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“Living with Loss”: A qualitative exploration of existential fears among people with advanced lung cancer in online lung cancer support groups

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Abstract

Objectives. With targeted therapies, people are surviving longer with advanced lung cancer and engaging in online lung cancer support communities. While these groups provide a sense of community, witnessing the death of peers can lead to emotional distress. This qualitative study aims to (1) explore the experience of witnessing death in online cancer support groups; (2) identify factors that contribute to the emotional struggles of witnessing the death of peers; and (3) identify strategies/options for dealing with losses in the cancer community.

Methods. We conducted a cross-sectional analysis of qualitative interviews exploring existential concerns with participants ($n = 25$) from oncogene-specific online lung cancer support groups. The principal investigator conducted study interviews between August 2018 and March 2019 where participants were asked about their cancer experiences and existential concerns. We used thematic analysis and NVIVO 11 software to examine and store the de-identified interview data.

Results. Participants indicated that they had often witnessed their peers die and felt the pain of the loss. Factors that played a part in their struggle with witnessing others' death included the closeness of the relationship with the person, the age of the person who died, seeing oneself in the experience of the other dying, disparities in care, and losing touch in the final stages. Participants used varied coping strategies such as celebrating the life of the individual who died, engaging in advocacy efforts, not focusing on the loss, participating in therapy, and bringing self-preserving thoughts.

Significance of results. Our study highlights the importance of addressing existential fears in online lung cancer support groups and incorporating conversations about death in spaces that deal with cancer.

Introduction

With advancements in molecular testing and targeted therapies, people with lung cancer are surviving longer and living with high symptom burden and psychological distress (Majeed et al. 2020; Mok et al. 2020; Mosher et al. 2016). As compared to other cancers, lung cancer is associated with poorer prognosis and stigmatization (Lehto 2017). In metastatic lung cancer, the 5-year relative survival rate is 9% (American Cancer Society 2023). Distressing symptoms such as poor appetite, dyspnea, fatigue, pain, and cough frequently result in high levels of symptom burden for people with advanced lung cancer (Polanski et al. 2016). Early integration of palliative care in this population is associated with clinically meaningful improvements in quality of life and mood, less aggressive care at the end of life, and longer survival (Temel et al. 2010). Peer support, defined as being helped by, exchanging information with, and encouraging others who have the same disease may help to foster empowerment and fulfill unmet care needs (Park et al. 2019; Ziegler et al. 2022). Peer supporters are underutilized in interventions targeting lung cancer, palliative care, and end-of-life issues (Kowitz et al. 2019). With increasing availability of online support since the COVID-19 pandemic, online support offers specific advantages such as wider reach through accessibility, more frequent and flexible participation, low costs, and potentially a degree of anonymity (Ziegler et al. 2022). They can help to connect people worldwide, providing a safe space to share their experiences, offer emotional support, and exchange information (Harkin et al. 2017; Kaal et al. 2018; Walsh and Al Achkar 2021).

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However, increased access to peers can also increase exposure to adverse outcomes, such as cancer progression or recurrence and the suffering of other people like them (Jablotschkin *et al.* 2022; Walsh and Al Achkar 2021). This may result in existential distress, particularly when hearing about those who have died (Jablotschkin *et al.* 2022; Walsh and Al Achkar 2021). Additionally, when group members compare their own situations with others in a downward comparison, this can lead to survivor's guilt (Jablotschkin *et al.* 2022).

Coping with another's death and grieving one's health-related losses within online cancer support groups can intensify a person's experience of pain (Pereira *et al.* 2021). People witnessing death in online cancer support groups may experience significant emotional distress, fearing they will suffer the same fate as those who have died. However, little has been written to characterize the experiences of people living with advanced lung cancer in online support groups as they encounter the death of their peers.

This study fills the critical knowledge gap by addressing 3 objectives: (1) to examine how people living with advanced lung cancer experience witnessing the death of their peers in online support groups; (2) to identify factors that play a part in the struggle of witnessing others' deaths; and (3) to discover strategies for coping with these losses.

Methods

Study design

This study employed a cross-sectional analysis of qualitative interview data. The principal investigator (MA) conducted in-depth qualitative interviews with people living with advanced lung cancer treated with targeted therapies to understand their experiences with the illness. All participants were recruited from online lung cancer support communities.

