

Pathways to a Lung Cancer Diagnosis

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Abstract

Purpose: The purpose of this qualitative descriptive study was to identify and describe pathways to a lung cancer diagnosis based on narratives of persons diagnosed with the disease.

Data sources: Eleven adults with lung cancer were recruited from an academic thoracic oncology clinic in a large city in the southeastern United States. Moderately structured interviews were conducted by an experienced nurse practitioner to obtain information regarding the participants' experiences leading to their diagnosis. Qualitative content analysis was used to develop a typology of pathways.

Conclusions: Findings revealed four distinct pathways: *missing opportunities, waiting and seeing, being alarmed, and being blindsided.*

Implications for practice: The *Pathways to a Lung Cancer Diagnosis Typology* has important implications for clinical practice and can be used to inform nurse practitioners and other healthcare providers who provide care for patients at risk for or diagnosed with lung cancer.

Pathways to a Lung Cancer Diagnosis

Lung cancer is the deadliest cancer, affecting men and women of all ethnic backgrounds with an estimated 1.6 million new diagnoses and 1.4 million deaths annually (ACS, 2014). Lung cancer's morbidity and mortality are directly related to its stage at diagnosis (Blair & Freeman, 2006). Most cases are diagnosed at Stage IV, which has a five-year relative survival rate of 1% (Luo, 2012). Five-year relative survival rates are 49% for Stage I and 30% for Stage II lung cancers. Therefore, finding ways to identify lung cancer patients earlier in their disease trajectory can improve morbidity and mortality.

Although lung cancer is often thought to be asymptomatic, many affected individuals have symptoms prior to diagnosis (Carter-Harris, 2014; Levealahti, Tishelman, & Ohlen, 2007). Some individuals perceive their symptoms as alarming and seek medical help promptly, whereas others do not and subsequently self-manage their symptoms for varying lengths of time (Levealahti et al., 2007; Smith, Pope, & Botha, 2005). Although delayed medical help-seeking behavior in lung cancer has been explored, the pathways taken as the disease unfolds and culminates in a diagnosis have not been described in depth from patients' perspectives (Brindle, Pope, Corner, Leydon, & Banerjee, 2012; Corner, Hopkinson, & Roffe, 2006; Giroux Leprieur et al., 2012). This information would help healthcare providers better understand patients' diverse experiences with symptom awareness and medical help-seeking prior to diagnosis and provide information to facilitate more timely diagnosis and treatment in this population. The purpose of this study, therefore, was to begin to identify and describe pathways to a lung cancer diagnosis based on narratives of persons diagnosed with the disease.

Design

This was a qualitative descriptive study of adults with all four stages of lung cancer. Qualitative description methods, as described by Sandelowski, are used to produce straightforward descriptions of life events shared by a group with common concerns (Sandelowski, 2000). Moderately structured interviews are often conducted to obtain participant narratives, and qualitative content analysis is typically used to produce a comprehensive summary of the experiences described by participants. Moderately structured interviews involve the use of prepared open-ended questions along with probes (Richards and

Morse, 2007). Qualitative description is especially useful for giving voice to those affected by illness to inform the development of interventions that target health concerns of most importance to them (Sullivan-Bolyani, 2005). Because we wished to identify and describe some common pathways to diagnosis experienced by individuals with lung cancer in a typology with high descriptive validity that could be easily used by clinicians, qualitative descriptive methods were deemed the most appropriate approach.

Procedure

A convenience sample of 11 participants was recruited from an academic thoracic oncology clinic in a city in the southeastern United States. Institutional review board approval from the University of Louisville was obtained prior to study recruitment. The inclusion criteria were: (1) lung cancer as a primary site; (2) able to speak and understand English; (3) capable of participating in an in-person interview; and (4) age 22 or older.

