


# BMJ Open Unmet needs and opportunities for improving care for patients with advanced lung cancer on targeted therapies: a qualitative study

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## ABSTRACT

**Objective** Lung cancer is increasingly recognised as a heterogeneous disease. Recent advances with targeted therapies for lung cancer with oncogenic mutations have greatly improved the prognosis for this subset of patients, yet little is known about their experiences. This study aimed to identify the needs and explore the healthcare experiences of these advanced patients with oncogenic mutation driven lung cancer.

**Design** Qualitative interviews with patients with advanced or metastatic non-small cell lung cancer with oncogenic alterations in anaplastic lymphoma kinase, epidermal growth factor receptor or c-ros oncogene 1.

**Settings** Patients were recruited from online lung cancer support groups within the USA. Interviews were conducted remotely or in person, transcribed verbatim and analysed using an iterative inductive and deductive process.

**Participants** We included 39 patients (11 males and 28 females) with a median age of 48.

**Results** Two primary theme categories emerged: patients' unmet needs and improving healthcare experiences. Unmet needs are related to patients' desire to view their disease as a chronic illness, aspire to live a meaningful existence without financial devastation, desire for understanding along with emotional support and needing help with practical matters. Improving healthcare experiences involved patients' desire to trust the expertise of clinical providers, receive reliable care and be treated holistically and as informed partners.

**Conclusions** Patients with lung cancer with oncogenic mutations live uncharted experiences. Targeted therapy brings hope, but uncertainty is daunting. Patients grapple with the meaning and purpose of their lives while day-to-day obligations remain challenging. Healthcare teams are instrumental in their care experiences, and patients desire providers who are up-to-date on advances in the field and treat them as whole persons.

## BACKGROUND

Lung cancer is the second most prevalent cancer in the USA and the leading cause of cancer death.<sup>1</sup> In 2018, 2.1 million new cases were diagnosed worldwide with 1.8 million reported lung cancer deaths.<sup>2</sup> Patients with lung cancer experience a significant burden

## Strengths and limitations of this study

- Strengths of the study include giving voice to a new group of patients with cancer, their needs and how their experience with healthcare can be improved.
- Sampling from online support groups allowed the inclusion of patients from broad geographic areas in the USA.
- The study captured the needs of these specific patients with cancer as their lung cancer experience starts to resemble that of chronic disease.
- Limitations of the study include our inability to recruit from diverse minority groups.
- The study does not explore variations between sub-groups of patients.

from the disease and its related symptoms and also the side effects of treatments.<sup>3</sup> On the existential side, studies describe the experience of living with lung cancer as one of 'loss' in addition to having aspects of guilt, blame and shame; stigmatisation; hope and despair; loneliness; changes in self-image and self-worth; anxiety and fear and uncertainty and worries.<sup>4-7</sup> While many patients with lung cancer are typically diagnosed at advanced stages, with survival ranging from a few months to less than a year,<sup>8</sup> recent advances have recognised the heterogeneity of this disease.<sup>9</sup>

Over the past decade, non-small cell lung cancer (NSCLC) has been defined at the molecular level by genetic tests identifying oncogenic mutations driving cancer growth. Three well-characterised, more frequent oncogenic alterations include epidermal growth factor receptor (EGFR) mutations (10%–35%), anaplastic lymphoma kinase (ALK) rearrangements (3%–7%) and c-ros oncogene 1 (ROS1) mutations (1%).<sup>10</sup> Oral tyrosine kinase inhibitors developed to target these mutations have demonstrated

high effectiveness, low side-effects and improvements in survival to many years. Median survival rates reported for patients with lung cancer characterised by these mutations (29.7 months for EGFR,<sup>11 12</sup> 52.1 months for ROS1<sup>13</sup> and 81 months for ALK<sup>14</sup>) are remarkably better than the generally poor prognosis of individuals lacking oncogenic alterations, and the overall historically short life-expectancy of patients with advanced lung cancer. Additionally, sequential effective therapies in development are further extending the lives of these patients, rendering oncogenic altered NSCLC to be a chronic disease rather than an immediately terminal one.<sup>15 16</sup>

The landscape of cancer care, in general, has shifted in the past few decades. What has become salient are issues related to long-term side effects and consequences of treatment, the early detection of relapse or secondary tumours and addressing patients' unmet needs.<sup>17–19</sup> Smith reviewed 11 qualitative and quantitative papers on the supportive care needs of patients living with different cancers and found informational support to be a significant need.<sup>18</sup> Other essential needs included emotional, financial and spiritual ones.<sup>18</sup> However, studies focused on the patients with *advanced* lung cancer are limited. In one study, Giuliani *et al* surveyed 80 Canadian patients with lung cancer (median age 71) to explore their unmet needs.<sup>19</sup> Four out of five patients reported at least one unmet need. No information was provided on the participation of patients with oncogenic alterations.