The study's first authors are female licensed social work clinicians and researchers with expertise in adolescent and young adult oncology and palliative care. NF serves as the director of a lung cancer program in a region of the US with some of the highest levels of lung cancer incidence and mortality. TSN is an associate professor of education policy with expertise in qualitative studies. The study's principal investigator and senior author, MA, is a practicing family medicine physician and stage IV lung cancer survivor with expertise in qualitative health research.

Study population

Participants were selected for the study based on meeting the following inclusion criteria: (1) having metastatic or advanced non-small cell lung cancer with 1 oncogenic alteration (EGFR (epidermal growth factor receptor), ALK (anaplastic lymphoma kinase), or ROS-1 (proto-oncogene tyrosine-protein kinase-1)); (2) being physically and psychologically well enough to participate; (3) having English proficiency; (4) receiving medical care in the USA; and (5) being a member of a lung cancer online support community. Purposive sampling was used to identify participants from specialized online groups focusing on oncogene-related lung cancer, serving both patients and caregivers. These groups include the ALK-Positive Facebook Group, ROSOneder, and EGFR Resisters. To join these forums, one must be diagnosed with lung cancer or be a caregiver, ensuring the exclusivity of membership. These platforms aim to provide insights from members and foster a sense of community. Typically, these groups have membership counts

ranging from several hundreds to just over a thousand, with participants hailing from various regions worldwide. Interaction within these communities mainly occurs via text forums on social media. Members frequently form connections, and on some occasions, they meet in-person at conferences or national advocacy events. In advanced lung cancer support groups, the loss of peers is common (Walsh and Al Achkar 2021). News of a member's passing is typically conveyed by family members, mutual acquaintances, or group posts.

Study procedures

The principal investigator conducted study interviews by phone, videoconference, or in-person between August 2018 and March 2019. The interviews explored how participants' cancer experiences may have changed over time and their existential concerns. This longitudinal exploration enables deeper understanding of patient experiences while living with advanced illness. The conversation centered on 3 main areas of interest: exploring the experience of witnessing death in online support groups among peers; identifying factors that contribute to the emotional struggles of patients who witness others' deaths; and identifying strategies for dealing with losses (see Appendix). Participant characteristics were collected verbally at the beginning of the interviews. Participants received a \$50 gift card as a token of appreciation for their participation in the study.

Analysis

We used NVIVO 11 to manage the de-identified interview data. The analysis aimed to examine the experience of witnessing death in online support groups, identify factors contributing to the emotional struggles of patients who witness others' deaths, and identify strategies for dealing with losses. Detailed methods used in the study can be found in previous publications (Al Achkar *et al.* 2020; Walsh and Al Achkar 2021).

The authors employed thematic analysis (Guest *et al.* 2012) to examine and organize the interview data. In the initial steps of the thematic analysis, the senior author, MA, read the transcript and identified question prompts and subsequent data relevant to the topic of this paper. He provided all authors with the same data to which they each individually performed the first round of coding by assigning short phrases and words to sections of the text. Next, all authors met bi-monthly via Zoom over a period of 6 months to discuss code names, definitions, and initial themes. They created a codebook to apply to the remaining interview data. They collected salient quotes from participants' interview data to represent each theme. In each meeting, the team reviewed codes line-by-line and discussed variances in codes until consensus was reached.

Results

We interviewed 25 participants from oncogene-specific online lung cancer support groups. Table 1 presents the participants' characteristics.

Witnessing death in online cancer support groups

People witness the death of their peers in online cancer support groups. They experience the emotional impacts of losing friends and mentors in the cancer community. They are challenged with

Table 1. Participant demographic and clinical characteristics (N = 25)

Demographic	Mean (range)/number of participants
Age	51.64 (30–75)
Gender	
Male	7
Female	18
Stage at time of interview	
IIIA-B	2
IV	23
Race	
White	23
Asian	2
Ethnicity	
Non-Hispanic	24
Hispanic	1
Education	
Some college	2
College	15
Masters	5
Doctorate (MD or PhD)	3
Insurance	
Medicaid	2
Medicare	3
Private	20
Region	
Northeast	3
Midwest	4
West	12
South	6

observing others struggle during their final moments. They also experience tensions while participating in support groups where the fear of death is salient.

