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In their own words: A qualitative study of the psychosocial concerns of posttreatment and long-term lung cancer survivors

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Abstract

Although lung cancer is the deadliest type of cancer, survival rates are improving. To address the dearth of literature about the concerns of lung cancer survivors, the authors conducted 21 in-depth interviews with lung cancer survivors that focused on experiences during diagnosis, treatment, and long-term survivorship. Emergent themes included feeling blamed for having caused their cancer, being stigmatized as throwaways, and long-term survivors' experiencing surprise that they are still alive, given poor overall survival rates. Survivors also desired increased public support. It is imperative for healthcare and public health professionals to learn more about needs of this population.

Keywords

lung cancer; survivors; stigma; blame; qualitative research; psychosocial

Background and significance

Lung cancer is the most common cancer that occurs in both men and women and accounts for more deaths than any other cancer in the United States (U.S. Cancer Statistics Working Group, 2014), with an overall 5-year survival rate of 17% (Surveillance, Epidemiology, & End Results Program, 2014). In fact, lung cancer survival is lower than other cancers, even when the disease is localized (Stage 1), with a survival rate of only 55%; by contrast, breast cancer survival at Stage 1 is 99% (Surveillance, Epidemiology, & End Results Program, 2014). Lung cancer death rates have been declining for men since 1991 and for women since 2003 (Edwards et al., 2015), yet relatively little is known about the long-term psychosocial concerns of the more than 400,000 lung cancer survivors in the United States (Chambers et al., 2012; Surveillance, Epidemiology, & End Results Program, 2015).

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Zabora and colleagues' seminal article on distress in cancer patients found persons with lung cancer to have higher levels of distress than persons with any other cancer (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Despite this early finding, relatively few studies have focused on the experiences and psychosocial concerns of lung cancer patients and survivors.¹ The limited studies that have been conducted corroborate and expand on that initial study, finding that lung cancer patients have increased levels of anxiety and depression, often feel shame or embarrassment about their diagnosis, and almost universally experience stigma related to their diagnosis (Brown & Cataldo, 2013; Brown Johnson, Brodsky, & Cataldo, 2014; Carlsen, Jensen, Jacobsen, Krasnik, & Johansen, 2005; Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011; Chapple, Ziebland, & McPherson, 2004; Devitt et al., 2010; Else-Quest, LoConte, Schiller, & Hyde, 2009; LoConte, Else-Quest, Eickhoff, Hyde, & Schiller, 2008).

Stigma can arise from several sources, including perceived character flaws or weaknesses and identifying with a stigmatized group (Goffman, 1963). Studies have found lung cancer stigma to result from feeling blamed by the broader society for having caused their cancer by smoking (a perceived character weakness). This finding holds true for ever-smokers (those who have smoked in the past but have quit) and never-smokers alike, because societal norms indicate that individuals with lung cancer are or have been smokers (Cataldo et al., 2011; Chapple et al., 2004; Conlon, Gilbert, Jones, & Aldredge, 2010). Further studies have linked lung cancer stigma itself to deleterious outcomes, such as increased anxiety and depression and decreased quality of life (Brown & Cataldo, 2013; Brown Johnson et al., 2014; Cataldo & Brodsky, 2013; Cataldo, Jahan, & Pongquan, 2012; Gonzalez & Jacobsen, 2012; Lebel et al., 2013). Stigma is experienced by lung cancer survivors on many levels, sometimes called "stacked stigma" (Conlon et al., 2010, p. 99), through interactions with acquaintances, friends, family, their healthcare providers (Chapple et al., 2004; Holland, Kelly, & Weinberger, 2010; Raleigh, 2010; Schonfeld & Timsit, 2008) and the broader society (Cataldo et al., 2011; Chapple et al., 2004). As a corollary, it is suggested that societal stigma may lead to less resource allocation for research and programs that address the needs of persons with lung cancer (Chapple et al., 2004; Conlon et al., 2010; Gritz, Sarna, Dresler, & Heaton, 2007; Hamann et al., 2014; Knapp-Oliver & Moyer, 2012).

