The Experience of a Diagnosis of Advanced Lung Cancer: Sleep Is Not a Priority When Living My Life

Suzanne S. Dickerson, DNS, RN, Eman Abu Sabbah, MS, RN, Patricia Ziegler, NP, RN, Hongbin Chen, MD, PhD, Lynn M. Steinbrenner, MD, and Grace Dean, PhD, RN

Sleep is essential to physical health, cognitive functioning, memory, and quality of life (Banks & Dinges, 2007; Durmer & Dinges, 2005); however, the role of sleep in the lives of patients with lung cancer is relatively uninvestigated. Lung cancer is the second most common form of cancer and the leading cause of cancer death in the United States (Siegel, Ward, Brawley, & Jemal, 2011). Limited research indicates that, when compared to other types of cancer, patients with lung cancer have the poorest sleep quality, and 52%–79% of those patients experience sleep-wake disturbances compared to the general population (10%–15%) (Davidson, MacLean, Brundage, & Schulze, 2002; Ginsburg, Quirt, Ginsburg, & MacKillop, 1995; Silberfarb, Hauri, Oxman, & Schnurr, 1993; Vena et al., 2006). Silberfarb et al. (1993) used polysomnography to demonstrate that patients with lung cancer had more trouble falling asleep and staying asleep, napped longer and more frequently, and stayed in bed longer; however, they did not get more sleep compared to patients with breast cancer and normal sleepers. These studies found that those objective measures often did not correlate with subjective measures of sleep and that the participants did not recognize the significance of their sleep-wake disturbances. Therefore, little is known about patients’ perceptions and experiences of problematic sleep and whether sleep disturbances were preexisting to the lung cancer diagnosis. Few qualitative studies were concerned with sleep disturbances except for one in which insomnia was one of the most distressing problems, along with pain and fatigue (Tishelman, Lövgren, Broberger, Hamberg, & Sprangers, 2010).

Minimal discussion has centered on the experiences of sleep disturbances that ultimately affect daily life. Disease- and treatment-related symptoms such as pain, dyspnea, and fatigue may interfere with sleep homeostasis and result in sleep-wake disturbances (Vena et al., 2006). When poor sleep is combined with any of those symptoms, symptom distress increases significantly with a decline in functional status and quality of life (Given, Given, Azzouz, & Stommel, 2001). In fact, studies have shown that patients with lung cancer consider the combination of insomnia, fatigue, and pain the most distressing of all symptom clusters (Degner & Sloan, 1995; Portenoy et al., 1994; Sarna, 1993). In addition, higher symptom distress scores are predictive of decreased survival time in patients with lung cancer, regardless of age.

Purpose/Objectives: To describe common practices and shared meanings of sleep-wake disturbances in individuals with newly diagnosed non-small cell lung cancer (NSCLC) before treatment and evaluate their preexisting sleep disturbances.

Research Approach: Open-ended interviews of patients newly diagnosed with lung cancer.

Setting: A Veterans Administration hospital and a comprehensive cancer center in the northeastern United States.

Participants: 26 patients newly diagnosed with NSCLC who chose chemotherapy treatment.

Methodologic Approach: Interpretive phenomenology based on Heideggarian hermeneutics.

Main Research Variables: Meaning of diagnosis on life experiences and sleep practices.

Findings: Participants described four related themes: (a) the diagnosis as devastating yet not surprising, (b) treatment as hope for more time, (c) keeping life normal, and (d) sleep patterns as long lived. The constitutive pattern that linked the themes was: sleep is not a priority when living life after a diagnosis of lung cancer.

Conclusions: Although participants did not complain about sleep difficulties, they described a history of sleep disturbances and poor sleep hygiene. Participants focused their trust on the treatment, giving them more time to follow their priorities and ignoring the effects of sleep deprivation on their quality of life.

Interpretation: Healthcare professionals may design interventions to encourage keeping life as normal as possible, focusing on improving sleep, which may ultimately prolong patients’ lives.
or stage of disease (Degner & Sloan, 1995). The primary purpose of this article is to provide the qualitative results of the initial interviews (prior to treatment) of an exploratory six-month longitudinal mixed methods study on sleep-wake disturbances of individuals in treatment for non-small cell lung cancer (NSCLC).

