

CLINICAL CORRESPONDENCE

Behavioral and psychosocial responses of people receiving treatment for advanced lung cancer during the COVID-19 pandemic: A qualitative analysis

Kelly A. Hyland^{1,2}  | Heather S.L. Jim²¹Department of Health Outcomes and Behavior, Moffitt Cancer Center, Tampa, Florida²Department of Psychology, University of South Florida, Tampa, Florida**Correspondence**

Kelly A. Hyland, Department of Health Outcomes and Behavior, Moffitt Cancer Center, 12902 Magnolia Dr, MRC-SCM, Tampa, FL 33612.

Email: kelly.hyland@moffitt.org

Funding information

H. Lee Moffitt Cancer Center and Research Institute; National Cancer Institute

KEYWORDS: COVID-19, lung cancer, oncology, pandemic, qualitative

1 | INTRODUCTION

Current available information suggests that people age 65+, those with underlying medical conditions such as lung disease, people with weakened immune systems, and people undergoing cancer treatment may be at increased risk for severe illness from the novel coronavirus (COVID-19).^{1,2} Lung cancer patients are likely to have some if not all of these risk factors, placing them at particularly high risk for severe outcomes.³ Several publications have commented on the challenges of delivering oncology care during the COVID-19 pandemic.⁴⁻⁶ However, very little is known to date on the experiences of patients receiving oncology care during this time.

Qualitative inquiry represents the best available tool for capturing social responses to a pandemic.⁷ This cross-sectional, qualitative analysis explored cancer patients' perceptions of and behavioral and psychosocial responses to COVID-19. Patients' naturalistic discussion of COVID-19 and response to a question about behavior change in response to COVID-19 during semi-structured interviews were analyzed to identify themes and characterize patients' perspectives and experience.

2 | METHODS

The current analysis examined qualitative data from a convenience sample of participants in a larger study evaluating the relationship of hope, goals, and psychological well-being in people with advanced stage lung cancer.

Eligibility criteria for the larger study were: (1) diagnosed with advanced stage lung cancer (AJCC Stage IIIB or IV for non-small cell lung cancer (NSCLC), extensive stage for small cell lung cancer (SCLC)), (2) ≥ 18 years old, (3) no previous history of cancer, (4) undergoing first line systemic treatment for lung cancer at Moffitt Cancer Center, (5) English-speaking, (6) able to provide informed consent.

After providing informed consent, participants completed a baseline questionnaire and semi-structured interview about their current goals. One month later participants completed a follow-up questionnaire and semi-structured interview about perceived progress toward current goals. Participants due for follow-up from March 20, 2020 to May 8, 2020 completed procedures via mail and telephone. Participants spontaneously discussed COVID-19 during follow-up interviews, including how the pandemic had impacted their lives and progress toward current goals. At the end of the interview, participants were asked whether they had changed their behavior in response to COVID-19 and, if yes, how. Interviews were audio recorded. At the time of interview, no participants were reporting symptoms suggesting the presence of COVID-19.

Participants' naturalistic mentions of COVID-19 during follow-up interviews and discussion of behavior change in response to the pandemic were analyzed. Analyses were rooted in grounded theory and themes were derived inductively as they emerged from the data.⁸ While interviews were ongoing, authors familiarized themselves with the data by reviewing audio tapes (KH) and identifying participant mentions of COVID-19. Relevant portions of interviews were transcribed (KH) and interview notes and transcriptions were reviewed (KH, HJ) to identify key themes.

3 | RESULTS

Participant characteristics are presented (Table 1). Several key themes emerged from the data. Main attributes of each theme are described, and exemplary quotes are displayed (Table 2).

3.1 | Cancer as the primary health threat

In general, cancer remained patients' primary concern. Patients varied in the degree to which they expressed COVID-related concerns. Those with more severe side effects focused on cancer-related concerns, while patients who were stable on treatment emphasized the threat of COVID-19. Most were focused on COVID-19 to the extent that it may interact with their cancer, and acutely felt the compound threat to their health.

3.2 | Changes in oncology practice and access to cancer care

Participants commented on changes in the delivery of their cancer care (eg, virtual visits). Participants had mixed feelings on COVID-19-related policies (eg, no visitors), but emphasized the criticalness of continuing to receive treatment.

