Comprehensive Psychosocial Distress Screening in Patients Newly Diagnosed with Lung Cancer – A Mixed Methods Study

COMPREHENSIVE PSYCHOSOCIAL DISTRESS SCREENING IN PATIENTS NEWLY DIAGNOSED WITH LUNG CANCER – A MIXED METHODS STUDY

A Dissertation Presented

By

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DEDICATION

This dissertation is dedicated to:

The memory of my Father, Dr Thompson S. Oluwasanmi whose love for me knew no bounds and, who would have been so proud of me. He taught me the value of hard work and tenacity. I will always love you my Adadidudumen.

My mother, Pharm. Florence O. Oluwasanmi, my Amomsie whom I love so dearly and whose prayers and love have sustained me all my life.

God Almighty my creator, my source of strength, wisdom, knowledge and understanding.

"I can do all things through Christ who strengthens me" – Philippians 4:13

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ABSTRACT

Background: Patients with newly diagnosed lung cancer have one of the highest rates of psychosocial distress which may be reduced by identifying factors associated with psychosocial distress. This dissertation examined the association of neighborhood-level Social Determinants of Health (SDOH) and delay in treatment initiation with psychosocial distress. It also qualitatively explored perceptions and practices of the lung cancer care team regarding psychosocial distress screening.

Methods: Sociodemographic, clinical, and SDOH data of patients newly diagnosed with lung cancer between 2017 and 2021 was analyzed via logistic regression. Thematic analysis was done for interviews conducted with the lung cancer care team.

Results: SDOH and delay in treatment were not significantly associated with psychosocial distress. However, a high deprivation level of SDOH was associated with delay in treatment initiation. Qualitatively, four principal themes emerged: (1) Timing and frequency of screening: Multiple screenings at different time points may be more effective; (2) Training needs: All staff would benefit from training; (3) Staffing needs: More psychologists and social workers are needed to address identified patient psychosocial distress and; (4) Opportunity for holistic patient care: Consistent communication of distress screening information to physicians and surgeons may enhance a holistic care model for patients.

Conclusions: The lung cancer care team valued psychosocial distress screening and identified opportunities for improving screening processes. The finding of association of high deprivation level of SDOH with greater delay in treatment initiation suggests that targeted interventions to reduce delay in treatment initiation, focusing on economically marginalized groups may be warranted.

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LIST OF ABBREVIATIONS

Abbreviation	Meaning
ACS	American Cancer Society
CoC	Commission on Cancer
DT	Distress Thermometer
ECOG	Eastern Cooperative Oncology Group
LDCT	Low Dose Computed Tomography
LCS	Lung Cancer Screening
NCDB	National Cancer Database
NCI	National Cancer Institute
NCCN	National Comprehensive Cancer Network
NSCLC	Non-Small Cell Lung Cancer
SCLC	Small Cell Lung Cancer
STORE	Standards for Oncology Registry Entry
SES	Socio-Economic Status
SDOH	Social Determinants of Health
TDF	Theoretical Domains Framework
TTI	Time to Treatment Initiation
UMMHC	UMass Memorial Health Care
UMMS	University of Massachusetts Chan Medical School

PREFACE

The work presented in this dissertation is currently in preparation for submission.

Chapter II:

Emidio OM, Cutrona SL, Person SD, Mazor KM, Frisard C, Lemon SC. **Relationship between Neighborhood-Level Social Determinants of Health and Psychosocial Distress in Patients Newly Diagnosed with Lung Cancer.** – Manuscript in preparation for submission

Chapter III:

Emidio OM, Cutrona SL, Person SD, Mazor KM, Frisard C, Lemon SC. **Relationship between Psychosocial Distress and Delay in Treatment Initiation in Patients with Newly Diagnosed Lung Cancer.** – Manuscript in preparation for submission

Chapter IV:

Emidio OM, Nagawa CS, ItoFukunaga M, Cutrona SL, Person SD, Mazor KM, Lemon SC. **Perceptions and Practices of a Lung Cancer Care Team Regarding Psychosocial Distress Screening in Patients with Lung Cancer: A Qualitative Study.** – Manuscript in preparation for submission

CHAPTER I: INTRODUCTION

Burden of Lung Cancer

Lung cancer is a global health problem. It is the second most frequently diagnosed cancer and the leading cause of cancer mortality worldwide, as well as in the United States (1-3). In 2020, there was an estimated 2.2 million new cases and 1.8 million deaths of lung cancer globally (3). In the United States, one out of 16 people will be diagnosed with lung cancer in their lifetime (4).

Over the past years, the overall annual number of new cancer cases has increased primarily because of an aging white and a growing black population (5, 6). The American Cancer Society estimates that there will be about 235,760 new diagnosis and 131,880 deaths from lung cancer in the United States in 2021 (2), potentially a 3% increase in incidence and 2.8% decrease in mortality from 2020 rates (7). The increase in incidence and reduction in mortality of lung cancer cases can partially be attributed to the implementation of Lung Cancer Screening (LCS) with Low Dose Computed Tomography (LDCT) (8). LCS increases the chances of early detection at a stage where treatment can effect a cure.

Although advances in detection and treatment has brought about some improvements in survival (1), the 5-year relative survival rates for the two main histologic categories of lung cancer 25% for Non–Small Cell Lung Cancer (NSCLC) and 7% for Small Cell Lung Cancer (SCLC) still remains quite lower than the other top cancers (2, 9).

Lung cancer is also associated with significant economic burden and national costs for lung cancer care is on the rise from an estimated $21.1 billion in 2015 to $23.8 billion in 2020 (10).

Disparities in Lung Cancer

Racial and ethnic differences in the descriptive epidemiology of lung cancer have been noted. Overall, Non-Hispanic black men have higher incidence and mortality rate while non-Hispanic white and Hispanic women have lower incidence and mortality rates. Non-Hispanic blacks are more likely to have distant stage of disease at diagnosis and have lower 5-year survival rates (11). Lung cancer is mostly a disease of older adults with an average age of 70 years at diagnosis (2, 9). As such, a diagnosis of lung cancer is often associated with greater medical, social, and economic burden (12, 13).

Risk Factors for Lung Cancer

According to the U.S. Environmental Protection Agency, the top 3 risk factors for lung cancer are tobacco smoking, exposure to radon and exposure to secondhand smoke (14, 15).

Tobacco smoking, the most common lung cancer risk factor accounts for about 90% of the lung cancer incidence and 80%-90% of lung cancer deaths in the United States (9, 15, 16). Compared to non-smokers, smokers can have as much as a 30 times higher likelihood of developing lung cancer (15, 17). Exposure to radon is reported as the overall second leading cause of lung cancer. It is the most common risk factor in non-smokers and the risk is heightened in smokers because of its synergistic effect with tobacco smoking (14). Exposure to secondhand smoke is ranked as the third leading risk factor of lung cancer and it can increase the risk of non-smokers developing lung cancer by 20% - 30% (9, 14).

Other risk factors include occupational exposures to substances such as asbestos, personal, or family history of lung cancer and previous chest radiation (15, 16).

Lung Cancer and Stigma

Largely due to the role of smoking as the leading cause of lung cancer, a stigma has been associated with a diagnosis of lung cancer (18, 19). This stigma often affects the patient, whether they smoke or not. The stigma may cause patients to conceal their diagnosis from family and friends, making it difficult to get the support (psychological, financial, social) needed (20). This stigma impacts negatively on their physical and psychological wellbeing (18-20). Evidence shows that about a third of patients with lung cancer feel responsible for their diagnosis, and this may impact negatively on their psychological well-being and lead to increased psychological distress including symptoms of anxiety to depression (18-20).

Lung Cancer and Psychosocial Distress

Psychosocial distress in the context of cancer is defined as “a multifactorial, unpleasant experience of a psychologic (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (21). It exists along a broad spectrum, ranging from feelings of vulnerability to limiting conditions such as depression and social isolation (22).

Patients with lung cancer, when compared to other cancer populations, have one of the highest proportions of psychosocial distress with reported rates ranging between 43.5% to 61.6% (12, 23-25). A few studies have analyzed a variety of factors associated with psychosocial distress in patients with lung cancer (25-27). Factors found to be associated with high psychosocial distress levels include younger age (25-27), female gender (26, 27), current cigarette smoking (26), advanced lung cancer disease (26, 27), receiving surgical or chemotherapy treatment (26) and a lower Eastern Cooperative Oncology Group performance score (26).

Research done in this area largely to date has examined demographic and clinical factors and despite evidence that patients with lung cancer are more likely to have unresolved, unmet social needs (28, 29), no prior study has been conducted to investigate the association of social determinants of health (SDOH) factors and psychosocial distress in this patient group.

Lung Cancer and Social Determinants of Health

Social determinants of health (SDOH) are “the conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks" (30). Healthy People 2030 grouped SDOH into 5 key areas: economic stability, education access and quality, health care access and quality, neighborhood and built environment, social and community context (30). SDOH factors such as income, education, employment, food security, and safe housing shape conditions of daily life and can impact health outcomes and are major underlying causes of health inequities (31-33). The SDOH of a community are often rooted its overall socio-economic status (SES), as those with lower socio-economic status (SES) tend to live in areas with poor SDOH (31). Addressing the SDOH typically requires systems, structural and/or policy based approaches; while challenging to intervene upon, these types of population-based interventions can have more far reaching effects than individual-based interventions (31).

A few previous studies have examined the role of SES among patients with lung cancer. For example, in a case control study analyzing lung cancer and socioeconomic status, it was reported that after adjusting for smoking, there was a significant association between low SES and the risk of lung cancer among males (84% increase) and females (54% increase) (34). SES was measured using the International Socio-Economic Index of occupational status (ISEI) which merges income, education, and occupation data. Another previous study also noted that low SES is associated with increased rates of tobacco smoking and with unsuccessful quit attempts (35).

Low SES and psychosocial distress are often independently associated with poorer health outcomes (21, 31, 36). Studies examining the relationship between SES and psychological distress have reported a synergistic effect of worsened health outcomes in distressed patients with low SES (37, 38). Patients experiencing low SES are also more likely to suffer the negative health outcomes associated with psychosocial distress. However, these studies were conducted in non-cancer populations. With the evidence of high prevalence of psychosocial distress in patients newly diagnosed with lung cancer, understanding the relationship between SDOH and psychosocial distress is warranted in this population.

