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

Morhaf Al Achkar,1 Lucille Marchand,1 Matthew Thompson,1 Laura Q M Chow,2 Debra Revere,3 Laura-Mae Baldwin1

ABSTRACT

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

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

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

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

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

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

BACKGROUND

Lung cancer is the second most prevalent cancer in the USA and the leading cause of cancer death.1 In 2018, 2.1 million new cases were diagnosed worldwide with 1.8 million reported lung cancer deaths.2 Patients with lung cancer experience a significant burden from the disease and its related symptoms and 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; stigmatisation; hope and despair; loneliness; changes in self-image and self-worth; anxiety and fear and uncertainty and worries.4–7 While many patients with lung cancer are typically diagnosed at advanced stages, with survival ranging from a few months to less than a year,8 recent advances have recognised 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-characterised, more frequent oncogenic alterations include epidermal growth factor receptor (EGFR) mutations (10%–35%), anaplastic lymphoma kinase (ALK) rearrangements (3%–7%) and c-ros oncogene 1 (ROSI) mutations (1%).10 Oral tyrosine kinase inhibitors developed to target these mutations have demonstrated

Strengths and limitations of this study

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

► Sampling from online support groups allowed the inclusion of patients from broad geographic areas in the USA.

► The study captured the needs of these specific patients with cancer as their lung cancer experience starts to resemble that of chronic disease.

► Limitations of the study include our inability to recruit from diverse minority groups.

► The study does not explore variations between subgroups of patients.
high effectiveness, low side-effects and improvements in survival to many years. Median survival rates reported for patients with lung cancer characterised by these mutations (29.7 months for EGFR, 52.1 months for ROS1, and 81 months for ALK) are remarkably better than the generally poor prognosis of individuals lacking oncogenic alterations, and the overall historically short life-expectancy of patients with advanced lung cancer. Additionally, sequential effective therapies in development are further extending the lives of these patients, rendering oncogenic altered NSCLC to be a chronic disease rather than an immediately terminal one.

The landscape of cancer care, in general, has shifted in the past few decades. What has become salient are issues related to long-term side effects and consequences of treatment, the early detection of relapse or secondary tumours and addressing patients’ unmet needs. 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. Other essential needs included emotional, financial and spiritual ones. However, studies focused on the patients with advanced lung cancer are limited. In one study, Giuliani et al surveyed 80 Canadian patients with lung cancer (median age 71) to explore their unmet needs. Four out of five patients reported at least one unmet need. No information was provided on the participation of patients with oncogenic alterations.

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

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

Study population
The patients met the following inclusion criteria: (1) advanced or metastatic NSCLC with an oncogenic alteration (ALK, EGFR, ROS1) at any point in survivorship; (2) psychologically and physically well enough to participate, as defined by the patient; (3) proficient in English and (4) receiving care in the USA. We identified patients using online oncogene-focused lung cancer groups of patients and their caregivers, namely the ALK-Positive Facebook Group, ROSOneder, and the EGFR Resisters. These are closed groups, and to join, the person must be a patient with lung cancer or a caregiver. The groups provide information and a sense of community to their members. Each had between a few hundred to a little over a thousand participants from all over the world. We intended that this study would include a series of follow-up interviews. Considering the anticipated attrition, we aimed to over-recruit participants. We also aimed to include a diverse representation of patients based on the duration of illness, the type of oncogenic alteration, gender, race and age.

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

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

The critical theory paradigm is sensitive to the specific values and assumptions of the research team. First, the research team assumed that people know their needs, and they are capable of naming them. Second, we were sensitive to issues of disparity as reflected in needs being met for some and not met for others. Third, we were sensitive to people’s entitlement to knowledge and the importance of empowering them. Finally, we engaged in peer debriefing as groups and as dyads, where MA met with the coauthors to review aspects of the work, including the coding and analysis, theme development and writing of the findings. Saturation of themes was
achieved after the analysis of 15–20 interviews. In addition to peer-debriefing, to enhance the trustworthiness of the work, we performed member checks. The paper draft was shared with patients with lung cancer and advocates from the online support groups, and their comments were included in the paper iterations.