**Methodologic Approach**

The interpretive, phenomenologic approach of Heideggerian hermeneutics was used to examine participants’ narratives that depicted the experiences of a lung cancer diagnosis and related sleep difficulties (Diekelmann, Allen, & Tanner, 1989). That provided the researchers with insight into the daily experiences of the participants, including what kept them awake and what they did to cope. Heidegger (1962) acknowledged that humans are self-interpreting beings, situated in time, and have background practices that are communicated through language. The interpretations are reflective and circular, and uncover understandings of the human situation as lived (Diekelmann & Ironside, 1998). As interpreters, the researchers made explicit presuppositions that are based on knowledge of the literature on sleep-wake disturbances in patients with lung cancer, knowledge of good sleep hygiene practices, and that patients are often unaware and underreport the severity and outcome of their sleep disturbances.

The interpretive team included an expert in hermeneutic methodology, a researcher who is an expert clinician and sleep expert, a PhD student trained in the methodology, and clinical experts in thoracic oncology who reviewed the interpretations to reveal any unwarranted interpretations not supported by the participants’ transcripts.

Interpretive phenomenology guided the development of the interview questions. Participants were asked to share stories of their experiences when they first were diagnosed with lung cancer and describe their normal sleep patterns before and after the diagnosis. All interviews were tape-recorded and transcribed to provide the text for analysis. The interviewer and researcher reviewed the tapes and transcripts to ensure their accuracy.

The texts provided the data, which were analyzed using a modified Heideggerian hermeneutical approach (Cohen, Kahn, & Steeves, 2000; Diekelmann et al., 1989; Diekelmann & Ironside, 1998). The research team analyzed the data in a circular process, identifying related themes and practices supported by verbatim excerpts, which were discussed at weekly meetings to reach consensus. Discrepancies in interpretations were clarified by referring to the transcripts or verifying with patients at the next interview. Patterns were identified that were constitutive (Diekelmann & Ironside, 1998), found in all interviews, and illustrated relationships among themes, which explicated common practices and shared meanings that formed the basis for understanding the experience over time as lived by the participants. In hermeneutics, results are always open to new interpretations; however, the hermeneutic process ensured that no unwarranted interpretations emerged and the results were focused and reflective of the text (Diekelmann & Ironside, 1998).

**Sample and Setting**

The prospective sample for this study included 26 individuals newly diagnosed with NSCLC from a Veterans Administration (VA) health system and a comprehensive cancer center. Of the 26 participants, only one was a nonsmoker, 62% were men, 15% were African American, 57% had a high school education, and all had an advanced-stage cancer diagnosis. Demographic characteristics are summarized in Table 1.

The diagnostic group of participants with NSCLC was selected for this study because of the high levels of

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N = 26 unless otherwise noted.
associated sleep-wake disturbances (Davidson et al., 2002; Ginsburg et al., 1995; Silberfarb et al., 1993; Vena et al., 2006). Sampling procedures for qualitative studies require a sample of participants who have appropriate knowledge and experience of the phenomenon as determined by the clinicians who recruited them; 26 participants were sufficient to reach saturation (Cohen et al., 2000; Morse, 1991).

The VA health system oncology clinic and the comprehensive cancer center provided socioeconomic, ethnic, and urban and rural diversity. Following diagnosis, patients were asked to volunteer for the study by a nurse practitioner or physician. Patients’ eligibility criteria included individuals with NSCLC who chose chemotherapy treatment, were aged 18 years or older, and who had a Karnofsky Performance Status of 70 or greater (i.e., able to care for self).

Findings

Four themes emerged from the data that described the participants’ diagnoses and sleep patterns prior to diagnosis. The constitutive pattern that linked the themes was: sleep is not a priority when living life after a diagnosis of lung cancer.

Theme 1: Diagnosis as Devastating Yet Not Surprising

Participants’ initial symptom experiences prior to diagnosis often were described as unrelated and nonspecific to the final diagnosis. Some participants’ cancers were discovered during their regular checkup, as one person said, “I just converted [insurance coverage] and they said, ‘Welcome aboard, let’s go to the doctor and let’s do a [CAT (computed axial tomography)] scan,’ and they found a mass [on the lung].” Another said, “I was preparing for an angiogram and the cardiologist asked me to have an x-ray. The next morning I had calls from two different doctors’ office[s], at which point I knew something was up.”

