and tension. In the absence

of care coordination and direct communication between providers, patients were faced with the difficult decision to discontinue care with their primary oncologist or revert to the original treatment plan with limited support.

Discussion

To our knowledge, this is the first study that explores the experience of lung cancer survivors with oncogenic alterations with their oncologists. We explore the experiences of patients with the more common oncogenes, EGFR, ALK, and ROS1. We report how patients value interactions that support their autonomy, demonstrate the competency of their providers, and foster connectedness. Patients commonly sought second opinions. Negotiating the recommendations received from two providers is an area that deserves attention to ensure patients receive quality and goal-concordant care.

Some patients reported that they had great relationships with their providers and felt that their perspectives were valued and respected. Conversely, some patients reported that they had difficulties accessing their doctors or their ideas were ignored. One key aspect that is often overlooked is that some patients want to use phytochemicals and herbal supplements, and this can negatively impact the relationship with some doctors as they may be hesitant to these options. Many over-the-counter supplements and herbs are not regulated by the FDA, thus patients may not know what they are ingesting. As many phytochemicals still have not been tested in clinical trials and due to unknown impurities and possible interactions, doctors are not keen on prescribing them. [20]

Cancer patients worry about leaving their care decision in the hand of one provider. Absent tumor board meetings in which consensus recommendation is reached by multi-disciplinary providers, patients resort to seeking second opinions, which has become a standard. Our study raises concerns for patients left to deal with tension and disconnects between providers who have limited direct communication operating within different systems without clear norms of practice that regulate their interactions. Second opinions require a thoughtful consultant and treating physician team to make it work; otherwise, it can create unnecessary tension and poor care for the patient.

Our study has three main practical implications. First, fellowship training programs need to pay attention to training oncologists on communication skills so they support not only the providing of evidence-based care but also doing that in a way that takes into consideration patients' preferences (including need for autonomy) and maintains relationships. This is especially relevant as lung cancer turns into a chronically manageable disease where the relationship can extend for years. Conversations that support a patient's informed

choice will span treatment decisions and will include end of life decisions as well. Second, another practical implication is on training oncologists to operate in teams that may include sub-specialists, and to navigate care from multiple institutes and by providers with overlapping scope of practice. This directly aligns with emerging models of inter-professional collaboration in cancer care [21]. Third, second opinions are sought by patients and ensuring the option is available to patients in an equitable way, as opposed to being the privilege of people with wealth and access, is critical so the disparity gap can be closed.

Our study has multiple strengths. The study provides unique insights into the patients' perspectives into the relationship and communication experiences with their oncologist. The longer time of engagement with the patient may potentially have allowed trust to be shared about sensitive experiences, especially to a researcher who is a cancer patient as well. We need to stress on the fact the experiences narrated here suggest that a huge amount of burden was placed on the patient to navigate their care. There needs to be a burden-shifting approach in care delivery. This can lead to the limitation noted below.

Limitations Our sample was drawn from a highly engaged population of patients who are typically self-advocates, as evidenced from the high level of education and access to private health insurance among the participants. Their experience suggests a more shared decision-making/autonomous model. All patients may not prefer this. Further, our sample was primarily of white individuals and majority with private insurances. We did not capture the experience of under-represented minorities on targeted therapy who may not equitably access second opinions. This issue of lack of representativeness is also because our sample was drawn primarily from online patient groups. Such groups are often homogeneous and composed of patients who are more educated, from a higher SES, and have access to the internet. [22, 23]

Future work will aim to develop evaluation tool for patients to gauge their experience with their oncologist. Future area of interest is exploring how the mode of second opinion (i.e., in-person, telehealth, phone, email) impacts patient care and experience. With COVID-19, telehealth has become a supported tool for patient communication and little is known about patient-provider interactions during telehealth encounters. In addition, it may be helpful to explore how patients seek second opinions. There are third-party companies that patients can contact for "second opinions" from clinical experts for a fee. This is mostly based on chart-review and may not accurately apply to patients' clinical status. Also, many reach out to experts via social media or email through their advocacy groups and consider these as "second opinions" even though the consultant has not met

them in-person and not familiar with their patient history. These tools can be powerful, yet can also create tension with treating physicians.

Author contribution MA conceptualized the project and conducted the interview. MA and CAW conducted the analysis. MA, UBR, EMJ, MS, CB, and CAW contributed to the literature review, discussion, and writing. All authors revised the manuscript and approved the final version.

Funding Casey Walsh was supported by a National Institutes of Health/National Cancer Institute grant (5T32 CA092408).

Data availability Not applicable.

Code availability Not applicable.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. The University of Washington Institutional Review Board approved the study (Study number: STUDY00005438).

Consent to participate Verbal informed consent was obtained from all individual participants included in the study.

Consent for publication Not applicable.

Conflict of interest The authors declare no competing interests.

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