Little is known about the experiences of this new group of patients with cancer. This is the first study to try to characterise the unmet needs of patients with advanced lung cancer on targeted therapy and to explore how their healthcare experiences with clinicians and care teams can be improved. Identifying the patients' needs and their perspectives on improving their experience with healthcare will potentially allow healthcare providers to better understand and support these patients.

## METHODS

### Study design

This is a qualitative in-depth interview study. The primary author (MA) interviewed patients with lung cancer to learn about their unmet needs and their suggestions for improving the experience with their healthcare teams. The University of Washington Institutional Review Board (IRB) reviewed and approved the study (Study number STUDY00005438).

### Study population

The patients met the following inclusion criteria: (1) advanced or metastatic NSCLC with an oncogenic alteration (ALK, EGFR, ROS1) at any point in survivorship; (2) psychologically and physically well enough to participate, as defined by the patient; (3) proficient in English and (4) receiving care in the USA. We identified patients using online oncogene-focused lung cancer groups of patients and their caregivers, namely the ALK-Positive

Facebook Group, ROSOneder, and the EGFR Resisters. These are closed groups, and to join, the person must be a patient with lung cancer or a caregiver. The groups provide information and a sense of community to their members. Each had between a few hundred to a little over a thousand participants from all over the world. We intended that this study would include a series of follow-up interviews. Considering the anticipated attrition, we aimed to over-recruit participants. We also aimed to include a diverse representation of patients based on the duration of illness, the type of oncogenic alteration, gender, race and age.

### Study procedures

Participants were given the choice of in-person, phone or video-conference interviews. Verbal informed consent was obtained at the beginning of the interviews. Each interview was audio-recorded and transcribed. The interview guide is included in online supplementary appendix 1. Participants were reimbursed \$50 for participation in the interview.

### Analysis

The lead author used NVIVO 11 to organise the data and conduct the analysis. Data analysis was conducted concurrently with the data collection, which allowed for ending the recruitment processes once saturation was achieved. The study used critical theory-based analysis methods, as outlined by Carspecken,<sup>20</sup> consisted of four steps: low-level coding, meaning field analysis, validity reconstruction and an iterative process of organising the themes of the findings. First, the transcripts were read multiple times by the lead author (MA). Low-level codes were then developed and organised hierarchically by topics. Second, meaning fields were completed for the utterances. To develop meaning fields, each utterance was associated with the meanings that an analyst felt that a person in the position of a participant in this conversation would understand interpretively. Third, MA thematically explored assumptions and reconstructed validity claims in the objective, normative and subjective domains. Validity claims refer in this study to utterances a speaker expresses to make themselves understood for someone who is taking a critical position on their claims. Finally, themes and subthemes emerged from the synthesis of the findings in an iterative process.

The critical theory paradigm is sensitive to the specific values and assumptions of the research team. First, the research team assumed that people know their needs, and they are capable of naming them. Second, we were sensitive to issues of disparity as reflected in needs being met for some and not met for others. Third, we were sensitive to people's entitlement to knowledge and the importance of empowering them. Finally, we engaged in peer debriefing as groups and as dyads, where MA met with the coauthors to review aspects of the work, including the coding and analysis, theme development and writing of the findings. Saturation of themes was

achieved after the analysis of 15–20 interviews. In addition to peer-debriefing, to enhance the trustworthiness of the work, we performed member checks. The paper draft was shared with patients with lung cancer and advocates from the online support groups, and their comments were included in the paper iterations.

