

Social determinants of health among family caregiver centered outcomes in lung cancer: a systematic review

Dede K. Teteh¹^, Madeleine Love², Marissa Ericson³, Marissa Chan⁴, Tanyanika Phillips⁵, Aroona Toor⁶, Betty Ferrell², Loretta Erhunmwunsee⁷, Susanne B. Montgomery⁸, Virginia Sun^{2,7}, Jae Y. Kim⁷

¹Department of Health Sciences, Crean College of Health and Behavioral Sciences, Chapman University, Orange, CA, USA; ²Division of Nursing Research and Education, Department of Population Sciences, City of Hope Comprehensive Cancer Center, Duarte, CA, USA; ³Department of Psychology, University of Southern California, Los Angeles, CA, USA; ⁴Department of Environmental Health, Harvard School of Public Health, Boston, MA, USA; ⁵Department of Medical Oncology & Therapeutics Research, City of Hope Comprehensive Cancer Center, Duarte, CA, USA; ⁶Department of Health Policy and Management, Milken Institute School of Public Health, George Washington University, Washington, DC, USA; ⁷Department of Surgery, City of Hope Comprehensive Cancer Center, Duarte, CA, USA; ⁸School of Behavioral Health, Loma Linda University, Loma Linda, CA, USA

Contributions: (I) Conception and design: JY Kim, V Sun, DK Teteh; (II) Administrative support: DK Teteh, M Love; (III) Provision of study materials or patients: JY Kim, V Sun, DK Teteh; (IV) Collection and assembly of data: DK Teteh, M Love, M Ericson, M Chan, B Ferrell, A Toor; (V) Data analysis and interpretation: DK Teteh, M Love, B Ferrell, V Sun, JY Kim; (VI) Manuscript writing: All authors; (VII) Final approval of manuscript: All authors.

*Correspondence to: Jae Y. Kim, MD. Department of Surgery, City of Hope Comprehensive Cancer Center, 1500 E Duarte Rd Duarte, CA 91010, USA. Email: jaekim@coh.org.

Background: Lung cancer is the leading cause of cancer death globally. Both lung cancer patients and family caregivers (FCGs) have unmet quality of life (QOL) needs. An understudied topic in lung cancer research is the role of social determinants of health (SDOH) on QOL outcomes for this population. The purpose of this review was to explore the state of research on SDOH FCGs centered outcomes in lung cancer.

Methods: The databases PubMed/MEDLINE, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature, and American Psychological Association (APA) PsycInfo were searched for peer-reviewed manuscripts evaluating defined SDOH domains on FCGs published within the last ten years. The information extracted using Covidence included patients, FCGs and study characteristics. Level of evidence and quality of articles were assessed using the Johns Hopkins Nursing Evidence-Based Practice Rating Scale. **Results:** Of the 344 full-text articles assessed, 19 were included in this review. The social and community context domain focused on caregiving stressors and interventions to reduce its effects. The health care access and quality domain showed barriers and underuse of psychosocial resources. The economic stability domain indicated marked economic burdens for FCGs. Four interconnected themes emerged among articles on the influence of SDOH on FCG-centered outcomes in lung cancer: (I) psychological well-being, (II) overall quality of life, (III) relationship quality, and (IV) economic hardship. Notably, most participants in the studies were White females. The tools used to measure SDOH factors included primarily demographic variables.

Conclusions: Current studies provide evidence on the role of SDOH factors on lung cancer FCGs' QOL. Expanded utilization of validated SDOH measures in future studies would provide greater consistency in data, that could in turn inform interventions to improve QOL. Further research focusing on the domains of education quality and access and neighborhood and built environment should be carried out to bridge gaps in knowledge.

Keywords: Social determinants of health (SDOH); family caregivers (FCGs); lung cancer; quality of life (QOL)

Submitted Nov 18, 2022. Accepted for publication Apr 13, 2023. Published online May 09, 2023. doi: 10.21037/jtd-22-1613

View this article at: https://dx.doi.org/10.21037/jtd-22-1613

[^] ORCID: 0000-0001-9552-148X.

Introduction

Cancer continues to be a growing health concern throughout the world. Historically, lung cancer has been one of the most disparate malignancies in the United States (1), with high levels of symptom burden and quality of life (QOL) needs that are challenging for both the patients and their family caregivers (FCGs) (2). FCGs are relatives or friends who assume care responsibilities for a patient (3). How a patient and their FCGs adapt to a lung cancer diagnosis and their ability to access quality and timely lung cancer care are influenced by an array of non-disease and non-clinical factors. These factors are referred to as social determinants of health (SDOH). The US Department of Health Human Services defines SDOH as the social and physical environmental conditions in which people live, work, age, play, and pray (4). The SDOH framework (Figure 1) includes five broad domains: economic stability, education access and quality, neighborhood and built environment, healthcare access and quality, and social and community context (5,6). The effects of SDOH on health outcomes can be disadvantageous (7,8). Compared to individuals living in higher socioeconomic status (SES) neighborhoods, individuals residing in lower SES neighborhoods have higher rates of morbidity and mortality from many diseases (9-11), including lung cancer (12-14). Similarly, studies have shown associations between low education, living

Highlight box

Key findings

- Current studies provide evidence of the critical role of social determinants of health (SDOH) factors on lung cancer family caregivers' (FCGs) quality of life.
- The studies included in this review largely focused on three out of the five SDOH domains: social and community context, healthcare access and quality and economic stability.
- Tools used to measure SDOH factors lacked standardization and primarily focused on demographic variables.

What is known and what is new?

- SDOH is an understudied topic in lung cancer research for FCGs.
- SDOH factors influence the overall quality of life of FCGs including their psychological well-being, relationship quality, and increased economic hardship.

What is the implication, and what should change now?

 SDOH factors significantly influence QOL of FCGs, and utilization of validated measures across all five domains would provide greater data consistency that could inform interventions to improve their health outcomes. in racially segregated neighborhoods, low social support and mortality for myocardial infarction, cerebrovascular disease, and lung cancer (15,16). Patients with cancer and FCGs often experience significant out of pocket costs and employment disruptions, resulting in financial toxicity (17). Other social conditions such as SES, behavioral needs, and environmental circumstances may impact QOL outcomes among patients with lung cancer (18).

Research on SDOH for FCGs has mainly focused on pediatric populations (19-21) and chronic conditions (22,23). Furthermore, studies have largely focused on three out of the five SDOH domains, with economic stability, social and community context, and healthcare access [including health literacy (24)] and quality dominating the literature (19). Other important domains, including education access and quality and neighborhood and built environment, are often not prioritized, or assessed. Another important yet understudied sub-factor within the social and community context domain is spirituality, which is defined as the belief in something greater than oneself, and guidance of that belief in understanding connections to self, others, nature, and the sacred (25-27). Spirituality has been found to encourage social cohesion, defined as the cooperative achievement of goals among individuals in a community that contributes to progressive health and economic outcomes (28,29).

While lung cancer incidence has been found to be associated with SDOH factors such as education, occupation, and income (30), our understanding of other SDOH domains on lung cancer FCG outcomes is limited. Although SDOH accounts for nearly 80% of an individual's health status (31), the literature is sparse regarding SDOH in relation to cancer caregiving, specifically in the context of lung cancer. Questions remain in understanding the relationships between SDOH and lung cancer outcomes for FCGs. Within this framework, a systematic review was conducted to determine the current state of the literature on SDOH for FCG-centered outcomes in lung cancer. We present this article in accordance with the PRISMA reporting checklist (available at https://jtd.amegroups.com/article/view/10.21037/jtd-22-1613/rc) (32).

Methods

Search strategy

The authors (DT, VS, JK) developed search strategy criteria with the assistance of a librarian using the following

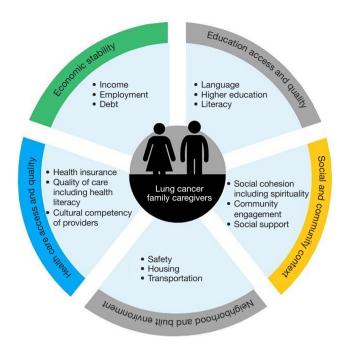


Figure 1 Social determinants of health framework for lung cancer family caregivers.

databases: PubMed/MEDLINE (Legacy version); Cochrane Library; Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with Full Text; and American Psychological Association (APA) PsycInfo. The following search terms were used: lung cancer, family caregivers, patients, and social determinants of health. The keywords were combined with synonyms, alternate spellings/word endings, and controlled vocabulary, such as Medical Subject Headings (MeSH), to retrieve relevant results. Social determinants of health factors were broken down into individual keywords such as education, economic status, healthcare disparities, etcetera. The complete list of search strategies, including MeSH terms, can be found in Appendix 1. The librarian performed all searches, with inputs from three authors (DT, VS, JK). This search strategy yielded 2,396 articles. The search results were further filtered limiting inclusion to studies published in the last ten years (January 2010-December 2020), human participants, and English language studies. For PubMed/ MEDLINE, we also filtered the articles by (I) age: all Adults; (II) publication types (refer to Appendix 1 for specifics). CINAHL results were limited to the Age Group "All Adult" and peer reviewed publications. After applying these criteria, the search strategy yielded 1991 sources after

removing duplicate records (n=7).

Eligibility criteria

We included peer-reviewed original manuscripts published between 2010–2020, if at least 25% of participants were adult family caregivers of lung cancer patients. Exclusion criteria eliminated studies that were published prior to 2010, non-English studies, not conducted in the United States, dissertations, and other non-peer reviewed manuscripts. Due to the complexity of SDOH and lung cancer outcomes among FCGs, we chose to limit the scope of this review to the United States. We also excluded studies with the following designs and/or topics: interventions, systematic literature reviews/meta-analyses, case studies, drug efficacy trials, lung cancer screening, and basic science studies.

Data abstraction

We performed title/abstract screening, full-text screening, and data abstraction using the Covidence systematic review software tool (33). DT, ML, ME, MC, VS, JK and BF participated in the title/abstract screening, full-text screening, and data abstraction. Disputes over inclusion were resolved via virtual face to face discussions between DT, VS, and JK until consensus was reached. Of the 1,991 titles/abstracts screened, we excluded 1,647. Three-hundred forty-four articles remained for full-text evaluation. Figure 2 illustrates the review process for final studies included in our qualitative synthesis. We then used the inclusion criteria to evaluate full-text articles and excluded an additional 338 studies. Using Covidence Extraction 2.0 template developed by DT in consultation with VS and JK, we abstracted the following information from each article selected for this review: (I) first author's last name; (II) publication year; (III) study design; (IV) stage of disease; (V) treatment type; (VI) family caregiver demographic information (age, race/ ethnicity, income, education level, setting); (VII) primary SDOH domain assignment; (VIII) secondary SDOH domain assignment; (IX) if SDOH domain selected was Social & Community context, was spirituality included; (X) if SDOH variables were connected to the outcome of the study or QOL of FCGs; (XI) type of validated SDOH tool used in data collection. DT, VS, and JK discussed assignments until consensus on domains was reached. For articles with a primary and secondary domain assignment, the primary domain assignments were included in the

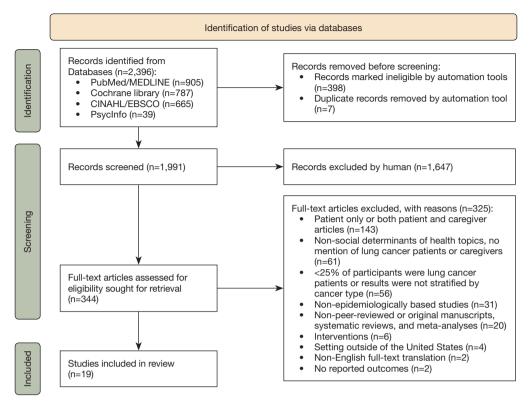


Figure 2 PRISMA flow diagram includes the number of records at various steps including identification of studies, screening, and final list of records for data extraction and analysis.

analysis and secondary domains were noted in result tables.

Level of evidence and quality assessment

The Johns Hopkins Nursing Evidence-Based Practice Rating Scale (34) was used to determine the level of evidence and quality, where each article was assigned a level of evidence rating between I–III and quality evidence score from A–C. Level I articles are experimental studies, and randomized controlled trials (RCT). Level II articles are quasi-experimental studies, systematic review of a combination of RCTs and quasi-experimental studies with or without meta-analysis, and level III articles are qualitative studies or non-experimental study designs. High quality articles received an A rating and low-quality articles received a C rating. DT, ML, VS, JK, and BF rated the manuscripts independently and DT made the final decision on the evidence and quality ratings for all articles.

