## PULMONOLOGY AND RESPIRATORY CARE (D BREEN, SECTION EDITOR)



# The Unique Role of Lung Cancer Nurse Navigators in Elderly Lung Cancer Patients

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#### **Abstract**

**Purpose of Review** Lung cancer care in the elderly is complex for both providers and patients, but a lung nurse navigator can help bridge the gap between providers and patients. The purpose of this paper is to review recent publications on the role of the lung nurse navigator and identify their importance in patient care with an emphasis on their impact on the elderly.

**Recent Findings** Nurse navigation programs vary greatly from institution to institution but are increasingly used in a variety of diseases and roles. Multiple recent studies have shown that nurse navigators lead to a significant improvement in screening rates, time to initial treatment, compliance with treatment, and patient satisfaction, as well as improvement in quality of life among vulnerable populations.

**Summary** Despite the growth within the navigation field, research still continues to be limited with respect to lung nurse navigators' contributions to patient outcomes and overall emotional well-being.

**Keywords** Lung cancer · Nurse navigator · Elderly

# Introduction

In 2019, more than 1.7 million new cancer cases are anticipated, with approximately 13% being newly diagnosed lung cancers [1]. Unfortunately, lung cancer remains one of the leading causes of cancer mortality within the USA despite being one of the most preventable cancers. One primary reason for this is that only 16% of patients are diagnosed at a localized stage, showing the importance of early diagnosis and quality, timely care [1].

Recent research has shown that vulnerable populations are most at risk for both a late diagnosis and not receiving the timely comprehensive care they need. This led to recommendations to begin or improve programs that will increase access to care [2•]. Vulnerable populations are defined as a subset of

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disadvantaged individuals, traditionally identified as racial or ethnic minorities, socioeconomically disadvantaged, children, and/or the elderly (who receive substandard care compared to the standard Caucasian population) [2•].

Significantly, the elderly (defined as patients 65 years and older) make up the largest subset of newly diagnosed cancer cases each year [3]. Furthermore, adults over the age of 85 are the fastest-growing population group in the USA with cancer risk increasing with age and peaking in the patient's 80s [1]. With the growing demands of the elderly, there is a need for increased focus on providing optimal care by helping these vulnerable adults navigate the healthcare system.

#### **Barriers to Effective Care**

Cancer care at baseline is a complex and multifactorial journey that is difficult for any patient to navigate, particularly for our more elderly patients. Barriers to standard oncology care can be physical or financial barriers such as geographic location, transportation, socioeconomic status, and insurance coverage, as well as psychosocial barriers such as patient education, perceptions of care, and social support [4–6]. Patient barriers are known to affect the process of care and treatment outcomes in cancer patients [5]. Vulnerable populations



appear to be affected more by these barriers, as seen in a study conducted by Siegel and associates that estimated approximately one third of adult American cancer deaths could be averted with the elimination of socioeconomic disparities [7]. Examples of this include lower rates of cancer screenings among poverty-stricken patients, leading to a delay in diagnosis and treatment [3]. In 2011, cancer costs were estimated at \$88.7 billion with rising out-of-pocket expenses contributing to patient financial toxicity [8•]. In addition to financial difficulties such as health insurance coverage, Hendren and associates found that the most common barriers for newly diagnosed cancer patients were difficulty with medical communication and lack of social support [5].

# **Cancer Care in the Elderly**

Unfortunately, the effect of these barriers is compounded in the elderly for multiple reasons. These patients are often retired and living on a fixed income, leading to significant financial stress. Furthermore, these patients are often sicker at baseline with the American Centers for Disease Control and Prevention estimating that 80% of older adults have at least one chronic condition with more than half having at least two [4]. These metabolic changes and comorbidities not only affect their ability to tolerate diagnostic tests and treatment but can also make it more difficult to attend appointments on a routine basis. Studies have also shown that the elderly face increased roadblocks in medical communication due to the reluctance to ask questions or share problems and goals of care with their healthcare provider [4, 8•]. Ideally, care is provided in a way that is consistent with the needs, values, and preferences of the patient, but without open communication lines, this can be difficult to achieve [8•].

Another barrier facing the elderly is that despite the large number of cancer patients among the elderly population, cancer research and trials have often excluded older adults [9]. Not until the creation of the International Society of Geriatric Oncology in 2000 did we start to see a drastic change in clinical trial inclusion criteria [10]. In 2015, the American Society of Clinical Oncology (ASCO) additionally created a subcommittee to improve evidence-based guidelines through further research of older adults [11]. Traditionally, clinical trials have used chronological age to identify patients; however, many studies are showing that functional age may give providers a better perspective for treatment tolerance and overall prognosis [4, 9, 10, 12]. Functional status, nutritional status, cognition, mood, and social environment can all interfere with cancer treatment tolerance and thus must be taken into account when caring for the elderly with cancer [9]. In review of the literature, many of these barriers can be addressed by nursing interventions along the cancer continuum.

