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Uncharted territory: Qualitative study of the unmet needs of patients with advanced lung cancer on targeted therapies

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Uncharted territory: Qualitative study of the unmet needs of patients with advanced lung cancer on targeted therapies

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Abstract

Objective: Lung cancer is increasingly recognized as a heterogeneous disease. Recent advances in identifying genetic mutations and targeted therapies have improved the prognosis of lung cancer in patients with these mutations, yet little is known about their experiences. Identify the needs and explore the health care experiences of patients with advanced lung cancer with oncogenic alterations.

Design: Qualitative interviews of patients with advanced or metastatic non-small cell lung cancer with one of the oncogenic alterations in ALK, EGFR, or ROS1.

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

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

Results: Three themes emerged in the area of unmet needs: Patients struggled to have meaningful lives while needing to work, manage finances, and navigate insurance. Patients needed understanding, emotional support, and extra practical assistance. Patients wanted their disease to be viewed as and treated as a chronic condition, which gives them hope and aligns the focus of management with their goals. In terms of improving their health care experience, two themes emerged. Patients wanted to have trust in their health care team, and they wanted to be engaged in conversations with health care providers as partners and approached holistically as people.

Conclusions: Lung cancer patients with oncogenic alterations live uncharted experiences. Targeted therapy is bringing hope, but uncertainty is still daunting. Patients grapple with the meaning of their lives and with living for a purpose, while mundane day-to-day matters remain challenging. Health care teams are instrumental in their care experiences, and patients desire providers who are up-to-date with advances in the field and centers that treat them as whole persons.

Strengths and limitations of this study

Strengths of the study include lending voice to patients in these qualitative interviews, so they name their needs and how their experience with health care can be improved.

Sampling from online support groups allowed the inclusion of patients from broad geographic areas in the United States.

The study captured the needs of this new cancer survivors as their lung cancer experience starts to resemble that of chronic disease.

Limitations of the study include our inability to recruit representation of minority groups.

The study does not reach groups of patients who have limited access to online support groups.

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Background

Lung cancer is the second most prevalent cancer in the United States and the leading cause of cancer death [1]. In 2019, it is expected that 228,150 new cases of lung cancer will be diagnosed, and the number of people dying of lung cancer (142,670) will be greater than that for breast, colon, and prostate cancers combined [2]. Patients with lung cancer experience a significant burden from not only the disease and its related symptoms, but also the side effects of treatments [3]. 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; stigmatization; hope and despair; loneliness; changes in self-image and self-worth; anxiety and fear; and uncertainty and worries [4,5,6,7]. While a significant proportion of lung cancer patients are at advanced stages at the time of diagnosis, with an overall survival rate of just a few months and an experience of progressive and fast decline [8], lung cancer is increasingly recognized as a heterogeneous disease [9]. Advances in identifying genetic mutations causing cancers that can be treated with targeted therapies have dramatically improved the prognosis and the lived experience of some groups of patients with lung cancer.

Over the past decade, non-small cell lung cancer (NSCLC) has been further defined at the molecular level using genetic tests that identify oncogenic alterations. While there are many such mutations, three main ones have targeted therapies with oral tyrosine kinase inhibitors, which improve prognosis and survival. These mutations and their frequencies in NSCLC include anaplastic lymphoma kinase (ALK) rearrangements (3–7%), epidermal growth factor receptor (EGFR) mutation (10–35%), and c-ros oncogene 1 (ROS1) (1%) [10]. With the emergence of targeted therapies, the median survival rates for these patient groups are reported as 29.7 months for EGFR [11,12], 52.1 months for ROS1 [13], and 81 months for ALK [14], which are remarkably better than individuals lacking oncogenic alterations. As patients receive effective sequential treatments for these conditions and live longer, NSCLC with these mutations is now being considered a chronic disease rather than an immediately terminal one [15,16].

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 tumors, and addressing patients’ unmet needs [17,18,19]. Smith reviewed 11 qualitative and quantitative papers on the supportive care needs of survivors of different cancers and found informational support to be a significant need [18]. Other essential needs included emotional, financial, and spiritual ones [18]. However, studies focused on the survivorship of patients with *advanced* lung cancer are limited. In one study, Giuliani et al. surveyed 80 Canadian lung cancer patients (median age 71) to explore their unmet needs [19]. 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 cancer survivors. The purpose of this study is to understand the unmet needs of patients with advanced lung cancer on targeted therapy and to explore how their health care experiences with clinicians and care teams can be improved. Identifying the patients’ needs and their perspectives on improving their experience with health care will potentially allow health care providers to better understand and support these patients.

Methods

We interviewed lung cancer patients to learn about their unmet needs and their suggestions for improving their experience with their health care teams. 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 United States. The University of Washington Institutional Review Board (IRB) reviewed and approved the study.