Results

Three hundred and forty-four articles met the criteria for

full text review, and 19 were included in the synthesis. The studies focused on three out of the five SDOH domains including social and community context, healthcare access and quality, and economic stability. Tables 1,2 present patient, family caregiver, and study characteristics including level of quality for each article. Fifty-eight percent of articles in this review were assigned to the social and community context domain. The Social and Community Context domain is described as the psychosocial context of a community including social cohesion, community engagement, and social support that can determine an individual's well-being (5,6). The health care access and quality domain involves the availability of health coverage and specialist healthcare providers, quality of care, and the cultural competency of healthcare providers (5). Thirty-two percent of articles in this review were assigned to the health care access and quality domain. The economic stability domain relates to factors such as income, employment, debt, and expenses, all of which can affect an individual's health (5). Eleven percent of articles in this review were assigned to the economic stability domain. Most caregivers were White females but one article highlighted the experiences

Table 1 Social and community context domain studies on lung cancer family caregivers

	Patient cha	aracteristics	tics Family caregiver characteristics		Study characteristics				
Primary author & year	Stage of disease	Treatment type	Age, years (range or mean)	Sex or gender (majority)	Race/ethnicity	Study design	Sample size	Location	Evidence level & quality
Williams 2013 (35)	1, 11, 111	С	18–84	Female	AA/B, AA, W,	Cohort	84	New Haven, CT	IIA
Grant 2013 (36)	I, II, III, IV	Other ^c	57	Female	AA/B, AA, NA, H/L, PI, W	Cohort	163	Duarte, CA	IIIB
Litzelman 2016 (37)	I, II, III, IV	C, R, S	20–71	Male	W, O	Cross Sectional	1,500	Multiple	IIIA
Mosher 2013 (38)	Other ^a	C, R, S	26–83	Female	AA/B, W	Cross Sectional	91	Indianapolis, IN	IIB
Dionne-Odom 2018 [†] (39)	IV	Other ^c	65.5	Female	AA/B, W, O	Cross Sectional	294	Multiple	IIIB
Kramer 2011 [†] (40)	I, II, III, IV	Other ^c	63	Female	AA/B, W	Cross Sectional	152	WI (Statewide)	IIIB
Kramer 2010 [†] (41)	Other ^b	Other ^c	63	Female	AA/B, W	Cross Sectional	155	WI (Statewide)	IIB
van Ryn 2011 [†] (42)	I, II, III, IV	C, R, S	21–80	Female	AA/B, AA, H, NA, W	Cross Sectional	335	Multiple	IIA
Mazanec 2011 (43)	Other ^a	Other ^c	39	Female	AA/B, W	Qualitative	14	Multiple	IIIC
Stone 2012 ¹ (44)	Other ^a	Other ^c	36–72	Female	AA/B, AA, W, O	Qualitative	35	Chicago, IL	IIIB
McDonnell 2019 (45)	I, II, III	Other ^c	54	Female	AA/B	Qualitative	26	Multiple	IIIA

[†], health care access and quality; ¹, neighborhood & built environment; ^aOther, stage of disease information not provided; ^bOther, deceased. ^cOther, treatment type information not provided; C, chemotherapy; R, radiation; S, surgery; W, White; AA/B, African American or Black; AA, Asian American; H/L, Hispanic/Latino; NA, Native American; PI, Pacific Islander including Hawaiian; O, Other groups.

of African American/Black females (45) and two articles focused primarily on White male caregivers (37,46).

Evidence level and quality assessment

Overall, studies included in this review revealed variations in evidence levels and the quality of the assessments (see *Tables 1,2*). Most of the studies were rated as either "high quality" or "good quality" with 42% of the studies classified with an A-rating ("high quality") and 53% of the studies classified with a B-rating ("good quality"). Only one study (5%) was assigned a C-rating, indicating a "low quality or major flaws" distinction. In terms of evidence levels, 63% of studies demonstrated level III evidence and 37% level II evidence.

Four general themes were observed across articles on the

influence of SDOH on FCG-centered outcomes in lung cancer: (I) overall quality of life, (II) relationship quality including spirituality, (III) psychological well-being, and (IV) financial toxicity.

Theme 1: overall QOL of FCGs

Four papers focused on the overall QOL of FCGs, with two papers exploring the relationship of race with caregiving. It is well documented that FCGs provide significant clinical care including treatment related side effects management for newly diagnosed lung cancer patients without training (42). McDonnell and colleagues reported family members need basic education, skills training, and support related to the lung cancer diagnosis and other cancers (45). Current methods to provide these services are limited in their accessibility, availability, and effectiveness. FCGs

Table 2 Health care access and quality domain & economic stability studies on lung cancer family caregivers

	Patient cha	racteristics	Family caregiver characteristics			Study characteristics			
Primary author & year	Stage of disease	Treatment type	Age, years (range or mean)	Sex or gender (majority)	Race/ ethnicity	Study design	Sample size	Location	Evidence level & quality
Health care access and o	quality domain								
Litzelman 2016 [‡] (46)	I, II, III, IV	C, R, S	20–71	Male	W, O	Cross Sectional	689	Multiple	IIIB
Martin 2012 (47)	I, II, III, IV	Other ^b	Other ^c	Female	AA/B, W	Cohort	607	Multiple	IIIA
Mosher 2013 [‡] (48)	I, II, III, IV	C, R, S	29–80	Female	AA/B, W, O	Cross Sectional	83	Multiple	IIIB
Mosher 2015 [‡] (49)	I, II, III, IV	C, R, S	53	Female	AA/B, W, O	Qualitative	21	New York, NY	IIIA
Williams 2012 [‡] (50)	Other ^a	С	52.3	Female	AA/B, AA, W, O	Qualitative	135	New Haven, CT	IIIB
Zhang 2012 (51)	II, III, IV	C, R, S	49–57	Female	AA/B, W	Cross Sectional	199	Cleveland, OH	IIA
Economic stability doma	in								
Van Houtven 2010 [‡] (52)	I, II, III, IV	C, R, S	Other ^c	Female	AA/B, H/L, W, O	Cross Sectional	865	Multiple	IIA
Mosher 2013 [‡] (53)	I, II, III, IV	C, R, S	29–80	Female	AA/B, W, O	Cross Sectional	83	Multiple	IIB

[‡], social and community context. ^aOther, stage of disease information not provided. ^bOther, treatment type information not provided. ^cOther, age range/mean information not provided. C, chemotherapy; R, radiation; S, surgery; W, White; AA/B, African American or Black; AA, Asian American; H/L, Hispanic/Latino; O, Other groups.

contributions to improving the patients' overall QOL are also often at the detriment of their own health, decreased economic mobility, and increased caregiving burden as they are also caring for other family members (36,42). In addition, racial disparities in the caregiving experience exist and despite greater preparedness for the caregiving role African American caregivers reported more weekly hours caregiving than whites (45,47). African American FCGs experience several stressors compounded with lack of access to resources (e.g., education, skills training) to support their caregiving roles (45). As discussed by Grant et al. (36) interventions to improve caregiver outcomes should include a holistic model of care that incorporates QOL domains (physical, psychological, social, spiritual well-being), addresses caregiver burden, provides skills training, and a self-care plan.

Theme 2: relationship quality

The role of a caregiver can impact an individual's quality of relationships on multiple levels, including relationships with family, friends, healthcare providers, and a higher power expressed through their spiritual journeys. Nine papers discussed the role of relationship quality in the lives of family caregivers of lung cancer patients, with two papers further exploring relationships with spirituality. While many caregivers of patients with lung cancer experience negative physical and mental health effects, relations with family members improved for a substantial minority of caregivers (38,50). Williams et al. reported that some caregivers found positive outcomes from the overall cancer experience, such as the opportunity to prioritize and develop new relationships, collaborate as a family, and practice better communication (50). Conversely, Kramer et al. reported that family conflict was found to be higher in family dynamics with a history of prior conflict (40,41). In addition, Kramer et al. also reported caregivers of patients with greater physiological and clinical care needs, and shared decisionmaking challenges were more likely to have greater family conflict (41). Further, older age was associated with less social stress, and better family functioning, but worse relationship quality while caring for a female patient was associated with less social stress and better relationship quality, but worse family functioning (37). For some, understanding the child-parent relationship in the context of the illness balanced with the consideration of other family members' perspectives and coping with the caregiving role posed additional relationship challenges (44). In addition to fostering relationships with family and friends, many caregivers turned to faith for comfort. Most caregivers found solace in religious practices, especially prayer (50). The strongest associations with low confidence in surrogate decision-making were low spiritual growth self-care and high use of avoidant coping (39). Moreover, Zhang *et al.* reported avoidant behavior demonstrated racial differences around end-of-life decision making, care and communication (51).

Theme 3: psychological well-being

Five articles describe the psychological well-being of caregiving with an emphasis on the negative health impact for FCGs due to various sociodemographic factors. As an important member of the treatment team, caregivers' health and psychological well-being are often correlated with how patients with cancer perceive their care (46). For example, when caregivers reported fair or poor self-related health, patients were more than three times more likely to report fair or poor perceived quality of care. Distinct from the patient's well-being, FCGs experience significant psychological stressors resulting in negative health outcomes related to several sociodemographic factors including ethnicity (35), education (35,48), stigma associated with mental health service use (49) and distance (43). Caregivers of patients receiving curative treatment (chemotherapy) have lower rates of depressive symptoms, but greater negative health impact related to the length of time in their caregiving role (median, 6.5 months) (35). Latino caregivers had significantly higher depressive symptoms than non-Latino caregivers, but additional research is warranted to understand the clinical significance of these findings with a larger sample. Caregivers with less than a college degree were more likely to have increased depressive symptoms indicating a mediating effect between lower socioeconomic status and negative psychological health outcomes. Greater levels of education (mean of 15 years) were also associated with the use of mental health services and complementary and alternative medicine methods to reduce caregiver burden (48). Additionally, Mosher and colleagues concluded caregivers perceived a conflict between mental health services use and the caregiving role

(prioritizing the patients' needs) (49). Although caregivers denied stigma associated with service use, their anticipated negative self-perceptions if they were to use services suggest that stigma may have influenced their decision to not seek services. Furthermore, Mazanec *et al.*, denoted distance caregivers (individuals who reside 100 miles from patient) of lung cancer patients diagnosed with advance lung cancer experience similar stressors as local caregivers in addition to unique psychosocial stressors due to geographic distance (43).

Theme 4: financial toxicity

Two articles described the significant economic burden experienced by caregivers of lung cancer patients. Most FCGs of lung cancer patients experienced one or more adverse economic or social changes since the patient's illness (52,53). Caregiving can be costly to family members in terms of both time and money (52). Caregivers often sacrifice both leisure time and time that could be spent working for pay. A substantial minority of caregivers lose their main source of family income or make a major change (e.g., delaying medical care for another family member) in family plans due to the cost of the illness (53). Other caregivers reported family members made major life changes (e.g., quit work) to care for the patient or their family lost most or all their savings since the patient's illness (53). Van Houtven et al., concluded the loss of major source of family income was also associated with the patient's receipt of surgery (52). Additionally, the economic burden was higher for caregivers of patients diagnosed at stage 4 versus stage 1; and spouses faced higher economic burden than other relatives or friends.

Discussion

This systematic literature review provides a broad overview of the relationship between SDOH and lung cancer outcomes for FCGs. While SDOH factors account for nearly 80% of an individual's health status (31), researchers continue to focus largely on social and community context, health care access and quality, and economic stability domains (19). FCGs remain an understudied group in oncology research, although they often experience the burden of SDOH related health outcomes which in turn often leads to poor health and decreased QOL (54). While most studies on FCGs focused on social and community context, there were no studies on the effect of the neighborhood and built environment and minimal context on the role of educational access. The lack of attention on FCGs' experiences within

the health care system was disconcerting, considering the significant role of caregiving on QOL for this population (47-50). Future studies should explore the unmet needs of FCGs in navigating the health care system in relation to time spent caregiving, shared decision-making processes with providers, and the potential health implications for themselves.