3.3 | Awareness of mortality and perceptions of risk

Participants cited awareness of the threat of mortality related to their lung cancer. COVID-19 posed an additional threat of mortality, and patients endorsed heightened perceived risk for poor outcomes should they contract COVID-19 due to their lung cancer.

TABLE 1 Participant Characteristics (N = 15)

Age M (SD)	65 (9.7)
Female N (%)	9 (60%)
Non-Hispanic White N (%)	15 (100%)
Cancer Diagnosis N (%)	
Stage IIIB NSCLC	2 (13%)
Stage IV NSCLC	12 (80%)
Extensive Stage SCLC	1 (7%)
Cancer Treatment N (%)	
Chemotherapy + immunotherapy + radiation therapy	3 (20%)
Targeted therapy	3 (21%)
Immunotherapy	2 (13%)
Chemotherapy + immunotherapy	2 (13%)
Clinical trial	5 (33%)

Abbreviations: NSCLC, non-small cell lung cancer; SCLC, small cell lung cancer.

Key Points

- The current analysis aimed to characterize the behavioral and psychosocial responses of people with advanced lung cancer to the COVID-19 pandemic.
- Qualitative analysis of patients' naturalistic mentions of COVID-19 and discussion of behavior change in response to COVID-19 during semi-structured interviews was performed to identify themes and characterize patients' perspectives and experience.
- Fifteen participants (M age = 65, 60% female) were interviewed from March 20 to May 8, 2020 and six themes emerged: cancer as the primary health threat, changes in oncology practice and access to cancer care, awareness of mortality and perceptions of risk, behavioral and psychosocial responses to COVID-19, sense of loss/mourning, and positive reinterpretation/greater appreciation for life.
- Qualitative analysis highlights the unique challenges and resilience of advanced cancer patients during the COVID-19 pandemic.
- Findings provide important and novel insight into patients' perceptions of and experience during COVID-19 and have implications for oncology providers.

3.4 | Behavioral and psychosocial responses to COVID-19

All participants reported changing their behavior in response to COVID-19. Some were accustomed to taking health-related precautions because of their cancer. Participants endorsed making changes consistent with general guidelines but with greater intensity because of the perceived higher stakes if they were exposed. Participants also endorsed additional, more significant changes related to their compromised health status.

Patients reported feeling scared and frustrated by the pandemic, and some endorsed increased anxiety and depressive symptoms. Participants, particularly those who were unpartnered, reported feeling lonely. Patients discussed different ways of coping, including spirituality and social support. While most reported limiting social contact, some continued to see family and friends under particular conditions. Participants received tangible support from friends and neighbors used technology to stay connected with loved ones.

3.5 | Sense of loss/mourning

Participants mourned the things that cancer had taken from them and how COVID-19 had taken even more. Participants discussed how

TABLE 2 Key qualitative themes

Theme	Attribute	Example
Cancer as the primary health threat	<p>Cancer-related functional limitations supersede COVID-19 limitations</p> <p>Emphasis on cancer-related challenges vs COVID-19 related limitations dependent on health status</p>	<p>"You know, I have sympathy and empathy for family and friends that are like "I'm going crazy, I've cleaned every drawer in the house and I've done every puzzle and I'm so bored and I don't know what to do"...and I'm like I've been living like this for 4, 5 months, you know...I want to do all the things you are able to do... at least you can get out for a walk..."</p> <p>"I don't go into work... I do have my computer here, and not because of the virus, but my vision is very difficult to deal with at this point... difficulties being on the computer all the time, put a crimp on what I used to do on a daily basis...so, I still do work, but not as much as I used to."</p> <p>"Things have changed a little bit...I've got some new cells that have popped up... it was not completely unexpected, the doctor was pretty ready for it... one thing is my level of pain has gone up...in the last 4 weeks it's been really a nagging situation..."</p> <p>"The coronavirus...that's about the only thing...my health has been fine, I really haven't had any roadblocks...it's been the COVID-19."</p>
Changes in oncology practice and access to cancer care	<p>Changes in oncology practice due to COVID-19</p> <p>Criticalness of continued access to cancer treatment</p>	<p>"I can't have anybody with me... I come in from over an hour away, one way, to drive in, I can't expect anyone to sit outside, and I never know how long I would be in there, could be 1,2,3,5 hours...I realize and I understand what they're doing, but have you thought about the patient and their support? And I guess they haven't... I don't know what they could do about it... put them in a gown, facemask, I don't know...but I mean, that's the support, I'm a widow, so now I'm going to be driving in there alone, going in alone, and not having anyone to be there with me."</p> <p>"... it's quieter at [cancer center]...it is different, everybody is wiping down things and it's just like wow...you know, you put your mask on and you sit 6 ft from somebody, wait for your MRI or CT scan or whatever... I think the biggest thing is just not having that interaction with the doctor, but that's okay too, you still talk to them on the phone, it's just different."</p> <p>"I've been able to keep all of those [appointments] and, thank god, because that's about all I do... and if I wasn't able to do that it would not be good, I don't think, because the treatments I think are helping, so, we'll see how long they continue to help."</p>
Awareness of mortality and perceptions of risk	Threat of mortality related to being a cancer patient during COVID-19	<p>"...just said to myself, what's going to happen this Christmas? The thing that's really frightening right now is they say this is going to leave, then it could come back, so that leaves me in a very precarious position, where I'm not feeling bad, but how do I make arrangements to do something, and then should I be up there [visiting family]? Should I be around people? And this is very sad... these people who are dying and they can't see their loved ones, that is really sad. And I hate to say it, but these are the kinds of things, they're on your mind. You don't know...they keep saying anyone over 65,</p>

