ORIGINAL RESEARCH

Evaluating the User-Perceived Benefit of a Virtual Lung Cancer Patient Education and Support Community: LVNG With Lung Cancer

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Authors' disclosures of conflicts of interest are found at the end of this article.

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In Memoriam
The authors are deeply saddened by the passing of coauthor Dann Wonser, MA, LPC. Dann passed away on June 28, 2024, 18 years after his diagnosis of stage 4 lung cancer. He was a passionate lung cancer patient advocate and author of Second Wind–Thriving with Cancer. You can visit www. dannwonser.com to read his blog where he shared his advice and experiences on his journey.

Abstract

Background: The accessibility and quality of network support for people living with lung cancer (PLW) and their support partners (SP) can vary. Virtual platforms provide unique opportunities for PLW/SP peer support and disease education. **Methods:** Using a novel dual approach, we determined the user-perceived impact of the AstraZeneca-sponsored Facebook community, *LVNG With Lung Cancer* (facebook.com/LVNGWith-LungCancerUS), and measured the social/behavioral impact on PLW/SP. Qualitative 1-hour phone interviews were conducted with community members aged ≥ 18 years. Additionally, inbound community comments (December 2015–October 2016) were retrospectively analyzed and categorized. **Results:** 18 PLW and 2 SP were interviewed. Mean years since diagnosis was 2.75 (range, 0.08–17). Of the total expressions of benefit (*n* = 513) made during the interviews, 32% focused on increased health knowledge; 28% on social impacts of the community (e.g., having a supportive environment); and 18% conveyed feelings of empowerment. Community membership led to behavioral change in many respondents: 55% asked their doctor more questions, and 50% gave advice to others. Inbound community comments (24,336 posts from 12,187 unique members) reflected the themes offered during interviews as important reasons to participate: 63% of posts asked for or shared cancer information; 98% provided emotional support/understanding; and 84% were inspirational/optimistic. **Conclusions:** This analysis of the real-world impact of a virtual community provided insight into the benefit that members derive. We hypothesize that once members' emotional and educational needs were met, they were empowered and/or inspired to take positive actions leading to better health behaviors and increased quality of life—an outcome that may apply to other diseases.

Lung cancer is the leading cause of cancer-related death worldwide (Sung et al., 2021) with a high symptom burden and mortality despite recent treatment advances (de Mello & Amaral, 2020). A lung cancer diagnosis is understandably difficult for both people living with lung cancer (PLW) and their support partners (SP) who will face complex emotional and educational barriers, as well as a substantial impact on their quality of life (QOL; Fitch, 2019; Grant et al., 2013; Lheureux et al., 2004). Many may feel stigmatized given the relationship between lung cancer and smoking, which is further associated with anxiety, depression, and reduced QOL (Brown Johnson et al., 2014; Fitch, 2019).

The physiological and psychological impact of lung cancer continues beyond diagnosis, and PLW and SPs can experience significant psychological distress, including the financial burden of treatment and reduced QOL through treatment, as well as the potential for disease progression (Bade et al., 2015; Grant et al., 2013; Hazell et al., 2020; Prapa et al., 2021; van Montfort et al., 2020). This is particularly the case for long-term survivors of lung cancer (Rauma et al., 2015; Yang et al., 2012) who may also have lower participation in patient advocacy programs compared with survivors of other cancers due to low survivorship and survivor guilt (American Cancer Society, 2021; Fitch, 2019; Vijayvergia et al., 2015).

Health-care providers and their organizations can be challenged to provide adequate support for the complex and dynamic needs of PLW and SPs (Fitch, 2019). Outside of therapeutic interventions, PLW and SPs have educational needs concerning lung cancer knowledge, recovery information, food selection, and support resources, as well as a need to connect with others to share experiences (Hsieh et al., 2018; McIllmurray et al., 2001; Nightingale et al., 2019). Indeed, access to education on lung cancer and a robust support network from peers can improve the QOL of PLW and SPs (Kedia et al., 2020; Kobayashi & Ishizaki, 2020) and is significantly associated with better SP health when provided to PLW, and vice versa, demonstrating the importance of dyadic support (Kelley et al., 2019; Luo et al., 2020).

As a result, PLW and SP support via online health groups is a growing dimension of patient care, providing information to: improve understanding about the disease, treatment options, and factors important for making treatment decisions; social support; and enabling participants to gain skills to be more active in health-care decisions and more positive about their health expectations (Kashian & Jacobson, 2020; Wicks et al., 2018; Willis, 2016; Zhou & Fan, 2019). In addition, these communities can provide support to PLW and SPs who may be less mobile or need to maintain social distancing (e.g., due to COVID-19).

Several studies have assessed the content and use of online oncology communities and the support provided (Attai et al., 2015; Falisi et al., 2017; Green et al., 2020; Harkin et al., 2020; Johansson et al., 2021; Kashian & Jacobson, 2020; Lu et al., 2017; McCaughan et al., 2017; Taylor & Pagliari, 2019; van Eenbergen et al., 2018; Walsh & Al Achkar, 2021), including some specifically for lung cancer (Lu et al., 2017; Taylor & Pagliari, 2019; Walsh & Al Achkar, 2021). However, few have reported on the emotional, behavioral, or intellectual changes resulting from participation in an online community (Attai et al., 2015; Falisi et al., 2017; Lu et al., 2017; McCaughan et al., 2017; van Eenbergen et al., 2017; Walsh & Al Achkar, 2021).

LVNG With Lung Cancer (https://www.facebook.com/LVNGWithLungCancerUS) is a Facebook group sponsored, managed, and moderated by AstraZeneca that aims to provide emotional support, health education, inspiration, and opportunities through original and curated content, and peer-to-peer connection for PLW and SPs; it does not mention or promote specific treatments. As of June 2022, over 220,000 participants are engaged with the *LVNG With* community.