The social and community context domain focused on QOL experiences of FCGs from a single time point, which minimizes generalizability. Moreover, we found increased psychosocial stressors due to several sociodemographic factors that are critical to understanding the social and environmental determinants of QOL outcomes for FCGs that are also understudied (35,43,46,48,49). While some patients are living longer because of screening and treatment advancements for lung cancer, the negative long-term effects of caregiving have not been studied extensively (55,56). For instance, FCGs who reported negative caregiving experiences reported worse physical and mental health effects 10 years after the patient's initial diagnosis (55). Importantly, conclusions based on the current evidence are applicable to predominantly non-Hispanic White female FCGs. It's critical to include underrepresented minorities and historically excluded groups in future research efforts as the patients and FCGs in these groups have the greatest cancer burden and lower QOL.

Spirituality has been shown to improve QOL for cancer patients and FCGs (57-59). Two studies included the observational (cohort and qualitative study designs) impact of spirituality on psychological well-being across multiple stages of the disease (39,50). FCGs used spirituality as a primary source of support to cope with treatment, survivorship, and end of life experiences. African American/Black female FCGs used faith as a primary source of social support (45). Spirituality has been shown to encourage social cohesion (28,29); and understanding its usage in intervention planning and development may improve QOL outcomes for FCGs.

Financial toxicity is also common among patients and FCGs during and after treatment; this in turn may impact access to care, clinical outcomes and QOL. FCGs experience considerable economic burdens related to their caregiving role (52,53); however, this area of study is underdeveloped and warrants additional research. Importantly, none of the studies in this review included research on neighborhood and built environment. The increased risk of environmental toxicants from residential (60-62) and occupational (63,64) settings and lung cancer diagnosis for patients are discussed in the literature. While evidence

suggests that educational attainment equates to a healthier and longer life (4), and low attainment is associated with treatment delays, functional impairment and poor QOL in lung cancer patients (65-67), no articles focused on this domain for FCGs. Extensive variations in the measure of education in the field of social science exists, in that education can be measured by years of completion, highest education qualification, or highest degree achieved (68). Future research should consider selection of commonly used measures individually and combined when analyzing the impact of educational attainment on health outcomes for lung cancer patients and FCGs.

Validated instruments are critical to our understanding of education, spirituality and other SDOH factors on FCG centered outcomes. They also ensure researchers are measuring intended study variables, minimizing researcher bias and subjectivity (69). Demographic variables such as age, sex or gender, race/ethnicity, education level, marital status, employment status, income, and health insurance status were primarily used across the studies in this review to provide some context of the populations' social position. This was expected, as efforts to standardize SDOH data collection tools and integration of these tools into primary care settings are recent (70). The field should move toward data collection strategies that include standardized tools such as the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE), Health Begins' Upstream Risks Screening Tool, the Accountable Health Communities Health-related Social Needs Screening Tool or include tools from the Patient-Reported Outcomes Measurement Information System (PROMIS) to provide critically needed information regarding social needs for lung cancer patients and their FCGs (Appendix 2). Further exploration of the unmet needs of FCGs across all SDOH domains using both qualitative (e.g., focus groups and key informant interviews) and quantitative approaches is clearly warranted.

Limitations and strengths

There are several limitations that should be considered in the interpretation of the results from this systematic literature review. Since we added a quality assessment component, the Johns Hopkins Nursing Evidence-Based Practice Rating Scale (34), we were able to report the quality of studies and the level of evidence varied widely. As the research on SDOH continues to evolve, the field should also consider testing interventions that address

SDOH needs of the most vulnerable populations. We also acknowledge that the process of assigning studies to their respective domains may not have been devoid of selection bias despite the considerable actions taken by the authors to reach consensus in appropriately assigning studies (4,71) including the engagement of subject matter experts. While not within the scope of this review, we acknowledge that racial/ethnic minorities especially African American/Black and Hispanic populations are disproportionally affected by this disease but are underrepresented in this already sparse SDOH FCG literature thus warranting additional research (72,73). Lastly, we also recognize research conducted outside the U.S. is important, but due to country-level differences in social and cancer care delivery structures, we chose to only focus on studies conducted in the U.S. as SDOH factors may differ across societal infrastructures.

Despite these limitations, there are also several strengths to note. To our knowledge this is the first review to classify studies by SDOH domains for lung cancer FCGs. Secondly, the authors included a deliberate discussion on the impact of spirituality on QOL—an understudied topic in SDOH research. Thirdly, we provide context on the dearth of research on lung cancer FCGs, and the critical need to better understand QOL outcomes in future SDOH studies. Fourthly, we excluded patients only and both patients and FCG articles across several locations (see Appendix 3) to provide specificity and useful information on the current state of the literature on the impact of SDOH domains on FCG-centered outcomes in lung cancer. Finally, we bring attention to the lack of validated SDOH instruments used and provide examples of tools and resources that researchers could consider adopting to promote better measurement uniformity in SDOH research (Appendix 2).

Conclusions

There is a lack of knowledge on SDOH domains such as education quality and access, and neighborhood and built environment for FCGs. Spirituality, while important in improving QOL of FCGs, remains an underdeveloped field of study. The increased integration of validated SDOH tools in research is critical to further our understanding of QOL outcomes for lung cancer patients and their FCGs.

Acknowledgments

We thank Andrea Lynch, MLIS for her assistance with the literature search.

Funding: This systematic review was supported by award number 3R01CA217841-03S1 from the National Cancer Institute, National Institute of Health.

Footnote

Reporting Checklist: The authors have completed the PRISMA reporting checklist. Available at https://jtd.amegroups.com/article/view/10.21037/jtd-22-1613/rc

Peer Review File: Available at https://jtd.amegroups.com/article/view/10.21037/jtd-22-1613/prf

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at https://jtd.amegroups. com/article/view/10.21037/jtd-22-1613/coif). LE reports payments from Lung Cancer Research Foundation and American Association of Thoracic Surgery. LE is a member of the scientific advisory board of Lung Cancer Research Foundation. LE sat on the health disparities advisory board of AstraZeneca in 2021. LE reports payments from AstraZeneca Pharmaceuticals for giving a presentation to the organization on Barriers to Lung Cancer Research (LCS) in July 2022. LE also reports payment from Gilead Oncology for giving a health equity presentation to the organization in March 2022. VS reports grants from National Cancer Institute and Patient-Centered Outcomes Research Institute. The other authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Open Access Statement: This is an Open Access article distributed in accordance with the Creative Commons Attribution-NonCommercial-NoDerivs 4.0 International License (CC BY-NC-ND 4.0), which permits the noncommercial replication and distribution of the article with the strict proviso that no changes or edits are made and the original work is properly cited (including links to both the formal publication through the relevant DOI and the license). See: https://creativecommons.org/licenses/by-nc-nd/4.0/.

References

1. Siegel RL, Miller KD, Fuchs HE, et al. Cancer statistics,

- 2022. CA Cancer J Clin 2022;72:7-33.
- Zhu S, Yang C, Li J, et al. Mediating factors between caregiver burden and quality of life in caregivers of older patients with newly diagnosed lung cancer. Age & Ageing 2021;50:i12-42.
- Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. J Clin Oncol 2017;35:96-112.
- U.S. Department of Health and Human Services. Social determinants of health 2020. Available online: https:// health.gov/healthypeople/objectives-and-data/browseobjectives
- Asare M, Flannery M, Kamen C. Social Determinants of Health: A Framework for Studying Cancer Health Disparities and Minority Participation in Research. Oncol Nurs Forum 2017;44:20-3.
- U.S. Department of Health and Human Services. Social determinants of health 2019. Available online: https:// www.healthypeople.gov/2020/topics-objectives/topic/ social-determinants-of-health.
- Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. Public Health Rep 2014;129 Suppl 2:19-31.
- 8. Cockerham WC, Hamby BW, Oates GR. The Social Determinants of Chronic Disease. Am J Prev Med 2017;52:S5-S12.
- Kawakami N, Li X, Sundquist K. Health-promoting and health-damaging neighbourhood resources and coronary heart disease: a follow-up study of 2 165 000 people. J Epidemiol Community Health 2011;65:866-72.
- Major JM, Doubeni CA, Freedman ND, et al. Neighborhood socioeconomic deprivation and mortality: NIH-AARP diet and health study. PLoS One 2010;5:e15538.
- Ribeiro AI, Amaro J, Lisi C, et al. Neighborhood Socioeconomic Deprivation and Allostatic Load: A Scoping Review. Int J Environ Res Public Health 2018;15:1092.
- Hystad P, Carpiano RM, Demers PA, et al. Neighbourhood socioeconomic status and individual lung cancer risk: evaluating long-term exposure measures and mediating mechanisms. Soc Sci Med 2013;97:95-103.
- 13. Meijer M, Bloomfield K, Engholm G. Neighbourhoods matter too: the association between neighbourhood socioeconomic position, population density and breast, prostate and lung cancer incidence in Denmark between 2004 and 2008. J Epidemiol Community Health

- 2013;67:6-13.
- Erhunmwunsee L, Joshi MB, Conlon DH, et al. Neighborhood-level socioeconomic determinants impact outcomes in nonsmall cell lung cancer patients in the Southeastern United States. Cancer 2012;118:5117-23.
- Galea S, Tracy M, Hoggatt KJ, et al. Estimated deaths attributable to social factors in the United States. Am J Public Health 2011;101:1456-65.
- 16. Goding Sauer A, Siegel RL, Jemal A, et al. Current Prevalence of Major Cancer Risk Factors and Screening Test Use in the United States: Disparities by Education and Race/Ethnicity. Cancer Epidemiol Biomarkers Prev 2019;28:629-42.
- 17. Abrams HR, Durbin S, Huang CX, et al. Financial toxicity in cancer care: origins, impact, and solutions. Transl Behav Med 2021;11:2043-54.
- 18. Zimmermann C, Burman D, Swami N, et al. Determinants of quality of life in patients with advanced cancer. Support Care Cancer 2011;19:621-9.
- Morone J. An Integrative Review of Social Determinants of Health Assessment and Screening Tools Used in Pediatrics. J Pediatr Nurs 2017;37:22-8.
- 20. Gottlieb L, Hessler D, Long D, et al. A randomized trial on screening for social determinants of health: the iScreen study. Pediatrics 2014;134:e1611-8.
- 21. Garg A, Toy S, Tripodis Y, et al. Addressing social determinants of health at well child care visits: a cluster RCT. Pediatrics 2015;135:e296-304.
- 22. Walker RJ, Smalls BL, Campbell JA, et al. Impact of social determinants of health on outcomes for type 2 diabetes: a systematic review. Endocrine 2014;47:29-48.
- 23. Cohen AK, Rai M, Rehkopf DH, et al. Educational attainment and obesity: a systematic review. Obes Rev 2013;14:989-1005.
- 24. Moore C, Hassett D, Dunne S. Health literacy in cancer caregivers: a systematic review. J Cancer Surviv 2021;15:825-36.
- 25. Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. J Palliat Med 2009;12:885-904.
- 26. Fisher J. The four domains model: Connecting spirituality, health and well-being. Religions 2011;2:17-28.
- National Consensus Project for Quality Palliative Care.
 National Consensus Project Clinical Practice Guidelines for Quality Care. 2018.
- 28. Kawachi I, Berkman L. Social cohesion, social capital, and health. Social Epidemiology 2000;174(7).