The researcher and the nurse reviewed the clinic schedule each day and identified potential participants who met inclusion criteria. The oncologist or nurse introduced the study to potential participants while they were in the exam room. When individuals indicated interest in hearing more about the study, the researcher was invited in to explain the study, confirm eligibility, and respond to questions. For eligible patients who were willing to participate, the written informed consent process was completed and an interview was scheduled. Most interviews took place in the clinic immediately following the participants' appointment with the oncologist, although one interview took place in a participant's home and another at the interviewer's academic office. Participant recruitment ended when sufficient information had been obtained to identify several distinct pathways and saturation was reached.

Data Collection

Study participants completed a brief socio-demographic questionnaire prior to the interview and then met face-to-face with the researcher (L.C.), an adult nurse practitioner with over a decade of experience in internal medicine and caring for oncology patients. The researcher was not employed as a nurse practitioner at the recruitment site. The interviews were digitally audiotaped and transcribed verbatim by the researcher (L.C.). The transcripts were de-identified and the link connecting participant

identification information was stored separately on a passphrase-protected, encrypted file server. Participants were asked to describe: (1) their perception of their health prior to their lung cancer diagnosis, (2) their initial symptoms, (3) their behavioral response to the symptoms, and (4) the events that occurred between the initial symptom(s) and their diagnosis. See Table 1 for questions asked in the moderately structured interviews. At the conclusion of the interview, participants were invited to ask questions or provide any additional information. Interviews were typically 45 to 60 minutes in length, and field notes were handwritten on the day of the interview by the researcher (L.C.).

Data Analysis

Data were analyzed using standard content analytic procedures (Neuendorf, 2002). Neuendorf (2002) defines content analysis as a systematic, objective, quantitative analysis of message characteristics in a narrative in which careful examination of human interactions is the focus. The first author (L.C.) coded each interview by providing labels for each relevant text unit, which is any word, phrase, sentence, or story that provided information to address the study purpose. The text units included information about events in which participants noticed symptoms, responded to symptoms, managed symptoms, or sought medical evaluation. The third author (C.B.D.), an expert in qualitative analysis, reviewed codes for accuracy. The first author (L.C.) then constructed a case-by-time matrix as described by Miles, Huberman, and Saldaña in which each row is represented by a case, with salient codes displayed along multiple columns to represent the unfolding of events over time (Miles, 2014). In order to identify several distinct pathways to diagnosis, the authors met on several occasions and, through discussion and consensus, used an iterative process to form categories of types of pathways. They juxtaposed rows with similar codes, returned to the transcripts to ensure that the matrix captured all salient events, and reached agreement on those cases that were most similar and therefore formed a category. The authors identified four categories representing four different pathways and wrote narratives that described each pathway. These descriptions, accompanied by case exemplars, are presented below.

Results

Sample

Eleven individuals ranging in age from 40 to 76 years participated. The majority of participants were female ($n = 7$) and Caucasian ($n = 8$), and most had advanced lung cancer. Four of the 11 individuals were never smokers. Three participants were diagnosed with early stage (Stage I or II), two with Stage III, and six with Stage IV lung cancer. See Table 2 for complete socio-demographic information.

All participants described the pathway that led to their lung cancer diagnosis. Participants' descriptions varied from an acute change or occurrence that led to diagnostic testing to a gradual awareness of a change in their health, with varied responses by the participant or the provider. The research team identified and labeled four distinct pathways: *missing opportunities*, *waiting and seeing*, *being alarmed*, and *being blindsided*. Table 3 presents the categories, related definitions, number of participants reflecting each category, stages at diagnosis, and smoking status. The typology is discussed below. For identity protection, all participants are referred to by age, gender, and occupation only.