Lung Cancer and Delayed Treatment Initiation

Diagnosis of cancer is a critical time often associated with the high degrees of disbelief and psychosocial distress (39, 40). Psychosocial distress can lead to difficulty in making healthcare decisions (41) and this may impact on the ability to make appropriate cancer treatment decisions (40, 42, 43). This may lead to delay in treatment initiation, adherence, or completion.

Time to Treatment Initiation (TTI) is defined as the number of days from date of initial diagnosis for cancer to date of first cancer-directed treatment initiation (44). An prospective study on time to initial cancer treatment in the United States reported that the time to treatment initiation in patients with cancer increased by 38% over a ten year period (2004-2013) (44). Factors that are associated with a delay in time to treatment initiation in patients with cancer include younger age, black race, low education, prior history of cancer, significant comorbidities, transfer of care and care at academic center (44-50).

With respect to lung cancer, time to treatment initiation is increasingly being used as an important outcome and quality metric in the care of patients with lung cancer (51), and a time to treatment initiation of six or less weeks is regarded as optimal (52, 53). A worsening risk of mortality has been a reported with time to treatment initiation over six weeks from diagnosis (54) and longer time to treatment initiation is associated with increased morbidity and decreased overall survival (50). It is recommended that patients with suspected lung cancer undergo early diagnosis, and prompt treatment in order to increase cure rates, quality of life, and survival (55). Given that patients with lung cancer have a high rate of psychosocial distress, a better understanding of the association between psychosocial distress and delay in treatment initiation among patients with lung cancer is necessary to garner knowledge to help prevent delay and improve medical management.

Implementation of Psychosocial Distress Screening in Lung Cancer Care

Addressing psychosocial distress has been identified as a critical component of comprehensive cancer care (56). Psychosocial distress screening helps identify cancer patients with distress, facilitate complete clinical assessments to ascertain cause and activate appropriate referral pathways (57). Screening also helps with identification of the most vulnerable patients so that we can intervene preemptively to prevent future distress (57). Early identification and management of psychosocial distress can help to improve distressed patients' health outcomes (36, 58), particularly in patients with lung cancer, who have an increased propensity to be distressed and also often have a poorer prognosis compared with other cancer patient populations (19, 59).

In 2015, the new accreditation standards for cancer centers were enacted by the Commission on Cancer (CoC). To be accredited, cancer programs must comply with CoC STANDARD 3.2 - "The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care." (60). This standard allows individual cancer programs to determine when and how often screenings occur, type of screening tool to use and the process of assessment and referral (61). Cancer centers' size, resources, and location are key determinants of how these requirements are enacted (60, 62). Thus, there is substantial institutional variability in screening processes, and achieving compliance with the CoC standard in certain cancer centers may be affected by factors peculiar to the setting. Therefore, a better understanding of contextual factors that promote effective screening and facilitate process adherence is necessary.

Despite the CoC's accreditation standards, a 2017 study that reviewed 8,409 EHRs across 55 cancer centers reported that the overall adherence rate to screening protocols (i.e., extent to which programs screened and responded appropriately) was only 62.7% (61). This rate varied by institution with the lowest rate found in NCI-designated Cancer Centers (43.3%) (61). A significant body of literature has suggested common barriers that may account for the low rate such as: lack of trained staff; poorly established distress screening protocols; lack of time for clinicians; and lack of institutional buy-in or support (63-65). However, none of this research was performed primarily in the context of lung cancer treatment. The high incidence of psychosocial distress in this patient group warrants research that aims to better understand the complexities of successfully performing psychosocial distress screening. Having contextual insight into what drives or hinders adherence to distress screening protocols in individual cancer centers may be a key to improving overall rates.

Dissertation Aims and Hypotheses

This dissertation had an overall goal of quantitatively examining experiences of psychosocial distress and qualitatively identifying ways to improve psychosocial distress screening in newly diagnosed patients with lung cancer, a patient population that experiences high levels of psychosocial distress.

In addition to examining standard demographic and clinical factors, this dissertation examined the association of social determinants of health factors and delay of treatment initiation with psychosocial distress. It aimed to provide rich qualitative data on barriers and facilitators to efficient and effective comprehensive psychosocial distress screening.

The specific aims of this dissertation are to:

Aim 1: Determine the prevalence of and examine the association between neighborhood-level SDOH and psychosocial distress among a sample of newly diagnosed patients with lung cancer within the UMass Memorial Health Care (UMMHC) System.

Hypothesis: Patients newly diagnosed with lung cancer who experienced greater neighborhood-level SDOH disadvantage (i.e., who live in a more socioeconomically deprived neighborhood) would experience higher levels of psychosocial distress.

Aim 2: Examine the relationship between psychosocial distress and delay in treatment initiation among a sample of patients newly diagnosed with lung cancer within UMMHC.

Hypothesis: Patients newly diagnosed lung cancer with elevated psychosocial distress will experience a delay in treatment initiation.

Aim 3: Qualitatively explore the perceptions and practices of the lung cancer care team (surgeons, physician-oncologists, nurses, psychologists, patient navigators, financial counsellors, nutritionist, social workers) regarding psychosocial distress screening within UMMHC.

CHAPTER II: RELATIONSHIP BETWEEN NEIGHBORHOOD-LEVEL SOCIAL DETERMINANTS OF HEALTH AND PSYCHOSOCIAL DISTRESS IN PATIENTS NEWLY DIAGNOSED WITH LUNG CANCER

Abstract

Objective: Patients with lung cancer experience high rates of psychosocial distress. Neighborhood-level social determinants of health (SDOH) have not been adequately investigated in relation to psychosocial distress even though patients with lung cancer are more likely to have unresolved, unmet social needs. The aim of this study is to examine the association between neighborhood-level SDOH and psychosocial distress among a sample of patients newly diagnosed with lung cancer.

Methods: This cross-sectional study included patients newly diagnosed with lung cancer within a large healthcare system in central Massachusetts between May 2017 and May 2021. The primary outcome was psychosocial distress, measured using the distress thermometer and dichotomized (distressed vs. not distressed) using a cut-off score of 4. The explanatory variables were the neighborhood-level SDOH indicators for income, and education. A composite exposure variable categorized into low to high deprivation levels was created. Covariates were age, gender, race/ethnicity, comorbidity index, cancer stage and insurance status. The proportion of patients with psychosocial distress was estimated. Multivariable logistic regression modeling was used to evaluate relationship of neighborhood-level SDOH indicators with psychosocial distress.

Results: The prevalence of psychosocial distress in the sample was 58.4%. Neighborhood-level SDOH indicators were not significantly associated with psychosocial distress. Higher odds of psychosocial distress were significantly associated with being female (OR=3.97 [95% CI=2.39 – 6.60]) and having distant ($OR_{distant}$=2.56 [95% CI=1.31 – 5.01]) or regional cancer ($OR_{regional}$=1.91 [95% CI=1.01 – 3.62]) vs. localized cancer. The age group 66 – 75 years vs. those aged ≤ 65 years were significantly associated with lower distress (0.43 [0.19 – 0.95]).

Conclusions: Psychosocial distress was consistently high across the SDOH deprivation categories; but the neighborhood level SDOH do not appear to be predictive of psychosocial distress at the time of diagnosis of lung cancer.

Introduction

Lung cancer is the second most frequently diagnosed cancer and the leading cause of cancer death worldwide (1, 3, 66). In 2020, there were an estimated 2.2 million new cases and 1.8 million deaths from lung cancer globally (3). Despite a decline in cancer death rates due to advances in early detection and treatment, lung cancer is still the leading cause of cancer death in both men and women in the United States (67, 68). The American Cancer Society estimates that there will be approximately 235,760 new cases and 131,880 deaths of lung cancer in the US in 2021 (1).

Psychosocial distress as defined in the National Comprehensive Cancer Network (NCCN) clinical guidelines is “a multifactorial, unpleasant experience of a psychologic (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature, that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment” (21). Psychosocial distress is a widely recognized occurrence among patients with cancer (39). As a result, the American College of Surgeons’ Commission on Cancer’s accreditation standards requires cancer centers to implement, monitor and document psychosocial distress screening as a means to ensure that patients with distress are identified and treated (69).

Consequences of psychosocial distress in patients with cancer include difficulty in making treatment decisions with resulting delay in care, disease progression, negative health outcomes, reduced quality of life, and poorer prognosis (41, 70, 71). In comparison with other cancer populations, patients with lung cancer have one of the highest rates of psychosocial distress, with reported rates ranging between 43.5% to 61.6% (12, 23-25). Factors that can contribute to this are poorer prognosis and increased burden of symptoms of the cancer (13, 72) as well as the stigma and self-blame associated with the disease due to the causal impact of prolonged tobacco use (13, 18, 20). In various studies, younger age, female gender, current cigarette smoking, advanced stage of disease, receiving surgery or chemotherapy and a higher ECOG scale of performance status score was found to be associated with higher levels of psychosocial distress (25-27). These studies were however limited to the examination of demographic and clinical factors only.

Social determinants of health (SDOH) are "the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks" (73). SDOH influence health care outcomes and disparities (74, 75). SDOH associated with lower socioeconomic levels have been linked with greater unmet health needs (physical and social), poorer health outcomes, health inequities and psychosocial distress (74-77). This is evidenced in patients with lung cancer who have been reported to have a high proportion of unmet social needs (28, 29). Patients with lung cancer have been reported to have greater healthcare inequities experienced by those who live in a more socioeconomically deprived area (78).

Despite the high prevalence of psychosocial distress and unmet social needs in this patient population, and the correlation of these factors with SDOH, to the best of our knowledge, no study has investigated the association of SDOH and psychosocial distress in patients with lung cancer. We hypothesized that newly diagnosed patients with lung cancer who experienced greater neighborhood-level SDOH disadvantage (i.e., who live in a more socioeconomically deprived neighborhood) would experience higher levels of psychosocial distress.