- U.S. Department of Health and Human Services. Social cohesion 2019. Available online: https://www. healthypeople.gov/2020/topics-objectives/topic/social-determinants-health/interventions-resources/social-cohesion#6.
- 30. Sidorchuk A, Agardh EE, Aremu O, et al. Socioeconomic differences in lung cancer incidence: a systematic review and meta-analysis. Cancer Causes Control 2009;20:459-71.
- The National Conference of State Legislatures. Racial and ethnic health disparities: What state legislators need to know 2013.
- 32. Page MJ, McKenzie JE, Bossuyt PM, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71.
- Babineau J. Product review: covidence (systematic review software). Journal of the Canadian Health Libraries Association 2014;35:68-71.
- 34. Newhouse R, Dearholt S, Poe S, Pugh L, White K. The Johns Hopkins nursing evidence-based practice rating scale. Baltimore, MD: The Johns Hopkins Hospital. 2005.
- 35. Williams AL, Tisch AJ, Dixon J, et al. Factors associated with depressive symptoms in cancer family caregivers of patients receiving chemotherapy. Support Care Cancer 2013;21:2387-94.
- Grant M, Sun V, Fujinami R, et al. Family caregiver burden/ skills preparedness, and quality of life in non-small cell lung cancer. Oncology Nursing Forum 2013;40:337-46.
- 37. Litzelman K, Kent EE, Rowland JH. Social factors in informal cancer caregivers: The interrelationships among social stressors, relationship quality, and family functioning in the CanCORS data set. Cancer 2016;122:278-86.
- 38. Mosher CE, Bakas T, Champion VL. Physical health, mental health, and life changes among family caregivers of patients with lung cancer. Oncol Nurs Forum 2013;40:53-61.
- Dionne-Odom JN, Ejem D, Azuero A, et al. Factors
 Associated with Family Caregivers' Confidence in Future
 Surrogate Decision Making for Persons with Cancer. J
 Palliat Med 2018;21:1705-12.
- 40. Kramer BJ, Kavanaugh M, Trentham-Dietz A, et al. Complicated grief symptoms in caregivers of persons with lung cancer: the role of family conflict, intrapsychic strains, and hospice utilization. Omega (Westport) 2010-2011;62:201-20.
- 41. Kramer BJ, Kavanaugh M, Trentham-Dietz A, et al. Predictors of family conflict at the end of life: the experience of spouses and adult children of persons with lung cancer. Gerontologist 2010;50:215-25.
- 42. van Ryn M, Sanders S, Kahn K, et al. Objective burden,

- resources, and other stressors among informal cancer caregivers: a hidden quality issue? Psychooncology 2011;20:44-52.
- 43. Mazanec P, Daly BJ, Ferrell BR, et al. Lack of communication and control: experiences of distance caregivers of parents with advanced cancer. Oncol Nurs Forum 2011;38:307-13.
- 44. Stone AM, Mikucki-Enyart S, Middleton A, et al. Caring for a Parent with Lung Cancer: Caregivers' Perspectives on the Role of Communication. Qualitative Health Research 2012;22:957-70.
- 45. McDonnell KK, Owens OL, Hilfinger Messias DK, et al. Health behavior changes in African American family members facing lung cancer: Tensions and compromises. Eur J Oncol Nurs 2019;38:57-64.
- 46. Litzelman K, Kent EE, Mollica M, et al. How Does Caregiver Well-Being Relate to Perceived Quality of Care in Patients With Cancer? Exploring Associations and Pathways. J Clin Oncol 2016;34:3554-61.
- 47. Martin MY, Sanders S, Griffin JM, et al. Racial variation in the cancer caregiving experience: a multisite study of colorectal and lung cancer caregivers. Cancer Nurs 2012;35:249-56.
- 48. Mosher CE, Champion VL, Hanna N, et al. Support service use and interest in support services among distressed family caregivers of lung cancer patients. Psychooncology 2013;22:1549-56.
- 49. Mosher CE, Given BA, Ostroff JS. Barriers to mental health service use among distressed family caregivers of lung cancer patients. Eur J Cancer Care (Engl) 2015;24:50-9.
- 50. Williams AL, Bakitas M. Cancer family caregivers: a new direction for interventions. J Palliat Med 2012;15:775-83.
- 51. Zhang AY, Zyzanski SJ, Siminoff LA. Ethnic differences in the caregiver's attitudes and preferences about the treatment and care of advanced lung cancer patients. Psychooncology 2012;21:1250-3.
- Van Houtven CH, Ramsey SD, Hornbrook MC, et al. Economic burden for informal caregivers of lung and colorectal cancer patients. Oncologist 2010;15:883-93.
- 53. Mosher CE, Champion VL, Azzoli CG, et al. Economic and social changes among distressed family caregivers of lung cancer patients. Support Care Cancer 2013;21:819-26.
- 54. Möllerberg ML, Sandgren A, Lithman T, et al. The effects of a cancer diagnosis on the health of a patient's partner: a population-based registry study of cancer in Sweden. Eur J Cancer Care (Engl) 2016;25:744-52.
- 55. Best AL, Shukla R, Adamu AM, et al. Impact of caregivers' negative response to cancer on long-term survivors' quality

- of life. Supportive Care in Cancer. 2021;29:679-86.
- Yeung NCY, Ramirez J, Lu Q. Perceived stress as a mediator between social constraints and sleep quality among Chinese American breast cancer survivors. Support Care Cancer 2017;25:2249-57.
- 57. Lalani N, Duggleby W, Olson J. Spirituality among family caregivers in palliative care: an integrative literature review. Int J Palliat Nurs 2018;24:80-91.
- 58. Jimenez-Fonseca P, Lorenzo-Seva U, Ferrando PJ, et al. The mediating role of spirituality (meaning, peace, faith) between psychological distress and mental adjustment in cancer patients. Support Care Cancer 2018;26:1411-8.
- 59. Best AL, Alcaraz KI, McQueen A, et al. Examining the mediating role of cancer-related problems on spirituality and self-rated health among African American cancer survivors: a report from the American Cancer Society's Studies of Cancer Survivors-II. Psycho-Oncology 2015;24:1051-9.
- Torres-Durán M, Ruano-Ravina A, Kelsey KT, et al. Small cell lung cancer in never-smokers. Eur Respir J 2016;47:947-53.
- Rodríguez-Martínez Á, Ruano-Ravina A, Torres-Durán M, et al. Small Cell Lung Cancer. Methodology and Preliminary Results of the SMALL CELL Study. Arch Bronconeumol 2017;53:675-81.
- 62. Torres-Durán M, Ruano-Ravina A, Parente-Lamelas I, et al. Residential radon and lung cancer characteristics in never smokers. Int J Radiat Biol 2015;91:605-10.
- 63. Consonni D, De Matteis S, Pesatori AC, et al. Lung cancer risk among bricklayers in a pooled analysis of case-control studies. Int J Cancer 2015;136:360-71.
- 64. Bracci PM, Sison J, Hansen H, et al. Cigarette smoking

Cite this article as: Teteh DK, Love M, Ericson M, Chan M, Phillips T, Toor A, Ferrell B, Erhunmwunsee L, Montgomery SB, Sun V, Kim JY. Social determinants of health among family caregiver centered outcomes in lung cancer: a systematic review. J Thorac Dis 2023;15(5):2824-2835. doi: 10.21037/jtd-22-1613

- associated with lung adenocarcinoma in situ in a large case-control study (SFBALCS). J Thorac Oncol 2012;7:1352-60.
- 65. Nipp RD, Fuchs G, El-Jawahri A, et al. Sarcopenia Is Associated with Quality of Life and Depression in Patients with Advanced Cancer. Oncologist 2018;23:97-104.
- 66. Billmeier SE, Ayanian JZ, He Y, et al. Predictors of nursing home admission, severe functional impairment, or death one year after surgery for non-small cell lung cancer. Ann Surg 2013;257:555-63.
- 67. Verma R, Pathmanathan S, Otty ZA, et al. Delays in lung cancer management pathways between rural and urban patients in North Queensland: a mixed methods study. Intern Med J 2018;48:1228-33.
- Connelly R, Gayle V, Lambert PS. A review of educational attainment measures for social survey research.
 Methodological Innovations 2016;9:2059799116638001. http://dx.doi.org/10.1177/2059799116638001
- 69. Solans-Domènech M, Pons JMV, Adam P, et al. Development and validation of a questionnaire to measure research impact. Research Evaluation 2019;28:253-62.
- LaForge K, Gold R, Cottrell E, et al. How 6 Organizations Developed Tools and Processes for Social Determinants of Health Screening in Primary Care: An Overview. J Ambul Care Manage 2018;41:2-14.
- 71. Artiga S, Hinton E. Determinants in Promoting Health and Health Equity. Kaiser Family Foundation; 2018 May 10.
- 72. Schabath MB, Cress D, Munoz-Antonia T. Racial and Ethnic Differences in the Epidemiology and Genomics of Lung Cancer. Cancer Control 2016;23:338-46.
- 73. Ryan BM. Lung cancer health disparities. Carcinogenesis 2018;39:741-51.

Appendix 1 List of search strategies

Database: PubMed/MEDLINE (Legacy version)

- Ran on: 5/28/2020Number of results: 905
- Limits/Filters used:
 - Humans, English, Last 10 years
 - Publication types: Clinical Study, Clinical Trial, Clinical Trial Protocol, Comparative Study, Consensus Development Conference, Controlled Clinical Trial, Evaluation Study, Guideline, Introductory Journal Article, Meta-Analysis, Multicenter Study, Observational Study, Practice Guideline, Pragmatic Clinical Trial, Randomized Controlled Trial, Review, Scientific Integrity Review, Systematic Reviews, Technical Report, Twin Study, Validation Study
- Search strategy used:
 - ("Lung Neoplasms" [Mesh]) OR ((bronchi OR Pulmonary OR "pulmonary Alveoli" OR Lung) AND ("Carcinoma" [Mesh] OR "Sarcoma" [Mesh] OR "adenocarcinoma" [MeSH] OR adenocarcinoma OR cancer OR tumor OR tumour OR oncology OR Oncologic OR Oncological OR Malignancies OR Malignancy OR Neoplasm OR Neoplasms OR carcinoma OR sarcoma OR chemotherapy OR chemotherapeutic OR cancer [sb]))
 - AND
 - (families OR family OR parent* OR partner* OR spouse* OR family OR carer* OR caregiver* OR "Sexual Partners" [Mesh] OR "Parents" [Mesh] OR "Spouses" [Mesh] OR "Family" [Mesh] OR "Caregivers" [Mesh])
 - AND
 - (age OR gender OR education OR educat* OR ethnic OR ethnic* OR race OR race* OR culture OR language OR language* OR occupation OR social class OR socioeconomic OR health social determinants OR social determinant* OR social capital OR residence OR geograph* OR equity OR disparit* OR sociology OR social OR network OR prejudice OR insurance OR health gradient OR health gap OR vulnerable OR urban OR rural OR poverty OR wealth OR rich OR poor OR discriminat* OR demograph* OR spirituality OR faith OR religion OR stress OR economic stability OR housing OR neighborhood OR built environment OR social context OR community context OR income OR "Social Determinants of Health" [Mesh] OR "Socioeconomic Factors" [Mesh] OR "Stress, Psychological" [Mesh] OR "Gender Identity" [Mesh] OR "Sex" [Mesh] OR "Education" [Mesh] OR "Educational Status" [Mesh] OR "Economic Status" [Mesh] OR "Ethnic Groups" [Mesh] OR "Race Factors" [Mesh] OR "Continental Population Groups" [Mesh] OR "Culture" [Mesh] OR "Language" [Mesh] OR "Occupations" [Mesh] OR "Religion" [Mesh] OR "Social Class" [Mesh] OR "Social Capital" [Mesh] OR "Residence Characteristics" [Mesh] OR "Geography" [Mesh] OR "Health Equity" [Mesh] OR "Healthcare Disparities" [Mesh] OR "Sociology" [Mesh] OR "Prejudice" [Mesh] OR "Insurance" [Mesh] OR "Vulnerable Populations" [Mesh] OR "Urban Population" [Mesh] OR "Rural Population" [Mesh] OR "Poverty" [Mesh] OR "Poverty Areas" [Mesh] OR "Social Discrimination" [Mesh] OR "Demography" [Mesh] OR "Spirituality" [Mesh] OR "Housing" [Mesh] OR "Income" [Mesh])
 - NOT child

Database: Cochrane Library via https://www.cochranelibrary.com/

- **A** Ran on: 5/29/2020
- ❖ Limits/Filters used: January 2010-December 2020
- Search strategy used: See attached PDF file with the search strategy details
- Number of results: 787

Database: Cumulative Index to Nursing and Allied Health Literature (CINAHL) Plus with Full Text via EBSCObost

Ran on: 5/29/2020Limits/Filters used:

© Journal of Thoracic Disease. All rights reserved.