Hearing about the deaths

Except for a few participants who have not yet experienced the loss of a fellow cancer survivor, most participants have experienced the death of their peers. They have lost friends and some lost mentors. Those active in the online support group see group members posting about those who died. One participant shared, “It is hard for everybody in that group because even though you don’t, maybe not know those people personally, you feel a connection to them in so many ways. And when one of them dies, you feel so sad for their family” (1016).

Watching others during their final struggle

Participants often have seen others through their final struggle in what they describe as “going down the hill.” In the online space, some patients who used to be active stop participating. Patients resort to the comfort of a smaller circle of family and friends. Their

peers are left to respect their wishes as they request no visitors. Some feel sad not to see them anymore as they hold themselves in a private space. They wonder about their emotions and whether they feel defeated. Some choose to pray, wishing the dying person not to suffer. One participant explained, “We’re a little more attuned to when someone is not doing well, right? So, when I see that someone’s posting something, then I kind of pray that they don’t suffer. You know they’re not going to come out of it better. So, you just kind of pray that they’re not suffering towards the end and that it’s like a happy death, if there’s such a thing?” (1017).

Experiencing the pain of loss

Witnessing the death of a peer survivor is very hard on participants, and it was portrayed by lung cancer group members as “tough,” “the hardest thing,” “gutting,” “scary,” and “deadly.” After the loss, participants dwelled on it and often felt knocked down by it. For some, it was not different from the death of a family member. It affects the person mentally as they start thinking more about their own death. One participant shared, “The longer you go, the more you worry because there’s going to be resistance I’d say that physically, I’m the same, but mentally, I’m probably worse. I tend to dwell on it more, especially there’d been a lot of deaths now in our group, in our EGFR Resisters group, and that’s really depressing. It kind of guts you” (2004).

Managing group engagement

Death occurs frequently in the support group, making the topic of death and dying constantly prominent. For some, it is the biggest challenge for the community, as it reminds survivors of their illness. One participant explained, “when I read those posts where people have passed or people are having trouble, it brings them more to the forefront and it’s not how I want to deal with it, I’m not pretending I’m not sick I know I’m sick, but I don’t want to focus on that, I want to focus on who I am” (1014). Further, people grow to care for others only to lose them, making forming new connections even harder. Most do not know how to deal with death and react to it with sadness.

Factors playing a part in the struggle of witnessing others’ death

The emotional impact of witnessing the death of peers through online cancer support group settings is related to multiple factors. The closeness of relationships, age of the deceased, personal similarities, disparities in care, and losing touch in the final stages contribute to the intensity of participants’ emotions.

Closeness of relationship with person

The difficulty in grappling with loss tends to be greater for those with whom participants have a closer relationship or stronger connection. Having known someone for a longer period or having met them in person can exacerbate the loss. As participants spend more time within the lung cancer support community, they feel the weight of the cumulative loss of peers in the community. One participant shared, “I suffer in degrees depending on whether I have formed a relationship or not with those particular people, and none of them live close to me that I know of” (3005).

The age of the person who dies

Participants experience a greater emotional impact when a younger person dies, especially when thinking about the bereaved loved ones, particularly children. One participant expressed, “It makes

me sad, that's all. It frightens me, scares me, it guts me I feel so bad for them – she left three little boys and I think about the little kid, like the smallest one is I guess six, waking up in the middle of the night with a nightmare, going to the bed looking for his mother, his mother is not there” (2004).

Seeing oneself in the experience of the other dying

It is distressing for participants to learn about others dying with a similar trajectory to their own. It feels very personal and elicits scary thoughts about their own dying process. There can also be denial about one's own mortality and the reality of dying sooner than expected. One participant explained, “I haven't had anybody that I personally know in the community pass away yet, but when I see it happen on Facebook or what not, when people announce it, I just feel really sad. And it also just kind of makes you think about your own mortality a lot more as in, ‘Oh it happened to this person, it could happen to me anytime’” (2001).

Disparities in care

Participants appreciate research advancements, but they can also raise questions about disparities in care and what else could have been done for the person. One participant shared, “When one of [the group members] dies, you feel so sad for their family and you think of everything they went through and you wonder why something else couldn't have worked for them like it's working for you. And, you know, it just reminds me to be on my toes and keep learning everything I can” (1016). Several participants voiced their appreciation for research in extending their lives; “So I think of all the people that didn't make it this far and I'm still here because of research and I'm really grateful for that” (1016).