Research related to the psychosocial concerns of lung cancer survivors, particularly long-term survivors, is under-represented in the literature. Therefore, the purpose of this study was to better understand the subjective experiences of individuals living with lung cancer, with a particular emphasis on the psychosocial concerns of posttreatment and long-term lung cancer survivors, to provide recommendations to healthcare and public health professionals on how to better serve this population of cancer survivors.

Method

We conducted 21 in-depth, semi-structured interviews with lung cancer survivors for this qualitative study to better understand their psychosocial concerns. To understand a range of perspectives, we used purposive sampling to recruit posttreatment survivors (6 months or

¹While we use the terminology *survivor* in this research, we have used *patient* when discussing research that uses that terminology.

greater since initial diagnosis to exclude those still under active treatment) with a mix of smoking histories, specifically, those who currently (at time of interview) smoked, former smokers, and those who had never smoked. Our study protocol was reviewed and approved by the institutional review boards of both the Centers for Disease Control and Prevention and RTI International. Each study participant received US\$75 for participating in the study.

Sample

We recruited study participants who had been previously diagnosed with lung cancer using two clinical care sites (i.e., hospital, cancer care center) and two health research recruiting firms (i.e., businesses that maintain databases of individuals who have voluntarily agreed to be contacted about participating in health studies). The initial plan was to recruit participants from three clinical sites located in the Southeastern United States. Delays in obtaining regulatory approvals for the study meant recruitment had to happen more quickly than originally planned to keep the study within the timeline of the contract with RTI. Therefore, recruitment methods were expanded to use health research recruiting firms and involvement of individuals from throughout the United States. Recruitment for the study began in October 2009, with all interviews completed between January 6, 2010, and March 6, 2010. While recruiting was not restricted to a single state or geographic region, the majority of survivors came from eastern U.S. states (New Jersey: $n = 6$, New York: $n = 4$, North Carolina: $n = 3$, Florida: $n = 2$, Georgia: $n = 2$, Pennsylvania: $n = 1$), with the remaining participants coming from the Midwestern United States (Illinois: $n = 1$, Indiana: $n = 1$, Ohio: $n = 1$).

Potential study participants were contacted first by clinical or recruitment staff to gauge their interest in participating in the study. A member of the study team then contacted those individuals who expressed interest in participating to provide additional information and do a full screening for eligibility. Potential participants met inclusion criteria if they were: diagnosed with lung cancer, first diagnosed at least 6 months before contact (to ensure a minimal period of time living with lung cancer), between 30 and 80 years old, and covered under a health care plan that included routine doctor visits, preventive health care, and medical treatments. Potential participants were excluded if they were not able to complete an interview in English, were unable to complete an hour-long interview in one or two sessions, or were already participating in a cancer-related research study. In addition, participants were categorized using the adult tobacco use definitions established by the Centers for Disease Control and Prevention's National Health Interview Survey. *Smokers* refers to those who smoked more than 100 cigarettes, 25 cigars, and/or 25 pipes in their lifetime and who smoke everyday or some days up until the time of diagnosis. *Former smokers* refers to those who had smoked more than 100 cigarettes, 25 cigars, and/or 25 pipes in their lifetime and who do not currently smoke and who had quit smoking before diagnosis with lung cancer. *Never-smokers* refers to those who have never smoked or have not smoked more than 100 cigarettes, 25 cigars, and/or 25 pipes in their lifetime.

If eligible, a study participant was mailed a written consent form. Through our recruiting partners, we screened and contacted 32 eligible individuals about participating in the study and 21 agreed to be interviewed.

Data collection

All interviews were conducted by telephone with an interviewer and note-taker participating on the calls. The interviewer (E.A.R.) followed a semi-structured interview guide that used open-ended questions and probes to explore survivors' experiences of the diagnostic process, treatment, coping, and changes to everyday living as a result of having had lung cancer. Specifically, questions centered on the following domains: the process of getting diagnosed, stigma and blame, coping, and receipt of formal and informal support. Of the 21 telephone interviews, 20 were recorded and transcribed verbatim, and the transcriptions were used for the analysis. Technical difficulties prevented recording of one interview; detailed notes taken at the time of this interview were used in the analysis.