- Date range: January 1, 2010-December 31, 2020
- Peer reviewed
- Human
- English language
- Subject: All adult
- Search strategy used: See attached PDF file with the search strategy details
- Number of results: 665

Database: APA PsycInfo via the Ovid platform

- **A** Ran on: 5/29/2020
- Limits/Filters used:
 - Human
 - English language
 - Year range: 2010 -2021
- Search strategy used: See attached PDF file with the search strategy details
- Number of results: 39

Appendix 2

Social determinants of health screening tools and resources

Tool	Description	SDH Domain Assessment	Reference
Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE)	21-item survey validated using the 8 "Gold Standard" stages of measure development. Available in English, Spanish, Chinese and 24 other languages	All SDH domains [†]	National Association of Community Health Centers. (2016). Retrieved from http://www. nachc.org/research-and-data/prapare
Epic version of PRAPARE Or PRAPARE-plus	13-item survey validated at three community health centers that includes adapted questions from PRAPARE, Institute of Medicine, and other validated SDH sources. Available in English and Spanish	All SDH domains [†]	Gold R, et al. (2017). Developing Electronic Health Record (EHR) Strategies Related to Health Center Patients' Social Determinants of Health. J Am Board Fam Med. 2017 Jul-Aug;30(4):428-447. doi: 10.3122/ jabfm.2017.04.170046. PMID: 28720625
Health Begins Upstream Risks Screening Tool	15-item survey adapted from Institute of Medicine and the National Academies Press	All SDH domains [†]	Rishi & Gottlieb (2015). Upstream risks screening tool and guide. Retrieved from https://www.aamc.org/media/25736/ download
Accountable Health Communities Health-related Social Needs Screening Tool	10-item survey used to identify unmet needs across five core domains developed using literature review and technical expert panel	All SDH domains [†]	Billioux, A., Verlander, K., Anthony, S., & Alley, D. (2017). Standardized screening for health-related social needs in clinical settings: the accountable health communities screening tool. NAM Perspectives.
WellRx	11-item survey validated in 3048 patients in 3 family medicine clinics in New Mexico	All SDH domains [†]	Page-Reeves J., <i>et al.</i> (2016). Journal of the American Board of Family Medicine, 29(3), 414–418. 10.3122/jabfm.2016.03.150272
Social Determinants of Health by US Census Tract	47-variables including race/ethnicity, education, socioeconomic status, racial residential segregation poverty level with 73,056 records using 2010 census tract and the American Community Survey data	All SDH domains [†] except Health Care Access and Quality	National Cancer Institute. (2021). Social determinants of health by US census tract. Retrieved from https://healthcaredelivery. cancer.gov/social-determinants/
Patient-Reported Outcomes Measurement Information System (PROMIS)	Over 300 measures of health outcomes including physical, mental, and social well-being for adult and pediatric populations. Available in multiple languages including English, Spanish, French, Xhosa, Bengali, Czech	Health Care Access and Quality, Social and Community Context	Ader DN. Developing the patient-reported outcomes measurement information system (PROMIS). Medical care. 2007 May 1;45(5):S1-2. doi: 10.1097/01.mlr.0000260537.45076.74

[†]SDH framework includes five broad domains: economic stability, education access and quality, neighborhood and built environment, healthcare access and quality, and social and community context.

Appendix 3

Economic Stability Domain Studies on Lung Cancer Patients and Family Caregivers (FCGs)

Primary author & year	Study design	Location	Population	Sample size	Evidence level & quality
Barbaret 2019 (1)	Cross sectional	Other: Europe & North America	Patients	74	IIIB
Adorno 2017 [*] (2)	Cross Sectional	North America	Patients	30	IIB
Dalton 2015 ^{&} (3)	Cohort	Europe	Patients	13045	IIIB
Hovanec 2018 [†] (4)	Other: Case Control	Other: Europe and North America	Patients	17021	IIA
Behrens 2016 (5)	Cohort	Europe	Patients	25580	IIIB
Cai 2011 [*] (6)	Cross Sectional	Asia	Patients	108	IIIB
Nicolau 2019 (7	Other: Case Control	North America	Patients	761	IIIA
Bensenor 2012 [†] (8)	Cross Sectional	South America	Patients	14566	IIA
Zhou 2017 [†] (9)	Other: Administrative Data	Asia	Patients	34678	IIIA
Shilling 2017 [*] (10)	Qualitative	Europe	Both	6 dyads	IIIA
Forrest 2015 [†] (11)	Cohort	Europe	Patients	22967	IIIA
Lee 2018 [†] (12)	Cross Sectional	Asia	Both	150 dyads	IIA

Secondary domain assignments: [†]Health care access and quality; *Social and community context; [&]Education access and quality.

Education Access and Quality & Neighborhood and Built Environment Domain Studies on Lung Cancer Patients

Primary author & year	Study design	Location	Population	Sample size	Evidence level & quality				
Education Access and Quality I	Education Access and Quality Domain Studies								
Verma 2018§ (13)	Qualitative	Australia	Patients	252	IIIB				
Billmeier 2013 (14)	Cohort	North America	Patients	1007	IIIA				
Nipp 2018 [*] (15)	Cross Sectional	North America	Patients	234	IIA				
Neighborhood and Built Enviror	nment Domain Studies								
Consonni 2015 (16)	Cohort	Europe	Patients	599	IIIB				
Nakano 2019 (17)	Cross Sectional	Asia	Patients	4	IIIC				
Brenner 2010 [†] (18)	Cross Sectional	North America	Patients	445	IIIB				
Petitte 2014 (19)	Non-Randomized Control Trial	North America	Patients	10	IIIC				
Torres-Durán 2014 (20)	Other: Case control	Europe	Patients	192	IIB				
Rodríguez-Martínez 2017 (21)	Other: Case Control	Europe	Patients	113	IIIA				
Torres-Durán 2016# (22)	Other: Case Series	Europe	Patients	19	IIIB				
Wang 2016 (23)	Cohort	North America	Patients	2148	IIA				
Goodridge 2010 [#] (24)	Cohort	North America	Patients	483	IIIA				
Torres-Durán 2015 [*] (25)	Other: Case Control	Europe	Patients	216	IIIB				
Sawicki 2013 [†] (26)	Cross Sectional	Europe	Patients	300	IIA				
Bracci 2012 [†] (27)	Other: Case-Control	North America	Patients	338	IIB				

Secondary domain assignments: [†]Health care access and quality; *Social and community context; [#]Economic stability; [§]Neighborhood and built environment.

Health Care Access and Quality Domain Studies on Lung Cancer Patients and Family Caregivers (FCGs)

Primary author & year	Study design	Location	Population	Sample size	Evidence leve & quality
Lee 2016 [*] (28)	Cohort	North America	Both	13 dyads	IIIB
Sun 2017 (29)	Other: Quasi-Experimental	North America	Both	38 Patients; 22 FCGs	IIB
Bakitas 2017 (30)	Qualitative	North America	Both	24 Patients; 20 FCGs	IIIB
Gustafson 2013 (31)	Randomized Controlled Trial	North America	Both	285 dyads	IA
Brady 2018 (32)	Cross Sectional	North America	Patients	72	IIB
Husain 2013 (33)	Cross Sectional	North America	Patients	116	IIA
Lee 2018 (34)	Cross Sectional	Other: Europe, Australia, Asia, South America	Patients	1,140	IIIB
Lynch 2010 (35)	Other: Clinical Audit	Europe	Patients	34	IIIB
Roulston 2013 (36)	Qualitative	Europe	Patients	52	IIIB
Wright 2016 [*] (37)	Cross Sectional	North America	Both	886 dyads	IIA
Bailey 2016 (38)	Qualitative	Europe	Both	24 Patients; 20 FCGs	IIIB
Ermers 2019 (39)	Cohort	Europe	Patients	95	IIB
Jarosek 2016# (40)	Cohort	North America	Patients	22,558	IIIA
Falchook 2017 (41)	Cross Sectional	North America	Patients	12,764	IIA
Hanratty 2012# (42)	Qualitative	Europe	Patients	13	IIIB
Ellis 2012 (43)	Qualitative	Europe	Both	37 Patients; 23 FCGs	IIIIB
Schook 2014 [*] (44)	Qualitative	Europe	Both	5 Patients; 20 FCGs	IIIB
Sikjær 2018 (45)	Cohort	Europe	Patients	20,787	IIA
Rose 2017 (46)	Cohort	Europe	Patients	20	IIB
Baumgardner 2018 (47)	Cohort	North America	Patients	14,380	IIA
Aubin 2011 [*] (48)	Cohort	North America	Patients	395	IIIB
Goulart 2013 (49)	Cohort	North America	Patients	28,977	IIIA
Lee 2019 (50)	Cross Sectional	Asia	Patients	118	IIIB
Eichler 2019 [*] (51)	Cross Sectional	Europe	Patients	604	IIIB
Shen 2016 [*] (52)	Cross Sectional	North America	Patients	231	IIIA
Bülbül 2017 [*] (53)	Cross Sectional	Other: Turkey	Patients	1,202	IIIB
Ellis 2017 (54)	Randomized Controlled Trial	North America	Both	70 dyads	IIIC
Billmeier 2011 (55)	Cohort	North America	Patients	679	IIB
Shi 2015 [*] (56)	Cross Sectional	Asia	Patients	104	IIA
Fukumoto 2015 (57)	Other: Case-Control	Asia	Patients	625	IIA
Nababan 2020 (58)	Qualitative	Australia	Patients	47	IIIA
Parsonage 2017 (59)	Qualitative	Europe	Patients	121	IIIB
Stegmann 2019 (60)	Qualitative	Europe	Patients	20	IIIB
Jacobsen 2011 [*] (61)	Randomized Controlled Trial	North America	Patients	67	IA
Pirl 2012 (62)	Randomized Controlled Trial	North America	Patients	151	IC
Temel 2017 [*] (63)	Randomized Controlled Trial	North America	Patients	191	IA

Primary author & year	Study design	Location	Population	Sample size	Evidence level & quality
Walton 2013 (64)	Qualitative	Other: New Zealand	Patients	20	IIIB
Burt 2010 (65)	Cross Sectional	Europe	Both	252 Patients; 135 FCGs	IIIB
Xiu 2020 (66)	Randomized Controlled Trial	Asia	FCGs	157	IC
Yennurajalingam 2018 (67)	Cross Sectional	North America	Patients	468	IIIB
Ellis 2017 (68)	Qualitative	Europe	Both	11 Patients; 3 FCGs	IIIC
Ledderer 2014 (69)	Qualitative	Europe	Both	5 dyads	IIIC
Owens 2020 (70)	Qualitative	North America	Both	6 dyads	IIIC
Bigay-Gamé 2018 (71)	Cohort	Europe	Patients	146	IIA
Banik 2017 (72)	Other: Longitudinal	Europe	Patients	102	IIB
Hanratty 2012* (73)	Qualitative	Europe	Patients	14	IIIB
Patel 2016 ^{&} (74)	Cohort	North America	Patients	1,044	IIA
Park 2012 [*] (75)	Cohort	North America	Patients	2,456	IIIA
Wiljer 2012 (76)	Cross Sectional	North America	Patients	95	IIIB
George 2010 (77)	Qualitative	North America	Patients	10	IIIB

Secondary domain assignments: *Social and community context; *Economic stability; *Education access and quality.

Social and Community Context Domain Studies on Lung Cancer Patients and Family Caregivers (FCGs)

Primary author & year	Study design	Location	Population	Sample size	Evidence level & quality
Manne 2012 (78)	Cohort	Australia	Both	77 dyads	IIIB
Milbury 2012 (79)	Cohort	North America	Both	169 patients; 167 FCGs	IIIB
Hobbs 2015 [†] (80)	Cohort	North America	Both	2932 dyads	IIIA
Milbury 2013 [#] (81)	Cohort	North America	Both	158 dyads	IIIB
Ersek 2017 (82)	Cohort	North America	Both	847 dyads	IIIB
Loh 2019 [†] (83)	Cohort	North America	Both	88 dyads	IIIB
Lee 2019 (84)	Cohort	North America	Both	113 dyads	IIIB
Litzelman 2016 (85)	Cohort	North America	Both	689 dyads	IIIA
Douglas 2013 (86)	Cohort	North America	Both	65 dyads	IIIB
Garlo 2010 (87)	Cohort	North America	Both	179 dyads	IIIB
DuBenske 2010 (88)	Cohort	North America	Both	72 dyads	IIIB
Buchanan 2010 (89)	Cohort	Europe	Patients	170	IIB
Lau 2018 (90)	Cohort	North America	Patients	1366	IIIB
Jacobs 2017 (91)	Cohort	North America	Both	191 dyads	IIIB
Lyons 2016 (92)	Cohort	North America	Patients	78	IIB
Oh 2019 (93)	Cross Sectional	Asia	Both	150 dyads	IIA
Cooley 2013 (94)	Cross Sectional	North America	Both	37 dyads	IIB

(continued)

