Lung Cancer Survivor Experiences With Post-Treatment Care: An Integrative Review

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PROBLEM IDENTIFICATION: Lung cancer survival rates are improving, and survivors may have unmet post-treatment care needs. Oncology nurses' understanding of these needs can guide development of holistic survivorship care.

LITERATURE SEARCH: A comprehensive search of CINAHL®, PubMed®, and Embase® databases was performed to explore lung cancer survivor experiences with post-treatment care.

DATA EVALUATION: The final sample included 25 studies that were critically appraised for methodologic quality.

SYNTHESIS: Eight themes were identified: relationships with healthcare providers, psychosocial issues such as stigma, disparities such as race or gender, guidance about health behaviors, understanding symptoms and physical activity, development of survivorship programs, self-care or self-management, and evaluating survivorship care plans.

IMPLICATIONS FOR RESEARCH: Issues, such as race, gender, and stigma, represent barriers to holistic lung cancer survivorship care. Little mention of care coordination emphasizes the need for research in this area. Understanding the interplay of symptom and healthy lifestyle management is needed.

KEYWORDS lung cancer; cancer survivors; post-treatment; survivorship care
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The population of cancer survivors in the United States is expected to grow to nearly 26 million by 2040 because of improvements in early detection and treatment options (Bluethmann et al., 2016). In addition, the number of individuals aged older than 65 years is expected to comprise most of the growth and will add to the complexity of care because of comorbidities (Bluethmann et al., 2016). Lung cancer survivors represent a small portion of the overall survivor population, even though lung cancer is the second most common cancer in the United States, with nearly 229,000 new cases diagnosed in 2020 (Siegel et al., 2020). Of note, an overall drop in cancer mortality of 29% since 1991 is mainly attributable to improvements in lung cancer mortality and decreases in smoking (Siegel et al., 2020). The National Lung Screening Trial (Aberle et al., 2011) and the Multicentric Italian Lung Detection trial (Pastorino et al., 2019) demonstrated the role of low-dose computed tomography in reducing lung cancer mortality, leading to standardized screening recommendations in specific populations. Uptake of these screening practices—as well as improvements in treatment options, such as targeted therapy and immunotherapy—are contributing to the growth of this survivor group, who may have needs not previously identified or addressed by their care teams (Giuliani et al., 2016; Swisher et al., 2020).

Lung cancer survivors have a high number of potential care disparities because of the disease itself, as well as cancer-related surgeries and treatments. Compared to noncancer controls and other cancer types, lung cancer survivors also have higher rates of comorbid conditions, such as congestive heart failure, chronic obstructive pulmonary disease, and diabetes (Bluethmann et al., 2016). Symptoms such as fatigue, pain, and dyspnea negatively affect quality of life (QOL). Psychosocial issues, such as stigma and guilt that survivors themselves have caused their

cancer, may precipitate delays or avoidance of seeking help for symptom management, smoking cessation, or healthy lifestyle guidance (Lehto, 2014; Rohan et al., 2016). In addition, early-stage lung cancer survival rates of 56% versus 18% for stage III (Siegel et al., 2020) contribute to potential care gaps related to a lack of knowledge of either group's specific needs. Because of these disparities, lung cancer survivors need individualized approaches to survivorship care.

Much of the lung cancer literature focuses on evaluating specific interventions to aid post-therapy symptom management versus comprehensive, holistic care. Although interventions to address such issues as dyspnea and fatigue are essential for QOL, they only encompass a portion of the required elements of survivorship care as described by the Institute of Medicine (IOM) report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006). Issues, such as financial distress related to employment, smoking cessation, and healthy lifestyle behaviors, are additional unmet needs (Earle et al., 2010; Farley et al., 2016; Kenzik et al., 2016). To adequately address every component of lung cancer survivorship care, care teams may also need to be interprofessional, and oncology nurses are uniquely positioned to lead these teams.

Globally, cancer survivorship care cannot be sustained with current care models. Lack of role delineation within care models is a primary issue (Alfano et al., 2019). Many survivors continue to report poor communication with healthcare providers as a barrier to well-coordinated care (Blanch-Hartigan et al., 2016). Specific areas for improvement include managing emotional needs, enabling self-management, and developing information portals for ease of access to health information (Lawn et al., 2017). In addition, lack of care coordination potentiates poor access to care, nonadherence to guideline-driven care, and the development of new comorbidities (Cordasco et al., 2019; Jansana et al., 2019; Shin et al., 2020). Because lung cancer survivors represent a relatively small portion of overall survivors, research addressing survivorship care in this population is vital. In a study of lung cancer survivors, only 11% were offered survivorship care plans (SCPs) as a post-treatment care tool (Berman et al., 2016). Overall, the use of SCPs has not resulted in improved outcomes; however, care plans may represent a tool to aid self-management of post-treatment needs (Reb et al., 2017). Self-care strategies and the need for other innovative approaches for follow-up are essential tools identified by lung cancer survivors (John, 2010; Sandeman & Wells, 2011). Healthcare professionals, including nurses, require an understanding of the needs of lung cancer survivors regarding their post-treatment care before developing innovative strategies and survivorship care models that provide well-coordinated, individualized care.

The purpose of this integrative review was to explore the current state of adult lung cancer survivor experiences with post-treatment care and to synthesize the findings to inform future research. Because survivorship can encompass various time points in the cancer journey, this review focused on care issues after completion of initial cancer treatment. The specific aims included exploration of the following topics:

- Aim 1: values, beliefs, and experiences with post-treatment care (survivor personal accounts of care, barriers, and expectations)
- Aim 2: cancer and noncancer healthcare needs (cancer-related symptom management, healthy lifestyle, and management of comorbid conditions)
- Aim 3: existing solutions for post-treatment care (SCPs, survivorship clinics, and models of survivorship care)

Methods

Integrative reviews are broad-based approaches to evaluate the literature to understand a phenomenon of interest and allow for the inclusion of empirical and theoretical research. Whittemore and Knafl's (2005) integrative review model guided this article and is an appropriate choice because cancer survivorship is a topic that crosses many disciplines and types of research. Whittemore and Knafl's model includes five steps: problem identification, literature review, data evaluation, data analysis, and synthesis of the findings.