The Typology

Missing opportunities. Six participants described a pathway that we have labeled *missing opportunities*. These participants were bothered by vague physical symptoms that persisted. The participants indicated that although they would normally have responded to such symptoms by waiting to see if they resolved on their own, the symptoms that were ultimately diagnosed as lung cancer did not subside and led them to visit their healthcare provider. All individuals were long-term smokers and all complained of a cough that was “lingering,” “persistent,” or “bad.” They also experienced other symptoms that included fatigue, unexplained weight loss, and musculoskeletal or chest pain. Each had at least one encounter, and sometimes several, with a healthcare provider but was not evaluated for lung cancer during these visits. Because the symptoms were viewed as vague, the providers did not initially link the symptoms to the possibility of lung cancer. Several of these participants indicated that their providers attributed the symptoms to something less serious, such as a respiratory infection, and therefore did not order a

diagnostic workup for lung cancer. Some participants themselves suggested a less dire cause of their symptoms, perhaps distracting the healthcare providers from considering lung cancer as the etiology. We labeled this pathway as *missing opportunities* because the participants did seek evaluation for their symptoms, in some cases on several occasions, but a diagnosis was “missed” because the symptoms were deemed to be due to other causes either by the patients themselves or the healthcare providers. These participants felt frustrated because valuable time had been lost in beginning treatment for their lung cancer.

One participant who had a pathway of *missing opportunities* was a 49-year-old truck driver who had smoked two packs of cigarettes per day for the past 20 years. He reported a lingering cough after returning from a family vacation. Because his entire family had coughs, he originally dismissed his symptoms as allergies because the family had traveled to a new part of the country. However, his wife’s and teenage children’s coughs resolved a few days after their return home from vacation, but his cough persisted. After being back from vacation for a month, he experienced a headache that led him to go to his healthcare provider. He described this encounter: “I just suggested that I thought I might have headaches from high blood pressure...so he immediately seen that I had high blood pressure and started treating the high blood pressure.” The participant experienced a lingering cough and prolonged headaches over the next three months, during which time the provider made several adjustments to his blood pressure medications. The participant was ultimately diagnosed with Stage IV non-small cell lung cancer that had metastasized to his brain.

Another participant who described a pathway of *missing opportunities* was a 50-year-old teacher’s assistant who had smoked one pack of cigarettes per day for the past 35 years. She had developed a cough that progressively worsened. She also experienced a headache and upper chest pain and visited her healthcare provider when her symptoms began to interfere with her sleep. After describing her symptoms to the provider she was treated for sinusitis and pneumonia, but her symptoms did not subside. She reported being frustrated at being treated without any diagnostic tests being performed except for the physical examination. She described an encounter with her healthcare provider that

occurred after unsuccessful treatment with three courses of antibiotics: “I was bawling and I said I cannot keep taking these Ibuprofens; somebody’s gotta do something for me and that’s when she did a CT.” She was diagnosed with Stage IV non-small cell lung cancer that had metastasized to her brain.

Another participant who described a pathway of *missing opportunities* was a 51-year-old farmer who had smoked two packs of cigarettes per day for 15 years but had quit five years previously. She had symptoms of overwhelming fatigue, muscular pain, and cough. She went to her healthcare provider when the symptoms became too much to bear and was told it was “all in her head.” Because she was reluctant to question the authority of her provider, she did not return for care for several months when her cough worsened. She described the following encounter with her provider:

[I] went to the doctor and they were checking me for everything else but never once did anybody do a chest x-ray...never once...they kept looking at labs...basically what they told me was that I had something systemic going on, they didn’t exactly know what it was. They kept putting me on antibiotics until after three antibiotics I went to the emergency room and they did a chest x-ray and told me I had lung cancer.

She was diagnosed with Stage IV non-small cell lung cancer in the emergency department.

Waiting and seeing. Three participants described a pathway that we have labeled *waiting and seeing*.

These patients were bothered by vague, intermittent symptoms like the participants in the first pathway, but sought help only when the symptoms significantly increased in number or severity. These participants indicated that they typically never sought medical care, so seeking help for their symptoms was not their usual practice. Once they did seek medical evaluation, they were then either diagnosed with something less serious or were diagnosed with lung cancer. This pathway was labeled *waiting and seeing* because participants tolerated symptoms that were overwhelming or interfered with their quality of life for some time by trying to “wish them away” and waiting to see if the symptoms would worsen or resolve.