METHODS
Study Design and Objectives
This evaluation study was designed using a novel mixed-methods approach. It compared results from in-depth, individual, exploratory qualitative interviews with a sample of participants engaging with the *LVNG With* community, with data from a retrospective analysis of comments and replies extracted from the *LVNG With* community site (Figure 1).
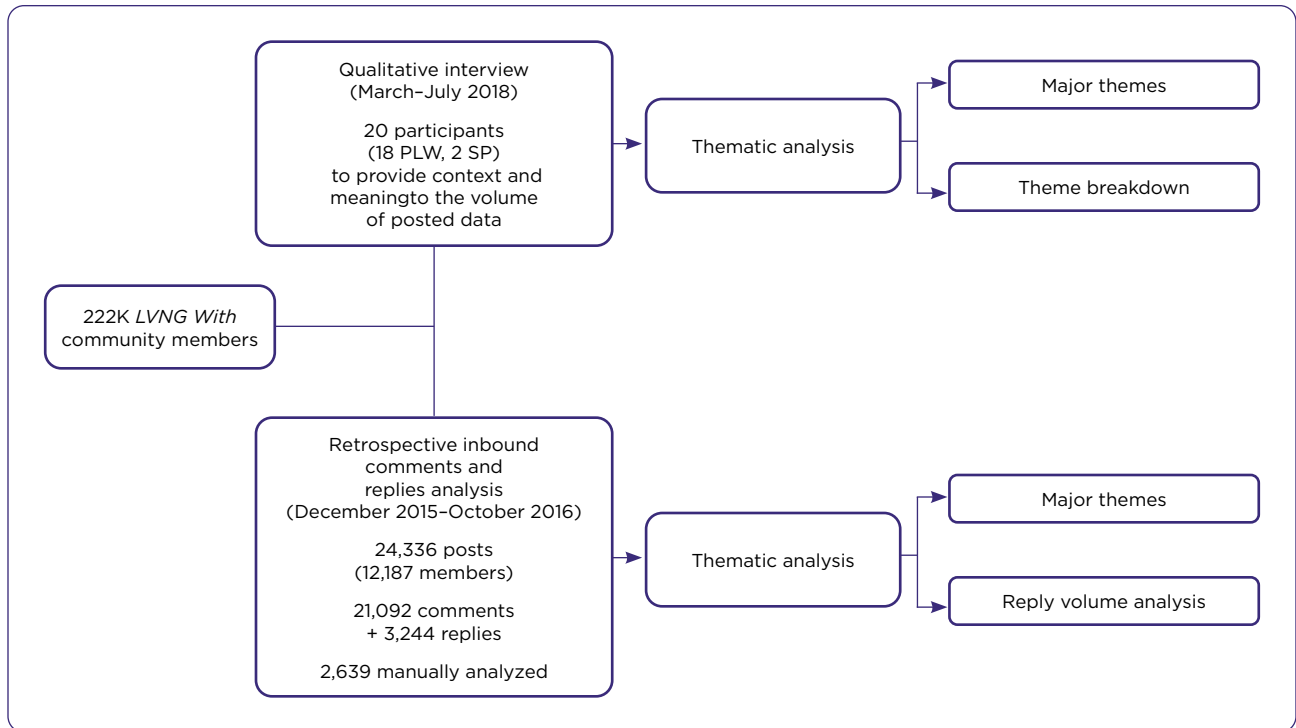
Figure 1. Dual thematic analyses of the *LVNG With* community: Qualitative interviews and retrospective analysis of participant posts. PLW = people living with lung cancer; SP = support partner.

The objectives were to assess the impact of engagement with the *LVNG With* community by PLW and SPs, and to identify what, if any, user-perceived benefits were associated with participation.

Qualitative Interviews

Trained qualitative research interviewers conducted 60-minute telephone interviews between March and July 2018 with participants who engaged with the *LVNG With* community. The qualitative interviews were conducted in accordance with the principles stated in the Declaration of Helsinki, Good Clinical Practice, and applicable regulatory requirements; interviews were approved by Institutional Review Boards (IRB), and all participants provided informed consent.

Adult participants were enrolled if they were: a PLW or an SP caring for someone actively on lung cancer treatment; a participant engaging with the *LVNG With* community who had selected "liked" or "follows" on the site; and well enough to participate in the interview process. Planned recruitment was 20 participants from across the US with the following diversity targets: both PLW and SPs

with ≥ 10 PLW; ≥ 20% male; inclusion of ethnic minority participants; and ≥ 3 participants who had engaged with the *LVNG With* site 0 to 1 time. Initial recruitment contact was made using a general posting on the site. Responding participants were provided with study and participation information. If interested, a study interviewer followed up with eligibility screening and consent forms. All interviewers were trained Health Research Associate research staff with experience conducting qualitative exploratory interviews with PLW and SPs and who underwent training specific to this study. Quality assurance procedures included mock interviews and random monitoring of interview voice files from each interviewer by the trainer. Following completion of the interview, each participant was compensated with $125 for their time.