Other participants had respiratory symptoms related to bronchitis, flu, or pneumonia that brought them to their healthcare providers. “I found out by mistake. I had pneumonia and they wanted to be sure, so they wanted a chest x-ray.” Another participant said, “If I did not have bronchitis, I never would have gone [to the doctors].” Other participants’ initial nonrespiratory symptoms included fatigue, weight loss, and back pain. “My back kept bothering me, and I went to my primary doctor and told him. [He] said, ‘Maybe you have a cold in your back. Let’s take a chest x-ray.’ They told me there was a spot on my lung.” Others’ symptoms were related to aging. One man, who noticed increasing fatigue, said “I worked all last summer, and I would feel a little more tired but I figured I was getting old, so I didn’t suspect . . . no pain or nothing like that.” Another said, “I kept losing weight, and not feeling good, so I went to the doctor and had a CAT scan done.”

Participants attributed their symptoms to other factors instead of a lung cancer diagnosis. The severity and frequency of the symptoms varied among participants, as well as the presence of chronic obstructive pulmonary disease (COPD) that made the diagnosis more elusive. Because of the lack of specific symptoms associated with lung cancer, participants were devastated by the news, although most were not surprised because of their smoking history. One participant said, “It was hard, devastating, because, not that I haven’t had warnings because, number one, I am a smoker; I’d never truly known but always suspected . . . but I thought I had a sinus infection or a flu.” Another participant who smoked said, “I have been a smoker all my life so [I was] kind of like, just waiting for it to happen.” A sense of responsibility for the diagnosis emerged from the interviews as exemplified by one statement. “I just figure whatever happened is my fault.” The devastating, yet expected, diagnosis led participants to discuss treatment options with their providers.

Theme 2: Treatment as Hope for More Time

All participants chose treatment after their lung cancer diagnosis based on discussions with their healthcare providers; it was explained that no cure existed as of yet, but participants were willing to give treatment a try to give them more time. The participants portrayed a view of the cancer diagnosis as a chronic illness to be treated rather than a death sentence. As one person said, “I know there is no cure for it, but it can be controlled . . . because there are things I love to do; so as long as it does not disrupt my life, I can handle that.”

The pervasive sense of hope emerged from the participants’ stories as they discussed the treatment options, stating a willingness to fight the cancer and put their faith and trust in the providers and the healthcare system. Some participants also included God in their hope and trust in treatment, as one participant said, “I believe they will shrink [the tumor] and put a little more time on my life; whatever God decides.” Another participant who smoked said, “I have been a smoker all my life so I was kind of like, just waiting for it to happen.” A sense of responsibility for the diagnosis emerged from the interviews as exemplified by one statement. “I just figure whatever happened is my fault.” The devastating, yet expected, diagnosis led participants to discuss treatment options with their providers.

I got it, but I do not know how long I will live with it, they do not know either. I could die tomorrow, who knows? But right now, as far as I am concerned, we have a chance to do something about it; so that is what I am doing, fighting back, fighting the cancer; maybe one day they will find a cure.
Older participants had an attitude of acceptance because they had lived a full life. This acceptance kept them from feeling despair as one participant said, “I am not depressed; I am 84 and have lived an active, full life. My spirits are good but I am anxious to get started [on treatment].” Another said, “I lived a lot longer than a lot of people I know.” However, younger participants were more anxious to start treatment and continue their normal life activities.

Before the diagnosis of lung cancer, a few participants had undergone past treatment for different types of cancer; while most patients expressed anger and anxiety regarding initiating treatment, those emotions were particularly evident in the patients who faced a cancer recurrence. Others had lived a long time with comorbidities such as COPD and had learned to adapt to their conditions. However, in spite of the anger, participants maintained hope for treatment to give them more time, as one person said, “You just do the best you can do, but you just got to deal with it.” During the initial interview, the hope that treatment provided pervaded their narratives as they tried not to think about the alternative. As the participants accepted and planned for treatment, they returned to focusing on their daily lives.