One participant who described a pathway of *waiting and seeing* was a 64-year-old retired postal worker who had smoked two packs of cigarettes per day for 10 years in her 20s but had quit more than 30 years prior. She described experiencing no energy, shortness of breath, weight loss, and “...a multitude of complaints” for a long time. She tolerated her symptoms for some time because she viewed them as vague, and it was only the combination of symptoms that finally spurred her to seek medical evaluation.

Other than her shortness of breath, which she thought was caused by “something else [other than lung cancer],” she did not think any of her symptoms were related to a problem with her lungs. She stated, “I never noticed a change with my lungs. I just noted a deterioration in my health.” She endured her symptoms for several months before seeking medical evaluation. The combination of shortness of breath and drastic weight loss frightened her, leading her to seek medical evaluation for her symptoms. During her first medical appointment, she underwent a CT scan that revealed Stage II lung cancer.

Being Alarmed. One participant described a pathway that we have labeled *being alarmed*. Unlike participants in the first two pathways, this participant experienced an acute, alarming symptom, hemoptysis, which was evaluated immediately and resulted in a prompt diagnosis of lung cancer.

The participant with this pathway was a 59-year-old art gallery owner who had smoked less than one pack of cigarettes per day in her early 20s but had quit 40 years previously. She reported:

I coughed up bright red blood when I was driving to work one morning...I coughed up bright red blood the next day on my way to work and it scared me. I called my doctor immediately and told them what happened and asked to be seen. They got me in the same day and did a chest x-ray which saw something but they needed to do a CT scan to tell me more.

She recounted a close relationship with her family physician and described how he personally shared her chest x-ray. She said he knew she was a photographer and called her into his office and held a normal chest x-ray up to the light to show what normal looked like. Then, he placed her chest x-ray in front of the light to show her the two spots about which he was concerned. Although a CT scan was scheduled that day, it took about one week to receive confirmation from the radiologist that she had Stage II non-small cell lung cancer.

Being Blindsided. One participant described a pathway that we have labeled *being blindsided*. Unlike the participants in the first three pathways, she had not experienced any symptoms related to lung cancer but it was discovered in the course of treatment for another illness. We labeled this pathway *being blindsided* because the participant had no symptoms of lung cancer and was shocked to learn of it incidentally.

The participant with this pathway was a 42-year-old medical receptionist who had never smoked. She had experienced upper back pain off and on for several months but dismissed it as related to homemaking activities with her three children and sitting at a desk for 10 hours a day at work. She then experienced an unrelated symptom that required breast surgery. In the course of pre-surgical testing for her breast problem, her healthcare provider ordered a chest x-ray. The participant was stunned to learn that the x-ray revealed that she had Stage IIIb non-small cell lung cancer.

Discussion

Although prior research has demonstrated that individuals delay medical help-seeking upon experiencing symptoms of lung cancer, this study contributes to our understanding of this phenomenon by developing a beginning typology of pathways that lead to a lung cancer diagnosis as described by patients themselves. The *Pathways to a Lung Cancer Diagnosis Typology* includes four pathways that differ in significant ways. *Missing opportunities* is a pathway in which individuals seek medical evaluation for vague but nagging symptoms but are not diagnosed with lung cancer in a timely fashion because the symptoms are attributed to less serious causes either by the individual or the healthcare provider. The hallmark of this pathway is the person's multiple visits to a healthcare provider before a diagnosis is made. *Waiting and seeing* is a pathway in which individuals experience vague but distressing symptoms but delay medical help-seeking because they believe symptoms will go away. The hallmark of this pathway is the person's long wait before seeking medical evaluation. *Being alarmed* is a pathway in which individuals experience an acute, alarming symptom of lung cancer, resulting in a timely diagnosis. The hallmark of this pathway is the person's immediate help-seeking and rapid diagnosis. *Being blindsided* is a pathway in which individuals have no notable symptoms of lung cancer but it is discovered in the course of a routine physical assessment or a diagnostic workup for another complaint. The hallmark of this pathway is the person's unexpected diagnosis of lung cancer during evaluation conducted for another purpose.