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. Participants were reimbursed \$50 for participation in the interview and were given the choice of in-person, phone, or video-conference interviews. Verbal informed consent was given at the beginning of the interviews. Each interview lasted approximately 60–90 minutes, was audio recorded and transcribed. The interviews began with questions on demographics and cancer characteristics. Conversations covered five topics: life before the cancer diagnosis, diagnosis of cancer, coping with cancer, life after the cancer diagnosis, and unmet needs.

Data analysis was conducted concurrently with the data collection. Our critical qualitative analysis methods, as outlined by Carspecken [20], consisted of four steps: low-level coding, meaning field analysis, validity reconstruction, and an iterative process of organizing the themes of the findings. First, the transcripts were read multiple times by the lead author (MA). Low-level codes were then developed and organized hierarchically by topics. Second, meaning fields were completed for the utterances. To develop meaning field, each utterances were associated with the meanings that an analyst felt that a person in the position of a participant in this conversation would understand interpretively. Third, the lead author thematically explored assumptions and reconstructed validity claims in the objective, normative, and subjective domains. Validity claims refers 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. We also engaged in peer debriefing as groups and as dyads, where the lead author met with the co-authors to review aspects of the work, including the coding and analysis, theme development, and writing of the findings. The lead author is a family doctor, PhD trained qualitative researcher, and lung cancer patient. Co-authors include family doctors and an oncologist. One co-author is a palliative care specialist. Five of the authors have significant experience with qualitative research including one who teaches courses in qualitative methodology.

Results

We interviewed 39 adult patients with lung cancer from 18 states. See Table 1 for patient demographics. In the process, we identified three main themes in the domain of unmet needs, and two in the area of improving health care experiences. In the sections below, we provide a narrative of these themes and their subthemes and refer to participant quotes in the accompanying tables.

3.1 Patients’ unmet needs

The three themes that emerged are related to patients’ struggles with living meaningful lives, their emotional needs and desire for support, and hope for making the disease a chronic one. Table 2 includes supportive quotes.

3.1.1 Patients struggled with living meaningful lives while needing to work, manage finances, navigate insurance, and pay bills.

While participants grappled with existential questions related to shorter survival and how to spend whatever time they had left in a meaningful way, some were stuck in the mundane problems of financial security.

Participants strove for meaningful lives but had to work to maintain solvency. Some also struggled to decide how long and how much to work. They desired balance so they could keep a healthier lifestyle and spend time with family, both of which were limited by working long hours. People who returned to work struggled when they were given responsibilities that exceeded their capacity, which was limited by physical fatigue and the emotional burden of the disease.

Patients who needed time off work quickly used up their benefits such as paid medical leave under the Family and Medical Leave Act (FMLA). For individuals whose work hours determined their pay, time off meant lost income. With difficulty in finding fulfilling jobs, some decided to go on disability. While conversations about early disability or retirement were salient, especially for older patients, decisions were difficult for some participants who feared that they might be stigmatized for taking advantage of the system.

Finances were a concern for all but the most affluent patients. Financial planning became especially tricky with uncertainty about prognosis. Some participants were concerned about navigating the complexities of health insurance; many participants had claims denied. They also struggled to understand co-pays. Some complained that insurance companies did not cover services they found useful for their care, such as acupuncture.

3.1.2 Patients needed understanding, emotional support, and extra practical assistance.

Patients desired understanding and support. They also wished for help with day-to-day matters.

With targeted therapy, patients lived uncharted experiences. Some who initially expected to die in a few months were living longer and with a reasonable quality of life. They had hope, yet still had fears, and emotional struggles were hard to describe. Feeling not alone and receiving emotional support were crucial for them. To navigate this new way of living, participants wanted to work with therapists who have cancer-specific experience, which was not always easy to find.

Participants wanted support groups with participants they could relate to. For some, in-person support groups were what they desired. Other patients did not feel they fit in traditional cancer support groups—lung cancer groups are primarily older participants, and middle-aged

women's groups are usually breast cancer survivors. Some wished to find groups matching their views on life and were troubled with, at times, an emphasis on religion and faith.

Participants also wanted help with mundane, day-to-day activities. At the same time, the decision to rely on caregivers frequently came with conflicts in younger individuals who used to be independent. Even for those with a supportive partner/spouse, cancer could be quite burdensome, and couples often needed help, especially with children. As participants took responsibility for their health and strove to maintain healthier behaviors, they struggled with little energy to shop and cook for themselves and wished for affordable services that provided simple, healthy food. Many patients also wanted help with transportation to and from appointments.

3.1.3 Patients desire to transform lung cancer into a chronic disease with less stigma.

Advances in treating the disease brought hope that it can be conceptualized as a chronic disease. Also, participants experiencing stigma related to the association of this cancer with smoking wanted to change these perceptions.