Materials and Methods

Study design & Setting

This study utilized a cross-sectional study design with patient data from the UMass Memorial Health Care (UMMHC) System. UMMHC is the largest health care system in Central and Western Massachusetts. The Cancer Center in UMMHC is accredited by the American College of Surgeons Commission on Cancer (CoC).

Study Sample

The sample in this study included all patients newly diagnosed with lung cancer seen within UMMHC between 2017 and 2021, who completed a psychosocial distress screening. A total of 1,516 patients were newly diagnosed with lung cancer and of these, 1,115 had no psychosocial distress scores data recorded, resulting in an analytic sample size of 401.

Data Sources

Data were obtained from the University of Massachusetts Chan Medical School (UMMS) Data Sciences Core, a unit of the UMMS Center for Data Science Resources. UMMS is the academic partner of UMMHC. The Data Sciences Core provides access to and support the use of multiple and complex data sources. Data for this study linked multiple data sources: (1) The Electronic Medical Records which was the data source for all socio-demographic and clinical data. (2) The psychosocial distress data obtained from the participants using the Distress Thermometer (DT) (58). In UMMHC, the distress thermometer is completed by patients at the time of the first in-person visit following a cancer diagnosis. Collection of the data is managed by the cancer center and subsequently uploaded into Electronic Medical Records. (3) Census level data using the 2010 census 5-year survey (2010ACSW) was obtained by geocoding participants' addresses to obtain the corresponding census tract information which provides neighborhood-level indices of SDOH. A manual chart review and data abstraction of the electronic medical records captured in EPIC was also conducted by a study team member (OE) to obtain missing data and to clarify ambiguous data.

Ethical Approval

Approval for the study and waiver of consent was received from the UMMS Committee for the Protection of Human Subjects in Research.

Measures

Psychosocial distress

The Distress Thermometer and its associated problem list (Figure 2.1) is the tool used to collect the psychosocial distress data in the UMMHC Cancer Center. The distress thermometer is given to all patients in the UMMHC Lung Cancer Clinic at their first visit following a lung cancer diagnosis. The distress thermometer is a validated, single-item patient-reported visual analogue scale developed by the National Comprehensive Cancer Network (NCCN) (58). It has a range of 0–10, with 0 indicating no distress and 10 indicating extreme distress. Patients are asked to circle the number that best describes how much distress they have experienced over the past week and a suggested cut-off value for the distress thermometer to identify distress by the NCCN is 4 (40, 58). Studies have been done to describe and outline the translation and validation of the distress thermometer in patients with cancer cross-culturally across different countries. In the majority of examined studies, a cut point of 4 to determine significant level of distress, maximized sensitivity and specificity when compared to an accepted well-established benchmark such as the Hospital Anxiety and Depression Scale (HADS) (79-83). In this study, we therefore categorized patients reporting a distress level of 4 or greater as distressed, and those reporting a distress level less than 4 as non-distressed.

Neighborhood-level social determinants of health

Neighborhood-level SDOH data were obtained by geocoding the participants' address at time of diagnosis, to obtain the corresponding census tract information from the 2010 census 5-year survey (2010ACSW). We chose standard economic indicators with known associations with health outcomes (84-86). These indicators and corresponding census tract data were income (median household income), and education (percent of high school graduates). For each census tract variable, the sample mean for each indicator was used as a cutoff. That is, each indicator was dichotomized to take on the value of 0 if equals to or greater than the SDOH indicator mean and 1 if less than the mean.

To address possible multicollinearity of these indicators (87), a composite SDOH variable was created by summing the two individual indicators. Each indicator had a score of 0 or 1., therefore, the composite SDOH variable had a score range of 0 to 2 and a higher score meant greater SDOH deprivation. A composite score of 0 was labeled as low, 1 as medium, and 2 as high deprivation level of neighborhood-level SDOH. This coding allowed us to compare individuals with higher deprivation levels of neighborhood-level SDOH to those with lower deprivation levels. The composite score had good reliability/internal consistency with a Cronbach's alpha of 0.82

Covariates

A priori choice of covariates was made based on factors found in the literature to be associated with psychosocial distress in patients with lung cancer (25-27). Sociodemographic and clinical information collected were age at diagnosis (≤65, 66-75, >75), gender, race/ethnicity (Hispanic/Latino, Non-Hispanic White, Non-Hispanic Others), cancer stage at diagnosis (stage I/localized, stage II & III/regional, stage IV/distant), insurance (Medicare/MassHealth/Private) and comorbidity disease count (0, 1, ≥2). We carefully curated a list of comorbid conditions that are often highly prevalent in lung cancer and are known to have a more severe interaction with lung cancer (88, 89). For the comorbidity count for each patient, we counted the number of these conditions that were present in the electronic health records using ICD-10 codes (90). The selected comorbid conditions included myocardial infarction, hypertension, congestive heart failure, peripheral vascular disease, cerebrovascular disease, COPD, diabetes, renal disease, liver disease and rheumatologic disease.

Statistical analysis

All statistical analyses were performed using Stata 17.0 statistical software (StataCorp, College Station, TX). Descriptive analysis was done to describe the sample characteristics and psychosocial distress using frequency distributions. Pearson's chi-square tests were used to evaluate the bivariate relationship between the psychosocial distress outcome and the demographic, clinical and neighborhood-level SDOH variables. Logistic regression models were used to evaluate predictors of clinically significant distress, defined as a DT score of ≥ 4. We first calculated the unadjusted odds ratios (OR) and 95% Confidence Interval (CI), then a fully adjusted model controlling for the sociodemographic and clinical variables provided adjusted odds ratios (aOR).

Results

Sample description

Approximately one-third of the 401 study participants were aged ≤ 65 years (33.9%), and 52% were female. Most participants (91%) were non-Hispanic white. One-quarter (25%) had localized (stage I) cancer and greater than 80% had at least one comorbid condition. All participants had a form of insurance and the majority (82%) had public insurance (Medicare or MassHealth). The mean neighborhood-level SDOH indicator values were $65,000 for median household income, and 88% for percentage of high school graduates. With respect to the categories of the neighborhood-level SDOH composite variable, almost half (48.7%) of the participants were classified in the low deprivation category (Table 2.1).

Prevalence of psychosocial distress

Of the 401 participants included in the study sample, 234 (58.4%) had distress score of ≥ 4. The prevalence of distress was significantly higher in participants who were female (72.1%), those younger than 66 years (66.2%), and have distant (stage IV) cancer (66.4%) (Table 1).

Logistic regression analysis

The neighborhood-level SDOH composite variable was not significantly associated with psychosocial distress even after fully adjusting for other a priori defined covariates (OR_{medium}= 1.27, 95%CI = 0.60 - 2.69), (OR_{high}= 0.78, 95%CI = 0.44 - 1.39) (Table 2). Using a fully adjusted model, female participants had a 3.97-times higher likelihood of psychosocial distress compared to male patients (OR = 3.97, 95%CI = 2.39 - 6.60). Participants aged 66-75 years had 57% lower likelihood of psychosocial distress compared with those aged below 65 years (OR = 0.43, 95%CI = 0.19 - 0.95). Having regional or distant stage cancer was significantly associated with higher risk of psychosocial distress, compared to than those with localized (stage I) cancer (OR_{reg} = 1.91, 95%CI = 1.01 - 3.62), ($OR_{distant}$ = 2.56, 95%CI = 1.31 - 5.01) (Table 2).

Discussion

The study was to our best knowledge the first to examine the relationship between SDOH and psychosocial distress in patients newly diagnosed with lung cancer. Our study findings, both in the univariable and multivariable analyses, showed no association between neighborhood-level SDOH and psychosocial distress levels. This study's results are inconsistent with our initial hypothesis. We expected that those participants with SDOH reflective of high deprivation levels would also have an increased probability of suffering from distress at the time of lung cancer diagnosis. Instead, we found a high proportion of clinically meaningful psychosocial distress across all SDOH deprivation levels, suggesting that the diagnosis of lung cancer may generate distress irrespective of the patient's neighborhood socioeconomic circumstances. This overall high proportion of patients with elevated psychosocial distress in the study sample (58.4%) is consistent with previous studies in patients with lung cancer (12, 23-25).

While cancer centers are required to implement psychosocial screening for accreditation(69), optimal screening time and referral practices remain a challenge. The trajectory of psychosocial distress after initial diagnosis remains unknown, as do population sub-group differences. In this study, psychosocial distress was ascertained only one time- at the first visit following diagnosis to the cancer center, which is the procedure of UMMHC. Therefore, we were unable to assess if the high level of psychosocial distress observed in this sample persisted throughout the course of treatment nor could we assess the association of neighborhood-level SDOH with psychosocial distress levels across different timepoints in the cancer care continuum.

We observed differences in psychosocial distress by gender, age group and cancer stage. Being female and having regional/distant disease compared to localized disease was significantly associated with higher likelihood of being distressed. While in comparison with those aged 65 years or younger, participants in the age group 66 to 75 years were less likely to report psychosocial distress. These results are consistent with the literature on factors associated with psychosocial distress among patients with lung cancer (26, 27). Our findings reinforce the need for lung cancer care centers to provide resources to meet the psychosocial needs of these patient groups.

The strengths of this study include its innovation at being the first to evaluate the association of SDOH and psychosocial distress in patients with lung cancer. As well as our approach in creating a SDOH composite variable for better analysis. Composite variables help reduce the incidence of Type I error and multicollinearity for regression analysis (87). An important observation was the high proportion of patients newly diagnosed with lung cancer who did not have documented psychosocial distress scores. Only about 26% had documented distress screening scores. There however did not appear to be a difference in the characteristics of those who had documented distress scores and those who did not. Like the study sample, most of the patients without distress scores were non-Hispanic white (89%), 52% were female and majority had public insurance. Some other limitations include lack of assessments of individual social risk factors in addition to the neighborhood level SDOH indicators which may lack precision; assessment of psychosocial distress at only one time (at the first visit to the cancer center), which precludes assessing if the absence of an association is consistent across different timepoints in the cancer continuum. Lastly, participants were from only one academic center which limits generalizability. However, the median values observed on the three SDOH indicators were very similar to national averages, indicating that our sample is somewhat reflective of the US population.