In the semi-structured interviews, an interview guide was used to ask PLW/SPs about: themselves and their everyday life with lung cancer; their entry into the *LVNG With* community; their level, including changes over time, of participation and how they partici-

Table 1. Participant Demographics from the *LVNG With* Community Qualitative Interviews

Characteristic, *n* (%)[a]	Value (*N* = 20 interviewees)
Age	
Mean (SD), years	58.6 (11.2)
Median (range), years	62.0 (29.0–74.0)
Gender	
Female	16 (80.0)
Male	4 (20.0)
Race	
White or Caucasian	15 (75.0)
Black or African American	4 (20.0)
Hispanic	1 (5.0)
Participant type	
Person living with lung cancer	18 (90.0)
Support partner	2 (10.0)
How often do you visit the *LVNG With* page on Facebook? (*N* = 19)	
Daily	7 (36.8)
Weekly	6 (31.6)
Monthly	6 (31.6)
Less than monthly	0 (0)
How often do you "like," "react," "share," or comment on *LVNG With* posts? (*N* = 20)	
Daily	3 (15.0)
Weekly	7 (35.0)
Monthly	7 (35.0)
Less than monthly	3 (15.0)
How many hours in an average day do you spend on the internet? (*N* = 15)	
Mean (SD)	2.3 (1.4)
Median (range)	3.0 (0.3–4.0)
How would you describe your initial participation in *LVNG With*? (*N* = 16)	
More a reader	10.0 (62.5)
More a writer	0 (0)
A mix of reader and writer	6 (37.5)

Note. [a]Unless otherwise stated. SD = standard deviation.

pated in the community; and the benefits they perceived and actions taken resulting from this participation. Topics explored included health outcomes, life impacts, QOL, feelings of empowerment, shifts in attitudes, health knowledge, and positive actions taken to support health and survivorship (Appendix A).

Interviews were audio recorded, transcripts deidentified, and concepts were identified, coded, and grouped by content and common theme, and prepared for qualitative analysis by Health Research Associate research staff. Saturation of concept was evaluated to identify the point at which no new information (appearance of new codes) was forthcoming. Demographic descriptions were summarized by descriptive statistics.

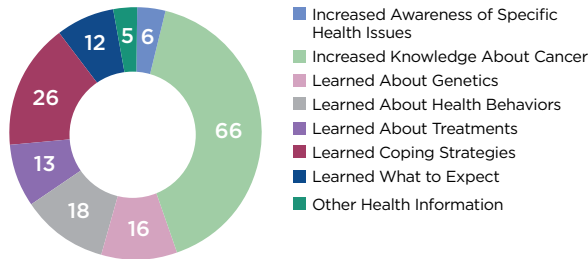### Retrospective Communications Analysis

Retrospective analysis of inbound community comments and replies posted on *LVNG With* and in response to moderator posts was conducted. Comments and replies from December 2015 to October 2016 were extracted using Google Analytics and summarized with descriptive statistics. Search strings were used to identify and quantify post threads most related to benefits of sharing, disease understanding, treatment, emotional support, and outcomes. Advertisements and emojis were excluded. Findings were grouped by content and common themes.

RESULTS

Participants and Datasets

Twenty participants (18 PLW and two SPs) completed the qualitative interviews (Table 1); 80% were female with a median age of 62 years (range, 29–74). The mean time since diagnosis was 2.75 years (range, 0.08–17). More than one third of those interviewed (36.8%) visited *LVNG With* daily and nearly two thirds (62.5%) initially participated "more as a reader." Saturation of concept was met in the first half of the interview process. The lack of new codes appearing after this point suggested that a sufficient number of participants had been interviewed to have a full picture of responses from a participant sample of this nature. Transcript coding identified 513 total expressions of benefit from participation that were grouped into 23
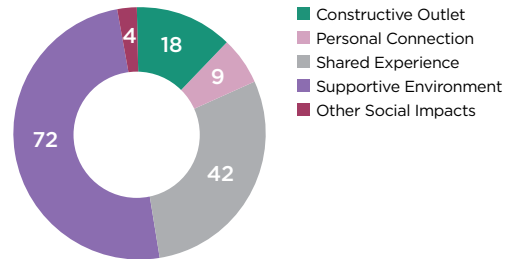
A. Health Knowledge: 32% Expressions of Benefit (162/513)

Legend:
- Increased Awareness of Specific Health Issues
- Increased Knowledge About Cancer
- Learned About Genetics
- Learned About Health Behaviors
- Learned About Treatments
- Learned Coping Strategies
- Learned What to Expect
- Other Health Information

Values: 5, 6, 66, 16, 18, 13, 26, 12

70% (14/20) of transcripts expressed increased knowledge of lung cancer

50% (10/20) of transcripts expressed that participants learned about health behaviors and coping strategies
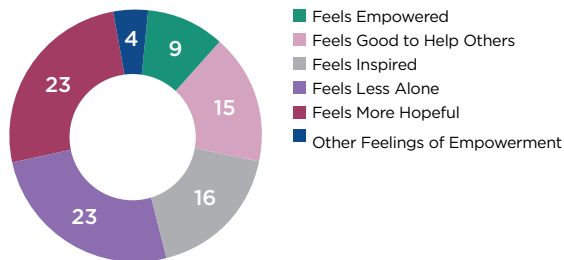
B. Social Impacts: 28% Expressions of Benefit (145/513)

Legend:
- Constructive Outlet
- Personal Connection
- Shared Experience
- Supportive Environment
- Other Social Impacts

Values: 18, 9, 42, 72, 4

80% (16/20) of transcripts expressed the benefit of a supportive environment

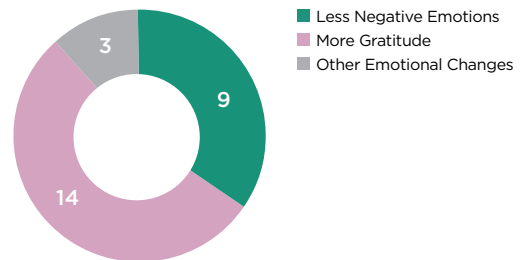65% (13/20) of transcripts expressed the benefit of the shared experience

C. Feelings of Empowerment: 18% Expressions of Benefit (90/513)

Legend:
- Feels Empowered
- Feels Good to Help Others
- Feels Inspired
- Feels Less Alone
- Feels More Hopeful
- Other Feelings of Empowerment