Participants hoped that research would change the course of the disease and turn it into a chronic condition. They wished to have their old selves back, enjoying being active and doing what they loved. For those who had maintained a functionality that was comparable to their pre-disease state, their wish was to live longer.

Participants knew treatments would fail and hoped for more options. They realized their medications would eventually stop working, and their few remaining options were limited. They hoped science would progress faster than their disease to bring extended survival.

Some patients were also troubled by continued prejudice against lung cancer in regard to smoking. They experienced stigma whenever they told someone they had lung cancer. Some were also troubled with perceptions that lung cancer received less funding than it should, and this disparity led to resentment. They wanted this stigma to change.

3.2 Improving health care experiences.

The themes related to improving health care experiences were wanting to have trust in the health care team, to be treated as an informed partner with intricate lived experiences, and to not focus solely on the disease but, rather, on the person. Table 3 includes supportive quotes.

3.2.1 Patients wanted to have trust in in the knowledge, efficiency, and reliability of their health care team.

Managing lung cancer with targeted therapy is a new frontier where expertise is still evolving. Patients wanted their doctors to be knowledgeable, and they hoped to find care efficient and reliable.

Patients wanted their health care team to be reliable and trustworthy. 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. They desired authentic and genuine care and could tell when they were

being pitied or when expressed support was not followed up with action. Sometimes, patients found themselves reminding their team of current standard-of-care practices. Some patients were frustrated at having to work hard to receive needed care and, at times, to schedule appointments.

Patients living far from major cancer centers struggled to find doctors locally with expertise and in whom they could have confidence. Knowledge is evolving at a faster pace than some providers could keep up with. To find trusted advice, patients often sought the expertise of nationally recognized doctors in distant centers, requiring difficult travel and expense. As the disease progressed, many patients wished to connect to clinical trials, even if it required taking long trips. While lung cancer treatment strategies prolonged survival and improved quality of life, some patients struggled with providers who still focused only on comfort care rather than aggressively seeking new treatment options, and this discordance in care goals was experienced as a source of stress.

Patients wanted more convenient and efficient services. Those living in rural areas had to travel to cancer centers, and this inconvenience made it harder to leverage services. In addition, when they got to the doctor, some had long waits to be seen. Some centers had idiosyncratic practices without accommodations, and patients felt resentful. At times, patients sensed doctors were rushing, as if the patient were not a top priority, and wished for more time to ask questions.

3.2.2 *Patients want to be treated in conversations like partners and approached holistically as people.*

In the era of widely available information, patients wanted to be informed and to participate in shared decision-making. They also had a preference for attention being paid to all aspects of their lived experiences.

Patients wanted to be treated as partners with their health team and hoped to learn from doctors as much as needed to participate in informed conversations about options. They wished to be given more information about the diagnosis and what it meant. They also wanted doctors to have more transparency in their thought processes so they would know and understand the plan. Patients wished care was coordinated between consultants. They also 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.

Participants viewed their cancer as a whole person condition and wanted their experience treated as such. Patients desired help in navigating the new diagnosis and treatment and wanted a holistic approach (e.g., to include consideration of mental health and financial needs) and accompanying resources. Some also wanted naturopathic experts to help with supplement choices, concerned that cancer centers only focus on biomedical treatments. They wanted cancer centers to orient patients to therapy or support groups. Many also wished they had received access to palliative care early in their cancer.

Discussion

Lung cancer patients with oncogenic alterations are living uncharted experiences. The positive prospects of targeted therapy have brought hope, but 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. Health care teams are instrumental in these patients' experiences, and patients desire both providers and cancer treatment centers that are up-to-date with advances in the field and treat them as whole persons. To our knowledge, this is the first study that explored the unmet needs of this new group of survivors and how health care experiences can be improved for them. Our study has important practical implications and provides grounds for future research to improve the experience of lung cancer patients with oncogenic alterations.

Lung cancer, like most other cancers, disrupts the biography of a person [21–24], but living for an unexpectedly long time with advanced stage lung cancer has left patients in uncharted cognitive and emotional territory. The uncertainty regarding how long they will continue to live makes it especially challenging for patients to conceptualize 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 prioritize immediate emotional and social goals over future-oriented ones that might expand horizons and involve knowledge acquisition [25–27]. This theory sheds light on the experience of the cancer patients in this study. 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 grappled with issues of not knowing how much to work, or whether to work at all, as opposed to spending time on other meaningful affairs. 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 health care providers in understanding and supporting patients.