Conclusion

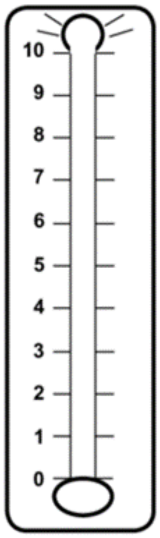
Psychosocial distress was consistently high across the levels of neighborhood SDOH in this sample of patients newly diagnosed with lung cancer, with no variation by SDOH deprivation level. Given that SDOH are known drivers of health inequities and access to healthcare, future research to further determine the association of SDOH and psychosocial distress at other points along the lung cancer care continuum is recommended.

Figure 2.1: Distress Thermometer and Problem List

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress



No distress

PROBLEM LIST

Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

YES	NO	Practical Problems
❑	❑	Child care
❑	❑	Housing
❑	❑	Insurance/financial
❑	❑	Transportation
❑	❑	Work/school
❑	❑	Treatment decisions
		Family Problems
❑	❑	Dealing with children
❑	❑	Dealing with partner
❑	❑	Ability to have children
❑	❑	Family health issues
		Emotional Problems
❑	❑	Depression
❑	❑	Fears
❑	❑	Nervousness
❑	❑	Sadness
❑	❑	Worry
❑	❑	Loss of interest in usual activities
❑	❑	**Spiritual/religious concerns**

YES	NO	Physical Problems
❑	❑	Appearance
❑	❑	Bathing/dressing
❑	❑	Breathing
❑	❑	Changes in urination
❑	❑	Constipation
❑	❑	Diarrhea
❑	❑	Eating
❑	❑	Fatigue
❑	❑	Feeling swollen
❑	❑	Fevers
❑	❑	Getting around
❑	❑	Indigestion
❑	❑	Memory/concentration
❑	❑	Mouth sores
❑	❑	Nausea
❑	❑	Nose dry/congested
❑	❑	Pain
❑	❑	Sexual
❑	❑	Skin dry/itchy
❑	❑	Sleep
❑	❑	Substance abuse
❑	❑	Tingling in hands/feet

Other Problems: ______________________

TABLE 2.1: Prevalence of psychosocial distress by participants' sociodemographic and clinical characteristics

	Total		No psychosocial distress (Score < 4)+		Psychosocial distress (Score ≥4)+		*P* Value
	N	%	N	%	N	%	
Overall	401	100	167	41.6	234	58.4	
SDOH composite variable*b (Deprivation level)							
Low	151	48.7	63	41.7	88	58.3	0.388
Medium	48	15.5	16	33.3	32	66.7	
High	111	35.8	50	45.0	61	55.0	
Gender							
Female	208	51.9	58	27.9	150	72.1	< 0.001
Male	193	48.1	109	56.5	84	43.5	
Age (years)							
≤ 65	136	33.9	46	33.8	90	66.2	0.033
66 -75	142	35.4	70	49.3	72	50.7	
≥ 76	123	30.7	51	41.5	72	58.5	
Race/Ethnicity*							
Non-Hispanic White	363	91.2	150	41.3	213	58.7	0.618
Non-Hispanic Other	18	4.5	7	38.9	11	61.1	
Hispanic/Latino	17	4.3	9	52.9	8	47.1	
Stage at diagnosis							
Localized	101	25.2	54	53.5	47	46.5	0.008
Regional	157	39.2	65	41.4	92	58.6	
Distant	143	35.7	48	33.6	95	66.4	
Comorbid Disease Score							
0	71	17.7	28	39.4	43	60.6	0.917
1	114	28.4	48	42.1	66	57.9	
≥2	216	53.9	91	42.1	125	57.9	
Health Insurance*							
Medicare	275	68.8	123	44.7	152	55.3	0.137
MassHealth	53	13.2	17	32.1	36	67.9	
Private	72	18.0	26	36.1	46	63.9	

*** Missing data on ethnicity (n=3), health insurance(n=1), SDOH (n=91).**
[b] Composed of neighborhood-level SDOH indicators for income, and education
[+]Distress scores range from 1-10

Table 2.2: Unadjusted and fully adjusted Odds Ratios (ORs) of psychosocial distress by participants' characteristics

	Unadjusted OR (95%CI)	**Adjusted OR (95%CI)**
SDOH composite variable (Deprivation level)		
Low	Ref	Ref
Medium	1.43 (0.72 – 2.83)	1.27 (0.60 – 2.69)
High	0.87 (0.53 – 1.43)	0.78 (0.44 -1.39)
Gender		
Male	Ref	Ref
Female	3.36 (2.21 – 5.09)	3.97 (2.39 – 6.60)
Age (years)		
≤ 65	Ref	Ref
66 -75	0.53 (0.32 – 0.85)	0.43 (0.19 – 0.95)
≥ 76	0.72 (0.44 – 1.20)	0.55 (0.23 – 1.30)
Race/Ethnicity		
Non-Hispanic White	Ref	Ref
Non-Hispanic Other	1.11 (0.42 – 2.92)	0.80 (0.26 – 2.46)
Hispanic/Latino	0.63 (0.24 – 1.66)	0.32 (0.09 – 1.12)
Stage at diagnosis		
Localized	Ref	Ref
Regional	1.63 (0.98 – 2.69)	1.91 (1.01 – 3.62)
Distant	2.27 (1.35 – 3.84)	2.56 (1.31 – 5.01)
Comorbid Disease Score		
0	Ref	Ref
1	0.90 (0.49 – 1.64)	1.16 (0.52 – 2.57)
≥2	0.89 (0.52 – 1.55)	0.94 (0.44 – 1.97)
Health Insurance		
Medicare	Ref	Ref
MassHealth	1.71 (0.92 – 3.20)	1.0 (0.38 – 2.63)
Private	1.43 (0.84 – 2.45)	0.69 (0.29 – 1.66)

CHAPTER III: RELATIONSHIP BETWEEN PSYCHOSOCIAL DISTRESS AND DELAY IN TREATMENT INITIATION IN PATIENTS WITH NEWLY DIAGNOSED LUNG CANCER

Abstract

Objective: In comparison with other cancer populations, patients newly diagnosed with lung cancer have one of the highest rates of psychosocial distress. Psychosocial distress may lead to difficulty in making healthcare decisions. This may lead to a delay in treatment initiation which is associated with substantially worsened prognosis in patients with cancer. In this study, we examine the relationship between psychosocial distress and delay in treatment initiation among a sample of patients newly diagnosed with lung cancer.

Methods: A prospective study of patients newly diagnosed with lung cancer with documented distress screening scores between May 2017 and May 2021 in a single health system was conducted. Psychosocial distress measured using the NCCN Distress Thermometer was dichotomized as (not distressed vs. distressed) using a cut-off score of 4. Delay in treatment initiation was dichotomized as first treatment after six weeks of diagnosis vs. within six weeks of diagnosis. Multivariable logistic regression modeling was used to evaluate the relationship between psychosocial distress and delay in treatment initiation. Covariates included age, gender, race/ethnicity, comorbidity count, cancer stage, insurance status and a composite variable of neighborhood-level social determinants of health (SDOH) indicators for income and education.

Results: Psychosocial distress was not significantly associated with delay in treatment initiation. Those living in a neighborhood with high deprivation vs. low deprivation had significantly higher odds of delay in treatment initiation (OR= 2.09, 95%CI = 1.16-3.74) while those with distant cancer stage vs. localized cancer stage had significantly lower odds of delay in treatment initiation (OR= 0.30, 95%CI = 0.15-0.60).

Conclusions: In this study, we found that psychosocial distress was not associated with delay in treatment. However, we discovered that patients with high deprivation level of neighborhood-level

SDOH were more likely to have delay in treatment. Focused interventions could reduce delay in treatment initiation in this patient population.

Key words: psychosocial distress, lung cancer, social determinants of health, time to treatment initiation

Introduction

Lung cancer is the second most frequently diagnosed cancer and the leading cause of cancer death worldwide (1, 3, 66). Lung cancer can have an aggressive tumor growth rate (91) and the majority of patients with lung cancer present with late stage disease, with less than a third presenting with early stage disease (92, 93). Therefore, early diagnosis and prompt treatment is crucial and recommended (53, 91). Time to treatment initiation (TTI), defined as the number of days from date of initial cancer diagnosis to date of first cancer-directed treatment initiation (44, 94), is widely used as a quality metric (50, 51). TTI of 6 weeks or less is regarded as optimal in lung cancer care (52, 53) and TTI of greater than 6 weeks is referred to as delayed (44). Delay in treatment initiation is associated with significantly worsened prognosis in patients with cancer (44, 95-97).

The diagnosis of cancer is a critical time often associated with a high degree of disbelief, anxiety and distress (39, 40). Psychosocial distress is "a multifactorial, unpleasant experience of a psychologic (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature, that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment" (21). Patients with lung cancer have one of the highest rates of psychosocial distress among cancer populations, with reported rates ranging between 43.5% to 61.6% (12, 23-25).

Research on factors associated with delay of treatment initiation in patients with cancer have largely focused on sociodemographic and clinical factors. Some identified risk factors associated with delay in treatment initiation includes black race, Hispanic ethnic group, lack of insurance, presence of comorbidities and early stage cancer (44, 98-101). There is evidence that psychosocial distress may lead to inability to make health care decisions, including cancer treatment decisions (40, 42, 43). This may lead to a delay in treatment initiation, treatment non-adherence and/or treatment non-completion. In patients with lung cancer, a delay in treatment initiation can lead to poorer prognosis and significantly decreased survival (50, 102). Therefore, research examining the relationship between psychosocial distress and delayed treatment initiation is warranted particularly in the context of lung cancer where there is a high rate of psychosocial distress. We hypothesized that patients newly diagnosed with lung cancer with elevated psychosocial distress will experience a delay in treatment initiation.

Materials and Methods

Study design & Setting

This study utilized a prospective study design with patient data from the UMass Memorial Health Care (UMMHC) System. UMMHC is the largest health care system in Central and Western Massachusetts. The Cancer Center in UMMHC is accredited by the American College of Surgeons Commission on Cancer.