Values: 9, 15, 16, 23, 23, 4

55% (11/20) of transcripts expressed that participants felt less alone

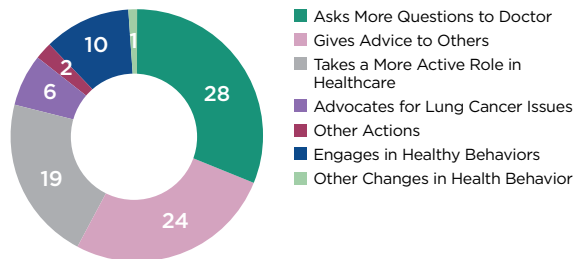40% (8/20) of transcripts expressed that participants felt inspired and more hopeful

D. Emotional changes: 5% Expressions of Benefit (26/513)

Legend:
- Less Negative Emotions
- More Gratitude
- Other Emotional Changes

Values: 9, 14, 3

35% (7/20) of transcripts expressed feeling fewer negative emotions

30% (6/20) of transcripts expressed feeling more gratitude

E. Actions: 15% Expressions of Benefit (79/513) and Behaviors: 2% Expressions of Benefit (11/513)

Legend:
- Asks More Questions to Doctor
- Gives Advice to Others
- Takes a More Active Role in Healthcare
- Advocates for Lung Cancer Issues
- Other Actions
- Engages in Healthy Behaviors
- Other Changes in Health Behavior

Values: 28, 24, 19, 6, 2, 10, 1

55% (11/20) of transcripts expressed that participants asked their doctor more questions

30% (6/20) of transcripts expressed that participants engaged in more healthy behaviors

Figure 2. Thematic analysis of expressions of benefit from qualitative interviews. Numbers in each segment of the pie chart correspond to the number of expressions for each concept mentioned in the interview transcripts.

unique concepts within four main themes: health knowledge, social impacts, feelings of empowerment, and emotional changes (Figure 2A–D); in addition, actions and behaviors that resulted from community engagement were explored (Figure 2E).

In the retrospective online analysis, there were 24,336 posts in total, comprising 21,092 comments and 3,244 replies, retrieved from 12,187 unique participants during the 11-month evaluation period. Of the 3,244 replies, 2,639 replies were relevant to the objectives outlined above and were analyzed for content (Figure 1).

Thematic Analysis of Benefits: Health Knowledge

Qualitative interview results showed that 32% of all expressions made about benefits focused on increased health knowledge (Figure 2A). Of the interview participants, 70% discussed increased knowledge of cancer, including specific health issues (25%), genetics (25%), and treatment knowledge (35%).

One participant commented, "It's answered so many questions of mine; that I probably would've waited so long for answers, but I've gotten answers pretty quickly." Another said, "[I learned about] the different testings (sic) that you can help, speak with your doctor about."

Learning coping strategies (50%) and good health behaviors (50%) were also listed as key benefits (Table 2).

In the retrospective analysis, 63% of comments/replies to posts were related to lung cancer understanding; "understanding" and "cancer" were the two most frequently used keywords from comments/replies.

Users shared their own experiences about disease symptoms, treatments, and/or diagnosis.

One participant said, "The new medicine is (...) a targeted treatment for the ALK mutation only." Another commented, "...I had pneumonia twice that wouldn't go away (...) found out I had a tumor which they biopsied..."

Additional educational resource information was shared in 15 posts that referred to educational resources (Lung Force, Free to Breathe, Lung Cancer Alliance, Lung Cancer Foundation), leading to 775 messages. Genetic information was widely shared; 10 posts that mentioned mutations led to 3,126 messages.

Thematic Analysis of Benefits: Social Impacts

In the qualitative study, social impacts accounted for 28% of all expressions of benefit (Figure 2B). Having a supportive environment and a forum to share experiences were most frequently cited by 80% and 65% of interview participants, respectively (Table 2). Having a constructive outlet to speak frankly (35%) and be accepted (30%) was important to PLW who did not want to overtax their family support systems.

In the retrospective analysis, the vast majority of comments and replies (98%) provided some sort of emotional support, sense of understanding, or both. Many of the emotional support comments/replies provided validation and wished each other well (prayers 34%; validation 21%; condolences 13%; sharing 12%; Table 2).

Additional findings on social impacts included the stigma of lung cancer as it relates to smoking (i.e., if you have lung cancer you must have been a smoker); 1,178 messages mentioned this recurrent theme.

Thematic Analysis of Benefits: Feelings of Empowerment

In the qualitative interviews, 18% of all expressions of benefit stated that participation in the virtual community gave feelings of empowerment, including feeling less alone (55% of interview participants) and feeling inspired to help others and being more hopeful (each 40%; Figure 2C and Table 2).

In a notable example from the qualitative interviews, a participant said the community provided her with the knowledge she needed to address her own symptoms and fears with her doctor, which ultimately led to an early lung cancer diagnosis through her self-advocacy. Prior to her diagnosis, she initially joined the community because a family member, who was supporting a PLW, was an existing member of the community. She first went to hospital with stomach pains and a lesion was incidentally found on her lung. She was sent to a pulmonologist who could not believe it was cancer based on her age (28 years) and non-smoker status, and advised to monitor it, even though it looked malignant. Despite doctors being

Table 2. Examples of Quotes from the Qualitative Interviews and Comments Identified in the Quantitative Analysis