MA is a family doctor, qualitative researcher and patient with lung cancer. Since he is known as a member of the cancer community, most participants interviewed with knowledge of his health status. LM is a palliative care physician and fellowship-trained qualitative researcher. She has done qualitative research on life review in patients with advanced cancer. DR is a qualitative health service researcher. MT and LMB are family physicians with extensive research experience. LC is an oncologist and researcher. We hoped that having the interviews conducted by a patient with lung cancer/researcher would allow for an in-depth understanding of the experience since it provided participants with a sense of relatability and may have made it easier for participants to share.

### Patient and public involvement

This study is patient-centred as it aimed to identify patients' needs, priorities and preferences. Patient gatekeepers were involved in recruiting for the study by disseminating the study announcement on the support and advocacy group online platforms and social media. The final paper will be disseminated to cancer support groups using social media.

### RESULTS

We interviewed 39 adult patients with lung cancer from 18 states. The median age was 48 years. Of the patients, two had stage 3b while the rest had stage 4. In terms of mutations, 20 had ALK, 13 had EGFR and 6 had ROS1. Interviews lasted between 31 and 99 min (median is 85 min) See [table 1](#) for patient demographics. We identified four main themes in the domain of unmet needs and four in the area of improving healthcare experiences. In the sections below, we provide a narrative of these themes and their subthemes and refer to participant quotes in the accompanying tables.

#### Patients' unmet needs

The themes that emerged are related to patients' desire to live with their disease as a chronic illness, aspiring for a meaningful existence without financial devastation, desiring understanding along with emotional support and wanting help with practical matters. [Box 1](#) includes supportive quotes.

#### Patients desire to have lung cancer become a chronic disease with less stigma

Advances in treating lung cancer brought hope that it could become a 'long-term chronic disease'. For those who had maintained a functionality similar to their predisease state, they wished for 'more time'. They hoped to continue to enjoy being active and doing what they loved. But

**Table 1** Patient characteristics (n=39)

Participant characteristics	Median (range)/Count
Age	48 (30–75) years
<65	33
≥65	6
Gender	
Male	11
Female	28
Region	
West	18
Northeast	8
Midwest	7
South	6
Cancer stage	
IV	37
IIIb	2
Time since diagnosis	21 (3–81) months
<6 months	4
6–12 months	8
>12 months	27
Mutation	
ALK	20
EGFR	13
Ros1	6
Race	
White	33
Asian	4
Others (Hispanic, or Biracial (Asian and Hispanic))	2
Insurance	
Private	33
Medicare	4
Medicaid	2
Interview method	
By phone	35
Video-conference	3
In person	1

participants knew treatments would fail, and they wanted more drug options. One person explained, 'It's like the old game Frogger, where you are trying to cross the river, and you jump on a rock, and then you need the next rock to come up before the one that you're standing on sinks'. They also wanted more research.

Patients were, however, troubled with the perception that lung cancer received less research funding than it should. They attributed this disparity to a continued prejudice. One person says, 'Every time I told somebody I had lung cancer, they said, 'Do you smoke?' I began to

**Box 1 Participant quotes related to patients' unmet needs****Patients desire to have lung cancer become a chronic disease with less stigma.**

I just want more time. (3004)

Make this a long-term chronic disease. That's one thing that I know everybody is working hard toward. (3002)

With the crizotinib, I know that eventually the cancer will mutate and continue to grow, and at that point, there are a couple of things that I can do, but it's like the old game Frogger, where you are trying to cross the river, and you jump on a rock, and then you need the next rock to come up before the one that you're standing on sinks. That's what it's like. So I'm standing on my rock, and I know it's going to sink, and I know there's one-half foot, and maybe another one's starting to come up, but I want that next rock so I can make it across to it. (3004)

Every time I told somebody I had lung cancer, they said, 'Do you smoke? How much do you smoke?' There's that instant association with smoking, and I began to understand that lung cancer is a highly stigmatised cancer. It's under-researched, and that needs to stop. We need to talk about it. We need to explain to people that anybody can get lung cancer. It's not just a smoker's disease, and even if a person did smoke and did get lung cancer, that doesn't mean that we shouldn't treat them. (3001)

**Patients need understanding and emotional support.**

It's very uncharted territory; everything is so grey. Will you live for five years? Maybe. Will you live for six months? Maybe. Could you live for ten years? Maybe. These targeted medicines are amazing. But it's very uncharted territory, especially emotionally. People don't pay a lot of attention to the emotional aspects of cancer; that's been the hardest part for me at my age (mid thirties). (1011)