Final sample

The 21 respondents (10 women, 11 men) ranged in age from 46 to 75 years (see Table 1). Self-reported survival time since diagnosis ranged from 1–17 years, with a mean of 6.1 years and a mode of 9 years. All respondents but one (Mason) were posttreatment survivors (although some had experienced recurrences through the years) and 13 (62%) had survived 5 or more years. Four respondents were classified as *never-smokers* and 17 were classified as *ever-smokers*. All but two of the ever-smokers in the study had quit at the time of diagnosis; the others were current smokers at the time of the interview. We attempted to collect information on stage of diagnosis, but most participants did not know their cancer stage. While they could describe whether the cancer had spread, we did not feel it was appropriate to include our interpretation of their cancer stage, on the basis of those descriptions.

Analysis

The research team used Atlas.ti 6.2 qualitative software for data management and assigned pseudonyms to protect participants' confidentiality. Three interviews were open-coded by three different investigators (E.A.R., J.E.B., and K.G.A.) to derive the codebook, which was refined until consensus was reached on each code. Using the refined codebook, the original three interviews were recoded by these three investigators with an acceptable interrater reliability of 80% (Hruschka et al., 2004). The three members of the Centers for Disease Control and Prevention team then independently coded the remaining 18 interviews with the final, refined codebook. Once coding was complete, we identified common ideas among the responses and classified codes and corresponding quotations into themes (Harry, Sturges, & Klingner, 2005; Richards, 2005). Themes that emerged from the analysis were categorized into two major groups: psychosocial concerns common across cancer survivors (on the basis of information published in the literature) and psychosocial concerns specific to lung cancer survivors. For instance, reported concerns related to fearing recurrence and adjusting to losses and limitations are common across cancer survivors (Hoffman, McCarthy, Recklitis, & Ng, 2009; Zebrack, 2000). As noted previously, concerns particular to lung cancer survivors were related to stigma and blame and their consequences. We focused this analysis on the latter themes. In conducting the analysis, we collapsed the smokers and former smokers categories of study participants into a single ever-smoker category ($n = 17$), because we found these groups to be fundamentally similar in their responses.

Trustworthiness

Qualitative methods of data analysis are evaluated for both the research process and the product. *Trustworthiness* describes the validation of methods used to analyze and represent qualitative data (Mishler, 1990). A detailed audit trail, documenting the research methods and processes, was maintained to ensure trustworthiness (Denzin & Lincoln, 2005; LeCompte, Preissle, & Tesch, 1993; Padgett, 2008). Researchers' perspectives, experiences, and values influence how qualitative data are interpreted (Charmaz, 2014; Mauthner & Doucet, 2003; Riessman, 1994). Individual investigators analyzing data for this report have backgrounds in oncology social work and sociology (E.A.R.), health education (K.G. A.), and anthropology (J.E.B. and J.P.), and all have public health backgrounds or experience.

Results

Psychosocial concerns specific to lung cancer survivors included feeling blamed for having caused their cancer (regardless of smoking status), being stigmatized as throwaways because of the blame assigned to them, experiencing surprise about their survival, and desiring increased public support and attention.

Feeling blamed

Lung cancer survivors described feeling blamed for having caused their cancer from many different sources, including society-at-large, healthcare providers, family and friends, and themselves. For example, Isabella described, as did many other respondents, having felt blamed by society for her cancer in a way that other cancer survivors—or even those with other preventable chronic diseases—are not:

I think I read this somewhere, that society, as well as your medical team—but more society—is sort of blaming when you get lung cancer...and this only adds to your distress... you're being blamed for your terrible condition. I mean, people don't blame you when your arteries are all clogged up and you're fifty pounds overweight and so your heart [has problems]...no one blames you for all of those things. But in lung cancer, the one question always comes up: "Did you smoke?"