The findings of this study are consistent with several previous studies on medical help-seeking behavior and lung cancer (Corner, Hopkinson, Fitzsimmons, Barclay, & Muers, 2005; Corner et al., 2006;

Tod, Craven, & Allmark, 2008; Tod & Joanne, 2010). Just as Quaife and colleagues (2014) found that the odds of waiting more than two weeks to seek help for a persistent cough were greater in those who did not recognize the cough as a warning sign for lung cancer, several of the participants in our study did not initially view their cough as a warning sign and thus did not seek immediate medical evaluation for it. Our study also resonates with the work of Molassiotis, Wilson, Brunton, and Chandler, who mapped patients' experiences from initial change in health to a cancer diagnosis and identified a number of patient-related factors (e.g. attribution of symptoms to common conditions, underestimation of the seriousness of symptoms) and practitioner-related factors (e.g., exploring common causes of symptoms without follow-up) that extended the pathway to diagnosis (Molassiotis, Wilson, Brunton, & Chandler, 2010). Our study extends existing literature, however, by identifying a beginning typology that is specific to a lung cancer diagnosis and that focuses on patient's experiences as they unfold over time. Our findings also challenge the perception that delays in seeking evaluation for symptoms of concern may be greatest in individuals with lower levels of educational attainment (Corner and Brindle, 2011). For example, all three of the participants in the *waiting and seeing* pathway held college degrees.

Limitations

The major limitation of this study was the small sample size. Although we were able to identify four distinct pathways, a larger sample would allow for the development of a more robust typology and a more comprehensive description of the key characteristics of each pathway. A larger sample may also result in the identification of additional pathways. Although two of the pathways we identified were based on the narratives of only one person each, our clinical experiences suggest that these pathways are likely to be common in this population. Finally, although patients with all stages of lung cancer were included in the sample, most were in Stage IV, which may have led to different results than if the sample had been equally distributed across stages. Future studies should include equal numbers of early and advanced stage lung cancer patients to examine whether they have experienced different pathways.

Practice Implications

Despite its limitations, the study provides implications for clinical practice. The *Pathways to a Lung Cancer Diagnosis Typology* can be used to inform nurse practitioners and other healthcare providers about the varied pathways patients experience on their journey to a lung cancer diagnosis. Awareness of these variations can assist providers in their efforts to provide more timely diagnoses and to better understand the challenges patients face even before they learn they have lung cancer.

The *missing opportunities* pathway indicates that when individuals present multiple times for a medical evaluation because they are bothered by persistent vague symptoms, particularly those that are respiratory in nature, lung cancer should be considered early on in the differential diagnoses. This is especially true for individuals at high-risk for lung cancer (i.e., long-term current or former smokers, environmentally or occupationally exposed individuals, or geographically at-risk individuals secondary to high radon levels). In addition, reciprocal patient-provider interactions may be particularly important to this pathway; the study participants' explanations of the cause of their symptoms seemed to influence the providers' responses to the symptoms, and vice versa. While healthcare providers should elicit patients' perspectives on the cause of their symptoms when taking a health history, providers should also be cognizant of the influence that symptom misattribution by patients might have on the providers' diagnostic considerations. In addition, with more primary care appointments being symptom focused, patient background information (particularly history of smoking) may be lost in the patient's history. The practice implications of the *waiting and seeing* pathway relate to health education. As these individuals delay seeking care despite experiencing alarming symptoms, nurse practitioners and other healthcare providers should develop or endorse community health education initiatives that alert high-risk individuals to the signs and symptoms that might serve as early warnings of lung cancer (see Table 4 for a list of common warning signs of lung cancer).