The issue of being young and feeling like my life was ripped away from me because of having cancer—a lot of lung cancer patients are older, have already had their children, already have their lives, and they get sick maybe with lung cancer at an older age. Me, I feel like I'm not a child, so I'm not in that group of young children with cancer, but I am not older either, so I'm somewhere in between. It would be great if there were some kind of group at the hospital that said, 'Oh, you fit into this demographic group' and 'You probably have questions about fertility, and walking through adjusting to cancer while living on your own and being an independent single person'. (1018)

**Patients want to live meaningfully without fear of financial devastation.**

I decided if I only have a couple of years left on this planet, I'm going to do what I want to do. I'm not going to work at (a coffee shop). I want to do something that is meaningful to me. But it is challenging, the money part, right now at least. (1008)

The financial aspect, I won't lie. It's been a hard thing to figure, and it's uncertain. You can only do so much financial planning when you have stage four cancer, because if you try to make a financial calculation about stage four cancer, you're probably going to get it wrong, especially now. You just don't know what's around the corner, and that's scary, but it's hopeful too. So, the other thing I say is, you know, if I would outlive my retirement savings, in a way, that's a good problem to have. (3001)

If I lost my job, would I be able to get a job with stage four lung cancer? And in my industry, everybody knows I have lung cancer. So, are they really going to hire the director or VP level to charge ahead in their company if that person can't even communicate if they're going to be around in three years? (1020)

I feel I'm in the position to help the mentally ill and have an influence over policy and trends in our state. So to walk away from that opportunity, to even think about it, is very difficult for me. Probably the most

Continued

**Box 1 Continued**

common thing that is said to me by people is, 'You look so good; you don't look sick'. I'm afraid that if I were to go on disability retirement, I would be stigmatised or people would doubt that I was really sick enough to be on disability retirement because of my outward appearance. (2007)

**Participants need help with daily practical matters.**

Mostly, (I wish I had) just another pairs of hands to watch kids while I have to go to doctor's appointments or help just make dinner once in a while. Having cancer is a full-time job with the numbers of doctor's appointments and some other things that we have to do. It's really burdensome. (1004)

It would be helpful if there were somebody available who could maybe drive us to an appointment that was going to be difficult for me to drive myself to. I'm now being treated in New York City, which is about an hour away from where I am. (2008)

understand that lung cancer is highly stigmatised. It is under-researched, and that needs to stop'.

**Patients need understanding and emotional support**

With targeted therapy, patients lived, as one person put it, 'very uncharted territory where everything is so grey. Will you live for 5 years? Maybe. Will you live for 6 months?' The experience is challenging, 'especially emotionally'. Not feeling alone and receiving emotional support were crucial for them. To navigate this new life, participants wanted to work with therapists who have experience treating cancer patients, which was not always easy to find.

Patients also wanted support groups with participants to whom they could relate. Some did not feel they fit in traditional cancer support groups since 'many lung cancer patients are older, already had their children, already had their lives. I feel like I'm not a child, so I'm not in that group of young children with cancer, but I am not older either, so I'm somewhere in between'. Other patients wished to find groups matching their views on life. Some were troubled with an emphasis on religion and faith in the available support groups.

**Patients want to live meaningfully without fear of financial devastation**

As participants grappled with how to spend whatever time they had left in a meaningful way, finances were a serious concern for all but the affluent. One participant explained, 'I decided if I only have a couple of years left on this planet, I'm not going to work at (a coffee shop). I want to do something meaningful to me. But it is challenging, the money part'. For individuals whose work hours determined their pay, time off meant lost income. Patients who worked salaried jobs used up their paid sick time quickly.

Financial planning became especially tricky with uncertainty about prognosis. One patient said, 'If you try to make a financial calculation about stage four cancer, you're probably going to get it wrong. Especially now, you don't know what's around the corner. I say, 'if I

would outlive my retirement savings, in a way, that's a good problem to have". As conversations about disability or early retirement become salient, especially for older patients, decisions are hard to make. Some feared that they might be stigmatised for taking advantage of the system. One patient complained, 'People say, 'You look good; you don't look sick'. I'm afraid that if I were to go on disability retirement, I would be stigmatised, or people would doubt that I was sick enough to be on disability retirement because of my outward appearance'.