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

**Patient and public involvement**

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

**RESULTS**

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

**Patients’ unmet needs**

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

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

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

| 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 | |
| <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 |
Box 1  Participant quotes related to patients’ unmet needs

Patients desire to have lung cancer become a chronic disease with less stigma.
I just want more time. (3004) Make this a long-term chronic disease. That’s one thing that I know everybody is working hard toward. (3002)
With the crizotinib, I know that eventually the cancer will mutate and continue to grow, and at that point, there are a couple of things that I can do, but it’s like the old game Frogger, where you are trying to cross the river, and you jump on a rock, and then you need the next rock to come up before the one that you’re standing on sinks. That’s what it’s like. So I’m standing on my rock, and I know it’s going to sink, and I know there’s one-half foot, and maybe another one’s starting to come up, but I want that next rock so I can make it across to it. (3004)
Every time I told somebody I had lung cancer, they said, ‘Do you smoke? How much do you smoke?’ There’s that instant association with smoking, and I began to understand that lung cancer is a highly stigmatised cancer. It’s under-researched, and that needs to stop. We need to talk about it. We need to explain to people that anybody can get lung cancer. It’s not just a smoker’s disease, and even if a person did smoke and did get lung cancer, that doesn’t mean that we shouldn’t treat them. (3001)

Patients need understanding and emotional support.
It’s very uncharted territory; everything is so grey. Will you live for five years? Maybe. Will you live for six months? Maybe. Could you live for ten years? Maybe. These targeted medicines are amazing. But it’s very uncharted territory, especially emotionally. People don’t pay a lot of attention to the emotional aspects of cancer; that’s been the hardest part for me at my age (mid thirties). (1011)
The issue of being young and feeling like my life was ripped away from me because of having cancer—a lot of lung cancer patients are older, have already had their children, already have their lives, and they get sick maybe with lung cancer at an older age. Me, I feel like I’m not a child, so I’m not in that group of young children with cancer, but I am not older either, so I’m somewhere in between. It would be great if there were some kind of group at the hospital that said, ‘Oh, you fit into this demographic group’ and ‘You probably have questions about fertility, and walking through adjusting to cancer while living on your own and being an independent single person’. (1018)

Patients want to live meaningfully without fear of financial devastation.
I decided if I only have a couple of years left on this planet, I’m going to do what I want to do. I’m not going to work at (a coffee shop). I want to do something that is meaningful to me. But it is challenging, the money part, right now at least. (1008)
The financial aspect, I won’t lie. It’s been a hard thing to figure, and it’s uncertain. You can only do so much financial planning when you have stage four cancer, because if you try to make a financial calculation about stage four cancer, you’re probably going to get it wrong, especially now. You just don’t know what’s around the corner, and that’s scary, but it’s hopeful too. So, the other thing I say is, you know, if I would outline my retirement savings, in a way, that’s a good problem to have. (3001)
If I lost my job, would I be able to get a job with stage four lung cancer? And in my industry, everybody knows I have lung cancer. So, are they really going to hire the director or VP level to charge ahead in their company if that person can’t even communicate if they’re going to be around in three years? (1020)
I feel I’m in the position to help the mentally ill and have an influence over policy and trends in our state. So to walk away from that opportunity, to even think about it, is very difficult for me. Probably the most common thing that is said to me by people is, ‘You look so good; you don’t look sick’. I’m afraid that if I were to go on disability retirement, I would be stigmatised or people would doubt that I was really sick enough to be on disability retirement because of my outward appearance. (2007)

Patients need helping with daily practical matters.
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)

Box 1  Continued

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

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

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

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

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

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

While lung cancer treatment strategies both prolonged survival and improved quality of life, some patients struggled with providers who still focused only on comfort care. One patient complained about their provider, ‘he is
not aggressive in his approach. He doesn’t know cutting-edge stuff. He doesn’t stay up-to-date because he believes in just making you comfortable. Whereas, for me, I want to live as long as I can, even if it’s one extra month.”

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

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

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

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

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

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

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

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

**DISCUSSION**

The experience of patients with oncogenic alteration driven NSCLC is uncharted. While novel targeted therapies have brought hope, quality of life and prolonged survival for this subset of patients, there is still daunting uncertainty. Patients grapple with the meaning of life and living with purpose, while the questions of mundane day-to-day matters still loom large. Healthcare teams are instrumental in these patients’ experiences. Patients desire both providers and cancer treatment centres that are up-to-date with advances in the field and treat them as whole persons. Our findings regarding unmet needs and improving healthcare experiences are consistent with the literature on needs of patients with cancer. Patients desired consideration of mental health and financial needs, and they desired access to resources. Some also wanted their cancer centres to provide complementary approaches. Instead, from their experience, ‘there wasn’t a whole lot of promotion of other things like healthy alternatives or seeing a dietician’. They wanted cancer centres to orient patients to therapy or support groups. One person complained, ‘Oncologists I’ve seen, they don’t deal with your psychological side. But all they have time for is reading the scan, telling you where you are, talking about the next steps’. Many also wished they had received access to palliative care early in their cancer. One person shared, ‘The palliative care team turned out to be nice and helpful. And I am sorry they did not send me to them sooner’.
many participants struggled to settle on a framework for life priorities and meaning-making. Many patients grappled with how much to work or whether work at all as opposed to doing other important activities. They struggled to understand their experience and be understood. Identifying this tension is the first practical implication of this study and is relevant for caregivers and healthcare providers in supporting these patients.