Similarly, Ethan described that his primary care physician blamed him for his cancer. "[My doctor] said, 'Well, you know, you really did that to yourself with your smoking all the time.'" Aiden poignantly described the feelings of self-blame that several other respondents who were ever-smokers discussed. He said, "Yeah, well [the lung cancer] was, that was something self-inflicted, you know, the smoking. Because I've been smoking since I was 17, since I went in the military." Some ever-smokers, while admitting their smoking contributed to their lung cancer, discussed feeling that this blame was somewhat undeserved. Many of them said that when they started smoking, the harms associated with smoking were not commonly known and that smoking was a completely acceptable social norm. Liam, who stated he blamed cigarettes for his lung cancer more than he blames himself, provided a detailed description of this outlook:

Well, I don't beat myself up about it but, I mean, I'm aware of the fact that [the lung cancer] was a result of my smoking. But at the time that I started smoking, you know, no one knew about these things [the harms of smoking]. [Interviewer: Yeah.

How old were you when you started?] 11½ I started smoking, you know, non-filtered cigarettes...[My friends and I] used to—I was raised in New York—and we, on the way to school you could stop at candy shops, you know, they had candy stores back then and you could buy single cigarettes for a nickel, or maybe it was a penny. They would open up a pack of cigarettes and lay them out on the counter and you could buy single cigarettes...We're talking about like 1945, you know, right after the Second World War. You could go in and buy a bottle of soda and get a piece of candy and one cigarette—and that would be lunch or breakfast, whatever time it was [laughter].

Being stigmatized

Related to feeling blamed, most respondents described having experienced stigma as a result of the perception that they had self-inflicted their cancer. Jack described a sentiment about feeling stigmatized common among ever- and never-smokers and associated the stigma with negative portrayals of lung cancer survivors:

Some people aren't sympathetic to lung cancer because [they believe] you smoked, and that's the general idea. It's a dirty cancer, you know...when they're showing pictures of [other cancer survivors, it's obvious that]...they got cancer through no fault of their own. You see a picture of a person who has lung cancer, and most of them don't look so good.

While many of the never-smokers stated they felt stigmatized, they described feeling unjustly stigmatized considering that they were not smokers. Never-smokers tried to separate themselves from the stigma by explaining their non-smoking status or even by not mentioning lung cancer at all. For example, Emma, whose lung cancer had metastasized to her bones, explained that she experiences sympathy—rather than stigma—from others if she omits mentioning her actual diagnosis of lung cancer. She admitted,

I initially started saying, "I have lung cancer, but I never smoked." And then I finally decided it was easier, depending on whether I wanted sympathy or not...[to not mention lung cancer and] to just tell people that I had cancer in the bone and that it had affected my spine.

Others related the stigma to a perceived lack of funding for clinical research in lung cancer. Sophia, while acknowledging that recently more research has been done on lung cancer, lamented a lack of lung cancer research, saying, "So, it's a stigma that probably prevents more...research on lung cancer...there is a certain stigma to it. I try not to think about those things."

Only three participants stated they did not experience stigma. Mason, a construction worker, said his doctor suggested his lung cancer (mesothelioma) was likely caused by his years of exposure to asbestos in his line of work. Abigail, the survivor in our sample with the most years since diagnosis (17), stated, "I mean, people would say, you know, 'How did you get it?'...But as far as blaming me...I've never been around anybody that would, would have the nerve to say something [like that]." Noah, (an ever-smoker) who had been diagnosed with HIV previously, said he had experienced stigma associated with HIV, but not with his

cancer diagnosis. Despite Noah's experience of not having felt stigmatized for the cancer himself, his response underscores the notion that blame for self-inducing one's illness and stigma are intertwined, as most other respondents voiced.

Noah explained,

I realized that stigma is attached to HIV because of how it's mostly contracted. So it didn't seem like there was a stigma to the cancer because it seemed like you didn't cause it to happen to you. But a lot of people think you caused HIV to happen to you. So it wasn't a thing where I would be ashamed to say I have cancer.

