A Voice that Wraps Around the Body — Communication Problems in the Advanced Stages of Non-small Cell Lung Cancer

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Introduction: Significant problems in clinician-patient communication have been described in the oncology literatures. Advanced stage non-small lung cancer, a devastating disease, can cause the communication between survivors, significant others, and clinicians to falter. To date, however, no studies have used qualitative methods to examine experiential aspects of living with non-small cell lung cancer. Nor have any studies evaluated the tools survivors might use to repair some of the damage caused by living with this disease.

Methods: Exploratory, two-part qualitative design.

Results: Survivors of non-small cell lung cancer live with multiple fears and losses. These include a diminished sense of self, the loss of health, fears of pain in a future tainted by the threat of death, and increased feelings of alienation due to the loss of previous sources of meaning in life. These experiences significantly affect cancer survivors abilities to communicate with clinicians and significant others.

Conclusions: Survivors of non-small cell lung cancer often have difficulty sharing their experiences with others not suffering a similar affliction. Through their narratives with other survivors, however, patients are better able to initiate a biopsychosocial mechanism which enables them to create a cognitive map. This cognitive map helps survivors share their experiences with others, thereby repairing some of the damage caused by this disease, including the harm done to their communication with other people.

INTRODUCTION

Lung cancer is the leading cause of cancer-related death around the world and in the United States, 164,100 new cases and 156,900 deaths occurred in the year 2000 \cite{1}. The majority of lung cancers are non-small lung cancers (NSCLC)\textsuperscript{d} \cite{1}. NSCLC is almost always caused by exposure to tobacco, including active cigarette smoking, pipe and cigar smoking, and exposure to second-hand smoke (passive smoking) \cite{2}. Other factors known to increase individual susceptibility to lung cancer include various occupational exposures (e.g., radon and asbestos), diet, gender, and genetic susceptibility \cite{2-3}. Since

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\textsuperscript{d} Abbreviations: HPA, hypothalamic-pituitary-axis; NSCLC, non-small cell lung cancers; SCLC, small cell lung cancer.

Received: July 12, 2001; Returned for revisions: September 5, 2001; Accepted: October 17, 2001.
no test provides adequate early detection, and symptoms are generally not present (except in the advanced stages of disease); patients are generally diagnosed with advanced-stage or metastatic disease (i.e. stage IIIB and stage IV) [2]. Treatments for advanced stage disease are rarely "successful." Thus few advanced stage NSCLC survivors are successfully "cured," or experience an extended disease-free survival time, as the majority of patients who undergo curative resection will develop recurrent metastatic disease within five years of their initial diagnosis [2]. Five-year survival rate combined for all stages of disease is approximately 14 percent [2]. Due to a generally grim prognosis, toxic treatment regimens, physical morbidity, and poor survival time-rates, patients with advanced staged NSCLC understandably experience far greater distress and feelings of alienation than survivors with other advanced tumours [4-5]. This includes difficulties sharing their experiences with other people [6-10].

In this paper, we suggest that NSCLC exacerbates a disruption between the mind, body, and the social world of the individual with cancer, a breach often reflected in a crisis in communication between clinicians and patients, as NSCLC survivors' experiences seemingly defy language. These communication problems stem from the lack of common overlap between language and experience, since others who exist outside the experience of NSCLC invariably fail to fully grasp the impact and meanings of this experience on the NSCLC patient who suffers [6, 11]. Nonetheless, narratives can assist in the mending of this breach because they can aid the patient in a process whereby psychosocial and physiological experiences can be integrated into the patient's life [6, 11-12]. In this manner, clinicians can use what they learn from NSCLC survivors' narrative accounts of illness as a means of decreasing psycho-

logical morbidity, including patient's feelings of being diminished by cancer, the despair, distress, and social isolation that is often characteristic of living with NSCLC. In addition, we also describe how this process of repair through narrative could potentially initiate a biopsychosocial mechanism, which begins when a NSCLC survivor seeks social support for their illness from other survivors. Through a complex process of learning, patients are better able to develop a cognitive map. This cognitive map, because it provides the survivor with a framework of what to expect from treatments, enhances a NSCLC survivor's ability to understand their own experiences articulated and mirrored through the lens of other survivors' experiences. As a consequence, NSCLC survivors are better able to narrate their concerns and share these experiences with other people, including their caregivers.

