

Live, Learn, Pass It on: A Patient Advocacy Engagement Project on the Lived Experience of Lung Cancer Survivors

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Abstract

Introduction: The objective of this project was to engage survivor–advocates by describing their experiences living with lung cancer in an era of increasing treatment options. **Methods:** This was a qualitative engagement project with participants from a lung cancer advocacy organization’s survivor advisory board. Interviews were conducted, transcribed, and analyzed for stages and associated experiences using interpretive phenomenological analysis and elements of narrative analysis, in partnership with the patient advocacy organization. **Results:** Of 27 engaged members, interviews were conducted with 19, mostly long-term survivors with stage 3 or 4 lung cancer. Within the quest for patient-centeredness, we identified 3 stages of the patient experience. The stage *Live* describes the journey of the lived experience; *Learn* describes the quest for knowledge, empowerment, and skills; and *Pass it on* describes making a difference through guiding others, building awareness, and community. **Conclusions:** Lung cancer survivor–advocates have an intertwined experience of their personal journey, the quest for knowledge, and developing advocacy. Future patient engagement can incorporate these findings into increasing the survivor-centeredness of partnerships and research, particularly for quality of life and shared decision-making.

Keywords

lung cancer, patient engagement, qualitative methods, patient experience, patient advocacy

Introduction

Lung cancer is the leading cause of cancer mortality in the United States, at 27% of cancer deaths, as well as internationally. Smoking continues to be the primary cause, but a growing percentage of diagnoses have no clear etiology; other factors such as second-hand smoke and exposure to hazards and environmental causes can also contribute to lung cancer. In 2015, an estimated 221 200 new cases were diagnosed, with 158 040 deaths and a 5-year survival of only 18% (1). The estimated direct medical cost in the United States was US\$12.1 billion in 2010, approximately 10% of total cancer medical expenditures (2). Of US\$134.8 billion in indirect costs associated with cancer deaths in 2005, over 25% was attributable to lung cancer (3).

Although treatment options remain limited, new options are emerging, but these also have significant toxicities and affect quality of life and have increased the complexity of decision-making. More effective anticancer treatments include therapy targeting genetic mutations (eg, rociletinib for epidermal growth factor receptor (4) or crizotinib for anaplastic lymphoma kinase and ROS proto-oncogene

1 (ROS1) gene rearrangements) (5) and immunotherapy (6) (eg, nivolumab) (7). Implementation of new evidence supporting screening with computerized tomography may also lead to diagnosis at more treatable stages (8).

Advocacy for this disease has been less active than in other cancers due in part to stigma from smoking. With the growing percentage of nonsmokers, emerging treatment options and long-term survivors with late-stage cancer, survivor advocacy is becoming increasingly important. Advocates are working to decrease stigma of a lung cancer diagnosis, spread information that lung cancer is more treatable, improve support for patients, and advocate for