Adding to the stress, some participants struggled to navigate the complexities of health insurance. Claims were denied, and patients were frustrated as they 'go through the appeal process with all the paperwork'.

### Participants need help with daily practical matters

Many participants struggled with little energy to attend to day-to-day chores like shopping and cooking. Some wished for affordable services that provided healthy food. Many patients also wanted help with transportation to and from appointments. Because, even with a supportive partner/spouse, cancer could be quite burdensome. Couples often needed help, especially with children. Some participants asked for, 'just another pair of hands to watch kids while I have to go to doctors appointments or help make dinner once in a while. Having cancer is a full-time job with the numbers of doctors appointments and some other things that we have to do. It's burdensome'. At the same time, the decision to rely on caregivers frequently came with conflicts in younger individuals who used to be independent.

### Improving healthcare experiences

The themes related to improving healthcare experiences included trusting in the expertise of the providers, desiring reliable care and wanting to be treated as informed partners using holistic approaches. **Box 2** includes supportive quotes.

#### Patients want to trust the expertise of their doctors

Managing lung cancer with targeted therapy is a new frontier where knowledge is evolving at a fast pace. Patients living far from major cancer centres struggled to find local doctors with expertise. This shortage is especially real for patients in rural areas. One participant explained, 'If I have progression, I don't have much confidence in my doctor. I will travel'.

As the disease progressed, many patients wished to connect to clinical trials, even if it required taking long trips, contrary to what their providers assumed. One patient explained, 'I got myself into a clinical trial and found the treatment that was best for me on my own. My local oncologist is supportive of it, but she didn't find it for me'.

While lung cancer treatment strategies both prolonged survival and improved quality of life, some patients struggled with providers who still focused only on comfort care. One patient complained about their provider, 'he is

## Box 2 Participant quotes related to improving healthcare experiences

### Patients want to trust the expertise of their doctors.

When we moved to (a smaller town), I knew I wasn't going to have the research university right here. And I love my pulmonologist, (but) when I do have a recurrence and some progression, I just don't have a lot of confidence in him. (But) I'm on Medicare now. I can go back to (major university cancer centre). (1012)

I feel my healthcare team here has done really well, except for my oncologist's assumption that I wouldn't travel for a clinical trial. I got myself into (a clinical trial). I found the treatment that was best for me on my own. My local oncologist is supportive of it, but she didn't find it for me. (3001)

This new doctor, he is not aggressive in his approach. He is a very conservative doctor. He doesn't know cutting-edge stuff. He doesn't really stay up-to-date with it because he believes in just making you comfortable for as long as you can. Whereas, for me, I want to live as long as I can, even if it's one extra month. I would ask him questions about stuff, and he would just kind of, you know, like pull me aside, which is incredibly difficult, because I know a fair amount about my disease. (1011)

### Patients want their healthcare team to be reliable and to follow through.

I just find the care coordinator smarmy. It's like she sort of says platitudes and looks serious and pitying me all the time, and every time she offers the same thing but never follows through with anything. So it's completely useless. She's like, 'Oh, this programme is for kids,' and I was like, 'Great, here's who we are, and here's what will be great. Could you follow through with referrals?' She'll come in, and she'll talk about the journey. I don't know; I just don't find her particularly compelling. (1019)

I pick up my clinical trial medicine there at the university hospital. They only had a 30 day supply. I live 10 hours away. I said, 'How am I going to get the next supply?' and the research nurse said, 'You have to come to pick it up'. And I said, 'You want me to spend \$400 and fly down there to get my medicine?' And she said, 'Well, I don't know any other option'. (1011)

### Patients want to be treated in conversations like informed partners.

Sometimes, my meetings with my oncologist seemed rushed. You can tell a lot is going on. She has a lot on her plate other than my cancer. She just wants to stick with the facts, and then when we're done discussing those, it's a pretty open-and-shut case. (1013)

My doctor's mentality is that she knows her stuff, and so she wants to see the patient; you go there and let her take care of you, but I want to know her thought process. (1015)

It should be mandatory for providers to attend sensitivity training to be able to begin to grasp what the patient is going through. (2009)

### Patients want to be approached holistically as persons

Someone should explain to patients and caregivers and families what the roads could look like down the road, and that's what I would say could be improved here. (3002)