Primary author & year	Study design	Location	Population	Sample size	Evidence level & quality
Zhang 2010 [†] (95)	Cross Sectional	North America	Both	184 Patients; 171 FCGs	IIA
Leydon 2012 (96)	Cross Sectional	Other: Africa, Europe, Asia	Both	113 Patients; 70 FCGs	IIIB
Madani 2018 (97)	Cross Sectional	Asia	Patients	25	IIIB
Hung 2018 [§] (98)	Cross Sectional	Asia	Patients	159	IIA
Dogan 2019 (99)	Cross Sectional	Europe	Patients	55	IIIB
Akin 2010 [†] (100)	Cross Sectional	Other: Asia and Europe	Patients	154	IIB
Nipp 2016 (101)	Cross Sectional	North America	Both	149 dyads	IIA
Kramer 2010 [†] (102)	Cross Sectional	North America	Both	155 dyads	IIB
Ostlund 2010 (103)	Cross Sectional	Europe	FCGs	84	IIIB
Malik 2013 (104)	Cross Sectional	Europe	FCGs	50	IIIB
Chen 2016 [†] (105)	Cross Sectional	Asia	Both	166 dyads	IIIB
Hu 2018 (106)	Cross Sectional	Asia	Both	116 dyads	IIIB
_obchuk 2012 (107)	Cross Sectional	North America	Both	304 dyads	IIIA
Miller 2017 (108)	Cross Sectional	North America	Both	109 dyads	IIB
Porter 2012 (109)	Cross Sectional	North America	Both	127 dyads	IIIA
Wood 2019 (110)	Cross Sectional	Europe	FCGs	427	IIA
_ee 2013 [†] (111)	Cross Sectional	Asia	Both	106 dyads	IIA
Martin 2014# (112)	Cross Sectional	North America	Patients	1773	IIIA
Chang 2015 ^{&} (113)	Cross Sectional	Asia	Patients	231	IIIB
Hechtner 2019 [†] (114)	Cross Sectional	Europe	Patients	555	IIIA
Skalla 2015 (115)	Cross Sectional	North America	Patients	15	IIIC
Cykert 2019 (116)	Other: Non-Randomized Control Trial	North America	Patients	3201	IIA
Borneman 2015 (117)	Other: Non-Randomized Control Trial	North America	Both	272 Patients; 203 FCs	IIA
Nguyen 2017 (118)	Other: Non-Randomized Control Trial	North America	Both	170 Patients; 156 FCGs	IIA
_i 2019 [†] (119)	Other: Non-Randomized Control Trial	Asia	Both	67 dyads	IIB
Milbury 2015 (120)	Other: Non-Randomized Control Trial	North America	Both	15 dyads	IIB
Milbury 2018 (121)	Other: Non-Randomized Control Trial	North America	Both	7 dyads	IIC
Sun 2016 (122)	Other: Quasi-Experimental	North America	Both	475 Patients; 354 FCGs	IIB
Lindau 2011 (123)	Qualitative	North America	Both	13 dyads	IIIA

(continued)

Primary author & year	Study design	Location	Population	Sample size	Evidence level & quality
Lowson 2013 [†] (124)	Qualitative	Europe	Patients	14	IIIC
Ngwenya 2016 (125)	Qualitative	Europe	Both	20 Patients; 17 FCGs	IIIB
Occhipinti 2018 (126)	Qualitative	Australia	Both	16 Patients; 12 FCGs	IIIB
Ewing 2016 (127)	Qualitative	Europe	Both	20 Patients; 17 FCGs	IIIB
Sihombing 2019 (128)	Qualitative	Asia	FCGs	9	IIIB
Steinvall 2011 (129)	Qualitative	Europe	FCGs	11	IIIB
Bottorff 2015 (130)	Qualitative	North America	FCGs	30	IIIB
Pardon 2012 (131)	Qualitative	Europe	Patients	85	IIIB
Pardon 2010 (132)	Qualitative	Europe	Patients	126	IIIA
Feliciano 2018 (133)	Qualitative	North America	Patients	17	IIIB
Pusa 2012 (134)	Qualitative	Europe	FCGs	11	IIIA
Ólafsdóttir 2018 [†] (135)	Qualitative	Europe	Both	7 Patients; 5 FCGs	IIIB
Hendriksen 2015 (136)	Qualitative	North America	Both	10 Patients; 5 FCGs	IIIB
Sjolander 2012 (137)	Qualitative	Europe	FCGs	17	IIIC
Villalobos 2018 (138)	Qualitative	Europe	Both	9 dyads	IIIB
McDonnell 2020 (139)	Qualitative	North America	Both	26 dyads	IIIC
McDonnell 2019 (140)	Qualitative	North America	Both	26 dyads	IIIB
Granger 2019 [†] (141)	Qualitative	Australia	Patients	7	IIIA
Kyte 2019§ (142)	Qualitative	Europe	Patients	14	IIIB
Wittenberg 2018 (143)	Pilot	North American	FGCs	20	IIIB
Chih 2013 [†] (144)	RCT	North America	FCGs	118	IA
DuBenske 2014 (145)	RCT	North America	FCGs	285	IA
Shaffer 2017 ^{&} (146)	RCT	North America	FCGs	275	IA
Namkoong 2012 [†] (147)	RCT	North America	FCGs	246	IB
Bastian 2013 [†] (148)	RCT	North America	FCGs	496	IA
Mosher 2019 (149)	RCT	North America	Both	50 dyads	IC
Schellekens 2017 (150)	RCT	Europe	Both	63 Patients; 44 FCGs	IB
Northouse 2013 (151)	RCT	North America	Both	141 dyads	IA
Porter 2011 (152)	RCT	North America	Both	233 dyads	IA
Winger 2018 [†] (153)	RCT	North America	Both	51 dyads	IC
Chen 2017 (154)	RCT	Asia	Both	132 dyads	IA

Secondary domain assignments: †Health care access and quality; *Economic stability; *Neighborhood and built environment; *Education access and quality.

References

1. Barbaret C, Delgado-Guay MO, Sanchez S, et al. Inequalities in Financial Distress, Symptoms, and Quality of Life Among Patients with Advanced Cancer in France and the U.S. Oncologist 2019;24:1121-7.

- 2. Adorno G, Wallace C. Preparation for the end of life and life completion during late-stage lung cancer: An exploratory analysis. Palliat Support Care 2017;15:554-64.
- 3. Dalton SO, Steding-Jessen M, Jakobsen E, et al. Socioeconomic position and survival after lung cancer: Influence of stage, treatment and comorbidity among Danish patients with lung cancer diagnosed in 2004-2010. Acta Oncol 2015;54:797-804.
- Hovanec J, Siemiatycki J, Conway DI, et al. Lung cancer and socioeconomic status in a pooled analysis of case-control studies. PLoS One 2018:13:e0192999.
- 5. Behrens T, Groß I, Siemiatycki J, et al. Occupational prestige, social mobility and the association with lung cancer in men. BMC Cancer 2016;16:395.
- 6. Cai C, Zhou Z, Yu L, et al. Predictors of the health-related quality of life of patients who are newly diagnosed with lung cancer in China. Nurs Health Sci 2011:13:262-8.
- Nicolau B, Madathil SA, Castonguay G, et al. Shared social mechanisms underlying the risk of nine cancers: A life course study. Int J Cancer 2019;144:59-67.
- 8. Bensenor IM, Lotufo PA. Household income, sex and respiratory mortality in São Paulo, Brazil, 1996-2010. Int J Tuberc Lung Dis 2012;16:1692-8.
- 9. Zhou LF, Zhang MX, Kong LQ, et al. Costs, Trends, and Related Factors in Treating Lung Cancer Patients in 67 Hospitals in Guangxi, China. Cancer Invest 2017;35:345-57.
- 10. Shilling V, Starkings R, Jenkins V, et al. The pervasive nature of uncertainty-a qualitative study of patients with advanced cancer and their informal caregivers. J Cancer Surviv 2017;11:590-603.
- 11. Forrest LF, Adams J, Rubin G, et al. The role of receipt and timeliness of treatment in socioeconomic inequalities in lung cancer survival: population-based, data-linkage study. Thorax 2015;70:138-45.
- 12. Lee YH, Liao YC, Shun SC, et al. Trajectories of caregiver burden and related factors in family caregivers of patients with lung cancer. Psychooncology 2018;27:1493-500.
- 13. Verma R, Pathmanathan S, Otty ZA, et al. Delays in lung cancer management pathways between rural and urban patients in North Queensland: a mixed methods study. Intern Med J 2018;48:1228-33.
- 14. Billmeier SE, Ayanian JZ, He Y, et al. Predictors of nursing home admission, severe functional impairment, or death one year after surgery for non-small cell lung cancer. Ann Surg 2013;257:555-63.
- 15. Nipp RD, Fuchs G, El-Jawahri A, et al. Sarcopenia Is Associated with Quality of Life and Depression in Patients with Advanced Cancer. Oncologist 2018;23:97-104.
- Consonni D, De Matteis S, Pesatori AC, et al. Lung cancer risk among bricklayers in a pooled analysis of case-control studies. Int J Cancer 2015;136:360-71.
- 17. Nakano M, Omae K, Tanaka A, et al. Possibility of lung cancer risk in indium-exposed workers: An 11-year multicenter cohort study. J Occup Health 2019;61:251-6.
- 18. Brenner DR, Hung RJ, Tsao MS, et al. Lung cancer risk in never-smokers: a population-based case-control study of epidemiologic risk factors. BMC Cancer 2010;10:285.
- 19. Petitte TM, Narsavage GL, Chen YJ, et al. Feasibility study: home telemonitoring for patients with lung cancer in a mountainous rural area. Oncol Nurs Forum 2014;41:153-61.
- 20. Torres-Durán M, Ruano-Ravina A, Parente-Lamelas I, et al. Lung cancer in never-smokers: a case-control study in a radon-prone area (Galicia, Spain). Eur Respir J 2014;44:994-1001.
- 21. Rodríguez-Martínez Á, Ruano-Ravina A, Torres-Durán M, et al. Small Cell Lung Cancer. Methodology and Preliminary Results of the SMALL CELL Study. Arch Bronconeumol 2017;53:675-81.
- 22. Torres-Durán M, Ruano-Ravina A, Kelsey KT, et al. Small cell lung cancer in never-smokers. Eur Respir J 2016;47:947-53.
- 23. Wang A, Qin F, Hedlin H, et al. Physical activity and sedentary behavior in relation to lung cancer incidence and mortality in older women: The Women's Health Initiative. Int J Cancer 2016;139:2178-92.
- 24. Goodridge D, Lawson J, Rennie D, et al. Rural/urban differences in health care utilization and place of death for persons with respiratory illness in the last year of life. Rural Remote Health 2010;10:1349.
- 25. Torres-Durán M, Ruano-Ravina A, Parente-Lamelas I, et al. Residential radon and lung cancer characteristics in never smokers. Int J Radiat Biol 2015;91:605-10.
- 26. Sawicki M, Szczyrek M, Krawczyk P, et al. Reasons for delay in diagnosis and treatment of lung cancer among patients in Lublin Voivodeship who were consulted in Thoracic Surgery Department. Ann Agric Environ Med 2013;20:72-6.
- 27. Bracci PM, Sison J, Hansen H, et al. Cigarette smoking associated with lung adenocarcinoma in situ in a large case-control study (SFBALCS). J Thorac Oncol 2012;7:1352-60.
- 28. Lee SC, Marks EG, Sanders JM, et al. Elucidating patient-perceived role in "decision-making" among African Americans receiving lung cancer care through a county safety-net system. J Cancer Surviv 2016;10:153-63.
- 29. Sun V, Raz DJ, Ruel N, et al. A Multimedia Self-management Intervention to Prepare Cancer Patients and Family Caregivers for Lung Surgery and Postoperative Recovery. Clin Lung Cancer 2017;18:e151-9.
- 30. Bakitas M, Dionne-Odom JN, Jackson L, et al. "There were more decisions and more options than just yes or no": Evaluating a