(Continues)

TABLE 2 (Continued)

Theme	Attribute	Example
	Heightened perceived health risk related to COVID-19	<p>anyone with a chronic or lung issue, taking chemotherapy, well it's like... I'm all of the above." "Well, yeah... I went and had a quick deed and a will drawn up...I know if I catch this, you know, it's over and done with for me." "...because of my lungs being compromised, we have to really pretty much stay sequestered...I'll always be maybe a little uncomfortable, because I don't think this is going away...I definitely will be on the side of caution, I won't be doing shopping that I used to do, so I definitely see change...people with lung cancer, you know I would be the worst...so, yeah, it affects your life, and it will probably permanently affect the way I feel in crowded environments."</p>
Behavioral and psychosocial responses to COVID-19	<p>Behavioral changes related to having advanced cancer during COVID-19</p> <p>Psychosocial challenges related to having advanced cancer during COVID-19</p>	<p>"I don't do 6 [feet] I do 20, and I don't go to grocery stores, my husband does that or our friends do it for us." "...well, yeah I went out today, went to the post office, dropped 2 bills in the mailbox so I didn't have to get out of the truck, then I went to CVS drive thru to pick up my prescriptions then back home...I even drove slow!" Because of my conditions...have not been going anywhere...we haven't been letting any friends in the house, we have two people in the neighborhood getting groceries and leaving them on the steps...pretty much very isolated. I have a short term disability policy through work, which I was on when all of this [the cancer] began, then I went back to work, and now with all of this [COVID-19], I just felt it was better for me...I'm currently back on disability. Nervous, frustrated, you know scared, in seclusion here, worry about our groceries, worry about if medication will be delivered on time, that I need desperately, worried about shopping, getting it delivered, for instance we just had Instacart delivered, we're in there scrubbing it down like crazy. "...Depression can certainly weigh on people...it's a horrible thing, and it can definitely bring you down in a heartbeat, and if you're by yourself sometimes, that's very difficult to get over, so a lot of times having family to be able to call on, you know, you just need somebody, and they'll come over...even though we're in this horrible situation, they'll come...and they can still be out in the driveway and be able to have a conversation, or go for a walk or something, so I think depression is probably the hardest thing for anyone at this point."</p>
Sense of loss/mourning	Cancer has already taken things away, now COVID-19 taking away things that were left	<p>"...last time I was in they let me get off oxygen, which was great...and I would have loved to go out to eat without having that pipe up my nose, and before the virus, occasionally we could go out to eat to our favorite restaurants, it was just something that I really enjoyed doing, and of course now we can't...and that really was the only place I went, it's not like I could go to the grocery</p>

solutions. It is important to recognize that changes in oncology practice may impact patients in different ways. While for some telemedicine offers convenience and reduces risk of exposure, others may miss the in-person clinical encounter. Additionally, clinicians should be aware that typical sources of support may not be available and consider ways to increase patient comfortability (eg, teleconference family).