LITERATURE REVIEW — ISSUES THAT AFFECT COMMUNICATION WITH ONCOLOGY PATIENTS

A review of the literature demonstrates that a variety of communication problems affect the care of oncology patients. The majority of these however, tend to over emphasize phenomena such as the medical interview and the breaking of bad news as focal points of inquiry [13-19]. These studies suggest that "oncology as a social practice" exacerbates problems in clinician-patient communication because delivering news about the cancer diagnosis, treatments, and metastases can cause the dialogue to falter. Other important barriers to effective clinician-patient communication have also been recently identified [20-23]. These physician-related barriers include the unwillingness to deal with the unrealistic expectations for "cure" on the part of patients [13, 17-19, 23-29]. Time constraints in seeing survivors and adequately addressing their informational
and emotional concerns [28, 30-32] and the lack of communication skills-training of clinicians [17, 20, 32, 34-35]. Patient-related barriers include poor communication skills by patients who may be unrealistic. A lack of involvement in the medical discussion of care, including inadequate information and expectations about what to expect from treatments and post-treatments as these impact health-related and global quality of life [17, 20, 32, 34-35]. The patient’s inability to accurately recall information [18, 28, 29]. And finally, patterns of communication between cancer patients and clinicians may be disrupted by the patient’s fear that related symptoms such as pain signify a return, or spread, of the cancer, serving as a premonition of death from this disease.

In this paper, we argue that the impaired communication between the clinician and the NSCLC patient that generally occurs due to the absence of a shared language and cultural experience can be partially mended through narrative. However, to begin to understand the origins of this impaired communication, we suggest a broadening of the definition of what communication means in states of health and illness. Implicit in this broader definition is that in states of health, all information from the external environment is communicated to and transformed into neural processes, ensuring the proper regulation of immune function in both brain and body, such that a relative state of homeostasis (health) is maintained [36, 38, 40-41]. Thus, the long-term process leading to the appearance of cancer, and the disruption of communication in terms of neuro-immune function is susceptible to modulation and modification by both endogenous (internal to the organism) and exogenous (external to the organism) factors, such as stress [36-38]. In response to immune challenges, certain lymphoid cells produce proteins, or cytokines, mediating various immune signals to the brain [40-41]. The brain then sends neurotransmitter and hormone-mediated signals via the autonomic nervous system and the pituitary-endocrine axis respectively. The hyperactivity of the hypothalamic-pituitary axis (HPA), a typical response to stress, induces increased production of stress-related hormones, such as cortisol, which then serve to either modulate the immune response, or possibly indirectly activate oncogenes by HPA axis hormones [39-41]. Nonetheless, while important evidence exists that could partially explain important transitions from health to illness in the human system at the molecular level, other research must also begin to understand the related social processes that broadly affect patterns of communication between clinicians and cancer patients. These include understanding the emotional, existential, and psychological paths that patients must take as they endeavor to make sense of their experiences with advanced-staged disease, and perhaps most significantly, how they adapt and communicate these experiences and concerns with other people.

SOCIAL SUPPORT

Human beings generally continue to learn and integrate information at all ages due to their social, cultural, historical, and emotional interactions with other people. Indeed, supportive interactions have been shown to modulate neuro-immune function in both healthy controls and in cancer patients [40-41]. Psychosocial interventions, emphasizing social support in the context of cancer support groups, have yielded improvements in fighting spirit, reductions in helplessness, anxiety, depression [40-41], enhanced satisfaction in life, communication and a decrease in anxiety, and distress [8-11, 40-44].