In order to understand and be understood, participants sought counseling and support groups to meet individuals with relatable experiences. Yet, finding the right community of support and belonging and the right conversant who understands and does not judge were perceived as challenges. Lung cancer is a heavily stigmatized disease [28]. Throughout the literature, the experience of patients with lung cancer has been portrayed as that of shame, loss, and guilt [7]. It is an “invisible cancer,” a “death sentence,” and a “smoker’s disease” [28]. Similarly, the advanced lung cancer participants in our study believe that stigma contributed to their receiving differential treatments from providers (e.g., not getting on-time diagnostic tests) and allocation of disproportionately lower research funding compared to other cancers. The perceptions of these forms of stigma are reported in the literature [29]. Interestingly, our study also found that patients identified a need to change the stigma of lung cancer. Some participants were reclaiming their voices by telling their narrative, making it their responsibility to call out prejudice against lung cancer. 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 health care interactions, an essential domain of the lived experience with lung cancer. 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 [30]. According to a systematic review of 38 articles about cancer patients' experiences of empowerment by Jørgensen et al. [30], patients view knowledge as power. This review indicates that patients desire access to information, seek information online, and view educational programs positively. Further, having an active role in deciding and investigating treatment options is considered essential for giving them a sense of

control. Patients value excellent provider communication that makes them feel respected [30]. Finally, support groups are instrumental as both sources of information and for their relational and social roles [30]. Our study supports this evidence, and we lend our voice to the patients asking for empowerment. Thus, inviting health care providers and cancer centers 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 expounded by some of our participants were not shared by all. Some interviewees just said that all of their needs were being met. Others only wanted more time or wanted the disease to become a chronic one with more treatment options. This highlights variations in the experiences of lung cancer patients in terms of their unmet needs and their relationships with health care. Variability in treating as well as diagnosing lung cancer have been documented previously with regard to race, gender, rural versus urban location, and socio-economic status [31–33]. In our study, despite multiple attempts, the majority of our sample was white middle or upper-middle class individuals, almost all with private insurance. We had only one Hispanic participant and no African Americans. The demographics of the participants, we acknowledge, could be viewed as a study limitation or a weakness in the sampling method since patients who use online support groups might be different from the general patient populations. It is possible that differential access to genetic testing may have directly contributed to a skewed sample.[34]. Even if we put aside access to genetic testing, our participants indicated that distance from major cancer centers was associated with difficulty accessing supportive services, clinical trials, and expertise in current treatment strategies. Unmet needs might be even more overwhelming among people with little to no insurance, those who lose their coverage while ill, vulnerable and diverse populations, and those with less education and less access to critical information about their cancer and treatment.

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. Health care providers and advocacy organizations 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 health care. Furthermore, large data might also be leveraged to explore variation in lung cancer outcomes for different patient groups and the relationship of these outcomes to variations in identifying genetic mutations and utilizing targeted therapy.

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Disclaimer

The author has not published or submitted any related papers from the same study.

Conflict of interest

Morhaf Al Achkar, Laura-Mae Baldwin, Lucille Marchand, Matthew Thompson, Debra Revere have no conflict of interest to report. Laura Chow serves as a paid consultant for Amgen. She has also received research funding to institutions that she works with and/or serves on the advisory board for: Novartis, Merck, Lilly/Imclone, Bristol Myers Squibb, AstraZeneca/Medimmune, Pfizer, Incyte, Takeda, VentiRx, Sanofi-Genzyme, Seattle Genetics, Dynavax, Genentech, Synthorx, and Alkermes.

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Author Statement

MA, LM, MT, LC, DR, and LMB contributed to the literature review and the conceptualization of the work. MA conducted the interviews. MA conducted the primary analysis of the data. LM, MT, LC, DR, and LMB did peer debriefing and review of analysis with MA individually and in groups. MA, LM, MT, LC, DR, and LMB all contributed to the writing of the discussion. All the authors reviewed and approved the final version of the study.

Transparency declaration

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The authors affirm that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted.

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Data sharing

Deidentified data will be shared upon request.

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- Table 1. Patient characteristics.
- Table 2. Participant quotes related to patients’ unmet needs.
- Table 3. Participant quotes related to improving health care experiences.

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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
Hispanic	1
Others (Biracial, Asian and Hispanic)	1
Insurance	
Private	33
Medicare	4
Medicaid	2
Interview Method	
By phone	35
Video-conference	3
In person	1

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Table 2. Participant quotes related to patients’ unmet needs.

<p>Patients struggled with living meaningful lives while needing to work, manage finances, navigate insurance, and pay bills.</p> <p>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)</p> <p>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 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 stigmatized or people would doubt that I was really sick enough to be on disability retirement because of my outward appearance. (2007)</p> <p>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 4 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)</p> <p>The one thing that I have run into [is] dealing with the insurance company. I’ve had some of my claims denied for my radiation treatment. So, I have to go through this whole appeal process and all this stuff. I’m already dealing with cancer; the last thing I need to do is be dealing with all this paperwork in relation to getting my claims paid. (1017)</p> <p>If I lost my job, would I be able to get a job with stage 4 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)</p>	
<p>Patients needed understanding, emotional support, and extra practical assistance.</p> <p>It’s very uncharted territory; everything is so gray. 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 (36). (1011)</p> <p>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)</p> <p>Mostly, [I wish I had] just another pair 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)</p> <p>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)</p>	
<p>Patients wanted to transform lung cancer into a chronic disease with less stigma.</p> <p>I just want more time. (3004)</p> <p>Make this a long-term chronic disease. That’s one thing that I know everybody is working hard toward. (3002)</p> <p>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 is 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)</p> <p>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 stigmatized 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)</p>	

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Table 3. Participant quotes related to improving health care experiences.