Experiencing surprise about survival

Survivors mentioned feeling surprised about having survived an often-lethal cancer. Jack's surprise was mixed with existential angst. He said, "I don't know why I was picked to survive this long...I don't know why I was spared. That bothers me. Maybe I should be doing something on Earth that I'm not doing." Ethan also expressed surprise at surviving a diagnosis of lung cancer and added that others share his surprise. He stated, "I guess I'm still surprised I'm alive. My friends—and some are nurses—my sister, my ex-brother-in-law who's an oncologist, [they] can't believe I'm still alive. Nobody can believe I'm alive." Building on this theme, Emma explained the confusion of people who are surprised she is alive and well 3 years after her diagnosis of metastatic lung cancer. Emma described the reaction of her daughter's friends when they ask how Emma is doing. Emma recounted her daughter's response to her friends, "I feel funny because when I say, 'Oh, she's doing great'" [the friends say] 'Wow, she's still around?' [Laughter] And then there's, you know, there is that kind of awkwardness." Emma continued in her own voice,

To some degree, they just don't quite know how to be helpful or useful anymore. You know, so there's a little bit of confusion, too, after a while with people, particularly the peripheral contacts. So we joke now that I just, you know, I just, I've confused everyone. [Laughter] Yeah, they just don't quite know what to do.

Emma went on to mention that even some family members are flummoxed by her survival, stating (while laughing), "I think I just haven't died soon enough for them."

Desiring increased public support and attention

Several respondents shared feeling frustrated with what they described as a lack of public attention to and interest in lung cancer, which they believed translated into a lack of an advocacy movement the size and scope as those for other cancers. They attributed this to the blame and stigma related to lung cancer. Emma emphatically made this point by comparing support for the breast cancer movement with support for the lung cancer movement:

If it's not pink and on an M&M, well God help you because there's just not a lot of sympathy or money out there for you...[with lung cancer] we have people dying. You know, where should our attention be? ...and that frustrates me. So, if I could become a poster child, I certainly would...I want to write a book that says, "Don't judge me."

She then expressed feeling that there were missed opportunities to study those lung cancer survivors with successful outcomes, saying, “Why isn’t anybody calling me and going, ‘Gosh, we’d like to find out about you’?...I just want to make sure somebody’s working on that...you’d just like to feel like this is all part of a bigger picture.” Another survivor, Jack, illustrated the overall theme, stating, “What I really wanted to [say] was the lack of support for people with lung cancer...[there should be] a national effort to reduce death from lung cancer, regardless of why people got it.” He went on to describe attempts at getting involved to support the lung cancer cause, particularly around fundraising, saying, “I can’t get anyone other than this local organization, and they don’t have any professional fundraising people.”

Finally, all respondents expressed eagerness to help other lung cancer patients by virtue of having participated in this research. Sophia commented, “I hope my input has helped even just a little bit.” Mason took it a step further, saying:

If you’ve got any more questions in the future, just feel free to call, you know. I mean, you know, if somebody, whatever, just got cancer and they need somebody to talk to, they’re more than welcome to call me.

Many also expressed gratitude that the research was being conducted at all, as Isabella poignantly articulated, “I’m so glad that you’re doing this [research] and that...somebody’s interested in lung cancer and these people aren’t just throwaways because people just assume they smoked and they brought it on themselves. I’m very happy about this.”

Discussion

Supporting the extant literature on blame and stigma in lung cancer patients, most participants in our study of lung cancer survivors, regardless of smoking status, reported experiencing blame and stigma related to their lung cancer diagnosis (Brown & Cataldo, 2013; Brown Johnson et al., 2014; Cataldo & Brodsky, 2013; Cataldo et al., 2012; Chambers et al., 2012; Chapple et al., 2004; Else-Quest et al., 2009; Hamann et al., 2014; LoConte et al., 2008). In addition to voicing their personal difficulties with coping with the stigma, participants expressed beliefs that this stigma translated into a lack of public empathy and support for lung cancer as a disease worthy of devoting resources to on a large scale. Several of our participants also expressed an existential issue not previously noted in the lung cancer literature, specifically, their own or others’ surprise that they are still alive after ostensibly having been given a terminal diagnosis (given the dismal survival rates of lung cancer—at all stages—as compared with other cancers).