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

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

The listed existential, financial and informational needs described by some of our participants were not shared by all. Some interviewees just said that all of their needs were being met. Some only wanted more time. Our study highlights variations in the experiences of patients with lung cancer in terms of their unmet needs and their relationships with healthcare. Variability in treating as well as diagnosing lung cancer have been documented previously with regard to race, gender, rural versus urban location and socioeconomic status. In our study, despite multiple attempts, the majority of our sample was white middle-class or upper-middle-class individuals, almost all with private insurance. The demographics of the participants, we acknowledge, is a study limitation and constraint due to the sampling method. Differential access to genetic testing may have directly contributed to a skewed representation at the patient population level. Even if we put aside access to genetic testing, our participants indicated that distance from major cancer centres was associated with difficulty accessing supportive services, clinical trials and expertise in current treatment strategies.

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

Acknowledgements The authors would like to acknowledge Christina Baik, Daniel Evans and Tomoko Sairenji for reviewing the manuscript and providing valuable insight. The authors also thank LUNeighbors, especially Upal Basu Roy, for helping connect with patient advocacy and support groups. They also thank patients and patient advocates Janet Freeman-Daily, Jill Feldman, Ivy Elkins and Tom Carroll, for helping connect us to research participants. They also acknowledge the ROSOneder support group, the ALK-Positive Facebook Support Group and the EGFR Resisters for supporting and promoting this work.

Contributors MA, LM, MT, LC, DR and L-MB contributed to the literature review and the conceptualization of the work. MA conducted the interviews and the primary analysis of the data. LM, LT, 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.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests MA, L-MB, LM, MT and DR have no conflict of interest to report. LC 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, Lilly/Imclone, Bristol Myers Squibb, AstraZeneca/Medimmune, Pfizer, Incyte, Takeda, VentiRx, Sanofi-Genezyme, Seattle Genetics, Dynavax, Genentech, Synthorx and Alkermes.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. Deidentified data will be shared on request.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made

Al Achkar M, et al. BMJ Open 2020;10:e032639. doi:10.1136/bmjopen-2019-032639

Open access
indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

ORCID ID
Morhaf Al Achkar http://orcid.org/0000-0002-4160-0550

REFERENCES

1. Siegel RL, Miller KD, Jemal A. Cancer statistics, 2017. CA Cancer J Clin 2017;67:7–30.
2. World Health Organization. Cancer. Available: https://www.who.int/news-room/fact-sheets/detail/cancer.
3. Harrop E, Noble S, Edwards M, et al. Managing, making sense of and finding meaning in advanced illness: a qualitative exploration of the coping and wellbeing experiences of patients with lung cancer. Soc Health Illn 2017;39:1448–64.
4. Reisgaard B, Frederiksen K. Illness-Related emotional experiences of patients living with incurable lung cancer: a qualitative metasynthesis. Cancer Nurs 2013;36:221–8.
5. Salander P, Lilliehorn S. To carry on as before: a meta-synthesis of references.
6. Murray SA, Kendall M, Grant E, et al. World Health Organization. Cancer. Available: https://www.who.int/
7. Hsieh L-Y, Chou F-J, Guo S-E. Information needs of patients with lung cancer from diagnosis until first treatment follow-up. PLoS One 2018;13:e0199515.
8. Harrison JD, Young JM, Price MA, et al. What are the unmet supportive care needs of people with cancer? A systematic review. Support Care Cancer 2009;17:1117–28.
9. Kwan JYY, Croke J, Panzarrella T, et al. Personalizing post-treatment cancer care: a cross-sectional survey of the needs and preferences of well survivors of breast cancer. Curr Oncol 2019;26:e138.
10. Laveaïlahi H, Tisheliman C, Ohlén J. Framing the onset of lung cancer biographically: narratives of continuity and disruption. Psychooncology 2007;16:466–73.
11. Hubbard G, Forlati L. Cancer as biographical disruption: constructions of living with cancer. Support Care Cancer 2012;20:2033–40.
12. Trusson D, Pilnick A, Roy S. A new normal?: women’s experiences of biographical disruption and liminality following treatment for early stage breast cancer. Soc Sci Med 2016;151:121–9.
13. Pinquart M, Silbereisen RK. Socioemotional selectivity in cancer patients whose behavior may have contributed to their disease. Psychooncology 2008;4:717–33.
14. Weiss J, Yang H, Weiss S, et al. Stigma, self-blame, and satisfaction with care among patients with lung cancer. J Psychosoc Oncol 2017;35:166–79.
15. Weiss J, Yang H, Weiss S, et al. Stigma, self-blame, and satisfaction with care among patients with lung cancer. J Psychosoc Oncol 2017;35:166–79.