Patients wanted to have trust in their health care team.
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 she 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)
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 program 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)
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 center]. (1012)
I feel my health care 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)
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)
Patients want to be treated as partners in conversations and approached holistically, like individuals.
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)
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)
There were terrible communication problems. I could call at 10 o'clock on a Monday morning, and I would get a voice mail machine, and I would call back, and I'd be put on hold for 10 minutes. Then I called again, and then I get the voice mail machine again. I'd leave a message, and nobody would call me back. It ended up leaving me with the feeling that, like, just nobody really cared about me as a patient, as a person. (2008)
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)
For my cancer center, 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)
[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're 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)

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Page
Reporting Item		Number
<hr/>		
Title		
#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Abstract

#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions

2

Introduction

Problem formulation

#3 Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement

4

Purpose or research question

#4 Purpose of the study and specific objectives or questions

4

Methods

Qualitative approach and research paradigm

#5 Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be

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1			discussed together.	
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4	Researcher	#6	Researchers' characteristics that may influence the	5
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16			transferability	
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20	Context	#7	Setting / site and salient contextual factors; rationale	5
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23	Sampling strategy	#8	How and why research participants, documents, or	5
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33	Ethical issues pertaining	#9	Documentation of approval by an appropriate ethics	5
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43	Data collection methods	#10	Types of data collected; details of data collection	5
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57	Data collection	#11	Description of instruments (e.g. interview guides,	5
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instruments and technologies		questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	17
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	18-19

1	Discussion			
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4	Intergration with prior	#18	Short summary of main findings; explanation of how	8-10
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6	work, implications,		findings and conclusions connect to, support, elaborate	
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8	transferability and		on, or challenge conclusions of earlier scholarship;	
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18	Limitations	#19	Trustworthiness and limitations of findings	10
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25	Conflicts of interest	#20	Potential sources of influence of perceived influence on	11
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27			study conduct and conclusions; how these were	
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32	Funding	#21	Sources of funding and other support; role of funders in	12
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34			data collection, interpretation and reporting	
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40 <https://www.goodreports.org/>, a tool made by the [EQUATOR Network](#) in collaboration with
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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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**Unmet needs and opportunities for improving care for patients with advanced lung cancer
on targeted therapies: A qualitative study**

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Keywords: NSCLC, oncogenic alterations, ALK, ROS1, EGFR, qualitative research.

Word Count: 3973 words

Abstract

Objective: Lung cancer is increasingly recognized 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 health care experiences of these advanced patients with oncogenic mutation driven lung cancer.

Design: Qualitative interviews with advanced or metastatic non-small cell lung cancer patients with oncogenic alterations in ALK, EGFR, or ROS1.

Settings: Patients were recruited from online lung cancer support groups within the United States. Interviews were conducted remotely or in person, transcribed verbatim and analyzed 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 health care 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 health care experiences involved patients' desire to trust the expertise of clinical providers, receive reliable care, and be treated holistically and as informed partners.

Conclusions: Lung cancer patients 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. Health care 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.

Strengths and limitations of this study

Strengths of the study include giving voice to a new group of cancer patients, their needs and how their experience with health care can be improved.

Sampling from online support groups allowed the inclusion of patients from broad geographic areas in the United States.

The study captured the needs of these specific cancer patients 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 subgroups of patients.

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Background

Lung cancer is the second most prevalent cancer in the United States and the leading cause of cancer death [1]. In 2018, 2.1 million new cases were diagnosed world-wide with 1.8 million reported lung cancer deaths [2]. Patients with lung cancer experience a significant burden from not only the disease and its related symptoms, but also the side effects of treatments [3]. 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; stigmatization; hope and despair; loneliness; changes in self-image and self-worth; anxiety and fear; and uncertainty and worries [4-7]. While many lung cancer patients are typically diagnosed at advanced stages, with survival ranging from a few months to less than a year [8], recent advances have recognized the heterogeneity of this disease [9].

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-characterized, 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%) [10]. 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 characterized by these mutations (29.7 months for EGFR [11,12], 52.1 months for ROS1 [13], and 81 months for ALK [14]) are remarkably better than the generally poor prognosis of individuals lacking oncogenic alterations, and the overall historically short life-expectancy of advanced lung cancer patients. 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 [15, 16].