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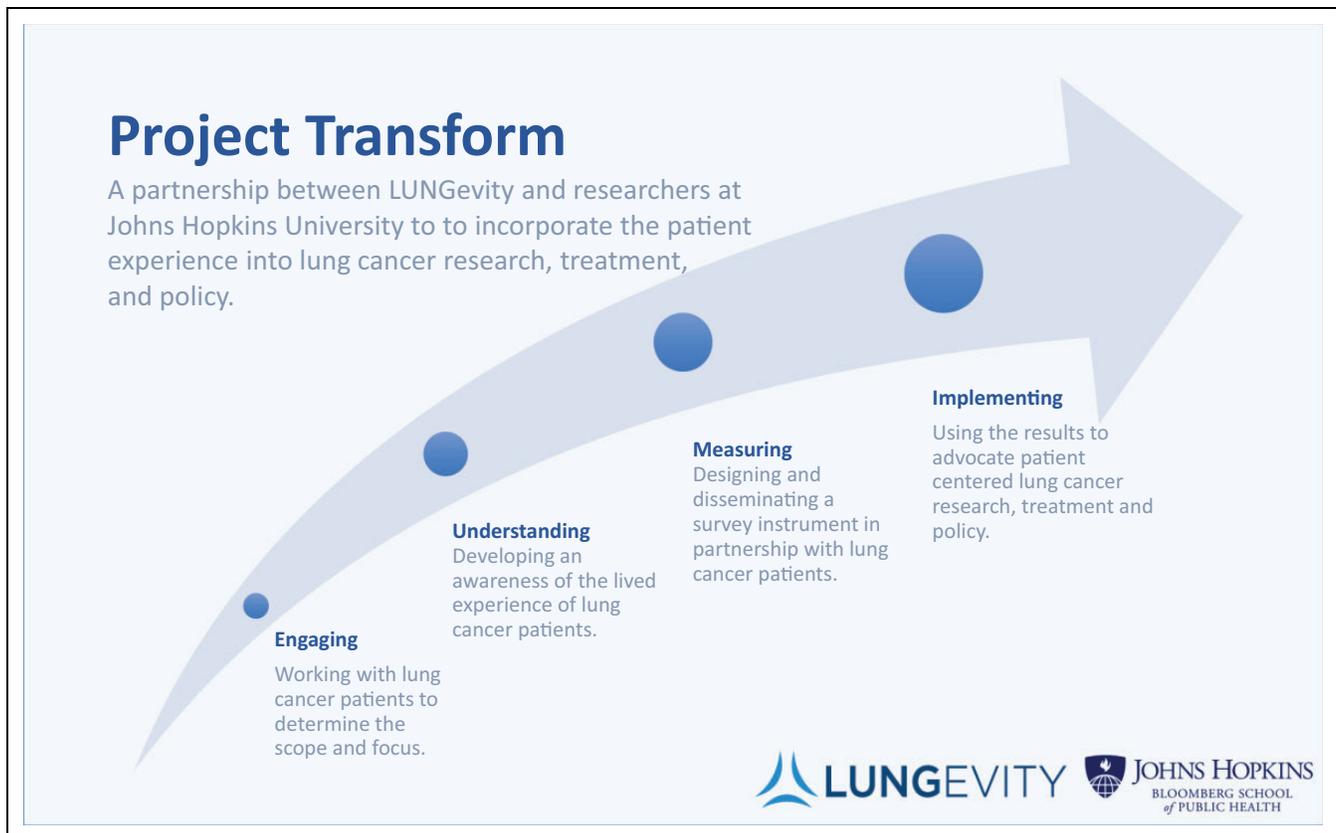


Figure 1. Patient-centered engagement framework.

research and programs to improve survival and quality of life. Survivors' voices are vital for empowering patients with knowledge from others' experiences, creating a lung cancer community and promoting important issues in medical care, research, and policy. Previous qualitative studies have evaluated specific issues such as coping with symptoms (9), treatment (10), stigma (11), and the experience of advanced lung cancer (12) but have not addressed the narrative of the emerging survivor-advocate in this new era.

To respond to this relative paucity of focus on survivors' perspectives, LUNGEvity—a US nonprofit focusing on lung cancer and on empowering survivors to be active decision makers and advocates—partnered with researchers at Johns Hopkins for this project. The overall goal was to understand how to improve the patient-centeredness of treatments (chemotherapy, immunotherapy, targeted therapies, and radiation therapy), provider-patient interactions, health systems, and policy, from the perspective of this very engaged group of people living with lung cancer. The approach taken in this project presents an important departure from the status quo of patient engagement by regarding these lung cancer survivors as partners in engagement rather than as study patients.

This project contrasts with previous patient-centered research. While others have focused on how people come to terms with and adjust to life-threatening disease using various conceptual models (13), this project sought to evaluate the lived experience of advocates living with lung

cancer through engagement with a lung cancer patient action committee (PAC) developed with LUNGEvity. The findings in this qualitative interview project describe the unique experiences of highly activated people living with lung cancer and ensure that each survivor's voice is heard. These findings are important as the initial phase in an ongoing engagement initiative with the advocacy organization to improve the patient-centeredness of emerging treatment options.