Search Strategy

The literature search was conducted with the assistance of two experienced health sciences librarians. CINAHL®, PubMed®, and Embase® databases were searched for relevant articles published between 2006 and 2020. The IOM report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006) is frequently cited in the survivorship literature and represents a driver of survivorship research; therefore, the year of its publication was used in choosing the start date for the search. Ancestry searches captured additional relevant literature. Search terms included keywords and controlled vocabulary: *cancer survivors*, *cancer survivorship*, *lung cancer*, *lung neoplasm*, *post-treatment care*, *care communication*, *transition*,

survivorship support, *survivorship care*, *care coordination*, *follow-up*, *transitional care*, and *models of care*.

Eligibility Criteria

Eligibility criteria included research focused on adult lung cancer survivors aged 18 years or older with a primary lung cancer diagnosis currently in the post-treatment phase of care, with a focus on at least one of the three integrative review's aims. Other criteria included being published in English, peer-reviewed, and conducted in the United States, United Kingdom, Ireland, Australia, or Canada. These countries were chosen as contrasts with the U.S. healthcare system. Eligible studies could contain a mixed population of survivors if separate lung cancer data were reported for the variables of interest. Survivors could not be receiving initial treatments or recovering from an acute intervention (e.g., survivors who had just been discharged from the hospital postsurgery) to focus the review on the care time points when survivors have less frequent interactions with their cancer care team. Cancer survivorship is often described as having phases, such as survivors in the initial diagnosis and early post-treatment phase versus survivors in the two to five years postdiagnosis phase. Because these phases are not well delineated in the literature (Surbone & Tralongo, 2016), great scrutiny was placed on evaluating studies that included survivors who completed initial treatment for their disease. Studies were excluded if there was no focus on lung cancer survivor values, beliefs, and experiences; cancer and noncancer health needs; or existing solutions for care. Excluded populations included metastatic lung disease from another primary cancer site or if the focus of the study was end-of-life issues.

Study Selection and Final Sample

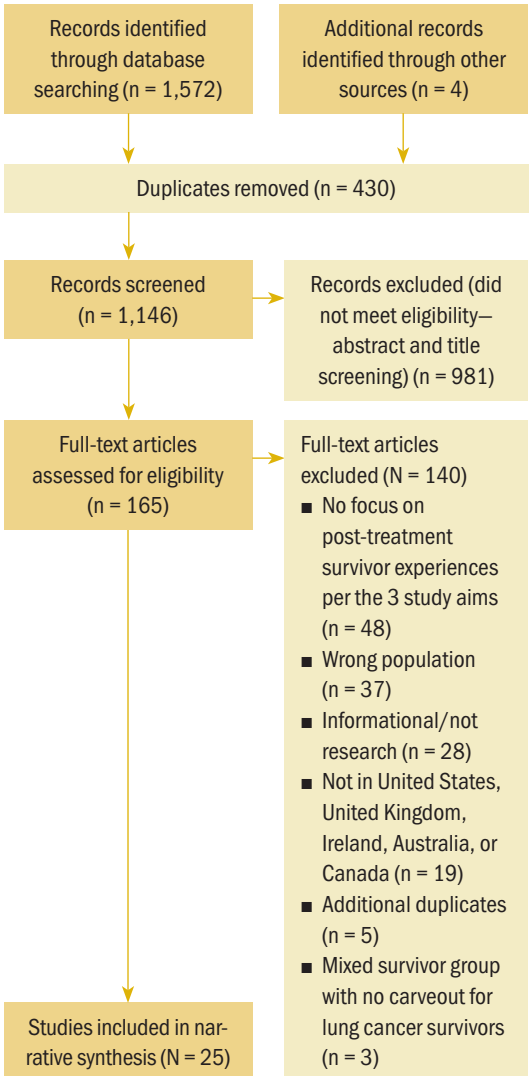
Covidence, a web-based screening and data extraction tool that facilitates the import of citations, removal of duplicate results, and tracking following PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines, was used to obtain the final sample. The database search resulted in 1,572 articles, with 430 duplicates. The remaining 1,142 articles, plus 4 articles found by ancestry search (manually added), were reviewed at the title/abstract level, ultimately yielding 165 articles for full-text review. The primary author performed the full-text review. A final count of 25 articles met the eligibility criteria. The PRISMA flow diagram, including reasons for excluded studies (Moher et al., 2009), is displayed in Figure 1.

The final 25 sample studies included quantitative (n = 15), qualitative (n = 9), and convergent-parallel mixed-methods designs (n = 1). The quantitative studies mainly used a cross-sectional descriptive design (n = 9). The majority of qualitative studies (n = 6) mentioned a specific qualitative methodology (e.g., ethnography, phenomenology).

Data Evaluation

The Quality Assessment Tool for Studies With Diverse Designs (Sirriyeh et al., 2012) was used to

FIGURE 1. PRISMA Flow Diagram



PRISMA— Preferred Reporting Items for Systematic Reviews and Meta-Analyses

critically appraise the studies. This tool is appropriate because it allows for the appraisal of quantitative, qualitative, and mixed-methods research. The Quality Assessment Tool for Studies With Diverse Designs is a 16-item instrument with each criterion scored on a four-point scale, ranging from 0 (no information) to 3 (complete information). Most (n = 14) of these criteria apply to quantitative and qualitative designs, and all 16 criteria apply to mixed-methods studies. The total maximum score for either quantitative or qualitative research is 42, and a mixed-methods study final score is 48. Higher scores represent higher-quality studies. The primary author performed the sample studies' appraisal by creating a table for each study with each item's score and audit trail. Summary results appear in the matrix table used for data analysis (see Table 1).

Scores for the 15 quantitative studies ranged from 16 to 38, with a median of 34, and scores for the nine qualitative studies ranged higher, from 24 to 39, with a median of 35. The highest-quality score was the mixed-methods study at 42, where the point range was higher (48) than other designs. Two sample studies scored below 30 (16 and 24); however, these studies provided valuable information and were not felt to affect the overall review. No studies received a perfect score.