Theme	Concepts covered in theme	Example quotes from qualitative interviews	Comments from quantitative analysis
Health knowledge	• Increased knowledge of cancer • Learning coping strategies • Learning good health behaviors	"It's answered so many questions of mine; that I probably would've waited so long for answers, but I've gotten answers pretty quickly." "[I learned about] the different testings that you can help, speak with your doctor about." "It's sharing information that I like (...) as to what other people are doing to cope and live with their daily struggles." "[I read] people talking about diets even if it's interesting, like there's maybe there's something I could change about mine."	"The new medicine is (...) a targeted treatment for the ALK mutation only." "...I had pneumonia twice that wouldn't go away (...) found out I had a tumor which they biopsied..."
Social impacts	• Having a supportive environment • Having a forum to share experiences	"[Thanks to the *LVNG With* community] the anxiousness is not as bad...I don't feel overwhelmed anymore" "The fact that other people have a condition just like I do. The fact that I'm not alone...they are dealing with the same thing I deal with on a daily basis."	"Keep the faith and fight." "I will be praying for you! I'm also on immunotherapy and my first CT."
Feelings of empowerment	• Feeling less alone • Feeling inspired to help others • Feeling more hopeful	"I'm making progress with my health because of it, that makes me feel empowered." "...But it still is a relief to know that you're not alone... There are other people going through this." "And hearing somebody else's stories and being able to identify with what they were saying or what they've been through obviously that it is very empowering, because you don't always have that in your own circle of family, because they haven't been through the experience."	N/A
Emotional change	• Feeling fewer negative emotions • Feeling more gratitude in their life	"[*LVNG With* has] made [my QOL] so much better... you're overwhelmed, so anxious, depressed, grieving... you get your questions answered, you're getting your life back." "I feel hopeful more than I did." "Yeah, I think it helped me to know that I'm important too, and what I do is important helping my husband."	"Thank you for brightening my husband's final few hours..." "...I'm doing chemotherapy now and I can say I feel good."
Actions and behavioral changes	• Engaging in more healthy behaviors • Asked their doctor more questions • Gave advice to others • Took a more active role in their health care	"[Post] did change my mindset about exercise, and I do get out there and try to do more." "I have brought it to my oncologist's attention that if we do biopsy any of the new spots that have popped up right now, we're watching them, but that I definitely want mutation testing, and would not have known to ask for that." "I've gone in and asked questions as to about mutations and why wasn't I tested and so oftentimes if I see or learn something through *LVNG With Lung Cancer* then I will go in and question my oncologist."	N/A

Note. ALK = anaplastic lymphoma kinase; CT = computerized tomography; N/A = not available; QOL = quality of life.

convinced that it was not lung cancer, the participant conducted her own research through *LVNG With* and additional lung cancer support groups. She was also contacted, through Facebook, by a person who shared their experience with her, as a means of support. Empowered with the knowledge and experiences from other PLW stories from the community about how they found their cancer or how they got diagnosed, she was able to successfully self-advocate and pushed for a second opinion. She was sent to a surgeon, as the location of the tumor necessitated surgery to obtain a biopsy. Although doubtful of a cancer diagnosis due to her age, the surgeon was willing to do the biopsy and a lobectomy was performed and the diagnosis of lung cancer confirmed.

Thematic Analysis of Benefits: Emotional Change

In the qualitative interviews, 5% of all expressions of benefit related specifically to emotional changes (Figure 2D). A total of 35% of interview participants reported feeling fewer negative emotions and 30% felt more gratitude in their life (Table 2).

In the retrospective analysis, the sentiment of comments, as interpreted by the research staff, showed > 84% of comments/replies were inspirational and optimistic, no matter if a "happy" (70%) or "sad" (24%) sentiment or event was communicated (Table 2; responses to a sad event, such as death, would be considered inspirational if there was an inspirational or optimistic tone to the exchange).

Thematic Analysis of Benefits: Actions and Behavioral Changes

In the qualitative interviews, 2% and 15% of all expressions of benefit were related to behavioral changes and actions taken, respectively (Figure 2E). A total of 30% of interview participants reported engaging in more healthy behaviors (Table 2), and 55%, 50%, and 35% reported actions like asking their doctor more questions, giving advice to others, and taking a more active role in their health care, respectively.

The retrospective analysis showed that users encouraged others to seek help and offered practical advice that could help others change their behavior to improve outcomes.

DISCUSSION

In this dual thematic analysis, we explored the social media experience of PLW and SPs to assess the potential value of participating in the *LVNG With* community and any associated changes in behaviors. Few studies focus on lung cancer PLW and SPs (Taylor & Pagliari, 2019; Walsh & Al Achkar, 2021), and our unique dual analysis study design allowed us to obtain a broader picture of patient-perceived benefit, resulting in a more holistic overview of patient perceptions.

We found that participation in the *LVNG With* community satisfies emotional needs in a way that leads to positive emotional and psychosocial changes, health outcomes, actions, and behaviors, with general improvements in QOL and well-being experienced by PLW and SPs. Participants described first joining the *LVNG With* community to fulfill both educational and emotional needs. They were experiencing an acute sense of isolation associated with the diagnosis and had a need to connect to others with similar experiences. While initial engagement was reported as "more as a reader" (62.5%) or a mix of reading and posting (37.5%), those engaging with the community for longer periods of time were more likely to share and give advice to newer participants.

Four main categories of benefits were identified from the qualitative study, and these themes were generally reflected in the retrospective analysis. The combined results describe community members' engagement developing through several phases (Figure 3):