Study Sample

All adult patients newly diagnosed with lung cancer seen within UMMHC between 2017 and 2021 with psychosocial distress screening information (n=401) were eligible for this study. Twenty-six patients had no data on the date of first cancer-directed treatment initiation, resulting in an analytic sample size of 375. Reasons for missing data included: refused treatment (n=9), died before treatment initiation (n=7), lost to follow-up (n=4), watchful surveillance (n=3) and transferred care/referred elsewhere (n=3).

Data Sources

Data were obtained from the University of Massachusetts Chan Medical School (UMMS) Data Sciences Core, a unit of the UMMS Center for Data Science Resources. UMMS is the academic partner of UMMHC. The Data Sciences Core provides access to and support of the use of multiple and complex data sources. A study team member (OE) performed a manual chart review and data abstraction of the electronic medical records to obtain missing data and to verify accuracy of data.

Ethical Approval

Approval for the study and waiver of consent was received from the UMMS Committee for the Protection of Human Subjects in Research.

Measures

Psychosocial distress

Psychosocial distress was measured with the Distress Thermometer (DT), a validated, single-item patient-reported visual analogue scale developed by the National Comprehensive Cancer Network (NCCN) (58). It has a range of 0–10, with 0 indicating no distress and 10 indicating extreme distress. Patients indicates the number that best describes how much distress they have experienced over the past week ands identify the source of the distress on the associated 39-item problem list (40, 58). The DT is used across the globe as a tool for clinically assessing psychosocial distress (79, 81, 82, 103, 104). The NCCN recommends that all patients with cancer be screened for distress a minimum of one time at a pivotal medical visit, such as at the time of diagnosis (58, 105). In UMMHC, the DT and the problem list is completed by patients at the time of the first in-person visit following a cancer diagnosis. Collection of the psychosocial distress data is managed by the Cancer Center and it is uploaded into the Electronic Health Records. In this study, we categorized patients reporting a distress level of 4 or greater as distressed, and those reporting a distress level less than 4 as non-distressed, consistent with previous studies (105).

Delay in Treatment Initiation

The National Cancer Database (NCDB) defines time to treatment initiation as the number of days from date of initial diagnosis for cancer to date of first cancer-directed treatment initiation (44). Per Standards for Oncology Registry Entry (STORE), date of initial diagnosis is defined as the first date a cancer diagnosis was clinically or histologically established and the date of first cancer-directed treatment initiation is defined as the date on which treatment (surgery, radiation, systemic, or other therapy) of the patient began at any facility. In the management of lung cancer, TTI within 6 weeks of diagnosis is regarded as optimal (52, 53) and TTI of greater than 6 weeks is refered to as delayed (44). Therefore, for this study, the delay in treatment initiation was analyzed as a binary indicator of whether the person received their first treatment within 6 weeks of diagnosis vs. greater than 6 weeks.

Covariates

We collected the following information; age at diagnosis, gender, race/ethnicity, cancer stage at diagnosis, insurance status, comorbidity count and neighborhood-level measures of income and education as a proxy for SDOH.

For the comorbidity count, we researched and created a list of comorbid conditions that are more prevalent in lung cancer and are known to have a more severe interaction with symptoms of lung cancer (88, 89). We counted the number of these conditions that were present in the electronic health records using ICD-10 codes (90). The selected comorbid conditions included myocardial infarction, hypertension, congestive heart failure, peripheral vascular disease, cerebrovascular disease, COPD, diabetes, renal disease, liver disease and rheumatologic disease.

SDOH data was obtained by geocoding participants' addresses at the time of diagnosis, to obtain the corresponding census tract information from the 2010 census 5-year survey (2010ACSW). We chose standard economic indicators with known associations with health outcomes (84-86). These indicators and corresponding census tract data were income (median household income) and education (percent of persons aged 25 years and older who is a high school graduate or more). To estimate the degree of disadvantage, for each SDOH variable, we used the sample mean value of the variable as a benchmark to classify patients into 2 index groups of "low deprivation"(≥ Mean) and "high deprivation"(< Mean). To address potential multicollinearity of these SDOH variables, we created a composite SDOH variable by using meaningful grouping, and summed up the values of the individual indicators (87). With each indicator having a score of 0 or 1 (low or high deprivation), the composite SDOH variable had a score range of 0 – 2. A higher score meant greater deprivation and it was labeled as 0-low, 1-medium, and 2-high deprivation. The composite score had good reliability/internal consistency with a Cronbach's alpha of 0.82.

Statistical analysis

All statistical analyses were performed using Stata 17.0 statistical software (StataCorp, College Station, TX). Descriptive analysis was done to describe the sample characteristics using frequency distributions. Pearson's chi-square tests were used to evaluate the relationship between delay in treatment initiation with psychosocial distress and the covariates. Logistic regression models were used to evaluate predictors of delayed treatment initiation. We first calculated the unadjusted odds ratio and 95% Confidence Intervals (CI), followed by a fully adjusted model which included all a priori defined covariates.

Results

Sample description

There was an analytic sample size of 375 patients in this study. The prevalence of elevated psychosocial distress was 58.1%. Approximately half were female (51.5%). Most participants (91%) were non-Hispanic white. Almost half (48.3%) were classifed in the category of low deprivation for neighborhood-level SDOH. Approximately one-quarter (25.6%) had localized (stage I) cancer and greater than 80% had at least one comorbid condition. All participants had a form of insurance and the majority (81.9%) had public insurance (Table 3.1).

Delay in Treatment Initiation

Of the 375 patients in the study, 122 (32.5%) had a delay in treatment initiation. The median (Inter-Quartile Range) time to treatment initiation was 4.7 (3-7.4) weeks. Among patients with a psychosocial distress score <4, 35.7% experienced delay in treatment initiation and among patients with psychosocial distress ≥4, 30.3% experienced delay in treatment initiation (P=0.27) (Table 3.1).

Logistic regression analysis

Psychosocial distress was not significantly associated with delay of treatment initiation in unadjusted (Odds Ratio (OR)=0.78, 95%CI = 0.51-1.21) or adjusted (OR=0.89, 95%CI = 0.51-1.55) analysis. In the adjusted model, patients living in a neighborhood with high deprivation vs. low deprivation had significantly higher odds of delay in treatment initiation (OR= 2.09, 95%CI = 1.16-3.74). Having distant cancer stages vs. localized cancer stage was associated with significantly lower odds of delay in treatment initiation (OR= 0.30, 95%CI = 0.15-0.60). No other covariate was staistically associated with delay in treatment initiation (Table 3.2).

Discussion

Our study was, to our knowledge, among the first to examine the relationship between psychosocial distress and delay in treatment initiation in patients newly diagnosed with lung cancer. We hypothesized that patients newly diagnosed with lung cancer with elevated psychosocial distress would experience a delay in treatment. However, no association was observed, suggesting that the presence of psychosocial distress was not predictive of a delay in treatment initiation in this sample of patients with lung cancer.

Our findings are in contrast to a prior study done among patients with various cancer types (breast, colorectal, gynaecological, head & neck – squamous, lung – non small cell and lymphoma), which reported that greater psychological distress at the first medical oncology visit was associated with longer time to treatment initiation (106). There are however some notable differences in that study and ours and this may account for some or all of the variance in both findings. First, our study examined psychosocial distress using the distress thermometer while this referenced study specifically examined only anxiety and depression, using the Hospital Anxiety and Depression Scale (HADS). Psychosocial distress exists along a broad spectrum ranging from typical feelings of vulnerability to limiting conditions such as depression, anxiety and social isolation (21) and the distress thermometer allows for assessment of psychosocial distress more globally across this spectrum (107). Therefore, it may be that depression and anxiety have a stronger impact on decision making, while the broader conceptualization of the distress thermometer (e.g. feelings of fear and vulnerability) may have a lesser impact, thus diluting the overall strength of association when the distress thermometer is used. Future research on the comparative impact of these conditions/symptomatologies on treatment initiation and the predictive ability of associated measurement tools is recommended. Another difference was how time to treatment initiation was operationalized in both studies. The referenced study, quantified time to treatment initiation as the time elapsed between the initial medical oncology visit and the first chemotherapy or chemoradiotherapy (nonsurgical) treatment. This is in contrast with the more standard definition of time to treatment initiation as the number of days from date of initial diagnosis for cancer to date of first cancer-directed treatment initiation(surgery, radiation, systemic, or other therapy) that is used in our study (44, 94). Lastly, the settings of both studies were different, and this may have had an effect on the results. The referenced study was done in a safety-net hospital setting while our study was set in a comprehensive cancer center with a multidisciplinary tumor board. Studies have shown that multidisciplinary tumor boards enables interdisciplinary collaboration which helps to maximize efficiency of management, access to multimodal therapy and equality in standards of care for all patients with cancer (108, 109). Also, a comprehensive cancer center such as our study setting may have more resources available for quick multidisciplinary psycho-oncology care. This overall prompt management of all diagnosed patients may prevent the observation of an association between psychosocial distress and delay in treatment initiation. Furthermore, patients with factors that have been found to be associated with delay in treatment initiation including black race (44, 101, 110), Hispanic ethnicity (101, 110, 111), and Medicaid/Medicare insurance (101) are often represented in greater numbers in the safety-net setting. These factors may moderate a positive association between psychosocial distress and delay in treatment initiation in that setting.

Interestingly, we found that neighborhood-level SDOH was associated with delayed treatment initiation. Patients living in a neighborhood with high deprivation compared to low deprivation had significantly higher odds of delay in treatment initiation. While research examining the association of SDOH factors in relation to delay in treatment initiation in patients with lung cancer is lacking, this finding is consistent with that of a study among patients with rectal and colon cancer, which reported that the lack of formal education or only having had primary education significantly increases the risk of delayed treatment (112). This disparity in timeliness of treatment is particularly concerning in the setting of our study which has facilities and processes that usually helps with uniformity of care across all patients (108). This suggests that factors beyond the type of and facilities in the healthcare setting may be responsible for this observation and further research is warranted. Lastly, the finding that localized cancer stage had a higher likelihood of delay in treatment initiation was consistent with the literature on factors associated with delay in cancer treatment (112-114) and may explain the observed paradoxical relationship between longer TTI and longer survival time (113).