Data Analysis

Analysis of the sample studies began using a matrix table. Key variables were extracted from each study: author; publication year; country; purpose; design; sample and setting; key study results, including limitations; and quality appraisal score. As described by Whittemore and Knafl (2005), an iterative process of comparing sample study results against the integrative review purpose and aims was used for data reduction. First, the 25 sample studies were sorted by the three study aims. Each grouping by aim was then analyzed and coded, and comparisons were made to identify themes. Table 2 illustrates the three integrative review aims, their respective themes, and cited studies. The first author conducted the data extraction and thematic analysis, and the co-authors reviewed and concurred on the thematic analysis. The primary author is an experienced oncology nurse; co-authors are doctoral prepared researchers and experienced oncology clinicians.

Results

Sample Characteristics

Study sample sizes ranged from 10 to 655 participants, representing a total of 3,192 lung cancer survivors. Studies with small sample sizes of 10–30 participants (n = 11) were mostly qualitative and appropriate for the respective study design. Nearly all studies (n = 23) included survivors who were fewer than seven years from their diagnosis and used a minimum requirement of two months post–completion of treatment as inclusion criteria. Research settings included National Cancer Institute–designated comprehensive cancer centers (n = 6), community-based cancer centers (n = 7), and practice or clinics settings (n = 7). The remaining studies were conducted using large consortium survey data. Sample studies were published in 16 different journals, with most (n = 21) having a cancer focus. Authors were primarily nurses (n = 10) or allied health professionals, such as social work or rehabilitative workers (n = 12); physicians led the remaining three studies.

Aim 1: Values, Beliefs, and Experiences With Post-Treatment Care

Aim 1, understanding the values, beliefs, and experiences of survivors with post-treatment care, included 11 studies, resulting in the following three themes: relationships with healthcare providers; psychosocial issues such as stigma, particularly as it relates to smoking status; and disparities such as race or gender.

Theme 1: Relationships with healthcare providers: In studies by Fitch (2020) and Sandeman and Wells (2011), a predominant belief was that the manner in which the healthcare team delivers communication is crucial to the survivor in that it connotates continuity and safety. Survivors bring specific worries and needs to their follow-up appointments and expect encouragement and reassurance from the care team (Sandeman & Wells, 2011). Coordination of care is vital to survivors' abilities to manage their emotional ups and downs (Fitch, 2020).

Theme 2: Psychosocial issues: Because of the known relationship between smoking and lung cancer, survivors often are subjected to the stigmatization that they caused their disease (Farley et al., 2016; Lehto, 2014; Rohan et al., 2016; Shen et al., 2015). The psychosocial consequences of dealing with the stigma and the development of interventions to help anxiety, depression, shame, and guilt surrounding a lung cancer diagnosis need to start with the healthcare providers. In qualitative studies by Farley et al. (2016) and Lehto (2014) evaluating interactions with care teams on smoking behaviors, participants expressed a desire to be approached at every encounter regarding cessation. They also need to feel that health professionals do not blame them for causing their lung cancer (Rohan et al., 2016). Post-traumatic growth

TABLE 1. Data Analysis and Quality Appraisal (N = 25)

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Aronson et al., 2016 (United States)	■ To examine the day-to-day lives of early-stage lung cancer survivors ■ Descriptive repeated measures	■ N = 59 ■ Regional cancer institute in Pennsylvania	■ Few daily stressors or somatic symptoms reported; findings create more positive picture than other studies. ■ Limitations: lack of diverse population; early stage; time of day of data collection may affect recall.	30
Brant et al., 2011 (United States)	■ To examine postchemotherapy symptom trajectories in cancer survivors and to determine if demographic characteristics predicted symptom trajectories ■ Descriptive design	■ N = 100 (lung: n = 41; colorectal: n = 28; lymphoma: n = 31) ■ Community cancer center in Montana	■ Symptoms present at first follow-up visit following chemotherapy ($p < 0.0001$) and persisted over 16 months; depression trajectory was predicted by sex ($p < 0.05$). Higher distress was predicted by younger age ($p < 0.05$). ■ Limitations: incomplete data; variety of stages and treatments may affect symptom trajectories; lack of racial and ethnic diversity; interpretation issues with depressed mood and distress scales	37
Chrischilles et al., 2015 (United States)	■ To evaluate the relationship between SCP and survivorship care and health outcomes reported by long-term lung and colorectal cancer survivors ■ Cross-sectional survey	■ N = 832 (622 colorectal cancer and 210 lung survivors) ■ Colorectal and lung survivors enrolled in the CanCORS study	■ Older and lung cancer survivors were significantly less likely to report receiving SCP; 1 in 4 survivors received both SCP elements. Study outcomes and perceived health status were better for survivors receiving both elements. ■ Limitations: patient self-report; SCP templates not studied; long-term survivors may have different needs than earlier-term survivors.	31
Clark et al., 2008 (United States)	■ To examine the relationship between motivational readiness for PA and QOL in long-term lung cancer survivors ■ Cross-sectional survey	■ N = 272 NSCLC survivors ■ Sample taken from a prospective cohort study: Epidemiology and Genetics of Lung Cancer Research Program at Mayo Clinic in Rochester, MN	■ Survivors who reported engaging in regular PA reported a better overall QOL, better QOL on all 5 domains of QOL functioning (mental, physical, social, emotional, and spiritual), and fewer symptoms compared to those with a sedentary lifestyle. ■ Limitations: lack of sample diversity (mostly White); self-reported PA (no direct measurement); need to factor variables such as self-efficacy	36

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TABLE 1. Data Analysis and Quality Appraisal (N = 25) *(Continued)*