For my cancer centre, there wasn't a whole lot of promotion of other things. So the patient needs seeing a therapist or going to a support group or engaging in some healthy alternatives, seeing a dietitian, just more sort of focused on the medical side. For my doctor's office in particular, there hasn't been a lot of focus on you, the holistic approach, I guess. (2007)

Oncologists I've seen, they don't deal with your psychological side. They're so busy that all they have time for is reading the scan, telling you where you are, talking about next steps. You don't get a chance to have a discussion about your psychological situation. (2010)

Continued

**Box 2 Continued**

The palliative care team turned out to be really nice and really helpful, and they call you every three months, and they ask how everything is. And they are always available; much more available than your oncologist in terms of easy to get through to. And I am sorry they did not send me to them sooner. (2003)

not aggressive in his approach. He doesn't know cutting-edge stuff. He doesn't stay up-to-date because he believes in just making you comfortable. Whereas, for me, I want to live as long as I can, even if it's one extra month'.

#### Patients want their healthcare team to be reliable and to follow through

Patients desired genuine care and could tell when they were being pitied or when expressed support was not followed up with action. One person complained, 'I find the care-coordinator 'smarmy'. She says platitudes and looks serious and pitying me all the time. Every time she offers the same thing, but never follows through. She'll come in, and she'll talk about the journey. I don't find her particularly compelling'.

Some patients were frustrated at having to work hard to receive needed care and, at times, to schedule appointments. Some centres had idiosyncratic practices without accommodations, which left patients feeling resentful. One patient complained, 'I live 10 hours away'. I said, 'How am I going to get the next supply?' and The research nurse said, 'You have to come to pick it up'. And I said, 'You want me to spend \$400 and fly down there to get my medicine?' And she said, 'Well, I don't know any other option'.

Also, from their own experiences, participants wished their cancer had been diagnosed earlier. They thought the possibility of lung cancer was quickly brushed off and insufficiently considered when they first presented to doctors.

#### Patients want to be treated in conversations like informed partners

In the era of widely available information, patients wanted to be informed and to participate in shared decision-making. But, at times, patients sensed doctors were rushing. One person explained, 'You can tell a lot is going on. The oncologist has a lot on her plate other than my cancer. She wants to stick with the facts, and then when we're done discussing those, it's a pretty open-and-shut case'. They also wanted to know 'the doctor's thought processes' to understand the plan. Instead, one person complained, 'My doctor's mentality is that she knows her stuff, and so she wants to see the patient; you go there and let her take care of you'. Further, they wanted their team to be more responsive to their needs and worries. Some participants went so far as to call for 'sensitivity training' for providers, so that patient experiences and perspectives could be better understood. While informational needs were salient for some patients, others felt their interactions with their providers were exemplary.

#### Patients want to be approached holistically as persons

Participants viewed their cancer as a whole person condition and wanted their experience treated as such. They wanted consideration of mental health and financial needs, and they desired access to resources. Some also wanted their cancer centres to provide complementary approaches. Instead, from their experience, 'there wasn't a whole lot of promotion of other things like healthy alternatives or seeing a dietitian'. They wanted cancer centres to orient patients to therapy or support groups. One person complained, 'Oncologists I've seen, they don't deal with your psychological side. But all they have time for is reading the scan, telling you where you are, talking about the next steps'. Many also wished they had received access to palliative care early in their cancer. One person shared, 'The palliative care team turned out to be nice and helpful. And I am sorry they did not send me to them sooner'.

#### DISCUSSION

The experience of patients with oncogenic alteration driven NSCLC is uncharted. While novel targeted therapies have brought hope, quality of life and prolonged survival for this subset of patients, there is still daunting uncertainty. Patients grapple with the meaning of life and living with purpose, while the questions of mundane day-to-day matters still loom large. Healthcare teams are instrumental in these patients' experiences. Patients desire both providers and cancer treatment centres that are up-to-date with advances in the field and treat them as whole persons. Our findings regarding unmet needs and improving healthcare experiences are consistent with the literature on needs of patients with cancer.<sup>18 19 21-24</sup> Further, our study provides an in-depth account regarding this new group of patients with cancer as they survive longer than initially anticipated. Patients with advanced stages of lung cancer are living for years rather than months, and with that, their needs start to resemble other cancer survivors who live with cancer as a chronic disease. Our work has important practical implications and provides grounds for future research to improve the experience of patients with lung cancer with oncogenic alterations.