**Theme 3: Keeping Life Normal**

Participants told stories that illuminated what was most important in their current lives, whether it was to continue working, caring for children and grandchildren, or generally continuing on with normal life. Although they understood that some accommodations would be made because of the treatments’ side effects, they generally wanted to continue “doing what they do,” and accepted that activities may take more time and effort. One participant said, “I have learned to somewhat live with the condition . . . I have things I have to do.” Another woman related, “I got to do what I got to do. I’m a single mom, and I have a granddaughter who’s lived with me since she was born. I have a foster child and a daycare . . . I really can’t just stop.” Others who had a previous diagnosis of a different cancer knew how to accommodate to the new diagnosis.

It is an experience I’ve had before, so you just have to take it day by day . . . and do the best you can . . . get things situated and get in a comfortable mode. You are going to get tired but you just got to deal with it . . . got to stay healthy as you can while you are going through it.

Some descriptions had fighting words, “I just keep going, that’s all you can do, I say ‘fight back,’ if you fight and lose, at least you know you fought back.” Others wanted to continue life as normal and not think about the outcomes. One person articulated this by saying, “I do not think about it; it is tough not to think about it, you try not to, but keep on going.” Another said, “I just keep going day by day. I don’t vary my routine much other than the sleep part of it.” Another person used that approach to cope with the diagnosis. “I am coping this minute. I try to put things off to the side . . . I keep it pretty much hidden from myself now.” Most of the participants did not talk about death.

Others had a positive attitude and engaged in activities that provided some distraction and purpose. One man said, “I try to keep positive . . . keep busy . . . do what you got to do. I went through the whole house and repainted it.” Another said, “I’m not going to complain now . . . it is not the end yet; there is no sense in complaining, do the best I can and keep on doing.” Other participants chose activities that they enjoyed. “I don’t dwell on it, and I am looking forward to going fishing as soon as the ice is gone.” Another enjoyed continuing to work “because I teach and we found out early enough, they went and redid the schedule so I will not miss work.” Positive attitude was valued as a way to keep up a normal life. “I’m just hoping—I have remained positive and hope that I am able to remain that way. I think the longer that any of us can remain positive, the better off we’re going to be.”

Participants described that a key component of keeping life normal was facilitated by family members who offered support through encouragement, as well as accompanying them to treatments.

I have been fortunate in the sense that I have got a tremendous amount of support from my family, our friends, and people at the church. This has helped a whole lot as far as my dealing with this . . . and remaining positive.

Participants’ stories also portrayed camaraderie at the hospital, which included the helpfulness of the healthcare team members and fellow patients. One participant said, “The treatments they give me and by the love they give [me] brightens me up and has turned me around. I feel so much better about [the diagnosis].” For some, it was the social nature of the relationships that brought normalcy to the clinical treatments. “It’s like a family in there. . . . They know each other by name, because they go in there so often and you can’t help but talk to the people around you.” Keeping life normal represented the participants’ desire to live and stay healthy enough to maintain purposeful lives even after a diagnosis of lung cancer.

**Theme 4: Sleep Habits as Long Lived**

Although very few participants worried about their sleep, most participants’ sleep history described trouble falling and staying asleep (insomnia), frequent awakenings (fragmented sleep), racing minds, and poor sleep hygiene (see Table 2). Only two participants recounted
stories of good sleep and healthy sleep hygiene practices such as regular bedtimes, not watching television before bed, and avoiding prolonged daytime naps. Participants’ lifestyles often were not conducive to good sleep practices because of swing-shift work or nighttime parenting obligations. Nighttime also was when daily worries interfered with sound sleep.

Difficulty falling asleep: Some participants described difficulties falling asleep, as one man said, “Well I never really had what you call a normal night’s sleep. I always had racing thoughts and I would lay in bed at night awake and think and weigh different things. I always slept but not real good.” Women had similar difficulties falling asleep.

I think all the time, I mean that’s a woman issue, isn’t it? My husband used to say, “Just go to bed and stop thinking.” You cannot do it, you cannot shut your brain off, you are worried. I’m not “what if this” or “what if that” or worried about myself, I’m worried about my kids.

One man considered his sleep difficulties normal.

I’ve always been that way, I do a lot of mental work . . . I solve a lot of problems lying in bed before I go to sleep and it has been a pattern for me, if I have encountered something during the day which is kind of a puzzle for me, and I have not yet scoped it out. If I bring to mind on that time, I will somehow, sometimes come up with an answer. I do not know if I’m encouraging [staying awake] or not, but that was the way it was when I was well.