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Coups et al., 2009 (United States)	■ To evaluate lung cancer survivor engagement in PA and examine the association between lung cancer survivors' PA and their QOL ■ Cross-sectional survey	■ N = 124 survivors of stage IA and IB NSCLC treated with surgery; 1–6 years postdiagnosis ■ Memorial Sloan Kettering Cancer Center in New York, NY	■ Participants' reported engagement in both moderate- and strenuous-intensity activities was lower during the post-treatment period compared with before diagnosis and at the current time. Two-thirds of participants did not meet PA guidelines; those who met guidelines reported better QOL. ■ Limitations: study design; recall inaccuracy; problems with reliability and validity of retrospective PA assessments; lack of sample diversity	34
Ellis et al., 2020 (United States)	■ To investigate health system factors that influence social support among Black and White breast and lung cancer survivors and racial differences in support ■ Retrospective, secondary qualitative	■ N = 12 Black survivors (breast: n = 8, lung: n = 4); N = 15 White survivors (breast: n = 9, lung: n = 6) ■ 2 cancer centers in North Carolina	■ Similarities and differences between White and Black participants on 4 themes: social support systems, side effect management, psychosocial support received from cancer care system, and professional healthcare experience among social support systems ■ Limitations: lack of generalizability; did not collect information about available community services; did not collect racial or socioeconomic status information on the informal support networks	38
Farley et al., 2016 (United Kingdom)	■ To explore views of surgical patients with lung cancer about smoking and preferences for support to help them to quit ■ Qualitative interviews	■ N = 22 postsurgical lung cancer survivors ■ United Kingdom	■ 3 themes: views about smoking, views about disclosing smoking behavior to healthcare professionals, and views about smoking cessation as part of cancer care ■ Limitation: small sample	33
Fitch, 2020 (Canada)	■ To gain insight regarding the current experiences of individuals diagnosed with lung cancer and their family caregivers given the evolving changes in lung cancer screening and treatment ■ Qualitative	■ N = 12 (8 survivors and 4 caregivers) ■ Recruited from practices located in Ontario, Canada	■ Major themes: challenges to diagnosis, managing symptoms, returning to "new normal," dealing with late effects, and frustration with lack of information and provision of self-management skills ■ Limitations: small sample; exploratory design	24

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TABLE 1. Data Analysis and Quality Appraisal (N = 25) *(Continued)*

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Hill-Kayser et al., 2009 (United States)	■ To compare demographic and care patterns between lung cancer survivors and the general survivor population using OncoLife™ (a web-based SCP builder) ■ Descriptive	■ N = 142 lung cancer survivor users of OncoLife (4% of comparison sample) ■ Overall comparison group of survivors was N = 3,343	■ 62% reported receiving oncologist-only follow-up care; 27% reported being monitored by a PCP and an oncologist; 6% had PCP-based care; 11% reported receiving survivorship information at the conclusion of therapy. ■ Limitations: tool is anonymous and cannot be validated or verified; poor generalizability	31
Huang et al., 2014 (United States)	■ To develop a novel TSP and assess for feasibility, cost-effectiveness, survivor acceptance, and outcomes ■ Descriptive; program feasibility	■ N = 655 ■ Comprehensive cancer center in New York	■ TSP is feasible, cost-effective, and acceptable to survivors, physicians, and nurses. ■ Limitations: lack of sample diversity; self-reported symptoms with missing data	34
John, 2010 (United States)	■ To describe self-care strategies used by patients with lung cancer to promote QOL ■ Qualitative phenomenology	■ N = 10 ■ Recruited from cancer clinics in Texas	■ 3 main categories found: meaning of QOL, effect of fatigue on QOL, and self-care strategies; fatigue has a significant impact on QOL; healthcare provider suggestions for management are not helpful. ■ Limitations: small sample; poor generalizability	35
Kenzik et al., 2016 (United States)	■ To describe the proportion of survivors reporting that a physician discussed strategies to improve health and identify which groups are more likely to report these discussions ■ Cross-sectional design	■ N = 874 cancer survivors (colorectal: n = 649, lung: n = 225) ■ CanCORS sample	■ Less discussion about diet in female and lung cancer survivors; about 59% reported a physician discussed strategies to improve health and exercise, 44% discussed diet, and 24% reported no discussions. ■ Limitations: did not assess all types of healthcare providers' discussions; did not identify advice versus discussion; height and weight data not collected	35
Krebs et al., 2012 (United States)	■ To examine health-related behaviors of early-stage lung cancer survivors who had curative surgical resection as primary treatment and remained disease-free during the follow-up period ■ Cross-sectional design	■ N = 183 ■ Recruited from thoracic and institutional database of a large NCI-designated cancer center	■ Most survivors adhere to health promotion recommendations except alcohol intake recommendations, which were exceeded by 5% of men and 17% of women. 23% engaged in the recommended PA guidelines for a typical week. ■ Limitations: self-report survey; poor generalizability; lack of sample diversity; study design	32

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TABLE 1. Data Analysis and Quality Appraisal (N = 25) *(Continued)*

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Lehto, 2014 (United States)	■ To describe patient focus group discussions about the lung cancer experience in relation to perceived stigmatization, smoking behaviors, and illness causes, and to discuss implications of these findings relative to the role of the nurse as a patient advocate ■ Qualitative	■ N = 11 ■ Community cancer center in the midwestern United States	■ 6 primary themes: societal attitudes; institutional practices and experiences; negative thoughts and emotions, such as guilt, self-blame and self-deprecation, regret, and anger; actual stigmatization experiences; smoking cessation (personal choices versus addiction); and causal attributions ■ Limitations: small sample; older population; lack of sample diversity	35
McDonnell et al., 2020 (United States)	■ To explore the social and behavioral factors associated with risk-reducing health behavior changes among dyads of African American lung cancer survivors and their family members ■ Qualitative using social cognitive theory	■ N = 26 African American dyads ■ 2 cancer programs in the southeastern United States	■ 4 themes: rethinking recovery and identifying information oversights; needing compassion, hope, and understanding; living longer with symptoms; and ability to compromise and change ■ Limitations: small convenience sample from 2 settings may cause variability; heterogeneous caregiver group; urban setting may provide different responses than higher socioeconomic settings.	39
Peddle-McIntyre et al., 2013 (Canada)	■ To examine the effects of a 10-week supervised progressive resistance exercise training program on lung cancer survivors' motivational outcomes based on the theory of planned behavior ■ Pre-/postintervention with no randomization	■ N = 17 (consented); N = 15 (completed) stage I–IIIB NSCLC or limited-stage small cell lung cancer ■ Recruited from lung clinics at a cancer center or through provincial cancer registry	■ Short-term supervised resistance exercise training may improve some motivational outcomes. Intentions appeared to be weakened after the intervention. Postintervention self-efficacy ($p = 0.022$), perceived controllability ($p = 0.032$), and postintervention intention ($p = 0.044$) ■ Limitations: lack of comparison group; small sample; sample may already be motivated to exercise; short follow-up	38
Poghosyan et al., 2015 (United States)	■ To investigate racial disparities in postsurgical health-related QOL among patients with NSCLC ■ Secondary analysis	■ N = 650 (complete data for all covariates) ■ CanCORS data set	■ Black patients reported lower MCS than White patients (47.4 versus 52.6, $p = 0.002$); no difference was found between White and Black patients on PCS. ■ Limitations: PCS and MCS scores were self-reported; imbalanced sample size (80% White versus 8% Black); missing data; later stage affects generalizability.	31