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 tumors, and addressing patients’ unmet needs [17,18,19]. 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 [18]. Other essential needs included emotional, financial, and spiritual ones [18]. However, studies focused on the patients with *advanced* lung cancer are limited. In one study, Giuliani et al. surveyed 80 Canadian lung cancer patients (median age 71) to explore their unmet needs [19]. 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 cancer patients. This is the first study to try to characterize the unmet needs of patients with advanced lung cancer on targeted therapy and to explore how their health care experiences with clinicians and care teams can be improved. Identifying the patients’ needs and their perspectives on improving their experience with health care will potentially allow health care providers to better understand and support these patients.

Methods

Study design: This is a qualitative in-depth interview study. The primary author (MA) interviewed lung cancer patients to learn about their unmet needs and their suggestions for improving the experience with their health care 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 United States. 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 lung cancer patient 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 Appendix 1. Participants were reimbursed \$50 for participation in the interview.

Analysis: The lead author used NVIVO 11 to organize 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 [20], consisted of four steps: low-level coding, meaning field analysis, validity reconstruction, and an iterative process of organizing the themes of the findings. First, the transcripts were read multiple times by the lead author (MA). Low-level codes were then developed and organized 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 co-authors 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 lung cancer patients and advocates from the online support groups, and their comments were included in the paper iterations.

MA is a family doctor, qualitative researcher, and lung cancer patient. 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 advanced cancer patients. 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 lung cancer patient/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-centered 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 minutes (median is 85 minutes) See Table 1 for patient demographics. We identified four main themes in the domain of unmet needs, and four in the area of improving health care experiences. In the sections below, we provide a narrative of these themes and their subthemes and refer to participant quotes in the accompanying tables.

1. 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. Table 2 includes supportive quotes.

1.1. 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 pre-disease state, they wished for “more time.” They hoped to continue to enjoy being active and doing what they loved. But 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 understand that lung cancer is highly stigmatized. It's under-researched, and that needs to stop."

1.2. Patients need understanding and emotional support.

With targeted therapy, patients lived, as one person put it, "*very uncharted territory where everything is so gray. Will you live for five years? Maybe. Will you live for six 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.

1.3. 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 stigmatized 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 stigmatized, 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.*"

1.4. 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.

2. Improving health care experiences.

The themes related to improving health care experiences included trusting in the expertise of the providers, desiring reliable care, and wanting to be treated as informed partners using holistic approaches. Table 3 includes supportive quotes.

2.1. 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 centers 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 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.”*

2.2. Patients want their health care 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 centers 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 she 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.

2.3. 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. She 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.

2.4. 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 centers 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 centers 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. Health care teams are instrumental in these patients' experiences. Patients desire both providers and cancer treatment centers 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 cancer patient needs [18, 19, 21-24]. Further, our study provides an in-depth account regarding this new group of cancer patients 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 lung cancer patients with oncogenic alterations.

Lung cancer, like most other cancers, disrupts the biography of a person [25-28], 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 conceptualize 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 prioritize immediate emotional and social goals over future-oriented ones that might expand horizons and involve knowledge acquisition [29-31]. This theory sheds light on the experience of cancer patients 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 health care providers in supporting these patients.

Lung cancer is a heavily stigmatized disease [32]. Throughout the literature, the experience of patients with lung cancer has been portrayed as that of shame, loss, and guilt [7]. It is an “invisible cancer,” a “death sentence,” and a “smoker’s disease” [32]. While many patients on targeted therapy perceived their experience to be qualitatively different than what they thought lung cancer would be like (e.g., quick death, steady progression, etc.), they still sensed stigma related to the diagnosis. Similarly, participants in our study believed that stigma contributed to their receiving variable treatments from providers (e.g., not getting on-time diagnostic tests) and to the allocation of disproportionately lower research funding compared to other cancers. The perceptions of these forms of stigma are reported in the literature [33]. 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 health care 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 [34]. According to a systematic review of 38 articles about cancer patients’ experiences of empowerment by Jørgensen et al. [34], patients view knowledge as power. This review indicates that patients desire access to information, seek information online, and view educational programs positively. Our study supports this evidence, and we lend our voice to the patients asking for empowerment. Thus, inviting health care providers and cancer centers 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 lung cancer patients in terms of their unmet needs and their relationships with health care. Variability in treating as well as diagnosing lung cancer have been documented previously with regard to