This study has several strengths. It is the first to assess the association between psychosocial distress and delay in treatment initiation in patients with lung cancer. It also included a well-validated measure of psychosocial distress and nearly complete data on time to treatment initiation. Creating a SDOH composite variable improved the veracity of our findings as composite variables help reduce the incidence of Type I error and multicollinearity for regression analysis (87). A limitation was that all participants were from a single academic center and were largely non-Hispanic White which limits generalizability.

Conclusion

In this study, we found no evidence of an association between psychosocial distress and delay in treatment initiation among patients newly diagnosed with lung cancer. However, our ad hoc finding that patients with lung cancer with high deprivation level of neighborhood-level SDOH were more likely to have delay in treatment initiation warrants further inquiry to understand factors responsible. It also reinforces the need for development and implementation of focused interventions and policies targeted at these vulnerable patient groups by lung cancer care centers and other stakeholders to prevent delay in treatment initiation.

TABLE 3.1: Prevalence of delay in treatment by participants' sociodemographic and clinical characteristics

	Total		No delay of TTI (≤ 6 weeks)		Delay of TTI (> 6 weeks)		
	N	%	N	%	N	%	*P* Value
Overall	375	100	253	67.5	122	32.5	
Psychosocial distress Score+							
< 4	157	41.9	101	64.3	56	35.7	0.271
≥ 4	218	58.1	152	69.7	86	30.3	
SDOH composite variable* (Deprivation level)							
Low	142	48.3	102	71.8	40	28.2	0.019
Medium	47	16.0	33	70.2	14	29.8	
High	105	35.7	58	55.2	47	44.8	
Stage							
Localized	96	25.6	47	49.0	49	51.0	0.000
Regional	149	39.7	100	67.1	49	32.9	
Distant	130	34.7	106	81.5	24	18.5	
Gender							
Female	193	51.5	127	65.8	66	34.2	0.479
Male	182	48.5	126	69.2	56	30.8	
Age (years)							
≤ 65	132	35.2	91	68.9	41	31.1	0.777
66 -75	132	35.2	86	65.2	46	34.8	
≥ 76	111	29.6	76	68.5	35	31.5	
Race/Ethnicity*							
Non-Hispanic White	339	91.1	229	67.6	110	32.4	0.670
Non-Hispanic Other	17	4.6	13	76.5	4	25.5	
Hispanic/Latino	16	4.3	10	62.5	6	37.5	
Comorbid Disease Score							
0	67	17.9	49	73.1	18	26.9	0.373
1	108	28.8	75	69.4	33	30.6	
≥2	200	53.3	129	64.5	71	35.5	
Health Insurance							
Medicare	253	67.5	164	64.8	89	35.2	0.259
MassHealth	51	13.6	36	70.6	15	29.4	
Private	71	18,9	53	74.7	18	25.3	

***Missing data on race/ethnicity (n=3), SDOH (n=81).**

+Distress scores range from 1-10

Table 3.2: Unadjusted and adjusted Odds Ratios (ORs) of delay of treatment by participants' characteristics

	Unadjusted OR (95%CI)	***Adjusted OR (95%CI)**
Psychosocial distress Score		
< 4	Ref	Ref
≥ 4	0.78 (0.51 – 1.21)	0.89 (0.51 – 2.31)
SDOH composite variable (Deprivation level)		
Low	Ref	Ref
Medium	1.08 (0.52 – 2.23)	1.09 (0.51 – 2.31)
High	2.10 (1.22 – 3.51)	2.09 (1.16 – 3.74)
Stage		
Localized	Ref	Ref
Regional	0.47 (0.28 – 0.79)	0.56 (0.30 – 1.05)
Distant	0.22 (0.12 – 0.39)	0.30 (0.15 – 0.60)
Gender		
Male	Ref	Ref
Female	1.17 (0.76 – 1.80)	0.99 (0.58 -1.70)
Age (years)		
≤ 65	Ref	Ref
66 -75	1.19 (0.71 – 1.98)	0.84 (0.38 – 1.86)
≥ 76	1.02 (0.59 – 1.76)	0.88 (0.38 – 2.05)
Race/Ethnicity		
Non-Hispanic White	Ref	Ref
Non-Hispanic Other	0.64 (0.20 – 2.01)	0.66 (0.19 – 2.29)
Hispanic/Latino	1.25 (0.44 – 3.52)	0.73 (0.99 – 2.75)
Comorbid Disease Score		
0	Ref	Ref
1	1.20 (0.61 – 2.36)	1.10 (0.48 – 2.51)
≥2	1.50 (0.81 – 2.77)	1.06 (0.49 – 2.31)
Health Insurance		
Medicare	Ref	Ref
MassHealth	0.77 (0.40 – 1.48)	0.72 (0.28 – 1.88)
Private	0.63 (0.35 – 1.13)	0.67 (0.28 – 1.60)

***Model adjusted for all listed variables**

CHAPTER IV: PERCEPTIONS AND PRACTICES OF A LUNG CANCER CARE TEAM REGARDING PSYCHOSOCIAL DISTRESS SCREENING IN PATIENTS WITH LUNG CANCER: A QUALITATIVE STUDY

Abstract

Background: Patients with lung cancer experience high rates of psychosocial distress. The American College of Surgeons' Commission on Cancer mandates cancer centers to implement, monitor and document psychosocial distress screening as a requirement for accreditation. This study explored perceptions and practices of the lung cancer care team at a single cancer center regarding psychosocial distress screening.

Methods: Semi-structured interviews were conducted with ten members of the lung cancer care team in various roles. A thematic analysis of the interview data was performed.

Results: Four principal themes were identified: (1) Timing and frequency of screening: Participants were satisfied overall with the current psychosocial distress screening processes, however, they believed that multiple screenings at different time points would be more effective; (2) Training needs: Training on use of the screening tool and on the follow-up process would be helpful; (3) Staffing needs: Additional staff, particularly psychologists and social workers are needed to address identified patient psychosocial distress and; (4) Opportunity for holistic patient care: Screening is important, and results would inform patient care decisions; If screening results are consistently communicated to the physicians and surgeons, it will enhance ability to utilize them in care decisions.

Conclusions: Results suggested that the lung cancer care team valued psychosocial distress screening. Opportunities for improving processes across the care continuum were identified. Considering the perceptions of the health care team in individual clinical programs is important in identifying contextual issues affecting the effective and efficient implementation of psychosocial distress screening and management among patients with lung cancer in clinical settings.

Key words: Psychosocial Distress Screening, Lung Cancer, Qualitative Study

Introduction

Lung cancer is the second most common cancer and the leading cause of cancer death globally including in the United States (1, 3). The diagnosis, symptoms, and treatment of lung cancer have been associated with elevated psychosocial distress (13, 70). Psychosocial distress as defined by the National Comprehensive Cancer Network (NCCN) is "a multifactorial, unpleasant experience of a psychologic (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature, that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment" (21). Patients with lung cancer have one of the highest rates of psychosocial distress among cancer populations, with published rates ranging from about 44% to 62% (12, 23-25). Elevated psychosocial distress level in patients with lung cancer is associated with negative health outcomes, reduced quality of life, and poorer prognosis (21, 70, 71). Early identification and prompt management of psychosocial distress can contribute to better health outcomes (36, 58).

Addressing psychosocial distress has been identified as a critical component of comprehensive cancer care and the NCCN has specified standards of care and issued clinical practice guidelines for psychosocial distress management that states that distress should be recognized, monitored, documented, and treated promptly (40, 56). To improve compliance with these standards and guidelines, the American College of Surgeons' Commission on Cancer (CoC) enacted a mandate in 2015 which stated that as a criterion for accreditation, cancer centers must develop and implement a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care (115). Despite the CoC's accreditation standards, a 2017 study that reviewed 8,409 EHRs across 55 cancer centers reported that the overall adherence rate to screening protocols (i.e., extent to which programs screened and responded appropriately) was only 62.7% (61). This rate varied by institution with the lowest rate found in NCI-designated Cancer Centers (43.3%) (61).

A significant body of literature has suggested common barriers that may account for the low rate such as: lack of trained staff; poorly established distress screening protocols; lack of time for clinicians; and lack of institutional buy-in or support (63-65). However, none of this research was focused primarily on the context of lung cancer. Patients with lung cancer have an increased propensity to be distressed and often have a poorer prognosis compared with other cancer patient populations (19, 59). Therefore, research assessing adherence to the CoC's psychosocial distress screening standards in this patient population is warranted.

This research aims to garner a better understanding of the complexities of comprehensive psychosocial distress screening in a single lung cancer clinic. Having contextual insight into what drives or hinders adherence to distress screening protocols in individual cancer centers may be a key to improving overall rates.

Methods

Setting and sample

Semi-structured interviews were conducted between September and November 2020 with care team members at the lung cancer clinic at the UMass Memorial Health Care (UMMHC). UMMHC is the largest healthcare system in Central and Western Massachusetts. The cancer center in UMMHC is accredited by the American College of Surgeons Commission on Cancer (CoC) and the lung cancer clinic offers the most advanced treatments and multidisciplinary care for lung cancer. This study was approved by the Institutional Review Board at the University of Massachusetts Chan Medical School.

We purposively sampled members of the lung cancer care team in various roles (surgeon, physician-oncologist, nurse practitioner, nurse navigator, psychologist, financial counsellor, Personal Care Assistant (PCA), and social worker) to ensure heterogeneity of perspectives. Recruitment emails were sent to eligible members of the lung cancer care team, explaining the study purpose, and inviting their participation. Members could decline participation via a reply to the recruitment e-mail within 2 weeks of receipt of email, or else they were contacted to schedule a time for an interview. Emails were sent to 21 members of the lung cancer care team and 3 declined to participate. We stopped interviewing after we completed 10 interviews because this was enough to reach thematic saturation.

Data Collection

The development of the interview guide was informed by the Theoretical Domains Framework (TDF). The TDF is a widely cited framework that is used in implementation research to theoretically assess implementation problems and examine the cognitive, affective, social, and environmental influences on behavior as it relates to implementation of evidence-based interventions (116, 117). Questions pertaining to the domains of Knowledge, Skills, Social/Professional Role and Identity, Beliefs about Capabilities, Optimism, Environmental Context and Resources, were created to explore the lung cancer care team members' perceptions and practices of psychosocial distress screening. The interview guide was pretested with a research team member (MI) and refined. After initial refinement, it was pilot tested with a lung cancer care team member to assure relevance and comprehension. (See interview guide, Figure 4.1).