Methods

This was a qualitative interview engagement project of survivor-advocates who were already sharing their lung cancer stories with others as the initial phase of an ongoing engagement initiative (Figure 1). This analysis focuses on the portion of the interviews trying to understand survivors' individual lung cancer experiences, learning about lung cancer, and involvement with advocacy and the lung cancer community.

Participants, Recruitment, and Interviews

Participants were drawn from a 27-member PAC established through the survivors' board of the advocacy organization, LUNGEvity. This group was specifically selected for their engagement in lung cancer advocacy. Members were

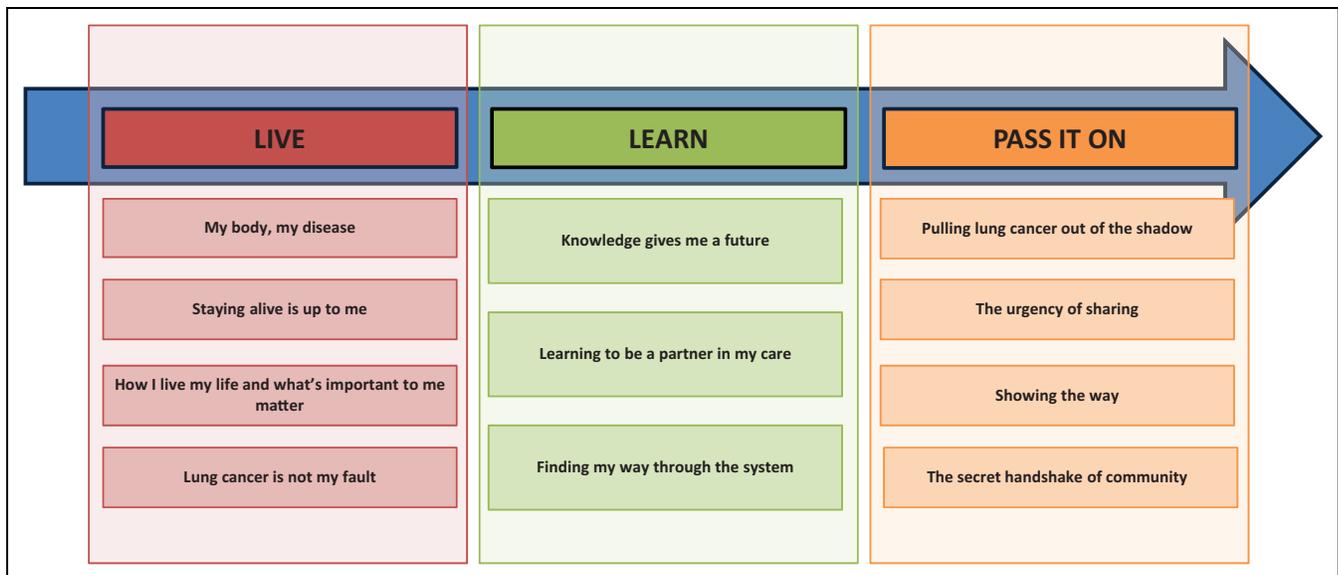


Figure 2. Patient-centeredness and the lived experience of the lung cancer advocacy narrative.

interviewed in person or by telephone or Skype. Participants were asked to focus on chemotherapy, immunotherapy, targeted therapies, and radiation therapy and the role of patient-centeredness. These analyses focus on the question, “Can you tell me a little about your experience with lung cancer and LUNGevity?”, as part of a larger interview, with additional probes to explore treatment history, experience living with and learning about lung cancer, advocacy experience in research, supporting other patients, and creating awareness. Results from portions of the interview focusing on other topics, including health policy, are presented elsewhere (14).