- During early interactions with the community, when information is the new participant's greatest need, health knowledge (cancer information, good health behaviors, and coping strategies) is sought.
- As they draw support and encouragement from other participants, they describe the positive social impacts of participation such as having a forum to share experiences and a supportive environment.
- The ability to release negative emotions and feel more gratitude resulted in feeling empowered, less alone, and inspired to help others.
- They then take actions and build better health behaviors to improve their QOL.
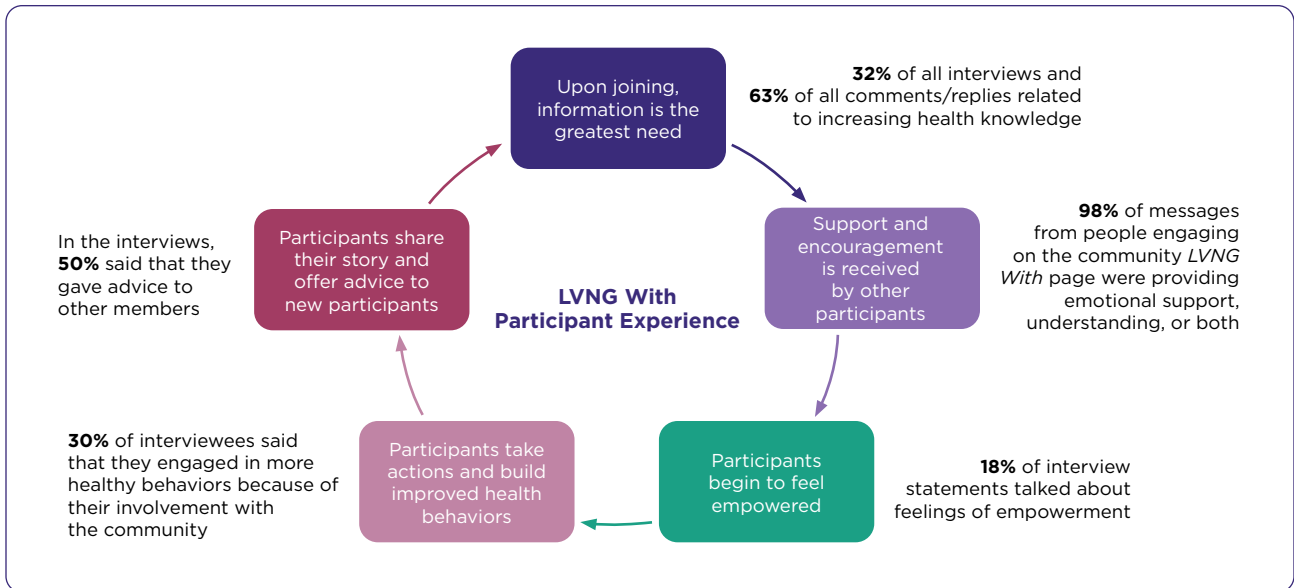
Figure 3. *LVNG With* participant involvement evolution of benefits.

- This leads to participants sharing their stories with the community and giving advice to new participants.

Notably, participants described new behaviors such as asking their clinicians more questions, making healthier living choices (e.g., exercising more), being more active in treatment-related decision-making, and being inspired to help others.

Similar themes have been shown in previous analyses of online oncology support communities with PLW and SPs gaining societal and emotional support, providing a sense of belonging and feeling a part of a group sharing the same experiences, and also gaining a useful source of health knowledge, prompting them to take more action around their own health-care decisions (Attai et al., 2015; Falisi et al., 2017; Green et al., 2020; Harkin et al., 2020; Johansson et al., 2021; Kashian & Jacobson, 2020; Lu et al., 2017; Taylor & Pagliari, 2019; van Eenbergen et al., 2017; van Eenbergen et al., 2018; Walsh & Al Achkar, 2021). In the qualitative analysis by Walsh & Al Achkar based on PLW interviews, similar types of engagement were observed (i.e., asking, responding, and passive observing) but the risks of engagement, including misinformation, feeling marginalized, and comparing oneself with others, were also highlighted (Walsh & Al Achkar, 2021). These negative aspects were not heard in the open-ended interviews with participants of the *LVNG With* community, and may depend on specific aspects of virtual community allowances and management. The *LVNG With* community is a moderated community to ensure scientific accuracy of the posted content, so no posts had misinformation or misrepresentation of scientific facts. Moderators ensure that the community is supportive, with no overtly negative comments or replies allowed; this is explicitly communicated to participants through community guidelines. Patients living with cancer and SPs were given an opportunity during the interview to describe emotions and feelings as a result of communications within the *LVNG With* community, and the lack of negative responses suggests that they were generally satisfied with the benefits they receive from engaging with the community.

Our study included both PLW and SPs, whose support needs from online communities may differ. Lu and colleagues (2017) noted differences in lung cancer-related topics of interest between PLW and SPs; for example, PLW were concerned most about symptoms while SPs were concerned most about treatments (Lu et al., 2017). Expanding our current qualitative analysis to involve more SPs may allow identification of additional support needs for SPs.

Limitations

Several limitations should be considered when assessing these results. As with all small qualitative research samples, there is potential bias due to the self-selection of the participants. While qualitative samples are generally small, there were some imbalances in participant demographics (i.e., gender and PLW vs. SP). This is often the case when self-selection of volunteers influences the mix of interview participants. However, since saturation of concept was achieved, robustness of the qualitative information the sample provided was attained.

As this analysis was based on a single interview per participant, it offers a temporal snapshot of their experience. Additional longitudinal research, with interviews at different timepoints in their journeys, may quantify the impact that *LVNG With* has on participants over the course of their experience.

CONCLUSIONS

The complementary qualitative and retrospective analyses of the virtual Facebook community, *LVNG With Lung Cancer*, provided a unique and holistic assessment of the potential benefit of an online support community for PLW and SPs, and highlighted the integral role of support groups in patient-centric care. We found that people join the *LVNG With* community because they have emotional and educational needs. Indeed, health information and community/emotional support are reported as major benefits that lead to feelings of empowerment to take positive actions and make changes that lead to better health behaviors, participation in their health care, helping others, and increasing their QOL. These perceived benefits of participating in the *LVNG With* community highlight the integral role of online support communities in patient-centric care and may be applicable to a wider range of diseases. ●

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Appendix A. Interview Guide for Qualitative Interviews

Study Objectives	Progression of Questions in Interview Guide
Overall Goal of the Study: To gain an understanding of the person living with lung cancer and their family members' perceived value for the benefits they may have experienced as members of the *LVNG With Lung Cancer* Facebook Community. Interview topics that will be explored include: • health outcomes • life impacts • quality of life • feelings of empowerment • shifts in attitudes • knowledge about health issues • positive actions taken to support health and survivors	**OVERALL FLOW:** **Descriptions about the participant** and their condition, to... **Descriptions about their entry into the *LVNG With LC* community,** including expectations and first impressions **Descriptions about their levels of participation,** including changes over time, and specific ways of **participation** **Descriptions about the benefits they see coming as a result of their participation,** including health outcomes, quality of life, and feelings **Actions they have taken as a result of their participation,** including an overall summary of what they feel their **participation** has provided for their life