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3 race, gender, rural versus urban location, and socio-economic status [35-37]. In our study,
4 despite multiple attempts, the majority of our sample was white middle- or upper-middle-class
5 individuals, almost all with private insurance. The demographics of the participants, we
6 acknowledge, is a study limitation and constraint due to the sampling method. Differential access
7 to genetic testing may have directly contributed to a skewed representation at the patient
8 population level [38]. Even if we put aside access to genetic testing, our participants indicated
9 that distance from major cancer centers was associated with difficulty accessing supportive
10 services, clinical trials, and expertise in current treatment strategies.
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14 Our study exposes the personal difficulties and vulnerabilities faced by patients with
15 advanced lung cancer as they navigate the uncharted territory of survivorship, and revises the
16 professional responsibilities of health professionals in treating and partnering with these patients.
17 Health care providers and advocacy organizations can use these findings as they move to provide the
18 kind of comprehensive support, information, and treatment patients need. Further studies should
19 quantitatively look into how variations by demographic attributes, associated in the literature
20 with disparity, relate to variations in unmet needs and experiences with health care. Furthermore,
21 large data might also be leveraged to explore variations in lung cancer outcomes for different
22 patient groups and the relationship of these outcomes to variations in identifying genetic
23 mutations and utilizing targeted therapy. Finally, more work needs to focus on assessing
24 individual patient priorities and approaching their experience holistically to address not only the
25 biological aspects but also the social, psychological, and existential issues.
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Disclaimer

The author has not published or submitted any related papers from the same study.

Conflict of interest

Morhaf Al Achkar, Laura-Mae Baldwin, Lucille Marchand, Matthew Thompson, Debra Revere have no conflict of interest to report. Laura QM Chow received honoraria as a consultant for Amgen. She has also received research funding to institutions that she works with and/or serves on the advisory board for: Novartis, Merck, Lily/Imclone, Bristol Myers Squibb, AstraZeneca/Medimmune, Pfizer, Incyte, Takeda, VentiRx, Sanofi-Genzyme, Seattle Genetics, Dynavax, Genentech, Synthorx, and Alkermes.

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Author Statement

MA, LM, MT, LC, DR, and LMB contributed to the literature review and the conceptualization of the work. MA conducted the interviews. MA conducted the primary analysis of the data. LM, MT, LC, DR, and LMB did peer debriefing and review of analysis with MA individually and in groups. MA, LM, MT, LC, DR, and LMB all contributed to the writing of the discussion. All the authors reviewed and approved the final version of the study.

Transparency declaration

The authors affirm that the manuscript is an honest, accurate, and transparent account of the study being reported; that no important aspects of the study have been omitted.

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Data sharing

Deidentified data will be shared upon request.

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Table 1. Patient characteristics.

Table 2. Participant quotes related to patients' unmet needs.

Table 3. Participant quotes related to improving health care experiences.

Appendix 1. Interview Guide.

For peer review only

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

Table 2. Participant quotes related to patients' unmet needs.

<i>Patients desire to have lung cancer become a chronic disease with less stigma.</i>	
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 stigmatized 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)	
<i>Patients need understanding and emotional support.</i>	
It's very uncharted territory; everything is so gray. 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)	
<i>Patients want to live meaningfully without fear of financial devastation.</i>	
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 4 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 4 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 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 stigmatized or people would doubt that I was really sick enough to be on disability retirement because of my outward appearance. (2007)	
<i>Participants need help with daily practical matters.</i>	
Mostly, [I wish I had] just another pair 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)	

Table 3. Participant quotes related to improving health care experiences.

<i>Patients want to trust the expertise of their doctors.</i>
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 center]. (1012)
I feel my health care 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)
<i>Patients want their health care team to be reliable and to follow through.</i>
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 program 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 she 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)
<i>Patients want to be treated in conversations like informed partners.</i>
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 to attend sensitivity training to be able to begin to grasp what the patient is going through. (2009)
<i>Patients want to be approached holistically as persons</i>
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 center, 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)
[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)

Appendix 1. Interview Guide.

Screening Questions

Date of birth:

State:

Gender:

Type of Cancer:

Mutation:

Date of Diagnosis:

Cancer Stage at time of Diagnosis:

Cancer Stage Now:

Race/Ethnicity:

Education:

Insurance:

Preference for interview (In-person, phone, or video-conference):

Are you Proficient in English? Yes/No:

Are you well enough physically and psychologically to participate? Yes/No:

Are you willing to share about your day to day life? Yes/No:

First Topic Domain: Life Before Cancer Diagnosis

- Lead-off question

“I want to know about your life before you received the cancer diagnosis. To get to that, I would like to ask if you could think back to the months before your diagnosis, when you were fine and had no cancer-related symptoms, and help me create a picture of what your life was like. I am interested in knowing everything to get a picture of what your life was before you received the diagnosis.”

- Covert categories: [day to day life; meaning-making; identity; self-image; what did the person do before; who the person was before; aspects of life relevant to the person; norms and values; education; how the person looks at oneself in the past; how much reconstruction is taking place; the tone of feeling when reflecting about the past; the relation to the old self; others.]
- Possible follow-up questions
 1. What interactions with your family were like?
 2. What things you did during the week vs the weekend?
 3. Tell me about significant other(s)
 4. Tell me what you did for work then. Describe your job to me.
 5. Tell me about what you did in your leisure time (friends back then, hobbies, etc.)