- decision aid for advanced cancer patients and their family caregivers. Palliat Support Care 2017:15:44-56.
- 31. Gustafson DH, DuBenske LL, Namkoong K, et al. An eHealth system supporting palliative care for patients with non-small cell lung cancer: a randomized trial. Cancer 2013;119:1744-51.
- 32. Brady GC, Roe JWG, O' Brien M, et al. An investigation of the prevalence of swallowing difficulties and impact on quality of life in patients with advanced lung cancer. Support Care Cancer 2018;26:515-9.
- 33. Husain A, Barbera L, Howell D, et al. Advanced lung cancer patients' experience with continuity of care and supportive care needs. Support Care Cancer 2013;21:1351-8.
- 34. Lee DH, Isobe H, Wirtz H, et al. Health care resource use among patients with advanced non-small cell lung cancer: the PlvOTAL retrospective observational study. BMC Health Serv Res 2018;18:147.
- 35. Lynch J, Goodhart F, Saunders Y, et al. Screening for psychological distress in patients with lung cancer: results of a clinical audit evaluating the use of the patient Distress Thermometer. Support Care Cancer 2010;19:193-202.
- 36. Roulston A, Wilkinson P, Haynes T, et al. Complementary therapy: perceptions of older people with lung or colorectal cancer. Int J Palliat Nurs 2013:19:333-9.
- 37. Wright AA, Keating NL, Ayanian JZ, et al. Family Perspectives on Aggressive Cancer Care Near the End of Life. JAMA 2016;315:284-92.
- 38. Bailey C, Hewison A, Karasouli E, et al. Hospital care following emergency admission: a critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease. J Clin Nurs 2016;25:2168-79.
- 39. Ermers DJM, van Bussel KJH, Perry M, et al. Advance care planning for patients with cancer in the palliative phase in Dutch general practices. Fam Pract 2019;36:587-93.
- 40. Jarosek SL, Shippee TP, Virnig BA. Place of Death of Individuals with Terminal Cancer: New Insights from Medicare Hospice Place-of-Service Codes. J Am Geriatr Soc 2016;64:1815-22.
- 41. Falchook AD, Dusetzina SB, Tian F, et al. Aggressive End-of-Life Care for Metastatic Cancer Patients Younger Than Age 65 Years. J Natl Cancer Inst 2017;109:djx028.
- 42. Hanratty B, Lowson E, Holmes L, et al. Funding health and social services for older people a qualitative study of care recipients in the last year of life. J R Soc Med 2012;105:201-7.
- 43. Ellis J, Wagland R, Tishelman C, et al. Considerations in developing and delivering a nonpharmacological intervention for symptom management in lung cancer: the views of patients and informal caregivers. J Pain Symptom Manage 2012;44:831-42.
- 44. Schook RM, Linssen C, Schramel FM, et al. Why do patients and caregivers seek answers from the Internet and online lung specialists? A qualitative study. J Med Internet Res 2014;16:e37.
- 45. Sikjær MG, Løkke A, Hilberg O. The influence of psychiatric disorders on the course of lung cancer, chronic obstructive pulmonary disease and tuberculosis. Respir Med 2018;135:35-41.
- 46. Rose P, Quail H, McPhelim J, et al. Experiences and outcomes of lung cancer patients using electronic assessments. Cancer Nursing Practice 2017;16:26-30.
- 47. Baumgardner J, Shahabi A, Linthicum M, et al. Greater Spending Associated with Improved Survival for Some Cancers in OCM-Defined Episodes. J Manag Care Spec Pharm 2018;24:504-13.
- 48. Aubin M, Vézina L, Verreault R, et al. Family physician involvement in cancer care and lung cancer patient emotional distress and quality of life. Support Care Cancer 2011;19:1719-27.
- 49. Goulart BH, Reyes CM, Fedorenko CR, et al. Referral and treatment patterns among patients with stages III and IV non-small-cell lung cancer. J Oncol Pract 2013;9:42-50.
- 50. Lee K, Oh EG, Kim S, et al. Symptom experiences and health-related quality of life among non-small cell lung cancer patients participating in clinical trials. J Clin Nurs 2019;28:2111-23.
- 51. Eichler M, Hechtner M, Wehler B, et al. Use of psychosocial services by lung cancer survivors in Germany: Results of a German multicenter study (LARIS). Strahlenther Onkol 2019;195:1018-27.
- 52. Shen MJ, Hamann HA, Thomas AJ, et al. Association between patient-provider communication and lung cancer stigma. Support Care Cancer 2016;24:2093-9.
- 53. Bülbül Y, Ozlu T, Arinc S, et al. Assessment of Palliative Care in Lung Cancer in Turkey. Med Princ Pract 2017;26:50-6.
- 54. Ellis KR, Janevic MR, Kershaw T, et al. Meaning-based coping, chronic conditions and quality of life in advanced cancer & caregiving. Psycho-Oncology 2017;26:1316-23.
- 55. Billmeier SE, Ayanian JZ, Zaslavsky AM, et al. Predictors and outcomes of limited resection for early-stage non-small cell lung cancer. J Natl Cancer Inst 2011;103:1621-9.
- 56. Shi Y, Gu F, Hou LL, et al. Self-reported depression among patients with non-small cell lung cancer. Thorac Cancer 2015;6:334-7.
- 57. Fukumoto K, Ito H, Matsuo K, et al. Cigarette smoke inhalation and risk of lung cancer: a case-control study in a large Japanese population. Eur J Cancer Prev 2015;24:195-200.
- 58. Nababan T, Hoskins A, Watters E, et al. 'I had to tell my GP I had lung cancer': patient perspectives of hospital- and community-based lung cancer care. Aust J Prim Health 2020;26:147-52.
- 59. Parsonage RK, Hiscock J, Law RJ, et al. Patient perspectives on delays in diagnosis and treatment of cancer: a qualitative analysis of

- free-text data. Br J Gen Pract 2017:67:e49-56.
- 60. Stegmann ME, Meijer JM, Nuver J, et al. Correspondence between primary and secondary care about patients with cancer: A qualitative mixed-methods analysis. Eur J Cancer Care (Engl) 2019;28:e12903.
- 61. Jacobsen J, Jackson V, Dahlin C, et al. Components of early outpatient palliative care consultation in patients with metastatic nonsmall cell lung cancer. J Palliat Med 2011;14:459-64.
- 62. Pirl WF, Greer JA, Traeger L, et al. Depression and survival in metastatic non-small-cell lung cancer: effects of early palliative care. J Clin Oncol 2012;30:1310-5.
- 63. Temel JS, Greer JA, El-Jawahri A, et al. Effects of Early Integrated Palliative Care in Patients With Lung and GI Cancer: A Randomized Clinical Trial. J Clin Oncol 2017;35:834-41.
- 64. Walton L, McNeill R, Stevens W, et al. Patient perceptions of barriers to the early diagnosis of lung cancer and advice for health service improvement. Fam Pract 2013;30:436-44.
- 65. Burt J, Plant H, Omar R, et al. Equity of use of specialist palliative care by age: cross-sectional study of lung cancer patients. Palliat Med 2010:24:641-50.
- 66. Xiu D, Fung YL, Lau BH, et al. Comparing dyadic cognitive behavioral therapy (CBT) with dyadic integrative body-mind-spirit intervention (I-BMS) for Chinese family caregivers of lung cancer patients: a randomized controlled trial. Support Care Cancer 2020;28:1523-33.
- 67. Yennurajalingam S, Kim YJ, Zhang Y, et al. Factors associated with patient-reported subjective well-being among advanced lung or non-colonic gastrointestinal cancer patients. Palliat Support Care 2018;16:23-31.
- 68. Ellis J, Warden J, Molassiotis A, et al. Participation in a randomised controlled feasibility study of a complex intervention for the management of the Respiratory Symptom Distress Cluster in lung cancer: patient, carer and research staff views. Eur J Cancer Care (Engl) 2017;26:e12538.
- 69. Ledderer L, la Cour K, Hansen HP. Outcome of supportive talks in a hospital setting: insights from cancer patients and their relatives. Patient 2014;7:219-29.
- 70. Owens OL, Smith KN, Beer JM, et al. A Qualitative Cultural Sensitivity Assessment of the Breathe Easier Mobile Application for Lung Cancer Survivors and Their Families. Oncol Nurs Forum 2020;47:331-41.
- 71. Bigay-Gamé L, Bota S, Greillier L, et al. Characteristics of Lung Cancer in Patients Younger than 40 Years: A Prospective Multicenter Analysis in France. Oncology 2018;95:337-43.
- 72. Banik A, Schwarzer R, Pawlowska I, et al. Women with family cancer history are at risk for poorer physical quality of life and lower self-efficacy: a longitudinal study among men and women with non-small cell lung cancer. Health Qual Life Outcomes 2017;15:62.
- 73. Hanratty B, Holmes L, Lowson E, et al. Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. J Pain Symptom Manage 2012;44:74-83.
- 74. Patel MI, Wang A, Kapphahn K, et al. Racial and Ethnic Variations in Lung Cancer Incidence and Mortality: Results From the Women's Health Initiative. J Clin Oncol 2016;34:360-8.
- 75. Park ER, Japuntich SJ, Rigotti NA, et al. A snapshot of smokers after lung and colorectal cancer diagnosis. Cancer 2012;118:3153-64.
- 76. Wiljer D, Walton T, Gilbert J, et al. Understanding the needs of lung cancer patients during the pre-diagnosis phase. J Cancer Educ 2012;27:494-500.
- 77. George M, Margolis ML. Race and lung cancer surgery--a qualitative analysis of relevant beliefs and management preferences. Oncol Nurs Forum 2010;37:740-8.
- 78. Manne S, Badr H, Kashy DA. A longitudinal analysis of intimacy processes and psychological distress among couples coping with head and neck or lung cancers. J Behav Med 2012;35:334-46.
- 79. Milbury K, Badr H, Carmack CL. The role of blame in the psychosocial adjustment of couples coping with lung cancer. Ann Behav Med 2012:44:331-40.
- 80. Hobbs GS, Landrum MB, Arora NK, et al. The role of families in decisions regarding cancer treatments. Cancer 2015;121:1079-87.
- 81. Milbury K, Badr H, Fossella F, et al. Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. Support Care Cancer 2013;21:2371-9.
- 82. Ersek M, Miller SC, Wagner TH, et al. Association between aggressive care and bereaved families' evaluation of end-of-life care for veterans with non-small cell lung cancer who died in Veterans Affairs facilities. Cancer 2017;123:3186-94.
- 83. Loh KP, Mohile SG, Lund JL, et al. Beliefs About Advanced Cancer Curability in Older Patients, Their Caregivers, and Oncologists. Oncologist 2019;24:e292-302.
- 84. Lee CS, Lyons KS. Patterns, relevance, and predictors of dyadic mental health over time in lung cancer. Psychooncology 2019;28:1721-7.
- 85. Litzelman K, Kent EE, Mollica M, et al. How Does Caregiver Well-Being Relate to Perceived Quality of Care in Patients With Cancer? Exploring Associations and Pathways. J Clin Oncol 2016;34:3554-61.
- 86. Douglas SL, Daly BJ. The impact of patient quality of life and spirituality upon caregiver depression for those with advanced cancer. Palliat Support Care 2013;11:389-96.
- 87. Garlo K, O'Leary JR, Van Ness PH, et al. Burden in caregivers of older adults with advanced illness. J Am Geriatr Soc 2010;58:2315-

22.