Losing touch in the final stages

Participants experience a sense of loss when care becomes more intimate (e.g., no visitors). One participant said, “Like my friend is very close with her son so she's made it known to him that she doesn't really want visitors. There's part of me that just says that is just sort of sad about that I can't see her, because she is a close friend” (3001).

Strategies/options in dealing with losses

Because participants found the online support communities meaningful and to avoid fully shutting off, they used strategies to help them stay connected and lean on each other. These included celebrating the life of the individual who died, acknowledging what they learned from each loss, advocating for the families of the person who died, not focusing on their loss, and acts of self-preservation.

Celebrating life

Members of the lung cancer support community often connected over the loss of a community member. They celebrated the life and the contributions that the member had on the group as a whole or for them personally. Strategies for celebrating the life of their peers included creating a scrapbook of memories in which they could reflect on their relationship and fun memories that they shared. One participant shared, “We were able to celebrate our friend's life and knowing that that's what she would want as well” (2005).

Engaging in advocacy efforts

The death of a member often spurred a desire to continue the bond they had with the deceased group member, whether it be continuing their activity within the group, their lung cancer advocacy efforts, or their chosen course of treatment. Advocacy served as a coping mechanism and offered hope for the future. Some members led initiatives to reduce the stigma associated with lung cancer. Another form of advocacy can be seen in praying for the deceased and the children of the deceased group members. One participant explained, “I feel that new life, that excitement and, and you know, those advocates that are out there doing everything they can to get the word out and get research dollars that keeps me excited and positive about the future” (2006).

Not focusing on the loss

Participants created space to honor their deceased peers while also taking time away to heal. Witnessing their peer's struggles and death often reminded them of their illness. Staying in their grief proved challenging to living in the moment as it set a difficult emotional tone for days. Members often took a few days to recover and keep a distance from reading posts. This emotional distance did not mean avoiding the reality of death. It gave participants the time to focus again on living and not being down. The decision to keep space comes for some as a corrective to the urge to check previous posts by the person and attempt to investigate what happened. They carry on with what one member described as “sleuth mode” until they get a reminder from a caregiver to take a break. One participant explained, “And so I guess my thing is I can't focus on that. I can acknowledge it. I can spend my time grieving on that, but I can't stay there. I have to keep looking at the positive stuff and the new drugs that come out and the researchers that want to do more stuff from the cancer” (2006).

Participating in therapy

Working with a therapist offered members strategies for coping with grief, building self-compassion, and reducing anxiety. Mental health tools to increase mindfulness and acceptance helped buffer threatening thoughts about death. Putting efforts to live mindfully in the moment and focusing on the present helped to refocus their thoughts away from their illness. Finally, practicing gratitude for their current health and social situations helped some members maintain a positive mindset. One participant revealed, “It is one of the reasons that I did begin therapy to really work on that. I obviously want to be around for as long as possible. It's one of the reasons that I do all of the other things that I do, the physical activity that I do, the spiritual, to help me cope with all of that. But also knowing and being in the healthcare field, I do also know that anything can happen at any given time” (2005). Another participant shared 1 specific strategy garnered from therapy: “So I think about it and then I use the, just my tools. We call it RAIN, which is like Recognize, I think it's like, Recognize, Accept, Investigate and Nurture. So those are the steps that I take” (2001).

Having self-preserving thoughts

To feel safer, some participants centered on the difference between their situation and that of the deceased one. They sought to identify reasons and factors that made them see their personal situation as different from the person who died. They contemplated how the other person might have had limited access to quality lung cancer treatment if they were not offered some treatment options or if they declined an offered treatment option. They resorted to becoming

more vigilant in their own health care by researching new treatments and clinical trials to rebuild some of the broken hope for the future. Acknowledging that they were doing all that they could do for their own illness provided some comfort and recognizing that people respond differently to treatment helped to reduce their worries. Lastly, learning that the person who died had a good death and no longer suffered from physical or existential pain, reduced feelings of distress. One participant reflected, “I think mine is like a self-preserving mechanism for me to think, ‘Well, there are all these other reasons why someone passed away that may not apply to me. So, in a sense, it makes me feel a little more at peace with it, I guess” (1017).