# **Nurse Navigation**

While nursing can play several roles within the oncology care continuum, the role of nurse navigator may be the most pivotal to overall care. Since nurse navigation's first conception in 1990 by Dr. Harold Freeman, the involvement of nurses within the multidisciplinary team has been shown to improve patient outcomes [13, 14]. Freeman was able to demonstrate that 5-year breast cancer survival rates improved through patient navigation by eliminating barriers and increasing access to screenings, and this process has since been replicated across several disease populations [14–16]. However, the role of the lung nurse navigator remains an evolving role in many institutions with little consistency or delineation of the role [17]. In response to this, there has been an increased effort from national societies to define nurse navigation and make it more consistent across the medical system (Table 1) [18, 19].

Logistically, nurse navigators coordinate the care provided by multiple providers to avoid duplication of testing, conflicting care plans, and hazardous polypharmacy and minimize patient confusion, all of which are particularly important when working with the elderly [17]. In other words, nurse navigators ensure care is patient-centered while directing patients through the complexities of the healthcare system by empowering patients through education and emotional support. Multiple studies have shown that these efforts result in improved understanding of the disease process, adherence to complex treatment regimens, and management of side effects, which ultimately lead to improved overall outcomes and satisfaction [5, 6, 20].

The tasks of nurse navigation are divided into four main categories: navigating the individual through communication, support, instruction, and coaching; facilitating care for the patient through interaction with others; maintaining resources; and documentation/record retrieval [21•]. From this, healthcare systems and nurse navigators break down these tasks into four foci across the spectrum of care, which includes screening, diagnosis, treatment, and survivorship/end of life [21•]. While most of the data on the effect of a quality nurse

**Table 1** Definition for the navigation process from the Academy of Oncology Nurse and Patient Navigators [18] and roles of the nurse navigator adapted from the Oncology Nursing Society [19]

Definition for the navigation process

 "Helping patients overcome healthcare system barriers and providing them with timely access to quality medical and psychosocial care from before cancer diagnosis through all phases of their cancer experience"

Role of the nurse navigator

- · Assess and address barriers to care
- · Provide education, resources, and referrals
- Facilitate shared decision-making
- · Promote advanced care planning
- · Support palliative care



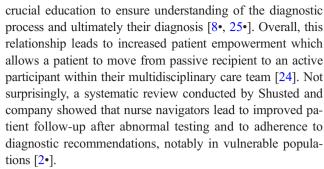
navigator program is from other cancers, much of it can be extrapolated to lung cancer as well.

## Screening

Lung nurse navigators often work with a myriad of specialists, which include general pulmonologists, interventional pulmonologists, radiologists, interventional radiologists, thoracic surgeons, medical oncologists, and radiation oncologists. Through this network of specialties, lung nurse navigators work to improve identification of at-risk patients for lung cancer and navigate them through the continuum of care. In many programs, screening is a main focus of the lung nurse navigator [2., 19]. Navigation programs as a whole have shown to increase screening rates; however, lung cancer screening still has significant room to improve [3, 15, 22]. In 2015, only 4% of the 6.8 million identified eligible Americans reported being screened for lung cancer through the use of low-dose computed tomography (LDCT) [3]. Similar findings were noted in a study conducted by Nishi and associates, where they found less than 5% of Medicare enrollees who were eligible for LDCT screenings completed these screenings in 2016 [22]. It is proposed that this discrepancy is due to many contributing factors which include lack of awareness by both patients and providers, logistical challenges, cultural beliefs and perceptions regarding cancer, and lack of motivation [15, 22, 23•]. Lung navigators can bridge this gap through the development of community networks and providing education on the importance of timely lung screenings not only to patients but also to providers [21•]. In a meta-analysis conducted by Ali-Faisal and associates, they found that the presence of nurse navigators increased the likelihood of cancer screenings almost 2.5 times compared to the usual care [15]. Unfortunately, there is limited evidence that directly correlates lung nurse navigation with completion of screening and diagnostic CTs, but preliminary data is promising especially when extrapolating from studies across all cancer populations [21•].