A study team member (OE) conducted all interviews. Interviews were conducted via zoom video or audio calls. Verbal consent was obtained at the start of each interview and the average length of interviews was 30-45 minutes. All participants who completed the interview received a

$25 gift card in appreciation of their time. Interviews were audio recorded and transcribed verbatim by a professional transcription company. Transcripts were checked against audio recording by the interviewer (OE) to ensure the quality of transcribed data. Any identifiable information was deleted, and study participants were assigned a unique study identifier.

Analysis

The transcribed interview data was analyzed according to standard comprehensive, thematic qualitative analysis methods (118). The coding process started with the generation of a start list of codes developed from the TDF conceptual framework and relevant literature (118, 119). An unstructured read of transcripts was performed as the interviews were completed to assess for saturation and new codes (120, 121). Each transcript was coded by two reviewers. Intercoder reliability between the two coders (OE & CN) was established by calculating the percent agreement on the coding of the interviews (122, 123). There was an initial 95% agreement and the discrepancies in coding were discussed and consensus was reached between the two coders. Themes were derived from the codes.

Results

Overall, ten lung cancer care team members participated in the interviews. The average age in this sample was 50 years and average years in practice was 19 years.

Four principal themes emerged from the data: (1) Timing and frequency of screening: Participants seemed satisfied overall with the psychosocial distress screening processes; however, they believed that multiple screenings at different time points would be more effective; (2) Training needs: Participants reported training on using screening tool and the follow-up process would be helpful; (3) Staffing needs: Additional staff, particularly psychologists and social workers, were a noted need to address identified patient psychosocial distress and; (4) Opportunity for holistic patient care: The majority agreed that screening was important, and results would inform patient care decisions; however, the screening results were not consistently communicated to the physicians and surgeons, which limited their ability to utilize them in care decisions. Summaries of each theme with sample illustrative quotes are presented below.

Timing and frequency of psychosocial distress screening:

The first theme that emerged from the interviews related to the timing and frequency of psychosocial distress screening. The interviewees seemed largely satisfied with the process to screen patients with lung cancer for psychosocial distress implemented at the cancer center. However, most of the participants believed that the screening which occurred only at one point (time of initial diagnosis) was not adequate.

"I think throughout every step of the (cancer) process they have to deal with, they should be rescreened." (PDS009)

"Distress levels changes over course of disease so I would say multiple visits" (PDS001)

Likewise, many participants believed that multiple screenings at different time points along the cancer continuum would be more effective.

"At time of diagnosis and at other different times too *when necessary." (PDS007)*

"… at initial presentation when you meet them as an outpatient and at some points during treatment because stresses change. Treatments have effects. An interval reevaluation of these stresses is important." (PDS006)

Training on screening tool and process would be helpful:

Most of the participants identified the need for training on psychosocial distress screening to improve awareness and knowledge. Some participants reported an interest in having training on the utility of the screening tool.

"I would like to be properly trained so that I am more confident (to perform screening)" (PDS009)

"Basic training of all practitioners and making it mainstream and simple to use is what's going to get compliance" (PDS008)

Participants also noted a need for further training on the process of distress identification and management based on the screening tool results.

"I think awareness in all faculty providers that we would be doing this (screening), and maybe an education session about what the distress thermometer actually means and when you would recommend an intervention and knowing how to intervene" (PDS003)

Not enough staff to address patient distress, particularly a need for more psychologists and social workers:

Most participants reported that there were not enough staff to manage patient distress efficiently when identified through the screening process.

"… we need more staff like - we have only one psychologist" (PDS008)

"There aren't enough social workers, absolutely. We only have one for the whole oncology – through all oncology we only have one social worker, which I think is horrible" (PDS002)

Addressing patient's distress promptly is not always feasible because of the paucity of social work staff.

"Well, there is only one social worker for the cancer center, so if there's a lot of consults, then it takes longer to get to a patient. So, I guess to improve upon it, they could add more social-work support" (PDS004)

Missed opportunity for holistic patient care:

The majority agreed that screening was important and integrating screening results into overall cancer care would positively affect patient outcomes.

"... if we manage patients taking into account the psychosocial distress, I think the treatment is more successful" (PDS010)

It was also noted that an effective and consistent means of communication of the screening results to the physicians and surgeons is needed.

"Now, if I had something like that to look at ahead of time, if it was part of the records, I would view it and see what I need to do to intervene." (PDS003)

Discussion

Guided by the Theoretical Domains Framework (124, 125), this study aimed to provide insights on the complexities of implementing comprehensive psychosocial distress screening in a single multidisciplinary lung cancer clinic with a goal of identifying potentially actionable information. Comprehensive distress screening not only assesses for the presence of psychosocial distress but also identifies appropriate referral for treatment pathways (40, 57). This is particularly important in patients with lung cancer, who have a higher prevalence of distress and often have a poorer prognosis compared with other cancer patient populations (19, 59). Four themes emerged from the interviews – timing and frequency of psychosocial distress screening; training on screening tool and process; staffing needs to address identified patient psychosocial distress; and opportunity for holistic patient care. These can be functionally grouped into two categories: (a) distress identification (screening process) and (b) distress management (post screening).

Distress Identification

To be accredited, cancer programs must comply with CoC STANDARD 3.2 - "The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care" (115). Institutional variability in screening processes exists because cancer centers' size and resources are key determinants influencing how these requirements are enacted (62, 115). The center's cancer committee determines what tool is used and the mode of administration which may be tailored to the clinic workflow (115). In this study, the participants believed that the distress thermometer was an efficient tool for the screening with the notable exception of one participant who believed that the DT was too subjective. Routine screening at the initial visit and at appropriate intervals for psychosocial distress have been recommended by the NCCN (40) but according to the process requirements by the CoC, a minimum of one time at a pivotal medical visit, such as at time of diagnosis, as determined by the program is adequate (115). Thus, in this lung cancer clinic, screening which was done at the first visit following a diagnosis, is consistent with CoC standards. This timing of screening was acceptable to the lung cancer care team participants in this study; however, most of them believed that performing more screenings at different time points along the cancer continuum would be more beneficial because stressors change with time. Training (on the tool and on the screening process) was identified as a potential area for improving the screening process in the clinic. Consistent with our findings, prior studies showed that a lack of staff knowledge about the screening is a barrier to implementation of distress screening (126, 127). Awareness and knowledge of the processes of comprehensive distress screening may facilitate better compliance.

Distress Management

Comprehensive distress screening involves not only the identification of distressed patients but also post screening evaluation, appropriate referral, and prompt treatment of distress (128). In our study, most of the participants noted that the number of available staff (psychologists and social support staff) was not enough to adequately address post-screening processes. Our study participants were extremely appreciative of the existing staff and described them as very hardworking and dedicated. However, they recognized that the demands of comprehensive distress screening sometimes overwhelmed the capacity of the existing staff. The CoC’s guidelines state that the distress screening results must be discussed with the patient at the medical visit. If the patient is noted to be distressed, a member of the patient’s oncology team must assess the patient to identify the cause of the distress and identify the appropriate referrals as needed (115). It has been noted that screening without the use of a defined patient referral plan does not improve outcomes (129). A review of twenty-four intervention studies of distress screening showed that screening is more effective when there is a plan for appropriate aftercare; that analysis found that only one in three distressed patients received psychosocial care after screening (130). This dovetails with the literature that noted that the availability of trained staff is necessary for effective screening and identified the lack of staff as a barrier in the implementation of comprehensive psychosocial distress screening (63, 131).

The participants agreed that screening was important and integrating screening results in overall cancer care would positively affect care delivery and subsequent patient outcomes. It was however noted that there was no set protocol for communicating screening results to the oncologists and surgeons. It is important that health care professionals are made aware of screening results because distress in patients with cancer often goes undetected by the health care professionals (132). In the study that evaluated the ability of 143 physicians to detect heightened distress in 2,297 patients with cancer, only 29% of patients with distress detected by a validated psychological screener were successfully identified by their physicians (132). This gap may be effectively improved by adhering to the CoC’s psychosocial care process requirement of documentation of the screening process, results, referral for services and any follow up in the policies and procedures and in the patient medical record to facilitate integrated, high-quality care (115).

Strengths and Limitations

This study is among the first to qualitatively examine implementation of psychosocial distress according to NCCN guidelines in the context of lung cancer care. The interviews produced rich qualitative data regarding the factors that influence the process and practices of comprehensive psychosocial distress screening in a multidisciplinary lung cancer clinic. A key limitation of our study may be limited generalizability because we recruited interviewees from a single cancer center. To address this, we used purposive sampling to select a heterogenous sample, representative of health care professionals generally involved in the management of patients with lung cancer.

Conclusion

Our study suggests that the lung cancer care team values psychosocial distress screening and would like to see it more broadly implemented across the care continuum. Eliciting the perceptions of the care team members helped to highlight contextual barriers that must be addressed to realize this goal. It also noted the importance of the integration of comprehensive distress screening into overall cancer management. Future research into strategies for better integration of comprehensive distress screening into the clinical workflow could benefit our patients and our caregivers.

<u>Figure 4.1: Interview Guide</u>

<u>INTERVIEW GUIDE</u>

NOTE: This qualitative interview is a conversation, and the interview may diverge from the script to clarify or probe responses or issues. Prompts/Probes are italicized.

BACKGROUND

1) What information do you routinely collect from your patients on factors regarding psychosocial distress and social determinants of health such as transportation, food access, housing, income etc.?

2) What are your perceptions/beliefs on the role of the cancer care team in helping patients with psychosocial factors?

SCREENING

3) How helpful/important is it to screen lung cancer patients for psychosocial factors?
- *How does screening make a difference in the management of patients?*

4) What the benefits and disadvantages of psychosocial distress screening?

5) When do you believe is the best time to screen a patient for psychosocial distress?
- *At what point along the cancer continuum?*

6) How confident are you in your ability to perform screening? If little/not confident, what would help improve your confidence to do this screening?

7) What tools do you use to screen for psychosocial distress?