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TABLE 1. Data Analysis and Quality Appraisal (N = 25) *(Continued)*

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Reb et al., 2017 (United States)	■ To evaluate the feasibility and acceptability of a Self-Management Survivorship Care Planning intervention in colorectal and lung cancer survivors ■ Single-group, pre– and postintervention mixed-methods study	■ 15 lung cancer survivors and 15 colorectal cancer survivors ■ Setting: NCI-designated comprehensive cancer center in southern California	■ Lung cancer survivors: longer time to complete SCP and scored lower on physical functioning scales; themes for qualitative: felt empowered, struggling with psychosocial concerns, suggestions for intervention (timing and content) ■ Limitations: small sample; no control group; qualitative data were robust but did not include probing questions.	42
Reed et al., 2018 (United States)	■ To describe survivors' self-reported discussions with healthcare providers and receipt of survivorship care and follow-up recommendations among a cohort of cancer survivors of breast, colorectal, lung, prostate, and melanoma ■ Cross-sectional from a survey (Experiences With Cancer Survivorship Survey)	■ N = 615 (n = 117 lung cancer survivors) ■ Random stratified sample from the Experiences With Cancer Survivorship Survey and participating in 3 identified health plans	■ 92% had discussions about the need for surveillance, 75% about late and long-term effects, 69% about lifestyle and health behaviors, and 53% about emotional and social needs. 88% reported receiving post-treatment care instructions, and 47% reported receiving a treatment summary; no difference among receipt of surveillance or health behavior recommendations by cancer type ($p = 0.85$ and $p = 0.66$, respectively); discussions of late and long-term effects occurred among 82% of prostate, 78% of breast, 73% of melanoma, 72% of colorectal, and 67% of lung cancer survivors ($p = 0.06$). ■ Limitations: study design; only insured survivors; years of survey may not reflect current practice.	30
Rohan et al., 2016 (United States)	■ To understand the subjective experiences of individuals living with lung cancer, with emphasis on the psychosocial concerns of post-treatment and long-term lung cancer survivorship; to provide recommendations to healthcare and public health professionals on how to better serve this population of cancer survivors ■ Qualitative interviews	■ N = 21 ■ Survivors from the eastern and midwestern United States (used 2 clinical sites plus 2 research recruiting firms to obtain sample)	■ Psychosocial concerns 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. ■ Limitations: convenience sample; recruitment firm did not collect demographics; did not include caregivers' or healthcare workers' perspectives	35

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TABLE 1. Data Analysis and Quality Appraisal (N = 25) *(Continued)*

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Sandeman & Wells, 2011 (Scotland)	■ To explore patients' experiences of routine follow-up and the meaning and significance of follow-up after treatment for lung cancer ■ Qualitative phenomenology using interviews	■ N = 10 (small cell lung cancer, NSCLC, and mesothelioma) ■ Recruited from 2 lung clinics in a large hospital in Scotland	■ 3 main themes included: relationship with oncology team, what patients bring to the visit (vulnerability or anxiety), and what patients take from the visit (encouragement or reassurance); lung cancer survivors have complex needs and are willing to accept nurse-led survivorship care. ■ Limitations: small sample; early in survivorship	32
Sarna et al., 2010 (United States)	■ To describe physical and emotional QOL of disease-free female NSCLC survivors and to determine characteristics associated with greater risk of disruptions ■ Longitudinal correlational design	■ N = 119 ■ Convenience sample from 5 states (California, Georgia, Connecticut, New York, Alabama)	■ Depressed mood, comorbidities, and dyspnea were factors related to poorer physical and emotional QOL. ■ Limitations: convenience sample; none of the women had received adjuvant therapy; small samples in some subcategories precluded comparisons of QOL profiles.	34
Shen et al., 2015 (United States)	■ To test the hypothesis that post-traumatic growth would buffer against the negative effect of lung cancer stigma on psychological distress and to examine how this effect differed according to timing of quitting history (pre- versus postdiagnosis quitting) ■ Cross-sectional design	■ N = 141 stage IA and IB NSCLC ■ NCI-designated comprehensive cancer center in New York	■ In prediagnosis quitters, stigma had a positive association with psychological distress at high levels of post-traumatic growth ($p = 0.003$). In postdiagnosis quitters, stigma had a positive association with psychological distress among those with low levels of post-traumatic growth ($p = 0.004$). ■ Limitations: study design; lack of sample diversity; stigma scale validity; low number of smokers in study	34
Swisher et al., 2020 (United States)	■ To determine the unmet needs of individuals with early-stage lung cancer as they moved from active treatment to survivorship and to assess the feasibility and effectiveness of a program to meet these needs ■ Observational, feasibility study	■ N = 84 lung cancer survivors ■ Lung cancer clinic at a large community cancer center ■ Follow-up assessment: N = 19	■ Survivors reported at least 1 unmet need, with a mean of 7 unmet needs, particularly related to breathing, fatigue, pain, and fear/anxiety. Fewer and/or less severe needs were identified postprogram. Program feasibility was established. ■ Limitations: large drop-off rate; implementation challenges included hesitancy of providers to refer, time constraints of survivors and staff, and lack of community resources.	16

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TABLE 1. Data Analysis and Quality Appraisal (N = 25) *(Continued)*