## **Diagnosis**

While patients often enter into navigation through screening, a large body of patients are also referred to navigators during the diagnostic phase of the continuum which consists of the initial diagnostic testing through the immediate pre-treatment phase [5, 21•]. Regardless of the timing of referral, the lung nurse navigator works to build a rapport with the patient that will promote comfort, empowerment, and clarity from the first interaction throughout the entire continuum of care. This relationship can have a major impact as patients who are undergoing diagnostic evaluation for cancer are notably anxious and often depressed, which can affect health-related quality of life [24]. Lung nurse navigators work to ease this angst by providing open and accessible communication and provide



In addition to this crucial supportive relationship, the nurse navigators also coordinate and streamline diagnostic testing for patients in an effort to minimize time to diagnosis and decrease biopsy complications [2•, 24]. One major aspect of this role is their coordination of multidisciplinary lung cancer tumor boards, which are designed to provide input that results in improved treatment plans for the patient [25•, 26, 27]. A retrospective study conducted over an 18-month period found that the implementation of an interprofessional lung cancer tumor board increased identification of early-stage non-small cell patients by 37% [26]. The nurse navigators are crucial to this impact by not only facilitating the tumor board and helping identify key patients to present but also by providing the follow-up for patients and explaining the tumor board recommendations in a manner that the patient can understand. Likely due to this close follow-up, studies show that nurse navigators decrease the time from diagnosis to treatment, which is a crucial time period in the care of cancer patients [16, 26]. Overall, patients guided by a lung nurse navigator progress from initial abnormal finding to appropriate treatment 19 days faster than those without the assistance of a nurse navigator [8•, 28].

This decrease in time to diagnosis is central to the novel "rapid" pathways that are being introduced around the world. For example, the UK National Health System (NHS) published a handbook in April 2018, detailing the goal of achieving 14-day and 28-day pathways from initial concern to lung cancer diagnosis by 2021 [29]. To achieve these goals, the patient must be seen by multiple providers and undergo many diagnostic studies in a short period of time which is particularly challenging for the elderly patient. As these rapid clinics become more common, the importance of an effective nurse navigator program will continue to increase.

## **Treatment**

The role of the lung nurse navigator during treatment is often quite different from other disciplines involved in the care of the patient, particularly in the care of the elderly. A lung nurse navigator is uniquely suited to help assess tolerance of therapy, ensure a good functional status, and to maintain an ongoing conversation about goals of care. Studies have shown that maintaining independence and preventing functional decline



and disability often are a health priority for older adults even without cancer [12]. One recommended method of doing so is utilizing the comprehensive geriatric assessment (CGA) which evaluates physiological changes, functional status, comorbidities, cognition, psychological status, social environment, nutritional status, and polypharmacy [9, 30, 31]. However, studies evaluating the utility of this scoring system are mixed. Corre and associates state that the CGA can help to identify patients with natural poor prognosis based on independent variables such as functional and nutritional status, both of which nurse navigators can help promote. Despite this, in their multicenter, phase III randomized trial, CGA-based allocation of chemotherapy did not improve the survival outcomes of elderly patients with stage IV non-small cell lung cancer [31]. However, a retrospective chart review by Zibrik and associates reported that after the implementation of a lung nurse navigator program, the percentage of patients receiving systemic therapy increased from 57 to 69% [16].

Other studies have found improvement in quality of life during treatment with the aid of nurse navigators. In a pilot study conducted by Reinke et al., 40 newly diagnosed patients were randomized into either a standard of care protocol or a nurse-led telephone intervention where they communicated on a regular interval over a 3-month period to discuss symptom management and goals of care and address any psychosocial needs [32]. Results demonstrated that participants reported not only a higher degree of satisfaction during their treatment but also avoided additional office visits for symptom management [32]. This however is in contrast to a randomized study conducted by Flannery and colleagues, which did not find a statistically significant difference between usual care and a similar nurse-led phone intervention [33]. The likely difference in results may be due to the small sample size and decreased intensity of the intervention as only 5.5 of the 8 planned interventions occurred on average. Despite the results, investigators continue to believe that conducting systematic and frequent symptom assessments is essential in minimizing symptom burden and thereby helping maintain patients' positive outlook [33]. This belief is validated by a systematic review conducted by Joo and colleagues that found the use of a nurse navigator or nurse-led case management improved patient's quality of life while also reducing the number of hospital admissions among vulnerable populations [20]. Furthermore, nurse navigation or nurse case management was shown to improve self-efficacy, symptom control, and satisfaction with care [20].