Second Topic Domain: Diagnosis of Cancer

- Lead-off question

“Now I want to learn about your cancer itself. Tell me the story of your cancer diagnosis and treatment. Pretend that you are telling your cancer diagnosis story to a friend and tell me everything starting from when you noticed the very first symptoms.”

- Covert categories: [the experience of early symptoms; the internal dialogues and making decision to seek help; going to the doctor the first time(s), the experience of making the diagnosis; the role of family and friends; the experience with healthcare; perceptions about doctors, nurses, and staff; opinions of the health system at large; receiving the diagnosis; the decisions around treatment; the treatment; side effects; others]
- Possible follow-up questions
 1. How did the disease present itself?

2. *How did you make the decision to seek help?*
3. *How was your experience with the doctors, hospitals, clinic staff?*
4. *How did you and your doctor make decisions about treatment?*
5. *How was your experience with treatment?*

Third Topic Domain: Coping with Cancer

- Lead-off question

“I want to focus now on what you are doing to cope with cancer. What are you doing on day-to-day basis to deal with cancer? Tell me everything in the area of health and wellbeing related to dealing with cancer. [if there are special treatment days] tell me about the treatment days.”

- Covert categories: [health related actions; exercise; diet; taking medications; alternative approaches; other categories the patient considers relevant; why are they doing every one; what are implicit theories behind the workings of these actions; support persons]
- Possible follow-up questions
 1. *What are some things that you are doing to deal with stress/live better/be healthier/dealt with cancer?*
 2. *What are some things you are doing to get better at dealing with cancer? (what are things you considered doing but you did not for any reason?)*
 3. *What have you found helpful?*
 4. *How do you get strength?*
 5. *How do you find meaning?*

Fourth Topic Domain: Life after Cancer diagnosis

- Lead-off question

“Now I want to learn about your life after cancer diagnosis. Tell me about your life now, the day to day life. Walk me through a typical day of your week.”

- Covert categories: [how is the patient with cancer living life. What is different from before; what is the same; work; school; family; relationships; emotions/feelings; desires; struggles; things that are going well; things that are not going well; resilience; others]
- Possible follow-up questions
 1. *How do you spend your time if not working?*
 2. *What are non-cancer related things you do on day to day?*
 3. *What changed from before?*
 4. *Other questions as in the first topic*

Fifth Topic Domain: Unmet Needs

- Lead-off question

“I want to focus now on your unmet needs. What is it that you need in order to make things better in your day to day life? I am speaking about the emotional need, physical need, and spiritual needs and any others.”

- Covert categories: [unmet needs; desires; wants; struggles; conflicts; limitations; perceptions of what can be helpful; perceptions of what is contributing to the person’s struggle; how can others help the person; how can the person help herself; others]
- Possible follow-up questions
 1. *How is your quality of life?*
 2. *What could improve your quality of life today?*
 3. *What do you need for your emotional wellbeing?*
 4. *What is it that can be done for you so you feel better health-wise?*
 5. *What is it that can be done to improve your experience with your healthcare team?*

Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQR reporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

	Reporting Item	Page Number
Title		
#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1

Page 27 of 29	BMJ Open		
1	Abstract		
2			
3			
4		#2	2
5		Summary of the key elements of the study using the	
6		abstract format of the intended publication; typically	
7		includes background, purpose, methods, results and	
8		conclusions	
9			
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14	Introduction		
15			
16			
17	Problem formulation	#3	4
18		Description and significance of the problem /	
19		phenomenon studied: review of relevant theory and	
20		empirical work; problem statement	
21			
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24			
25	Purpose or research	#4	4
26	question	Purpose of the study and specific objectives or questions	
27			
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29			
30	Methods		
31			
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33	Qualitative approach and	#5	5
34	research paradigm	Qualitative approach (e.g. ethnography, grounded	
35		theory, case study, phenomenology, narrative research)	
36		and guiding theory if appropriate; identifying the	
37		research paradigm (e.g. postpositivist, constructivist /	
38		interpretivist) is also recommended; rationale. The	
39		rationale should briefly discuss the justification for	
40		choosing that theory, approach, method or technique	
41		rather than other options available; the assumptions and	
42		limitations implicit in those choices and how those	
43		choices influence study conclusions and transferability.	
44		As appropriate the rationale for several items might be	
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discussed together.

Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	5
Context	#7	Setting / site and salient contextual factors; rationale	5
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	5
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	5
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale	5
Data collection	#11	Description of instruments (e.g. interview guides,	5

instruments and technologies		questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	17
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	5-8
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	18-19

Discussion

Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	8-10
Limitations	#19	Trustworthiness and limitations of findings	10
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	11
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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