One man had been diagnosed with insomnia. “I am not sleeping now. I have got terrible insomnia. They are treating me for that with pills to relax.” However, only 31% of the participants had sleeping pills or took over-the-counter sleep aids.

Nighttime awakenings: Once the participants fell asleep they often described frequent awakenings that lead to fragmented sleep. Frequently, participants described getting up to go to the bathroom. “I get up a couple times a night to go to the bathroom, sometimes I have a hard time falling back to sleep.” Some describe the inability to sleep for long times. “I sleep probably the first part of the night, four to five hours, then it gets a little more difficult to get back to sleep, and I may get two more hours.” Various participants described symptoms that could be related to awakenings such as back or chest pain, shortness of breath, cough, and restless legs. One man related his awakenings to restless legs. “I have a nerve condition that keeps me up and [feels like] a worm thing that runs up and down my leg.” Others said their medication kept them awake, such as steroid use. Another participant discussed the progression of sleep problems. “I use to get four hours before I’d wake up, and now it is down to an hour and a half, two hours, which is not enough really.”

Sleep hygiene practices: Participants described their use of caffeine and alcohol which could influence sleep. Once awake, participants often could not return to sleep, as one said he would, “wander around or watch TV or something, once I go back to sleep it usually doesn’t last very long.” The participants described daytime fatigue that led to naps, which may have contributed to fragmented nighttime sleep. The sleep patterns they described were typical occurrences for years, part of their lives, and not interpreted as abnormal.

Constitutive Pattern: Sleep Is Not a Priority When Living My Life

The participants’ stories of their diagnoses of lung cancer conveyed the experience of the devastation of diagnosis and a hope for more time. With this feeling
of hope, they trusted the healthcare providers to plan a course of treatment that they were willing to include in their lives. Participants’ priorities were living and doing what they normally did and, usually, these priorities did not include the focus of obtaining restful sleep. Therefore, the participants’ sleep remained fragmented, leading to fatigue and a frequent napping schedule that additionally contributed to poor sleep consolidation at night. Participants’ overall priority was living their lives and not worrying about sleep, as one woman described, “I really can’t just stop. Whenever it gets to the point that I can’t, then I don’t have a choice . . . but, sometimes, just maybe move a little slower.”

Discussion

The findings of this study reflect only the stories of participants who chose treatment for lung cancer. However, the themes and patterns from this analysis provide insight into understanding the experiences of people receiving treatment for NSCLC.

The current participants were devastated but not surprised by the diagnosis, which is a common experience because of the lack of specific symptoms related to lung cancer (Tod, Craven, & Allmark, 2008). The participants contended with common respiratory illness and comorbidities, such as COPD, that masked lung cancer–related symptoms that were similarly described in other research as contributors to diagnostic delay (Molassiotis, Wilson, Brunton, & Chandler, 2010; Murray et al., 2002; Tod et al., 2008). Almost all of the current study participants acknowledged a smoking history, but they did not dwell on it. Those findings are unlike other studies, which described a sense of shame and stigma (Berterö, Vanhanen, & Appelin, 2008; Chapple, Ziebland, & McPherson, 2004; Dias & Turato, 2006) increasing the psychological distress of patients (Joyce, Schwartz, & Huhmann, 2008). Although the diagnosis was devastating in the current study, it was tempered by the hope treatment offered.

Participants in the current study expressed a strong sense of hope for a longer life, grounded in treatment expectations, trust in healthcare providers, and a belief that lung cancer is a chronic disease. Similar studies linked hope with improved health status and preserving quality of life (Berterö et al., 2008; Efkors & Petersson, 2004). However, in other studies, thoughts of death were common among patients with lung cancer (Berterö et al., 2008; Murray et al., 2002) and more evident in patients with advanced stages of lung cancer (Lehto & Therrien, 2010; Moore, Chamberlain, & Khuri, 2001; Nissim, Gagliese, & Rodin, 2009). Surprisingly, participants in the current study distanced themselves from thinking of imminent death in spite of their advanced stages of cancer diagnosis (IIIA, IIIB, and IV) and, instead focused on treatment options and their acceptance of disease.