TO BEGIN
• Introduce yourself and your association with the study
• Explain the purpose of the interview
• Thank participant for willingness to participate
• Assure participant of confidentiality
• Let participant know the general process of how the interview will proceed

THE PRIMARY OBJECTIVE OF THIS INTERVIEW
This interview will take approximately 45 minutes. I will be asking you a variety of questions that will help me to better understand your experiences as a member of the *LVNG With Lung Cancer* Facebook Community. I may also refer to the community as '*LVNG With*' during our conversation.

How this Interview will work:

I will be asking general questions about your experience, and after each one there will be some time for you to respond. Please respond with whatever is on your mind. There are no right or wrong answers

To begin the interview, I want to remind you that it is being recorded. I will try to not use your name from the point that I turn the recorder on, and I will ask you to try and not use your name or the names of friends or family in any of your responses. This will help keep the interview anonymous.

I will only be using the recording to remind me of the important things you said so we can represent everything more accurately at the end of the study. The recordings from each interview will be transcribed, and then put together with transcripts from everyone else taking part in these interviews.

It will not be possible to identify you individually in any of the reports that result from these interviews. This study information will be used by AstraZeneca to understand more about how to best support persons living with lung cancer and their family members who make use of the *LVNG With Lung Cancer* Facebook community.

Do you have any questions before we start?

Appendix A. Interview Guide for Qualitative Interviews   **(cont.)**

FIRST DISCUSSION ITEM
(Purpose: To settle the participant, develop a rapport, and learn a little about them)

To start with, I would like to <u>learn a little bit about you</u>. Can you please tell me if you are caring for a person being treated for lung cancer or if you are a person with lung cancer?

<u>For Loved Ones of Someone Diagnosed:</u>
Is the person you care for a relative? *(Describe):* _____
Can you describe what an average day in your life is like?
• What types of things do you do to support your loved one living with lung cancer…_____?
• What are your other responsibilities like during an average day?
• About how much time in an average day do you spend on the internet in general?
• How much time do you spend on social media (Facebook, Twitter, Myspace etc.)?
• Do you generally think of yourself as a busy person or as someone who has a lot of time for things?

<u>For People living with lung cancer:</u>
How long has it been since your diagnosis of Lung Cancer?_____
Can you describe what an average day in your life is like?
• What type of activities do you do during an average day?
• Do you work at a job outside of the home._____?
• If Yes, what type of work do you do? Is it full time? Part time?
• Do you receive support from loved ones?
• If Yes, what type of support do you receive?
• Can you describe some of the ways your life has changed since your diagnosis?

[Interviewer:] Let participant offer ways first, then probe other areas they have not mentioned. *(Ability to work, physical activities, social activities and relationship, sleep, eating, self-care, caring for home and family, hobbies and recreation, any others?)*

• About how much time in an average day do you spend on the internet in general?
• How much time do you spend on social media (Facebook, Twitter, Myspace etc.)?
• Do you generally think of yourself as a busy person or as someone who has a lot of time for things?

<u>For both Person living with lung cancer and loved ones:</u>
• How often do you look at your Facebook feed? (Every couple of days? Every day? Multiple times a day?)
• What other types of sites outside of *LVNG With* do you like/follow?

SECOND DISCUSSION ITEM
(Purpose: To focus patient on their participation in the LVNG With Lung Cancer Community and start to get levels of participation from their perspective)

Next, can you tell me about when you first became aware of the *LVNG With Lung Cancer* Facebook community?
• How did you first hear about it or become aware of it?
• Did you remember what made you interested enough to look into it?
• What were you looking for at the time that made you look into it?
• Do you recall what your first impressions were when you first joined?
• Did you already know anyone that was a member of this community?
• Can you describe what you thought you might gain from being a part of this community?
  » *What did you think you would find?*
  » *What benefits did you think it would provide?*

Appendix A. Interview Guide for Qualitative Interviews   (cont.)

THIRD DISCUSSION ITEM
(Purpose: To identify the amount of time the subject invests in engaging in the LVNG With Lung Cancer community)

When you first started to follow the *LVNG With* site....
- How would you describe your overall level of participation with the community?
- How often did you read the comments from other members of the community?
- How often did you reply to comments made by others?
- How often did you add comments to the page, yourself?
    » *What types of topics did you write about?*
    » *Did you share stories? If yes, what kind of stories did you share?*
    » *Did you respond that you "liked" what you read from others?*
    » *What were your main reasons for contributing comments?*
    » *What was it about what you read that compelled you or inspired you to add a comment? How about to reply to others? How about to just "like" something?*

- How often do you repost content from the *LVNG With Lung Cancer* Community?
- Would you describe your initial participation as:
    » more a reader,
    » more a writer
    » or a mix of the two? What proportions?

If more a reader or more a writer: Can you tell me a little more about that being your preferred level of participation when you first started?

[Interviewer:] If they read more than they comment, explore why that is.
- Were you more comfortable reading and not commenting?
- Was there something in particular that stopped you from adding comments or sharing stories?
- What types of benefits did you feel you got from being mostly a reader at the time? (In what ways did you find that to be a helpful thing for you?)