Study and Country	Purpose and Design	Sample and Setting	Results and Limitations	QATSDD Score
Webb & McDonnell, 2018 (United States)	■ To describe the experience of female African American lung cancer survivors, their perception of living with lung cancer, and ability to adopt positive health behaviors ■ Descriptive, qualitative design	■ N = 18 ■ 2 community hospital centers in the southeastern United States	■ Qualitative data analysis resulted in 4 themes: living proof that lung cancer is not an automatic death sentence, learning to live with burdensome symptoms, communication barriers affect self-care, and African American women need to support one another. ■ Limitations: small sample; may not reflect the experiences of all female African American lung cancer survivors	37

CanCORS— Cancer Care Outcomes Research and Surveillance Consortium; MCS—mental component score; NCI—National Cancer Institute; NSCLC—non-small cell lung cancer; PA—physical activity; PCP—primary care provider; PCS—physical component score; QATSDD—Quality Assessment Tool for Studies With Diverse Designs; QOL—quality of life; SCP—survivorship care plan; TSP—thoracic survivorship program
Note. The QATSDD is a 16-item instrument with each criterion scored on a 4-point scale, ranging from 0 (no information) to 3 (complete information). Most (n = 14) of these criteria apply to quantitative and qualitative designs, and all 16 criteria apply to mixed-methods studies. The total maximum score for either quantitative or qualitative research is 42, and a mixed-methods study final score is 48. Higher scores represent higher-quality studies.

may be a moderator to stigma and associated distress in lung cancer survivors who quit smoking after diagnosis (Shen et al., 2015). Developing post-traumatic growth interventions may help to improve the psychological effects of stigma in this population.

Aronson et al. (2016) conducted a repeated-measures study evaluating daily stressors, including worry, mood, and symptoms. The study results include few daily stressors for early-stage lung cancer survivors, which paints a much different picture than the other studies included in this theme. The authors conclude that some degree of worry may be a positive effect, as lung cancer survivors place the seriousness of their diagnosis in context.

Theme 3: Disparities: Racial and gender disparities have been identified as issues surrounding health care for many diseases, including cancer. QOL can be affected within these groups—specifically, lower mental health component scores for both Black and female survivors (Poghosyan et al., 2015; Sarna et al., 2010). Identified patterns among African American and Black survivors have shown the need for understanding how support systems interact with the care trajectory, clear communication with healthcare providers, additional tools to self-manage symptoms, and information about available resources (Ellis et al., 2020; Webb & McDonnell, 2018). African American and Black survivors report a desire to learn about healthy lifestyle behaviors, but they perceive that having a lung cancer diagnosis precludes this offering. Many feel that the diagnosis does not equate to death, and survivors should be provided with tools to live out their lives in a healthy manner. The lack of the care team's ability to include support networks can create other disparities because White survivors have more access to health professionals in their networks versus Black survivors who rely on peers to help with such issues as symptom management (Ellis et al., 2020).

Aim 2: Cancer and Noncancer Healthcare Needs

Aim 2, exploring the healthcare needs of lung cancer survivors, included six studies with the following two themes: the need for guidance about health behaviors to reduce risk of illness and improve overall health, and understanding symptoms experienced post-treatment, particularly those that affect the ability to engage in physical activity.

Theme 1: Guidance about health behaviors: Lung cancer survivors surveyed in two studies (Kenzik et al., 2016; Krebs et al., 2012) reported the frequency of discussions with physicians about healthy behaviors. Kenzik et al. (2016) found that although discussions were occurring, specific behaviors, such as a healthy diet, were discussed less frequently with lung cancer survivors versus colorectal survivors ($p = 0.002$). In addition, the proportion of survivors not

TABLE 2. Themes Sorted by Study Aim

Theme	Studies
Aim 1: Values, beliefs, and experiences with post-treatment care	
Relationships with healthcare providers	Fitch, 2020; Sandeman & Wells, 2011
Psychosocial issues such as stigma, particularly as it relates to smoking status	Aronson et al., 2016; Farley et al., 2016; Lehto, 2014; Rohan et al., 2016; Shen et al., 2015
Disparities such as race or gender	Ellis et al., 2020; Poghosyan et al., 2015; Sarna et al., 2010; Webb & McDonnell, 2018
Aim 2: Cancer and noncancer healthcare needs	
The need for guidance about health behaviors to reduce risk of illness and improve overall health	Kenzik et al., 2016; Krebs et al., 2012; McDonnell et al., 2020
Understanding symptoms experienced post-treatment, particularly those that affect the ability to engage in physical activity	Brant et al., 2011; Clark et al., 2008; Coups et al., 2009
Aim 3: Existing solutions for post-treatment care	
Solutions focused on the development of survivorship programs	Huang et al., 2014; Peddle-McIntyre et al., 2013; Swisher et al., 2020
Solutions related to self-care or self-management	John, 2010; Reb et al., 2017
Evaluating the use of survivorship care plans	Chrischilles et al., 2015; Hill-Kayser et al., 2009; Reb et al., 2017; Reed et al., 2018

having healthy behavior discussions was significant (exercise: 59%; diet: 44%). Krebs et al. (2012) found high adherence rates among early-stage lung cancer survivors for healthy behaviors and cancer screenings; however, the surveyed group did not meet the recommended level of exercise ($p < 0.05$) of 150 minutes per week. McDonnell et al. (2020) conducted a qualitative study with African American dyads regarding healthy behaviors. Predominant themes were that survivors wanted to help improve their overall health condition by engaging in healthy lifestyle changes; however, lack of referrals to appropriate clinicians, poor communication related to health literacy, and the need for practical solutions often hindered their efforts.

Theme 2: Understanding symptoms and physical activity: Brant et al. (2011) studied the trajectory of symptoms post-treatment and predictive demographic factors in a mixed group of survivors, of which lung survivors represented the largest portion ($n = 41$) of the sample ($N = 100$). Persistent symptoms, such as depressed mood, pain, fatigue, and sleep disturbance, more than 16 months post-treatment imply the need for comprehensive assessments to tailor interventions in physical and psychological manifestations appropriately.