The suspension or cancellation of usual activities or meaningful experiences due to COVID-19 may be particularly devastating for patients with life-limiting illness given significant uncertainty about their health and the future. Patients expressed a sense of loss about what cancer had already taken from them, and how this was compounded by limitations imposed by COVID-19. Clinicians can empathize with patients' sense of mourning while continuing to serve as a trusted authority on recommended health-related precautions.

Fear, frustration, sadness, and loneliness are common and justified emotions during a global pandemic. However, these emotions may be particularly challenging for patients with a history of anxiety or depression, or who are already experiencing heightened distress related to cancer. Greater loneliness has been associated with worse quality of life and greater depressive symptomology in lung cancer patients, highlighting the potential negative consequences of COVID-19-related isolation for patient wellbeing.⁹ Clinicians should regularly screen for symptoms of distress and loneliness using brief, validated measures¹⁰ and continue to refer patients to psychosocial services when appropriate.

Results of this small, exploratory study provide a snapshot of the experience of patients with advanced cancer at a single academic cancer center during the COVID-19 pandemic. All participants were non-Hispanic White, limiting the generalizability of study findings to patients from racial and ethnic minority groups. Additionally, findings may not reflect the experience of patients receiving care in other regions where the impact of COVID-19 may be different, or in the community setting. Importantly, qualitative analysis highlights the unique challenges and resilience of advanced cancer patients during COVID-19. Oncology providers are well positioned to assess for practical and psychosocial challenges and refer for psychosocial services as needed.

ACKNOWLEDGMENTS

The authors would like to thank Paul Jacobsen, Ph.D. for his assistance with the manuscript. This work was supported in part by the National Cancer Institute (P30 CA076292) and the Population Research, Interventions, and Measurement Core Facility at the H. Lee Moffitt Cancer Center and Research Institute, a National Cancer Institute-designated comprehensive cancer center.

CONFLICT OF INTEREST

Heather S. L. Jim reports consulting for RedHill BioPharma, Janssen Scientific Affairs, and Merck.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

ORCID

Kelly A. Hyland  <https://orcid.org/0000-0001-9864-5306>

REFERENCES

1. CDC. Coronavirus Disease 2019 (COVID-19). Centers for Disease Control and Prevention. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/groups-at-higher-risk.html>; 2020.
2. Liang W, Guan W, Chen R, et al. Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. *Lancet Oncol*. 2020;21(3):335-337.
3. Dai M, Liu D, Liu M, et al. Patients with cancer appear more vulnerable to SARS-CoV-2: a multi-center study during the COVID-19 outbreak. *Cancer Discov*. 2020;10(6):783-791. <https://cancerdiscovery.aacrjournals.org/content/early/2020/04/24/2159-8290.CD-20-0422>.
4. Burki TK. Cancer guidelines during the COVID-19 pandemic. *Lancet Oncol*. 2020;21(5):629-630. [https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045\(20\)30217-5/abstract](https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(20)30217-5/abstract).
5. Schrag D, Hershman DL, Basch E. Oncology practice during the COVID-19 pandemic. *JAMA*. 2020;323(20):2005-2006. <http://jamanetwork.com/journals/jama/fullarticle/2764728>.
6. Mei H, Dong X, Wang Y, Tang L, Hu Y. Managing patients with cancer during the COVID-19 pandemic: frontline experience from Wuhan. *Lancet Oncol*. 2020;21(5):634-636.
7. Teti M, Schatz E, Liebenberg L. Methods in the time of COVID-19: the vital role of qualitative inquiries. *Int J Qual Methods*. 2020;19:1609406920920962.
8. Glaser BG. The constant comparative method of qualitative analysis. *Soc Probl*. 1965;12(4):436-445.
9. Hyland KA, Small BJ, Gray JE, et al. Loneliness as a mediator of the relationship of social cognitive variables with depressive symptoms and quality of life in lung cancer patients beginning treatment. *Psychooncology*. 2019;28(6):1234-1242.
10. Distress Thermometer and Problem List Information. <https://www.nccn.org/about/permissions/thermometer.aspx>; 2020.

How to cite this article: Hyland KA, Jim HSL. Behavioral and psychosocial responses of people receiving treatment for advanced lung cancer during the COVID-19 pandemic: A qualitative analysis. *Psycho-Oncology*. 2020;29:1387-1392. <https://doi.org/10.1002/pon.5445>