Our results support Goffman’s (1963) theory that stigma arises from a perceived character flaw (in this case, smoking) and by associating lung cancer survivors—whether correctly or incorrectly—with a stigmatized group (in this case, smokers) (Raleigh, 2010). Survivors in our study were often assigned blame—either by themselves or others—for their lung cancer and experienced stacked stigma (Conlon et al., 2010) through interactions with acquaintances, friends, family, their healthcare providers (Chapple et al., 2004; Holland et al., 2010; Raleigh, 2010; Schonfeld & Timsit, 2008) and the broader society (Cataldo et al., 2011; Chapple et al., 2004). Of particular concern is the notion that health care providers

could be contributing to this stigma by imposing judgment on those diagnosed with lung cancer.

Consistent with other studies (Brown & Cataldo, 2013; Chapple et al., 2004), never-smokers in our study actively separated themselves from those sources of stigma, either by asserting their non-smoking status or not disclosing their lung cancer diagnosis. However, this practice might unwittingly further stigmatize the ever-smoker lung cancer survivors (Brown & Cataldo, 2013). A potential long-term implication of this finding is that blame and stigma can leave some lung cancer survivors feeling alienated from society; they may avoid discussing lung cancer among their social networks, shrouding the disease even further. Given this phenomenon, it is imperative for oncology health care clinicians and public health professionals to work to ameliorate effects of blame and stigma, by both educating lung cancer survivors on the tactics the tobacco industry uses to ensure addiction (U.S. Department of Health and Human Services (2014) and encouraging lung cancer survivors to engage in peer support services (Lung Cancer Alliance, n.d.). Oncology social workers, with their knowledge of psychosocial interventions and their person-in-situation perspective, have the expertise required to be at the forefront of these efforts.

This cycle of blame and stigma is evocative of the stigma experienced by people diagnosed with AIDS, as was one of our respondents, particularly during the early years of the epidemic (Herek, Capitanio, & Widaman, 2002; Weiner, 1993). Gritz and colleagues (2007) advocated that lung cancer survivors should look to AIDS activists as a model as they seek to transform society's views of lung cancer and lung cancer survivors. Specific examples of how HIV-positive African American women accomplished this can be found in Buseh and Stevens' (2007) longitudinal, qualitative study in which they found various strategies, including characterizing stigma as ignorance and becoming advocates for their cause, to be effective in counteracting the stigma attributed to them.

A related theme that emerged from this research concerned the lack of broader public support for lung cancer, which our respondents attributed directly to the stigma attached to lung cancer. This supports previous research that found societal stigma leads to decreased funding and support for research and programmatic assistance for lung cancer patients (Chapple et al., 2004; Conlon et al., 2010; Gritz et al., 2007; Hamann et al., 2014; Knapp-Oliver & Moyer, 2012). Although public support for lung cancer advocacy historically has been comparatively limited, particularly during the time when many of the long-term survivors in our study were undergoing treatment, two major factors point to more recent increases in public support, a trend that has been growing for several years. First, advocacy organizations have brought lung cancer stigma into the public discourse in an effort to raise awareness and with a long-term goal of decreasing lung cancer mortality. For example, in 2012, the Lung Cancer Alliance launched a bold campaign called, "No One Deserves to Die of Lung Cancer," which addressed lung cancer stigma and blame candidly in an effort to "inspire a reexamination of long held beliefs and recalibrate attitudes about lung cancer because no one deserves to die" (Fenton-Ambrose, 2012). Other organizations have similar overall goals of reducing lung cancer deaths and focus on survivor empowerment and funding research in lung cancer (Bonnie J. Addario Lung Cancer Foundation, n.d.; Caring Ambassadors Program, n.d.).

Second, following the results of a large clinical trial (Aberle et al., 2011) and comprehensive review of the literature, the United States Preventive Services Task Force issued a “B” recommendation in 2013 for lung cancer screening with low-dose computed tomography for individuals at high risk (U.S. Preventive Services Task Force, September 2014.) Effective use of this screening may lead to improved lung cancer survival rates as a result of earlier detection. Although these are important new directions, tobacco prevention and cessation remain the most important ways to prevent lung cancer. Multiple resources and programs are available and continually improved upon to assist smokers and lung cancer survivors in quitting tobacco use (Centers for Disease Control and Prevention, 2015; McAfee, Davis, Alexander, Pechacek, & Bunnell, 2013). As the number of long-term survivors grows, so will their ability to bring better awareness to issues related to lung cancer.