Discussion

Our study represents the first qualitative exploration of how people living with lung cancer cope with witnessing the death of their peers in online support groups. We identified factors that render some experiences more challenging than others, as well as coping strategies to help manage losses. Our findings suggest that hearing about the death of peers in the cancer community can cause significant emotional distress, and as such participation in support groups can become a source of tension at times. Factors contributing to the struggle of witnessing death include the closeness of the relationship with the deceased, younger age of the deceased, identifying with the experience of the dying individual, disparities in care, and losing touch in the final stages. Strategies for coping with losses encompass celebrating life, engaging in advocacy, participating in therapy, and embracing self-preserving thoughts. Our study adds to the literature on supporting cancer patients with end-of-life concerns (Adorno and Wallace 2017; Perez et al. 2020).

Previous research has underscored the benefits of community support groups and peer support for mental health (Breitbart et al. 2010; Shim et al. 2011). Our study juxtaposes these benefits with the experience of witnessing death in online support groups, an aspect often overlooked. Our findings demonstrate that encountering death in online support groups can pose a serious challenge. The tension arising from living in a liminal space and sharing life experiences with those who are dying can be overwhelming for some (Adorno 2015; Currin-McCulloch et al. 2021). Significant literature has explored end-of-life and death experiences, such as those of AYA (Perez et al. 2020; Pritchard et al. 2011; Sansom-Daly et al. 2020) and breast cancer survivors (Kenne Sarenmalm et al. 2009). However, the experience of lung cancer patients surviving for years due to targeted therapies while grappling with many unknowns and multiple notions of death remains unexplored. Our study emphasizes the existential fear and ambiguity experienced by people living with lung cancer in online support groups as they face the death of their peers.

Our study offers insights into the nuances of encountering death and highlights the need to improve resources for people living with advanced lung cancer seeking virtual community and support. Our findings expand knowledge about the benefits of mutual aid groups, suggesting that shared coping with distressing life events may outweigh the distress caused by increased exposure to others facing the same stressful life event (Gitterman and Schulman 2005). Developing strategies to manage loss experiences is crucial, especially for individuals struggling in the moment. Practical applications of our findings encompass the need to consider the effects of connecting with peers in the cancer community, including frequent confrontation with death. Identifying strategies for individuals and

communities to receive support during loss experiences is vital, as is the early integration of palliative care services (Irwin et al. 2013).

This study's strengths include its focus on the often-overlooked advocacy community in lung cancer. Conducting interviews about existential concerns following trust-building and openness garnered through an initial interview potentially facilitated more nuanced and candid conversations. Additionally, the interviewer, a known cancer survivor in the lung cancer community, likely increased participants' openness. Lastly, our study encompassed patients from 3 lung cancer sub-communities, presenting a broad range of experiences.

Although these qualitative data come from a longitudinal study of people living with advanced lung cancer, the participants only received prompts about their experiences in living with the loss of others during their second interview. As such, their experiences of witnessing the death of others describe their feelings at the time of this interview and their feelings likely vary over time. The study's majority female and White sample creates challenges in applying the participants' lived experiences with lung cancer to those with marginalized identities for which social determinants may limit access to lung cancer treatment and psychosocial support resources. The perspectives of people who attend online support groups may vary from those who attend in-person meetings or who choose not to seek group support. Online groups have the benefits of integrating people who live in rural areas, lack transportation, have rare conditions and treatment protocols, or have physical limitations that prohibit in-person attendance. However, those who experience economic or technical barriers may be less likely to join online support groups. Thus, the generalizability of these findings is limited to the study sample.

Future research could focus on opportunities to integrate support for grief and loss in online lung cancer support communities. Further research is also needed to explore the effectiveness of coping strategies identified in this study, such as celebrating life, engaging in advocacy, participating in therapy, and embracing self-preserving thoughts. In conclusion, this study highlights the challenges that people living with advanced lung cancer face in witnessing the death of their peers in online support groups.

Our study emphasizes the importance of addressing existential fears experienced by people living with advanced lung cancer in online support groups and incorporating conversations about death in cancer-related spaces. We hope this study stimulates discussions and interventions that better support patients coping with grief and loss in the lung cancer community. Practical examples include psychoeducation from cancer providers that discusses both the benefits and stressors that can occur due to online lung cancer support group participation. This could include open dialogues about the potential that they may experience loss and grief and see themselves in the experiences of others. Online lung cancer support groups could be facilitated or moderated by social work and/or palliative care clinicians to provide grief support and resources. Additionally, experts in grief could join groups to answer questions and normalize the experiences of witnessing the decline and/or death of peers with lung cancer.

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