THE DISTRESS THERMOMETER

8) Are you familiar with The Distress Thermometer? Can you describe it?
- *how did you become aware of it and how do you utilize it?*
(show participant a copy of the distress thermometer and describe it to the participant: *The Distress Thermometer is the most widely used rapid screening tool for assessing psychological distress in people affected by cancer. It measures distress in a similar way to pain. on a scale of zero to 10, 10 being the worst)*

9) In the lung cancer clinic, how is the distress thermometer administered and by who?

10) What are your thoughts about the present mode of administration of the distress thermometer in the clinic?
- *Is it efficient and effective? Does it fit into the clinic workflow?*

11) How are you made aware of patients screening results?
- *how does this inform care? How can this process be improved? If not made aware, would you like to be informed?*

FOLLOW-UP

12) Is there a referral/follow-up protocol in place for patients identified with psychosocial distress in this center? Can you describe it?
- *What factor(s) determine referral and to whom referral is made to? (Score, Problem list etc.)*

13) Do you believe this process is efficient? How can it be improved?

ENVIROMENT

14) How adequate are the resources available for the implementation of psychosocial distress screening?
- *What is missing? How can this be improved?*

15) Regarding psychosocial distress screening and management, what would you like to see done differently in the cancer center?

ADVICE

- What additional advice do you have for successful implementation of psychosocial distress screening?

CHAPTER V: DISCUSSION AND CONCLUSIONS

Discussion

The three aims of this dissertation were to: (1) examine the association of SDOH factors with psychosocial distress in patients newly diagnosed with lung cancer; (2) examine the association of psychosocial distress on delay in treatment initiation among patients newly diagnosed with lung cancer and (3) to examine the perceptions and practices of the lung cancer care team regarding psychosocial distress screening. For the first and second aims, electronic health record data from a cohort of patients with newly diagnosed adult lung cancer with documented psychosocial distress screening in a single academic center was used. For the third aim, data was obtained from semi-structured interviews conducted with lung cancer care team members at an accredited multidisciplinary cancer center.

For the first aim of this dissertation, we found that 58.4% of patients newly diagnosed with lung cancer experienced elevated psychosocial distress. This finding is consistent with reports from previous studies in patients with lung cancer (12, 23-25). The prevalence of distress was significantly higher in participants who were female, those younger than 66 years, and have distant cancer stage. A few studies that have analyzed a variety of predictors for distress in patients with lung cancer also reported similar positive associations (25-27). Research done in this area largely examined the demographic and clinical factors and despite the evidence that patients with lung cancer are more likely to have unresolved, unmet social needs (28, 29), no prior study has been conducted to investigate the association of social determinants of health (SDOH) factors and psychosocial distress. In our study, we created a neighborhood-level social determinants of health (SDOH) composite variable for analysis. SDOH was not significantly associated with psychosocial distress even after fully adjusting for other sociodemographic and clinical covariates. This is inconsistent with our initial hypothesis. We expected that those participants with SDOH reflective of high deprivation levels would also have an increased probability of suffering from distress at the time of lung cancer diagnosis. Instead, we found a high proportion of clinically meaningful psychosocial distress across all SDOH deprivation levels, suggesting that the diagnosis of lung cancer may generate distress irrespective of the patient's neighborhood socioeconomic circumstances. Important questions which this dissertation could not explore remain, including whether the association between SDOH and psychosocial distress differs at different time points along the lung cancer continuum and whether different indicators of SDOH influence psychosocial distress.

For the second aim, we examined the relationship between psychosocial distress and delay in treatment initiation in patients newly diagnosed with lung cancer. We hypothesized that newly diagnosed patients with lung cancer with psychosocial distress would experience a delay in treatment. However, no significant association between psychosocial distress and delay in treatment initiation was observed. Our findings suggested that the presence of psychosocial distress was not predictive of a delay in treatment initiation in this sample of patients with lung cancer. An explanation for this finding may be related to the use of a multidisciplinary tumor board (MTB) for the management of lung cancer in the setting of our study. Studies have shown that MTBs enables interdisciplinary collaboration which helps to maximize efficiency of management, access to multimodal therapy and equality in standards of care for all patients with cancer (108, 109). Interestingly, we found that neighborhood-level SDOH was associated with delayed treatment initiation. Patients living in a neighborhood with high deprivation compared to low deprivation had significantly higher odds of delay in treatment initiation. SDOH is highly correlated with socioeconomic status (SES), and those with lower SES tend to live in areas with poor SDOH (31). This disparity in timeliness of treatment is concerning particularly in this setting which has an MTB which is intended to help with uniformity of care across all patients (108). This suggests that factors beyond the type of and facilities in the healthcare setting may be responsible for this observation and further research is warranted. We also found that having localized cancer stage was significantly associated with a higher likelihood of delay in treatment initiation. This was consistent with the literature on factors associated with delay in cancer treatment (112-114) and may explain the observed paradoxical relationship between longer time to treatment initiation and longer survival time (113, 133). Patients with late-stage disease were found to have a shorter time to treatment initiation but they also have a shorter survival time. This may be due to this patient group having worse prognostic factors, which may have been the reason for the quicker treatment start and for the shorter survival time (113).

For the third and final aim, we explored the perceptions and beliefs of the lung cancer care team in various roles, to better understand the complexities of comprehensive distress screening in a single multidisciplinary lung cancer clinic. We utilized the Theoretical Domains Framework (TDF) to develop the interview guide. This allowed for the exploration of context specific factors that can influence the success of comprehensive psychosocial distress screening in this setting. Four main themes emerged from the interviews: (1) timing and frequency of psychosocial distress screening; (2) training on screening tool and process; (3) staffing needs to address identified psychosocial distress; and (4) missed opportunity for holistic patient care. The majority of the care team believed that performing more screenings at different time points along the cancer continuum would be more beneficial because stressors change with time. Training (on the tool and on the screening process) was identified as a potential area for improving the screening process in the clinic. This supports reports from previous studies that noted that a lack of staff knowledge about the screening is a barrier to implementation of psychosocial distress screening (126, 127). While appreciative of the dedication and expertise of the existing staff available for psychosocial care, the care team noted that the number of staff particularly, psychologists and social support staff was not sometimes enough to adequately address the demands of comprehensive distress screening. Lastly, the care team agreed that integrating screening results in overall cancer care would positively affect patient outcomes, however there was no set protocol for consistently communicating screening results to the oncologists and surgeons. Research has shown that distress in patients with cancer often goes undetected by the health care professionals (132). Therefore, our findings buttress the importance of further research on efficient and effective ways in which health care professionals are made aware of screening results to improve holistic patient care.

Strengths and Limitations

This dissertation was among the first to examine the association of SDOH indicators with psychosocial distress and the role of psychosocial distress on delay in treatment initiation among patients newly diagnosed with lung cancer. It was also one of the first studies to evaluate the association of SDOH and delay in treatment initiation with psychosocial distress in patients with lung cancer. Creating a SDOH composite variable improved the veracity of our findings as composite variables help reduce the incidence of Type I error and multicollinearity for regression analysis(87). It also included use of a well-validated measure of psychosocial distress and the empirical and theoretical development of a qualitative data collection tool. This study is among the first to qualitatively examine implementation of psychosocial distress according to NCCN guidelines primarily in the context of lung cancer care. Using mixed methods for this dissertation helped to provide enriched information by using qualitative research to identify issues not obtained by quantitative research. Some limitations of this study include lack of assessments of individual social risk factors and additional indicators of SDOH in addition to the neighborhood level SDOH indicators which may lack precision; assessment of psychosocial distress at only one time (at the first visit to the cancer center), which precludes assessing if the absence of an association is consistent across different timepoints in the cancer continuum. Lastly, participants and interviewees were from only one academic center which limits generalizability. However, the median values observed on the SDOH indicators were very similar to national averages, indicating that our sample is somewhat reflective of the US population. In addition, we used purposive sampling to select a heterogenous sample of interviewees, representative of health care professionals generally involved in the management of lung patients with cancer.

Future Directions

Longitudinal research to better understand the trajectory of psychosocial distress from the high rates observed at diagnosis across the different stages of the lung cancer continuum is necessary because stressors may change overtime. Exploring forward the interaction of psychosocial distress and the SDOH across the cancer continuum is also warranted because SDOH strongly influence health related behaviors and are known drivers of disparities in healthcare (134), therefore may have a significant effect on attenuating or aggravating psychosocial distress at different times. Future studies that will investigate additional measures of SDOH is recommended because SDOH has 5 key areas - economic stability, education access and quality, health care access and quality, neighborhood and built environment, social and community context (30) and in this study we could only access measures for economic stability and education.

Based on our findings of an association between SDOH factors and delay in treatment, we recommend future studies to better understand how SDOH interacts with treatment adherence or completion. This finding also reinforces the need for lung cancer care centers and other stakeholders to develop and implement targeted interventions to prevent delay in treatment initiation, particularly to these identified vulnerable patient groups.

Our results bring to light the necessity for evaluation of psychosocial distress screening activities. Cancer centers can accomplish this by assessing 3 main areas: (1) adoption – select a standardized tool, formulate guidelines and policies, and set up a screening committee. (2) implementation – set up a screening process that works with the clinic workflow and setting up referral pathways. (3) maintenance - documentation and auditing.

Finally, comprehensive psychosocial distress screening when tailored to the workflow of the practice improves compliance with the CoC guidelines and better outcomes(69) therefore, additional research on how best to efficiently and effectively integrate comprehensive distress screen into overall cancer management is recommended.

Conclusion

This dissertation extends current research on psychosocial distress in patients newly diagnosed with lung cancer. In addition to standard demographic and clinical factors, we examined and reported on novel indicators of social determinants of health and delay of treatment initiation in this patient population. It provided rich qualitative data on ways to improve comprehensive distress screening in the context of lung cancer care. Identification of the most vulnerable subsets of patients with lung cancer who are more likely to experience psychosocial distress is necessary so that interventions can be made preemptively to prevent distress. In accordance with established guidelines, better integration of comprehensive distress screening into the clinic’s workflow and into overall lung cancer management will promote a holistic, patient centered care that could benefit both our patients and their caregivers.

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