Coups et al. (2009) evaluated physical activity changes across the cancer trajectory. Survivors in early phases of cancer survivorship had lower engagement, and those in later phases had higher engagement, contributing to improved QOL. However, lung cancer survivors did not meet the recommended exercise guidelines for survivors. Clark et al. (2008) assessed motivational readiness for physical activity based on the transtheoretical model of behavior change (Prochaska et al., 1992). Findings include a clear association of QOL, symptom management, and physical activity in lung cancer survivors. In addition, lung cancer survivors who were regularly physically active reported significant improvements in QOL compared to sedentary survivors. Causal factors for this finding are unknown; however, the authors concluded that uncontrolled symptoms could also account for less physical activity.

Aim 3: Existing Solutions for Post-Treatment Care

The third aim included a review of existing solutions for post-treatment care. Although solutions varied, analysis of eight studies resulted in three themes as

follows: solutions focused on the development of survivorship programs, solutions related to self-care or self-management, and evaluating the use of SCPs.

Theme 1: Development of survivorship programs: Researchers studied the effects of a 10-week supervised exercise program to improve lung cancer survivors' motivational outcomes using the theory of planned behavior (Peddle-McIntyre et al., 2013). The Theory of Planned Behavior is a social cognitive theory that focuses on intention as the main predictor of behavior change (Ajzen, 1991). Participation in the program improved self-efficacy ($p = 0.022$), perceived controllability ($p = 0.032$), and affective attitude ($p = 0.09$). Self-efficacy was also correlated with planning ($p < 0.046$). The sustainability of exercise programs can potentially effect further improvement to lung cancer survivors' QOL.

Swisher et al. (2020) assessed the unmet needs of lung cancer survivors and then developed a program to meet those needs, mainly by connecting survivors to community resources. Participants reported a range of one to seven unmet needs at baseline, mostly related to specific symptoms. Postprogram evaluations revealed fewer or less severe conditions. In contrast, researchers at Memorial Sloan Kettering Cancer Center in New York, New York, developed a thoracic survivorship program for lung cancer survivors at least one year postsurgery (Huang et al., 2014), testing feasibility and acceptance of the program by survivors. Reported post-treatment symptoms included fatigue, anxiety, pain, dyspnea, and depression. Follow-up evaluations revealed that 92% of survivors wished to continue their post-treatment care in the program, led by a nurse practitioner versus routine follow-up with the thoracic surgeon.

Theme 2: Self-care or self-management: John (2010) described self-care strategies used by lung survivors to improve QOL. Survivors first identified their personal meaning of QOL and then factors negatively affecting QOL. Because lung cancer survivors were not satisfied with healthcare providers' recommendations (rest) for combating fatigue, they developed strategies such as budgeting time and energy, maintaining relationships with family and peers, and prayer. Reb et al. (2017) designed a mixed-methods study of self-management SCPs (SM-SCPs). Care plan development was feasible for survivors and revealed improvements in symptom control, self-efficacy, and total QOL. The qualitative component showed that survivors appreciated having a plan, had unmet psychosocial needs, and provided suggestions for the SM-SCP content.

Theme 3: Evaluating SCPs: Researchers evaluated relationships between SCPs and health outcomes based on the receipt of two measures: a written summary of cancer treatment and instructions about follow-up providers (Chrischilles et al., 2015). Results revealed that receipt of SCPs might lead to improved physician communication, ability to meet recommended exercise, adherence to follow-up visits, and confidence in the care team leader (Chrischilles et al., 2015). In a mixed survivor population study (Reed et al., 2018), receipt of written SCPs and verbal instructions were assessed. Lung cancer survivors reported the least number of discussions about late and long-term side effects ($p = 0.06$), and survivors in all groups reported low levels of discussions regarding emotional needs. Hill-Kayser et al. (2009) assessed data from survivors using OncoLife™ (https://oncolife.oncolink.org), a publicly available SCP tool that survivors can use to create their plans. Lung cancer survivors reported receiving multimodality treatments and comprised 4% of total survivors who used the program. Only 11% of the lung cancer survivors reported receiving an SCP from their provider at the end of treatment. Also, many lung cancer survivors did not receive consistent care from their primary care providers. Finally, Reb et al. (2017) reported positive findings from an SCP intervention using self-management skills. Results showed improvements in multiple mental and physical well-being measures. Qualitative data revealed empowerment for survivors, indicating that survivorship care interventions can meet the unmet needs of this population.

Discussion

The purpose of this integrative review was to explore the current state of adult lung cancer survivor experiences with post-treatment care by understanding the values, beliefs, and experiences of lung cancer survivors, their cancer and noncancer healthcare needs, and existing solutions for post-treatment care. The resultant eight themes provide insight toward closing care gaps in this group.

Lung cancer survivors value the relationships they have with their care teams. Two studies revealed that the approach used to deliver communication is vitally important because it conveys a sense of caring and security in these relationships (Fitch, 2020; Sandeman & Wells, 2011). This theme is recurrent in survivorship literature for all types of cancer survivors (Blanch-Hartigan et al., 2016; Economou & Reb, 2017; Thorne & Stajduhar, 2012). Despite the identified need to engage survivors, help them with self-management skills, and

address emotional concerns common in all survivors, lung cancer survivors need to feel safe through appropriate communications from their care teams. Nurses can augment communications by engaging in therapeutic relationships, ensuring a caring environment, and addressing the survivors' physical and psychosocial needs during the post-treatment care phase.

The relationship between smoking and lung cancer is a well-established causal effect. A recurrent theme in the literature was that lung cancer survivors experience a great deal of stigma that they caused their disease, even in the never-smoker cohort. This stigma can lead to deeper issues, such as depression, anxiety, and shame, that prevent lung cancer survivors from seeking help (Farley et al., 2016; Lehto, 2014; Rohan et al., 2016; Shen et al., 2015). Finding interventions to help reduce stigma in lung cancer survivors is imperative to improving this population's psychological health because stigma is compounded by inequities related to race and gender.