Three team members experienced in qualitative interviewing and/or working with lung cancer survivors conducted interviews, with 2 members present for most interviews. The interviews probed specific aspects of participants’ narratives, with later interviews focused on addressing gaps and evolving stages of the patient experience. Since this was an engagement project with an advisory board, the Johns Hopkins School of Public Health determined that this was not human patients research (IRB 6404).

Analysis

The project used interpretive phenomenological analysis (IPA) (15), a well-established qualitative method for exploring lived experience with illness, how participants make sense of those experiences, and the meaning experiences hold.

Interviews were recorded and transcribed, with detailed field note taking. The team first developed preliminary categories of experiences and overarching stages based on 2 team members’ coding of 9 initial interviews. Based on these categories, the team recoded all interviews, identified additional experiences and stages, and extracted representative quotes to illustrate each stage. The team achieved

triangulation through independent coding and regular team discussions with multiple iterations of coding and reclassification, including a representative from the patient advocacy organization. The RATS qualitative guidelines, which emphasize the Relevance of the question, the Appropriateness of the qualitative method, Transparency of procedures, and the Soundness of the interpretive approach (15), guided the project (16).

Results

Of 27 survivors in the Patient Advisory Committee, 19 (70%) completed interviews. Patients had varying cancer type, disease severity (stages 1-4), years since diagnosis (1–13), and experiences with treatment (radiation, surgery, chemotherapy, immunotherapy, and targeted therapy). Some had no current disease, but most were living with chronic lung cancer.

Survivors described their experience as a journey and quest for survivorship for themselves, for learning about their disease and care, and for advocacy and helping others. Survivors’ experience of patient-centeredness fit into 3 stages: *Live*, *Learn*, and *Pass it on*. There was significant overlap between experiences, as survivors’ experience leads to efforts to learn about the disease and treatments and both of these affect how they work to pass it on. Each stage and experience is described subsequently, illustrated with example quotes reflecting the range of perspectives (Figure 2).

Stage 1. Live: The stage “Live” refers to survivors’ personal lived experience with lung cancer themselves.

My body, my disease refers to the personal impact of lung cancer. The journey through lung cancer took many forms, including improvement or apparent cure for some and, for others, recurrences, worsening of metastatic disease or living with the cancer as a chronic, controlled disease. Many

survivors emphasized the emotional and physical toll on survivors and families.

...they removed part of the lung...I cannot have the same distance that I used to do or the same breathing pattern like I used to have...that takes a big chunk out of you. So I learned, tried to learn to live again, but it's taking a little bit longer...I guess you could say I'm still in shock... (Participant 11)

And that's really frustrating to me, "cause...in my mind I can do all these things. You know, my body should be able to keep up with me. I should be able to do these things. And it's frustrating when I can't. (Participant 15)

I'm trying to be a person who's living with lung cancer, and I know it's there, or possibly there, and as long as it doesn't bother me, I won't bother it... (Participant 18)

Staying alive is up to me addresses how survivors adjusted to living with the illness and its aftermath. This includes issues around tests and treatments, including genetic testing and availability of future treatments that survivors hoped would keep them alive for some time to come.

They've got stuff for me, so...if for whatever reason they slow down and stop working maybe they got something to juice them back up again. If I get another four years and then I got to get them juiced up again, what do I care? (Participant 4)

There are a lot of options. I'm on the first line of targeted therapy, and there's two more now after it. I have two plan Bs in place and even a third one now in clinical trial. (Participant 16)

How I live my life and what's important to me matter refers to interactions between the lung cancer experience and what was important in survivors' lives. These include family and children; friends and support networks, including other survivors; and other goals.

I need to be able to look my kids in the eyes and know I did everything in my power...My goal is to live to raise my kids, because my dad never did. (Participant 10)

The things that I've been able to experience in my life, the high school and college graduations...and I've been there to celebrate to the very maximum with them. (Participant 8)

Finally, *lung cancer is not my fault* addresses the effect of the stigma and guilt of lung cancer, a disease strongly associated with (although not always caused by) smoking and that has been felt to be untreatable.