FOURTH DISCUSSION ITEM
(Purpose: To get a description of changes in levels of interaction over time and identify current levels of interaction)

- About how long have you been a member of this community?
- Has your level of interaction or participation changed over that time?
    » If Yes, can you describe what has changed about it?
    » Was there something in particular that contributed to that change? (Describe)
- Have your attitudes about participating changed any since you first became a member? (If Yes, Describe)

How would you describe your current level of interaction with the *LVNG With* Community?
- How often do you read the comments from other community members now?
- Do you read the *LVNG With* posts more often or less often than you used to?
- When *LVNG With* posts show up on your social media feed, do you pause to read them? Do you read each one or do you scan across them and focus on other content?
- What type of content do you focus on? How do you prioritize what to read?
- Can you describe how you feel about the *LVNG With* posts? And how about relative to other content in your Facebook feed? (What kind of priority do you give them, if any?)
- How often do you add comments or stories to the *LVNG With* Community yourself?
- What would the typical circumstance be for you to respond you "liked" something that you read?
- Can you describe a typical circumstance that would make you want to add a comment or a story?

Appendix A. Interview Guide for Qualitative Interviews   (cont.)

FIFTH DISCUSSION ITEM
(Purpose: To encourage the participant to start thinking about the benefits they have for the community)

If you think about the time from when you first started to be involved with this Facebook community, up until now… how would you describe the affects you have experienced from your participation?
- How have your interactions with this website affected you?
- How has your activity on this site (reading, posting, and commenting) affected your interactions with others or how you think about yourself? Your lung cancer?

SIXTH DISCUSSION ITEM
(Purpose: To focus on specific areas of benefit)

How would you describe what you get from being part of the *LVNG With Lung Cancer* Community?
- How would you describe what you get from the *LVNG With* content and posts?
- How about from the reactions/comments made by other community members?
- Do you value these things the same way or are they different for you?

How has your participation in the *LVNG With Lung Cancer* community affected your overall quality of life?
- What stands out the most in terms of the benefits you get from visiting this site?
- Has there been anything from your involvement with the community that has had an effect on your quality of life that you could describe?
[Interviewer] Get detailed description

SEVENTH DISCUSSION ITEM
(Purpose: To focus on specific feelings resulting from participation)

Can you describe any particular emotions or feelings that you have experienced as a result of your participation with the *LVNG With Lung Cancer* Community?
- What do you feel when you read what others contribute?
- How do you feel about the things that you contribute?
- How do you usually feel about making replies to what other members of the community comment or post?
- If they are writers: How do you feel about the responses you get from others about your comments?

Are there ways that you feel you get support from the *LVNG With Lung Cancer* Community?
[Interviewer] Get detailed description.

Are there times when your activity on the site leaves you feeling empowered or stronger for having been a part of this community?
- Can you describe what that is like?
- Is this feeling associated with any particular type of participation with the community?

Are there times when you take inspiration from any of the stories? (Describe)
Do you ever feel that you have added something to your awareness or education about particular topics or issues? (Describe)
- What activities online are the most comfortable for you? (for example, liking, posting, comments, sharing)
- What activities are the most challenging or uncomfortable for you? Why?

Has your experience with *LVNG With* affected you negatively in any way?

Appendix A. Interview Guide for Qualitative Interviews   (cont.)

EIGHTH DISCUSSION ITEM
(Purpose: To explore positive actions that subjects may have taken as a result of their participation)

Has anything happened since you have been participating with this Facebook community that helped you take any specific actions or steps that ended up improving your (*or your loved one's*) emotional well-being?
- Can you describe the details?
- What was the interaction that encouraged you to take action?
- What did you do?
- What happened?

Is there anything from your interaction with this community that encouraged you to take an action that affected your (*or your loved one's*) health? Can you describe that?
- Can you describe the type of interaction?
- What action did you take?
- How was your (your loved one's) health affected?

Because of your involvement with the community, how has your medical knowledge about your health (*your loved one's health*) changed?
- Do you feel more or less educated about your health from participating in the *LVNG With* community? (Describe)
- Can you describe some of the new awarenesses that you may have gained?
- Did these come from reading comments from others, or from exploring other sources of information as a result of *LVNG With* content?

Because of your involvement with the community, how likely are you to play an active role in your care (*your loved one's care*)?
- Has your participation with the community led to a different relationship with your healthcare team? (Do you partner with your doctor differently?)
- Do you discuss things like your treatment plan with others on the website?
- Or participating in clinical trials?
- Or about what you would consider as a next step if your situation changed?
- Do you bring up topics with your healthcare team as a result of *LVNG With*?
  e.g. treatment? genetic/biomarker/mutation testing?
- What (if anything) have you spoken to your healthcare team about that you may have learned from *LVNG With*?

Have you made any changes in your approach to you or your loved one's health care as a result of anything that came from your participation in this community? [Interviewer] Get detailed description.

Appendix A. Interview Guide for Qualitative Interviews   **(cont.)**

NINTH DISCUSSION ITEM
(Purpose: To explore the participant's overall assessment of the benefits of their participation.)

Looking back over your participation with this community... did you find what you were expecting to find when you first started following it?
- Less than you were expecting/hoping for?
- More than you were expecting/hoping for?

What is it that keeps you participating?

What would you say the strongest benefit to you is?

Have you recommended this community to anyone else, either by the "sharing" option in Facebook or through other ways? (Describe)
- How did you describe to others what they would gain from joining it?

TENTH DISCUSSION ITEM
(Purpose: To explore overall attitudes about social media)

[Interviewer]: check earlier answers about what other social media they participate in before asking this question.

Can you describe what you have gotten from participating in social media in general?
- Describe any changes in how you manage your healthcare because of your reading or interacting with social media sites
- Describe any changes in your relationships with your healthcare providers overall as a result of your interaction or reading of social media sites
- Describe any changes in your healthcare decisions or level of knowledge as a result of your interaction with or reading of social media sites
- Has there been anything else that has changed because of your participation in social media in general? (Describe)

We are at the end of my questions now. Is there anything else I have not asked that you would like to add?

THANK YOU VERY MUCH FOR YOUR TIME TODAY