Racial and gender disparities were identified in four studies with a sub-focus on care networks. Differences were noted between White and Black survivors in how they access networks and how healthcare professionals integrate these networks into care (Ellis et al., 2020; Webb & McDonnell, 2018). The lung cancer diagnosis should be placed into context without judgment to support survivors' needs for healthy behaviors (Poghosyan et al., 2015). Women with comorbid conditions, depression, and dyspnea may benefit from coordinated screening for these issues, leading to better supportive care measures (Sarna et al., 2010). Because nurses often spend the most time with survivors' networks, they are the ideal professionals to integrate these important support systems into care by leveraging teachable moments and using education skills such as teach-back for self-care interventions and symptom management.

Lung cancer survivors have healthcare needs related to both their cancer diagnosis and comorbid conditions. Promoting healthy lifestyle behaviors is a key component of survivorship care (Denlinger et al., 2018). However, documentation that healthcare providers have discussed these behaviors with survivors is sometimes lacking (Denlinger et al., 2014). Lung cancer survivors want to engage in healthy behaviors; therefore, it is incumbent on the healthcare team to provide useful tools and to plan for these discussions during care encounters. One aspect that may hinder engagement in healthy behaviors is that lung cancer survivors experience a wide range of physical symptoms related to both the disease and the treatments.

KNOWLEDGE TRANSLATION

- Lung cancer survivors want to engage in healthy lifestyle behaviors but are often overlooked because of stigma associated with the diagnosis.
- Individualized care based on a clear survivor definition, including stage of disease and phase of survivorship, is needed.
- Nurse-led care models are vital to providing care to the growing lung cancer survivor population.

Engaging in physical activity has been demonstrated to improve cancer survivors' QOL (Conn et al., 2006); therefore, their ability to engage in and improve physical activity is crucial and may be directly related to the presence and control of post-treatment symptoms. Nurses can play an integral role in promoting these behaviors during survivorship by engaging survivors in discussions about lifestyle behaviors, assessing readiness for change, and making appropriate referrals to support services.

With the recommendations set forth by the IOM's report on cancer survivorship (Hewitt et al., 2006), solutions to improve care often revolve around the development of coordinated programs to aid in symptom management or to ensure adherence to follow-up guidelines. Survivorship programs led by nurses have been well accepted and provide expanded options for survivors (Huang et al., 2014). A variety of care programs may be needed for lung cancer survivors, depending on cancer type, stage, treatment, or symptom burdens, and may include self-management and self-care strategies. This review included examples of valid self-management methods to help lung cancer survivors maintain control over their health and survivorship trajectories (John, 2010; Reb et al., 2017). Sun et al. (2021) proposed an intervention study to determine the efficacy of a telehealth intervention program to improve care delivery and outcomes in lung and colorectal cancer survivors. Their study focused on empowering survivors using the Chronic Care Model (Wagner et al., 2005) and post-treatment care shared between oncology and primary care providers. Engaging survivors is a key component of survivorship programs; therefore, the knowledge gained from the described study (Sun et al., 2021) will further contribute to closing care gaps.

SCPs are another tool intended to bridge care gaps by summarizing treatments, follow-up, screening, and health recommendations for survivors that can be shared with their current and future care providers.

SCPs were first recommended by IOM's report (Hewitt et al., 2006) and subsequently adopted by national cancer quality groups, such as the American College of Surgeons Commission on Cancer. However, the implementation of SCPs has been fraught with problems, mainly related to healthcare providers' ability to create and distribute the plans (Jacobsen et al., 2018). Although no significant studies to date have supported improved outcomes related to survival and recurrence, SCPs may still be necessary for specific groups of survivors or metrics, such as patient satisfaction. The care coordination provided using SCPs is particularly crucial. Studies specifically focused on this component were lacking within the scope of this review. For lung cancer survivors, SCPs may offer a streamlined manner to manage a very complicated disease trajectory.

Limitations

Despite efforts to conduct a thorough review, the search strategy may have failed to capture all relevant literature. In addition, other research databases could have been added to broaden the scope of the search. The sample contained no randomized clinical trials that would contribute to the quality of the review. A large proportion of the data collected was based on self-reported surveys, which may have introduced recall bias. Also, many studies only involved postsurgery survivors and lacked sample diversity.

The definition of "survivorship" in the literature is a limitation because it may evoke different meanings for survivors and care providers. For example, results from an unpublished survey conducted at the primary author's institution (Denlinger & Filchner, 2020) revealed that only 10% of providers use the National Cancer Institute (2020) definition of survivorship, starting at the time of cancer diagnosis and continuing through the end of life. In comparison, almost 40% of providers define a survivor as someone who has completed initial treatment and has a disease-free status, regardless of time since the end of treatment (Denlinger & Filchner, 2020). Finally, it was challenging to make specific conclusions because of the variability of survivors' stage of disease and treatment types. These two factors can significantly alter the experiences and needs of lung cancer survivors.

Implications for Nursing Research

The 2019–2022 Research Agenda of the Oncology Nursing Society (Von Ah et al., 2019) identifies survivorship as a cross-cutting theme across research priorities of symptom science, health disparities, and palliative and psychosocial care. This integrative review has identified multiple gaps that align with these research priorities. Implications for future research include understanding how race, gender, and other socioeconomic factors interact and become systemic barriers in the receipt or delivery of post-treatment care in lung cancer survivors. Survivor support systems and how survivors use these systems affect the care trajectory and need further exploration. Stigma is frequently described by survivors and warrants further investigation. Studies should focus on individualized care based on a clear survivor definition, including stage of disease and phase of survivorship. Exercise and symptom management are survivor experiences that require further evaluation within the scope of care models. Survivors who are never-smokers are underrepresented in the literature and require further study. Also, little mention of care coordination emphasizes the need for research in this area. Further understanding the perspectives of key stakeholders, such as caregivers and health professionals, is warranted within the scope of survivorship care. Finally, the use of nurse-led interprofessional care models is imperative to providing care to the growing lung cancer survivor population.

Conclusion

This integrative review focused on the post-treatment care of lung cancer survivors, including experiences, healthcare needs, and existing solutions for care. Results indicate an underrepresentation of studies aimed at understanding the special care needed by this growing population of survivors. Lung cancer survivors want to be engaged in their care and use healthy lifestyle habits but are often overlooked because of the stigma associated with the diagnosis. Nurses play an essential role to effect change for the care of these individuals and to influence societal misconceptions about lung cancer.

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