The first thing that always comes up is... "Oh, did you smoke"... (Participant 1)

Even my friends that I love and love me that will always point out, "Well, you know, I never smoked." (Participant 12)

"Stage four lung cancer," and he hesitated with his examination and then just [stopped] without finishing it. Like he was just writing me off. (Participant 5)

Stage 2. Learn: The stage "Learn" refers to survivors' personal, lived experience with learning about lung cancer and related issues.

Knowledge gives me a future addresses the importance of accessing knowledge and ways to approach this. This includes methods that survivors used to begin obtaining knowledge, through friends or the Internet and through advanced lung cancer advocacy opportunities such as project panels or access to scientists. There were also specific types of knowledge that survivors felt were most critical, particularly genetic testing, clinical trials, and different and emerging treatments.

I'm very lucky to be cancer-free. So I do not need treatments right now, but I am always interested in seeing, what are those drugs that may be available to me in the future, in case...I mean I know the reality that lung cancer, you know, can come back. (Participant 12)

I had been hearing online from people throughout the year about a new mutation called ROS1...I gave them permission to test...I had a very, very strong indication of a ROS1 mutation. Three days later I've flown out [of state]. I took my first pill...And my very first scan there was no evidence of disease and have been for 28 months. (Participant 9)

Learning to be empowered in my care addressed the importance of being your own advocate—that no one is going to do it for you—and making sure of access to all the latest information and using it well with providers. Many had experiences with providers not being up to date on lung cancer's treatability, and even that oncologists may not be up to date on the latest knowledge, as science is advancing so fast. This also included issues of communication and decision-making and the importance of keeping up with information and asking the right questions.

The first meeting [with my oncologist] I left thinking that I had no say in what treatment I got and that's not okay with me. (Participant 13)

I approach my doctor and tell him what I'm thinking and get his feedback, if he disagrees, and so I advocate for what I feel is the best treatment available. (Participant 6)

I have to empower myself as well as, you know, allow my physicians to work for me. But, my thing is, I tell my doctor all the time, "You work for me." Most of us, when we go to the doctors, we don't realize that, we think that we work for them. But they work for you. Now, he can tell me "...I don't think this is right, this is right. I think you should do this." But I still know that I have the ability to say "No. It's my choice, it's my decision." (Participant 19)

I know now more than ever that I really am the person who cares the most about my future, even with all these great people who are concerned about me. (Participant 14)

Finding my way through the system refers to the challenges of learning how to navigate between providers and centers, including learning the best places for care and getting to a tertiary center. Participants also discussed ensuring receiving

the best care from their perspective, particularly second opinions and access and eligibility for trials.

I actually went down to the second trial to get entered into it. I know it frustrated the doctors to learn I was also talking to another trial. But I don't care, this is my life. (Participant 3)

I said, "You can test it next week, but don't test it now, because I don't want to get kicked out of this trial that may save my life." (Participant 3)

Stage 3. Pass it on: The stage "Pass it on" refers to survivors' experience with becoming and acting as educators for other patients and as advocates.

Pulling lung cancer out of the shadows relates to public involvement with lung cancer issues. This particularly involved dealing with stigma, including the perception that lung cancer survivors should be blamed for getting it due to the association with smoking, and the perception that it is a disease without good treatment options. This led to difficulties of talking publicly about a disease with stigma and the importance of addressing it. Participants described lung cancer as different from other cancers because of lack of support and need for a unique community and because of the importance of speaking with drug companies, the Food and Drug Administration, and others.

It's not just the smoking part, but it's, you know, the whole idea of lung cancer . . . It's like everybody says that it's a bad cancer, it's the worst you can get. And they just don't always have the support system there for it. (Participant 3)

I'm hopeful that there will be a true outpouring, nationwide, of compassion for people with lung cancer, like an awakening so to speak, enlightenment, of, "Hey, these people do matter". (Participant 7)

The urgency of sharing stories was very important, and many felt a responsibility to do this with patients, in their communities and in any venue available. This included involvement in local and national organizations and through the media to spread important information on lung cancer, share personal stories, and improve perceptions and funding.