- 88. DuBenske LL, Chih MY, Gustafson DH, et al. Caregivers' participation in the oncology clinic visit mediates the relationship between their information competence and their need fulfillment and clinic visit satisfaction. Patient Educ Couns 2010;81 Suppl:S94-9.
- 89. Buchanan D, Milroy R, Baker L, et al. Perceptions of anxiety in lung cancer patients and their support network. Support Care Cancer 2010;18:29-36.
- 90. Lau SKM, Gannavarapu BS, Carter K, et al. Impact of Socioeconomic Status on Pretreatment Weight Loss and Survival in Non-Small-Cell Lung Cancer. J Oncol Pract 2018;14:e211-20.
- 91. Jacobs JM, Shaffer KM, Nipp RD, et al. Distress is Interdependent in Patients and Caregivers with Newly Diagnosed Incurable Cancers. Ann Behav Med 2017;51:519-31.
- 92. Lyons KS, Miller LM, McCarthy MJ. The Roles of Dyadic Appraisal and Coping in Couples With Lung Cancer. J Fam Nurs 2016;22:493-514.
- 93. Oh S, Ryu E. Does Holding Back Cancer-Related Concern Affect Couples' Marital Relationship and Quality of Life of Patients with Lung Cancer? An Actor-Partner Interdependence Mediation Modeling Approach. Asian Nurs Res (Korean Soc Nurs Sci) 2019:13:277-85.
- 94. Cooley ME, Finn KT, Wang Q, et al. Health Behaviors, Readiness to Change, and Interest in Health Promotion Programs Among Smokers With Lung Cancer and Their Family Members. Cancer Nursing 2013;36:145-154.
- 95. Zhang AY, Zyzanski SJ, Siminoff LA. Differential patient-caregiver opinions of treatment and care for advanced lung cancer patients. Soc Sci Med 2010;70:1155-8.
- 96. Leydon GM, Guerin M, Eyles C, et al. 'What matters to me': an international online survey of people treating, affected by and living with lung cancer. Future Oncol 2012;8:883-96.
- 97. Madani H, Pourmemari M, Moghimi M, et al. Hopelessness, Perceived Social Support and their Relationship in Iranian Patients with Cancer. Asia Pac J Oncol Nurs 2018;5:314-9.
- 98. Hung HY, Wu LM, Chen KP. Determinants of Quality of Life in Lung Cancer Patients. J Nurs Scholarsh 2018;50:257-64.
- 99. Dogan N, Tan M. Quality of Life And Social Support in Patients with Lung Cancer. International Journal of Caring Sciences 2019:12:263-9.
- 100. Akin S, Can G, Aydiner A, et al. Quality of life, symptom experience and distress of lung cancer patients undergoing chemotherapy. Eur J Oncol Nurs 2010:14:400-9.
- 101. Nipp RD, El-Jawahri A, Fishbein JN, et al. Factors associated with depression and anxiety symptoms in family caregivers of patients with incurable cancer. Ann Oncol 2016;27:1607-12.
- 102. Kramer BJ, Kavanaugh M, Trentham-Dietz A, et al. Predictors of family conflict at the end of life: the experience of spouses and adult children of persons with lung cancer. Gerontologist 2010;50:215-25.
- 103. Ostlund U, Wennman-Larsen A, Persson C, et al. Mental health in significant others of patients dying from lung cancer. Psychooncology 2010:19:29-37.
- 104. Malik FA, Gysels M, Higginson IJ. Living with breathlessness: a survey of caregivers of breathless patients with lung cancer or heart failure. Palliat Med 2013;27:647-56.
- 105. Chen SC, Chiou SC, Yu CJ, et al. The unmet supportive care needs-what advanced lung cancer patients' caregivers need and related factors. Support Care Cancer 2016;24:2999-3009.
- 106. Hu X, Peng X, Su Y, et al. Caregiver burden among Chinese family caregivers of patients with lung cancer: A cross-sectional survey. Eur J Oncol Nurs 2018;37:74-80.
- 107. Lobchuk MM, McClement SE, McPherson CJ, et al. Impact of patient smoking behavior on empathic helping by family caregivers in lung cancer. Oncol Nurs Forum 2012;39:E112-21.
- 108. Miller LM, Sullivan DR, Lyons KS. Dyadic Perceptions of the Decision Process in Families Living With Lung Cancer. Oncol Nurs Forum 2017;44:108-15.
- 109. Porter LS, Keefe FJ, Davis D, et al. Attachment styles in patients with lung cancer and their spouses: associations with patient and spouse adjustment. Support Care Cancer 2012;20:2459-66.
- 110. Wood R, Taylor-Stokes G, Lees M. The humanistic burden associated with caring for patients with advanced non-small cell lung cancer (NSCLC) in three European countries-a real-world survey of caregivers. Support Care Cancer 2019;27:1709-19.
- 111. Lee YH, Liao YC, Liao WY, et al. Anxiety, depression and related factors in family caregivers of newly diagnosed lung cancer patients before first treatment. Psychooncology 2013;22:2617-23.
- 112. Martin MY, Fouad MN, Oster RA, et al. What do cancer patients worry about when making decisions about treatment? Variation across racial/ethnic groups. Support Care Cancer 2014;22:233-44.
- 113. Chang NW, Lin KC, Hsu WH, et al. The effect of gender on health-related quality of life and related factors in post-lobectomy lung-cancer patients. Eur J Oncol Nurs 2015;19:292-300.
- 114. Hechtner M, Eichler M, Wehler B, et al. Quality of Life in NSCLC Survivors A Multicenter Cross-Sectional Study. J Thorac Oncol 2019;14:420-35.
- 115. Skalla KA, Ferrell B. Challenges in assessing spiritual distress in survivors of cancer. Clin J Oncol Nurs 2015;19:99-104.
- 116. Cykert S, Eng E, Walker P, et al. A system-based intervention to reduce Black-White disparities in the treatment of early stage lung

- cancer: A pragmatic trial at five cancer centers. Cancer Med 2019:8:1095-102.
- 117. Borneman T, Sun V, Williams AC, et al. Support for Patients and Family Caregivers in Lung Cancer. Journal of Hospice & Palliative Nursing 2015;17:309-318.
- 118. Nguyen HQ, Cuyegkeng T, Phung TO, et al. Integration of a Palliative Care Intervention into Community Practice for Lung Cancer: A Study Protocol and Lessons Learned with Implementation. J Palliat Med 2017;20:1327-37.
- 119. Li Y, Ling L, Zhanyu P. Effect of Wellness Education on Quality of Life of Patients With Non-Small Cell Lung Cancer Treated With First-Line Icotinib and on Their Family Caregivers. Integr Cancer Ther 2019;18:1534735419842373.
- 120. Milbury K, Mallaiah S, Lopez G, et al. Vivekananda Yoga Program for Patients With Advanced Lung Cancer and Their Family Caregivers. Integr Cancer Ther 2015;14:446-51.
- 121. Milbury K, Engle R, Tsao A, et al. Pilot Testing of a Brief Couple-Based Mind-Body Intervention for Patients With Metastatic Non-Small Cell Lung Cancer and Their Partners. J Pain Symptom Manage 2018;55:953-61.
- 122. Sun V, Kim JY, Irish TL, et al. Palliative care and spiritual well-being in lung cancer patients and family caregivers. Psychooncology 2016;25:1448-55.
- 123. Lindau ST, Surawska H, Paice J, et al. Communication about sexuality and intimacy in couples affected by lung cancer and their clinical-care providers. Psychooncology 2011;20:179-85.
- 124. Lowson E, Hanratty B, Holmes L, et al. From 'conductor' to 'second fiddle': older adult care recipients' perspectives on transitions in family caring at hospital admission. Int J Nurs Stud 2013;50:1197-205.
- 125. Ngwenya N, Farquhar M, Ewing G. Sharing bad news of a lung cancer diagnosis: understanding through communication privacy management theory. Psychooncology 2016;25:913-8.
- 126. Occhipinti S, Dunn J, O'Connell DL, et al. Lung Cancer Stigma across the Social Network: Patient and Caregiver Perspectives. J Thorac Oncol 2018;13:1443-53.
- 127. Ewing G, Ngwenya N, Benson J, et al. Sharing news of a lung cancer diagnosis with adult family members and friends: a qualitative study to inform a supportive intervention. Patient Educ Couns 2016;99:378-85.
- 128. Sihombing Y, Waluyo A, Yona S. The experience of caring for an advanced lung cancer spouse: Vulnerable journey of caregiving. Enfermeria Clinica 2019;29:891-6.
- 129. Steinvall K, Johansson H, Berterö C. Balancing a changed life situation: the lived experience from next of kin to persons with inoperable lung cancer. Am J Hosp Palliat Care 2011;28:82-9.
- 130. Bottorff JL, Robinson CA, Sarbit G, et al. A Motivational, Gender-Sensitive Smoking Cessation Resource for Family Members of Patients With Lung Cancer. Oncol Nurs Forum 2015;42:363-70.
- 131. Pardon K, Deschepper R, Vander Stichele R, et al. Preferred and actual involvement of advanced lung cancer patients and their families in end-of-life decision making: a multicenter study in 13 hospitals in Flanders, Belgium. J Pain Symptom Manage 2012;43:515-26.
- 132. Pardon K, Deschepper R, Stichele RV, et al. Preferences of patients with advanced lung cancer regarding the involvement of family and others in medical decision-making. J Palliat Med 2010;13:1199-203.
- 133. Feliciano J, Becker B, Shukla M, et al. Lung cancer and family-centered patient concerns. Support Care Cancer 2018;26:3047-53.
- 134. Pusa S, Persson C, Sundin K. Significant others' lived experiences following a lung cancer trajectory From diagnosis through and after the death of a family member. European Journal of Oncology Nursing 2012;16:34-41.
- 135. Ólafsdóttir KL, Jónsdóttir H, Fridriksdóttir N, et al. Integrating nurse-facilitated advance care planning for patients newly diagnosed with advanced lung cancer. Int J Palliat Nurs 2018;24:170-7.
- 136. Hendriksen E, Williams E, Sporn N, et al. Worried together: a qualitative study of shared anxiety in patients with metastatic non-small cell lung cancer and their family caregivers. Support Care Cancer 2015;23:1035-41.
- 137. Sjolander C, Ahlstrom G. The meaning and validation of social support networks for close family of persons with advanced cancer. BMC Nurs 2012;11:17.
- 138. Villalobos M, Coulibaly K, Krug K, et al. A longitudinal communication approach in advanced lung cancer: A qualitative study of patients', relatives' and staff's perspectives. European Journal of Cancer Care 2018;27:1.
- 139. McDonnell KK, Owens OL, Hilfinger Messias DK, et al. After Ringing the Bell: Receptivity of and Preferences for Healthy Behaviors in African American Dyads Surviving Lung Cancer. Oncol Nurs Forum 2020;47:281-91.
- 140. McDonnell KK, Owens OL, Hilfinger Messias DK, et al. Health behavior changes in African American family members facing lung cancer: Tensions and compromises. Eur J Oncol Nurs 2019;38:57-64.
- 141. Granger CL, Parry SM, Edbrooke L, et al. Improving the delivery of physical activity services in lung cancer: A qualitative representation of the patient's perspective. Eur J Cancer Care (Engl) 2019;28:e12946.
- 142. Kyte K, Ekstedt M, Rustoen T, et al. Longing to get back on track: Patients' experiences and supportive care needs after lung cancer surgery. J Clin Nurs 2019;28:1546-54.
- 143. Wittenberg E, Ferrell B, Koczywas M, et al. Pilot Study of a Communication Coaching Telephone Intervention for Lung Cancer Caregivers. Cancer Nurs 2018;41:506-12.
- 144. Chih MY, DuBenske LL, Hawkins RP, et al. Communicating advanced cancer patients' symptoms via the Internet: a pooled analysis of two randomized trials examining caregiver preparedness, physical burden, and negative mood. Palliat Med 2013;27:533-43.

- 145. DuBenske LL, Gustafson DH, Namkoong K, et al. CHESS improves cancer caregivers' burden and mood: results of an eHealth RCT. Health Psychol 2014;33:1261-72.
- 146. Shaffer KM, Jacobs JM, Nipp RD, et al. Mental and physical health correlates among family caregivers of patients with newly-diagnosed incurable cancer: a hierarchical linear regression analysis. Support Care Cancer 2017;25:965-71.
- 147. Namkoong K, DuBenske LL, Shaw BR, et al. Creating a bond between caregivers online: effect on caregivers' coping strategies. J Health Commun 2012;17:125-40.
- 148. Bastian LA, Fish LJ, Peterson BL, et al. Assessment of the impact of adjunctive proactive telephone counseling to promote smoking cessation among lung cancer patients' social networks. Am J Health Promot 2013;27:181-90.
- 149. Mosher CE, Secinti E, Hirsh AT, et al. Acceptance and Commitment Therapy for Symptom Interference in Advanced Lung Cancer and Caregiver Distress: A Pilot Randomized Trial. J Pain Symptom Manage 2019;58:632-44.
- 150. Schellekens MPJ, van den Hurk DGM, Prins JB, et al. Mindfulness-based stress reduction added to care as usual for lung cancer patients and/or their partners: A multicentre randomized controlled trial. Psychooncology 2017;26:2118-26.
- 151. Northouse LL, Mood DW, Schafenacker A, et al. Randomized clinical trial of a brief and extensive dyadic intervention for advanced cancer patients and their family caregivers. Psychooncology 2013;22:555-63.
- 152. Porter LS, Keefe FJ, Garst J, et al. Caregiver-assisted coping skills training for lung cancer: results of a randomized clinical trial. J Pain Symptom Manage 2011;41:1-13.
- 153. Winger JG, Rand KL, Hanna N, et al. Coping Skills Practice and Symptom Change: A Secondary Analysis of a Pilot Telephone Symptom Management Intervention for Lung Cancer Patients and Their Family Caregivers. J Pain Symptom Manage 2018;55:1341-1349.e4.
- 154. Chen HL, Liu K, You QS. Effects of couple based coping intervention on self-efficacy and quality of life in patients with resected lung cancer. Patient Educ Couns 2017;100:2297-302.