The practice implications of the *being alarmed* and *being blindsided* trajectories lie in the consideration that due to the acuity of the symptoms or the blow of an unexpected diagnosis, these individuals may need different psychological and social support than those who have experienced

symptoms for some time or those who realize they are being evaluated for lung cancer. Finally, nurse practitioners and other healthcare providers should inquire about all patients' pathways to diagnosis as the nature of the pathway may well affect the patients' initial response to their disease and their attitudes toward their healthcare as they embark on their treatment journey.

Conclusion

Although the typology we present here provides only a beginning framework, the identification of the distinct pathways can help nurse practitioners and healthcare providers broaden their understanding of the multitude and complex ways lung cancer patients arrive at a diagnosis. Early symptoms of lung cancer are varied and can include persistent cough, fatigue, weight loss, and unexplained pain. Early detection and timely treatment of lung cancer can be best informed by a framework that considers the reciprocal influence of the diverse symptom presentation of lung cancer, variations in individuals' awareness of risk and responses to the emergence of symptoms, and provider practices in regards to this deadly disease.

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Table 1. *Questions asked in the semi-structured interviews*

Tell me about the last time you felt healthy.

Tell me about the first time you noticed a change in your health.

What changed in your health that concerned you?

What happened that made you decide to seek evaluation for your symptom?

Tell me about when you were diagnosed with lung cancer.

Tell me about what happened between the time you became aware of a change in your health and seeing your healthcare provider.

What kind of health complaints did you have when you first went to the doctor?

Table 2. Socio-demographic Characteristics of Participants

Sociodemographic Details	Participants (N = 11)
Age	
Age range	40-76 years
Mean age	56 years
Gender	
Female	7
Male	4
Ethnicity	
African-American	3
Caucasian	8
Marital Status	
Married	6
Divorced	1
Widowed	1
Single	3
Employment Status	
Employed Full-time	5
Retired	4
Unemployed	2
Live Alone	
Yes	2
No	9
Education Level	
Some High School	1
High School Graduate	4
College Graduate	6
Stage at Diagnosis	
Stage 4	6
Stage 3	2
Stage 2	2
Stage 1	1
Smoking Status at Diagnosis	
Current Smoker	3
Former Smoker	5
Never Smoker	3

Table 3. Categories, related definition, number of participants reflecting each category, stage at diagnosis, smoking status, and education level

Pathway	Definition	No. of Participants	Stage at Diagnosis	Smoking Status	
<i>Missing opportunities</i>	<i>A pathway in which individuals seek medical evaluation for symptoms but the diagnosis is delayed because the interpersonal dynamic between the patient and healthcare provider leads the provider down a path pursuing differential diagnoses that do not include lung cancer.</i>	6	Stage 4 (n=6)	Current Smoker (n=3) Former Smoker (n=3)	Hi
<i>Waiting and seeing</i>	<i>A pathway in which individuals experience vague but distressing symptoms but delay medical help-seeking because they believe the symptoms will go away.</i>	3	Stage 3 (n=1) Stage 2 (n=1) Stage 1 (n=1)	Former Smoker (n=1) Never Smoker (n=2)	
<i>Being alarmed</i>	<i>A pathway in which individuals experience an acute, alarming symptom of lung cancer spurring them to seek medical evaluation immediately resulting in diagnosis.</i>	1	Stage 2 (n=1)	Former Smoker (n=1)	Hi
<i>Being blindsided</i>	<i>A pathway in which the lung cancer diagnosis is discovered in the course of evaluation for another concern.</i>	1	Stage 3 (n=1)	Never Smoker (n=1)	

Table 4. *Warnings signs of lung cancer*

Persistent cough

Shortness of air

Hemoptysis

Recurrent pneumonia or bronchitis

Hoarseness

Unexplained weight loss

Fatigue

Pain (musculoskeletal, chest area, substernal, back, shoulders)

Unexplained anemia

Adapted from the American Cancer Society, 2014