Implications for Nursing

Nurses should be aware of the potential for creating false hope because of misinterpretation of anticancer therapy (Steinvall, Johansson, & Berterö, 2011), to allow time for patients’ anticipatory grief and preparation for death. Participants in the current study strove to maintain their normal life while adapting to the diagnosis, ignoring the effect of their poor sleep patterns on their lives. Consistent with previous studies (Efkors & Peterson, 2004; Lehto, 2011), participants kept busy, enjoyed life, and thought positively. “Living as usual” also was confirmed in Berterö et al.’s (2008) study; keeping life normal influenced quality of life and maintained independence and a sense of control over the situation.

Family, friends, and the healthcare team assisted participants in the current study in keeping life normal by facilitating normal life activities. Similar research demonstrated that the family provides practical and emotional support (Holt et al., 2009; Illingworth, Forbat, Hubbard, & Kearney, 2010; Maliski, Sarna, Evangelista, & Padilla, 2003), encouraging acceptance when they are unable to control the situation (Sjölander & Berterö, 2008). The healthcare team support was vital to participants to enable a feeling of control and enhance their feeling of confidence (Efkors & Petersson, 2004; Sjölander & Berterö, 2008).

The current study findings illustrate how past lifestyles shaped participants’ sleep patterns and habits. Although few perceived their sleep as poor, the narratives portrayed sleep difficulties, particularly the inability to fall asleep and frequent awakening, similar to a previous report by Chen, Yu, and Yang (2008). Chen et al. (2008) also found early awakenings and frequent nocturia to be related to poorer cognitive function and functional status in patients with lung cancer during chemotherapy. Although previous studies discussed patients’ fears of death (Berterö et al., 2008; Lehto, 2011; Lehto & Therrien, 2010), participants in the current study did not express concern about fear of death keeping them awake. Although participants described a variety of symptoms such as pain, cough, dyspnea, and fatigue, none of them associated the symptoms with poor sleep despite needing a nap during the day. The number of participants in the current study with sleep issues (92%) is far more than the 50% cited in the current literature on incidence in patients with lung cancer (Durmer & Dinges, 2005). In addition, few participants used sleeping pills or other nonpharmacologic means to manage these problems. The sleep problems were preexisting and not a priority for participants, which could become
problematic as the patients begin chemotherapy and the effects worsen. The potential for exacerbation of sleep problems with the upcoming chemotherapy and the effects of poor sleep on cognitive function and functional status supports Chen et al.’s (2008) suggestion that sleep problems need to be assessed and routinely treated despite the lack of awareness by the already fatigued patients. Educational programs for providers and patients could increase awareness of the need for evaluating sleep, improve knowledge of good sleep hygiene, and promote behavioral interventions to improve sleep in patients, ultimately improving their ability to live their lives.

Conclusion

The current study describes significant sleep-wake disturbances in patients newly diagnosed with lung cancer that were present early on and are reflected in their lifestyles. As they planned to begin their chemotherapy, they embraced hope for more time, but their priority was living their life and not worrying about sleep. However, while focusing on their priorities, they may suffer the consequences of poor sleep, which would inhibit their ability to do what they want. The study will continue to follow the patients over the course of their chemotherapy to see how they manage their lives.

Suzanne S. Dickerson, DNS, RN, is an associate professor and Eman Abu Sabbah, MS, RN, is a doctoral student, both in the School of Nursing at the University at Buffalo in New York; Patricia Ziegler, NP, RN, is a nurse practitioner at the VA Western New York Health System in Buffalo; Hongbin Chen, MD, PhD, is an assistant professor in the Department of Medicine at Roswell Park Cancer Institute in Buffalo and a clinical assistant professor in the School of Medicine and Biomedical Sciences at the University at Buffalo; Lynn M. Steinbrenner, MD, is the chief of the hematology/oncology department at the VA Western New York Health System; and Grace Dean, PhD, RN, is an assistant professor in the School of Nursing at the University at Buffalo. This study was funded by the ONS Foundation and the National Lung Cancer Partnership. Dickerson can be reached at sdickers@buffalo.edu, with copy to editor at ONFEditor@ons.org. (Submitted October 2011. Accepted for publication February 28, 2012.)

Digital Object Identifier: 10.1188/12.ONF.492-499

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