Lung cancer, like most other cancers, disrupts the biography of a person,<sup>25-28</sup> but with targeted therapies, living for an unexpectedly long time while having advanced-stage cancer has left patients in an uncharted cognitive and emotional territory. The uncertainty regarding how long they will continue to live makes it especially challenging for patients to conceptualise their current priorities and future plans. According to socioemotional selectivity theory, as the amount of time remaining in life appears to shrink, we tend to prioritise immediate emotional and social goals over future-oriented ones that might expand horizons and involve knowledge acquisition.<sup>29-31</sup> This theory sheds light on the experience of patients with cancer in this study. But, given the uncertainty about whether they would live for years or months,

many participants struggled to settle on a framework for life priorities and meaning-making. Many patients grappled with how much to work or whether work at all as opposed to doing other important activities. They struggled to understand their experience and be understood. Identifying this tension is the first practical implication of this study and is relevant for caregivers and healthcare providers in supporting these patients.

Lung cancer is a heavily stigmatised disease.<sup>32</sup> Throughout the literature, the experience of patients with lung cancer has been portrayed as that of shame, loss and guilt.<sup>7</sup> It is an ‘invisible cancer’, a ‘death sentence’ and a ‘smoker’s disease’.<sup>32</sup> While many patients on targeted therapy perceived their experience to be qualitatively different than what they thought lung cancer would be like (eg, quick death, steady progression and so on), they still sensed stigma related to the diagnosis. Similarly, participants in our study believed that stigma contributed to their receiving variable treatments from providers (eg, not getting on-time diagnostic tests) and to the allocation of disproportionately lower research funding compared with other cancers. The perceptions of these forms of stigma are reported in the literature.<sup>33</sup> Thus, calling attention to positions of prejudice and inviting attention to stigma combine to create the second practical implication of this study.

Participants also sought ways to be empowered in their healthcare interactions. Patients on targeted therapy are forming communities where they share information and experiences. Participants wanted to be partners, empowered during their conversations with providers, and these findings from our study are in line with cancer patient empowerment literature.<sup>34</sup> According to a systematic review of 38 articles about experiences of empowerment of patients with cancer by Jørgensen *et al*,<sup>34</sup> patients view knowledge as power. This review indicates that patients desire access to information, seek information online and view educational programmes positively. Our study supports this evidence, and we lend our voice to the patients asking for empowerment. Thus, inviting healthcare providers and cancer centres to identify opportunities to engage patients and address their needs as persons is the third practical implication of this study.

The listed existential, financial and informational needs described by some of our participants were not shared by all. Some interviewees just said that all of their needs were being met. Some only wanted more time. Our study highlights variations in the experiences of patients with lung cancer in terms of their unmet needs and their relationships with healthcare. Variability in treating as well as diagnosing lung cancer have been documented previously with regard to race, gender, rural versus urban location and socioeconomic status.<sup>35–37</sup> In our study, despite multiple attempts, the majority of our sample was white middle-class or upper-middle-class individuals, almost all with private insurance. The demographics of the participants, we acknowledge, is a study limitation and constraint due to the sampling method. Differential

access to genetic testing may have directly contributed to a skewed representation at the patient population level.<sup>38</sup> Even if we put aside access to genetic testing, our participants indicated that distance from major cancer centres was associated with difficulty accessing supportive services, clinical trials and expertise in current treatment strategies.

Our study exposes the personal difficulties and vulnerabilities faced by patients with advanced lung cancer as they navigate the uncharted territory of survivorship and revises the professional responsibilities of health professionals in treating and partnering with these patients. Healthcare providers and advocacy organisations can use these findings as they move to provide the kind of comprehensive support, information and treatment patients need. Further studies should quantitatively look into how variations by demographic attributes, associated in the literature with disparity, relate to variations in unmet needs and experiences with healthcare. Furthermore, large data might also be leveraged to explore variations in lung cancer outcomes for different patient groups and the relationship of these outcomes to variations in identifying genetic mutations and using targeted therapy. Finally, more work needs to focus on assessing individual patient priorities and approaching their experience holistically to address the biological aspects and the social, psychological and existential issues.

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