Lung cancer survivors’ experiencing their own and others’ surprise at their long-term survival was a novel finding of this study. Although an existential concern that needs to be addressed, this finding also has practical ramifications: the potential for disruption or lack of continuity in quality of care that can result from not adequately planning for long-term survival after cancer treatment ends. The National Cancer Policy Forum of the Institute of Medicine recommend that all cancer survivors be prepared with a survivorship care plan (Ganz, Casillas, & Hahn, 2008; Hewitt, Greenfield, & Stovall, 2005). Such planning can include steps to recording survivors’ primary cancer treatments, coordinating ongoing cancer-related care and surveillance, helping survivors adjust to the long-term effects of their treatment, while supporting on-going health and lifestyle changes, and providing for their psychosocial wellbeing (American Society of Clinical Oncology, 2014; Earle, 2006). While potentially challenging to any cancer survivor, planning for long-term needs may be especially difficult for lung cancer survivors who, as a whole, have low expectations for long-term survival and bear the added burden of stigma. Oncology social workers have the potential to play a critical role in helping lung cancer survivors plan for their futures.

Our study has several limitations. Recruitment was a convenience sample of lung cancer survivors from a limited number of states, and demographic data collected by a recruitment firm did not include race/ethnicity or sociodemographic status of participants. Similar to any other qualitative inquiry, our findings are not statistically generalizable to other settings. In addition, our results do not include the views of family members or health care providers, whose insights might have led to a fuller understanding of the phenomena described by lung cancer survivors. To mitigate these limitations, we used rigorous methods, including negative case analysis and generating continual documentation (an audit trail) over time. In addition, we considered alternate explanations for the patterns we observed, and our report underwent scrutiny by public health experts who were not directly involved in the study.

Our study also has several strengths. Given the paucity of data about the experiences of posttreatment and long-term lung cancer survivors, qualitative inquiry was appropriate to ascertain a depth of understanding of the lived experiences of lung cancer survivors not possible with quantitative instruments. This approach left open the possibility for discovering ideas, such as the surprise about survival, that were not already represented in the literature. Important for our study population, qualitative methods give voice to those

who feel stigmatized, marginalized, or otherwise disempowered (Hesse-Biber, 2010), as most of our respondents described having experienced.

The subjective experiences of lung cancer survivors, particularly long-term survivors, are under-represented in the literature. Our results provide valuable insights into the psychosocial concerns of these survivors. It is imperative for oncology social workers, other healthcare professionals, and public health practitioners to learn more about the concerns and needs of this population and provide interventions that meet those needs and support lung cancer survivors in their efforts to advocate for themselves. In addition, public health programs, such as the National Comprehensive Cancer Control Program—funded by the Centers for Disease Control and Prevention—are increasingly focused on cancer survivorship (Belle Isle, Plescia, La Porta, & Shepherd, 2010). These programs can work to reduce the blame, stigma, and other negative reactions experienced by lung cancer survivors by educating the public and implementing large-scale programs that address the needs of this historically under-served population.

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Table 1

Participant demographics.

Pseudonym	Sex	Age at the time of interview	Years of survival at the time of interview	Smoking status		
				Never-smoker	Ever-smoker	Ever-smoker
Abigail	F	74	17	×		
Aiden	M	66	5		×	
Ava	F	51	4	×		
Benjamin	M	69	5		×	
Chloe	F	70	9	×		
Ella	F	70	2		×	
Emily	F	63	1		×	
Emma	F	55	3	×		
Ethan	M	69	8		×	
Isabella	F	70	9		×	
Jack	M	64	7		×	
Jacob	M	62	5		×	
Liam	M	75	9		×	
Logan	M	75	2		×	
Lucas	M	68	6		×	
Mason	M	46	1		×	
Mia	F	62	3		×	
Noah	M	55	9		×	
Olivia	F	73	13		×	
Sophia	F	61	8		×	
Stephen	M	63	2		×	

Note. All ever-smokers had quit either before or at time of diagnosis, except for two participants (Mason and Stephen).