We have a responsibility to move an issue forward and if it seems it's not being moved or if it needs help, then that's kind of part of what we do. (Participant 12)

Wherever I can—I feel somebody that has survived—somebody that has lived longer than the average, I feel obligated in my role to stand up and speak from as high a perch as I can possibly speak. (Participant 17)

Showing the way involved becoming a guide to other patients. Many were very involved in survivor-to-patient navigation and support, filling important gaps to help others learn, be their own advocates, and navigate health-care systems.

Like they didn't know where to begin, it's like you're on an airplane, you're dropped in a foreign country, you don't speak

the language. So what I did, "Okay, here's what you start with." Because patients, and their families especially, need some kind of control. (Participant 10)

It's really about trying to get those people out of the dark or out of the loneliness of the disease so that they can be advocates. (Participant 12)

The secret handshake of community was also vital—including the value of the feeling of community, being able to share with survivors who understood, and the importance of being around other survivors.

It was just such an amazing, amazing experience to be around other people who had not only survived with stage four cancers . . . And then I started meeting people who had survived 10 years with stage four, and that was very, very uplifting. (Participant 5)

. . . we have a secret handshake. Everybody knows. You don't have to walk in that room—no one's going to say, "Did you smoke?" No one's going to say, "What did you feel like when you first learned you got diagnosed?" We know. (Participant 17)

Discussion

This engagement of survivors and advocates explored the lived experience of lung cancer survivors as a journey and quest for their own survivorship, for learning about their disease and care, and for advocacy and helping others. The 3 stages *Live*, *Learn*, and *Pass it On* all have important implications for patient-centeredness across care, research, and advocacy, including personalizing the experience of living with cancer and its care; sources and ways to learn about gaining lung cancer knowledge, ways of navigating the system, and application; and sharing stories, becoming an advocate, and being part of a survivor community.

This exploration of the experience of engaged survivor advocates, complements, and adds to existing lung cancer qualitative explorations of quality of life (17), the experience of disease and treatment and receiving support and impact on decision-making (18), and the experience of stigma (11). Our findings illustrate the narrative of the lived experience of survivors and the stages they experience, and the importance of patient-centeredness to improve the experience throughout the lung cancer journey.

The purpose of this project was to partner with survivors to learn how their lived experience could better frame future efforts to improve the patient-centeredness of lung cancer treatment specifically. We did not seek to generate generalizable findings but rather aimed to describe the unique experiences of survivor-advocates. As the first step in a survivor engagement project, we first needed to understand their stories and perspectives to frame how best to move toward partnering with them. This approach differs from traditional qualitative research in that we did not frame this project within an existing conceptual framework or use a grounded theory approach. Instead, we used IPA, with the

goal of describing the survivors' lived experience. As a patient engagement project, the goal was not to place these findings within the context of other research on phenomena such as coping but to work with survivors to better understand their lived experiences and how best to partner with them. In addition, the perspectives of these survivor-advocates differ somewhat from priorities of the medical and public health community, including different perceptions on the importance of prevention through smoking cessation and engagement of physicians (19).

In conclusion, although approaches to improve the patient-centeredness of oncology care are being implemented (20,21), the perspectives of these survivor-advocates demonstrate the need for unique aspects in lung cancer care, particularly the need to address stigma and the emergence of new treatments. Future steps will incorporate this understanding of survivors' lived experience, learning about lung cancer, and becoming advocates into making future partnerships more survivor-centered.

Authors' Note

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Andrea Ferris, MBA, is the president and chairman of LUNGEvity, the leading lung cancer focused non-profit in the United States. Recognizing the need to build awareness and understanding about lung cancer, LUNGEvity has built the largest grassroots network of events and advocates across the country.

John F.P. Bridges, PhD, MEd, is an international leader in the application of stated-preference methods. Through his research, Bridges advances and applies a variety of methods to study the priorities and preferences of patients and other stakeholders in medicine.