Lastly, treatment is often aimed to cure or to prolong one's life, but when advocating for our elderly patients, this focus may change from quantity to quality of life [8•, 12]. As a result, patient advocacy becomes the primary priority of a lung nurse navigator, with a particular focus on understanding the patient's goals and values and validating that they are consistent with the plan of care.

## Survivorship/End of Life

With advancements in lung cancer treatment and with continued improvements of screening programs, patients are living longer and therefore create a diversity of further health hurdles and experiences to be addressed by patients and navigators alike [17]. As a result, more patients require long-term follow-up in lung cancer survivor clinics. Although there is limited research on the role of nurse navigators in this setting, the relationship and rapport that they have developed with patients would certainly continue to be helpful; however, more research is being initiated [34]. In this phase, lung nurse navigators can educate patients on needed health maintenance and surveillance protocols to promote continued disease-free status and ensure patients are not lost to follow-up. Nurse navigators also provide an additional point of contact for primary care providers during this time to ensure provider understanding of previously provided treatment as well as recommended surveillance [35].

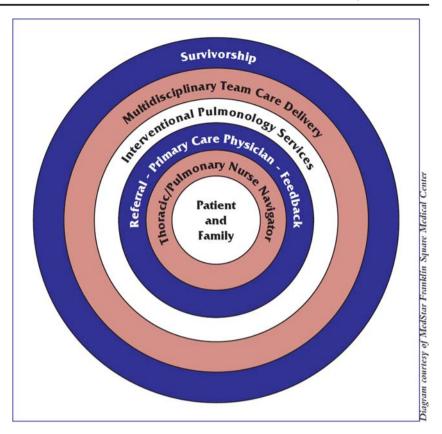
However, the nurse navigators also play a major role for those patients who are approaching the end of their life. Nurse navigation in this phase is focused not only on the physical symptoms but also the psychosocial and spiritual distress experienced by patients and their families [8•]. As noted, focus for the elderly lung cancer patient may not be the quantity of life, but instead the quality. It is imperative that the lung nurse navigator engages with the patient and their family to ensure understanding of goals in order to properly advocate on the patient's behalf. This often can be a time of needed education for patients and their families to understand and prepare advanced directives and living wills accordingly. With the long-standing relationship that the nurse navigators have developed, they are uniquely suited to help the patients with this very personal decision.

## **Conclusion**

Clearly, the lung nurse navigator plays a major and unique role in the care of the patient throughout the oncologic care continuum and is becoming even more important with elderly patients. At this time, the bulk of the literature shows great variety in the focus of each navigation program, but there is a consistent trend towards improved patient care. There have been several efforts to standardize navigation programs through guidelines and competencies; however, implementation has not been specified or mandated [19, 36, 37]. One major limitation of this review is the limited research specifically designed to study the impact of nurse navigators in the elderly, but it is reasonable to extrapolate the data obtained from the general oncologic population. Over the last several years, there has been increased emphasis in the field which we welcome, including the new January 2019 National



**Fig. 1** The central role of the lung nurse navigator



Comprehensive Cancer Network (NCCN) guidelines for caring for the elderly [38].

Despite the lack of strong evidence to date, we have seen significant improvement in patient care and satisfaction within our clinic with the use of a strong nurse navigator program. Our ideal role of the nurse navigator can be seen in Fig. 1, which emphasizes the central nature of their position. They participate in all aspects of care, helping guide the patient and serving as the first line of contact for the patient throughout the cancer continuum. Their relationship with the patient is their most valuable tool and outstrips any benefit from specializing in a single foci of care such as lung cancer screening.

In conclusion, lung nurse navigators improve screening utilization, time to diagnosis and treatment, patient satisfaction, and many other major criteria in the care of the lung cancer patient by removing barriers to care. By building a rapport and meaningful connection with both the patient and their family, the nurse navigator can properly ensure alignment of patient's goals and values with plans of care and optimize communication between all disciplines involved in the care. In order for lung nurse navigators to be truly effective, they must possess not only an understanding of cancer biology and lung physiology, symptom management, treatment variables, and side effects but also the ability to educate and advise patients, families, and providers; understand informed consent; and maintain confidentiality, all while being empathetic and culturally competent [2•]. Of course, more

studies are needed to further optimize the role of the lung nurse navigator and to promote general education of the values for this type of program.

#### **Compliance with Ethical Standards**

**Conflict of Interest** The authors declare no conflicts of interest. The views expressed in this article are those of the authors and do not reflect the official policy of the Department of the Army, Department of Defense or US Government.

**Human and Animal Rights** This article does not contain any studies with human or animal subjects performed by any of the authors.

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