One of the central tenets of social support in the context of oncology is that survivors share their narrative accounts of
illness situated in the context of their life experiences with others who are similarly afflicted. This is because narrative is crucial to the process of recognizing and integrating repressed and alienated selves that suffer since it is one of two fundamental modes of cognitive functioning [45-46]. In contrast with paradigmatic thinking, which emphasizes formal categorization, narrative thinking emphasizes the structuring of events in terms of the human calculus of actions, thoughts, and feelings [45]. Narrative is also an important tool that can be used to probe, resurrect and forge connections between unstable, situated selves in the context of illness [46], as over time the patient can begin to express their feelings in a supportive context where their unique encounters with illness can be understood. Feeling understood, the cancer survivor ideally begins to build a cognitive structure over time that supports a bridge between the memories and images of who they are, with who they have been, and who they might realistically become as they go through treatments and beyond. Social support through the medium of narrative then works to begin to systematically repair some unknown portion of the neuro-immune link, which had previously extensively engaged in interactions between the internal and the external environment prior to illness. This repair, initiated by the cancer patient in the context of socially supportive encounters, serves to reconcile certain disparities in the individual body/self as situated in a social context of the illness. In this manner, patient’s narratives not only give shape to their experiences with NSCLC cancer as they provide the patient with a language for their experiences but also a language to communicate and share aspects of these experiences with other people. In this way, patients’ narratives can also aid the clinician as they attempt to understand the underlying cognitive processes, motivations, and cultural frameworks that inform human thought processes across culturally diverse cancer patient populations [47].

METHODS

The product of a qualitative study is a narrative [48]. To address these important concerns, we designed a two-part qualitative study. Qualitative research can be defined as the process of summarizing and interpreting data to develop theoretical insights that describe and explain social phenomena such as interactions, experiences, roles, perspectives, symbols, and organizations. In terms of health care analysis, qualitative research can also offer insight into the emotional and experiential phenomenon to define the whats, hows, and the whys of everyday life experience. Examples include inquiry about the multiple meanings of illness to patients and their families, or about the attitudes and behaviors that affect dynamics between patients and clinicians.

The initial phase of this qualitative study (i.e., November 1998 through February 1999) sought survivors’ understandings of lung cancer treatments, and related symptoms, including pain, distress, alienation, and cognitive dysfunction. What emerged from these early interviews was the observation that the majority of patients enrolled in our study also described a loss of self due to the difficulties entailed in describing and sharing their experiences with others that did not also have lung cancer. Therefore, to better understand these barriers to communication, we designed a second part of the study (March 1999 until November 2000). This part of the study was designed to further evaluate the potential role of survivor’s narratives as a vehicle to communicate their experiences with others and as an attempt to repair some of the damage caused by this disease.
We are not aware of any studies that have ethnographically explored narrative accounts of patients’ experiences with NSCLC. Because this was a pilot study, and previous reports were unavailable to suggest what concerns NSCLC survivors might have on the subject, interviews followed an open-ended semi-structured format. This format allowed specific questions to be asked of each patient and also permitted each patient to contribute information that was important to them. Interviews lasted one and one-half to four hours and were conducted and tape-recorded either at the cancer center or over a meal. It seemed appropriate to conduct open-ended, semi-structured interviews rather than to administer a fixed response questionnaire since this helped to prevent a distortion of patient’s responses by the researcher and allowed for the emergence of unanticipated findings. Subjects spoke about their diagnosis, their feelings about having advanced-stage NSCLC cancer, its effects on their social and family lives, social support, medical and family histories, and their perceptions of how they were treated by health professionals. After transcribing and then reading the interviews, cases were coded by categories, themes and patterns. By situating these narratives in the context of their lives, the goal was to remain faithful to what these survivors meant as they described their experiences. The interview questions are listed in Table 1. This qualitative analysis is based on approximately 150 hours of interviews.

Sample

The investigators received approval from the institutional review board prior to the beginning of this study. To explore the broad experience of living with NSCLC, we conducted a two-part study. Twenty-six survivors with advanced-staged NSCLC were recruited and interviewed for this study between November 1998 and November 2000 at The University of Texas M.D. Anderson Cancer Center in Houston, Texas. Because NSCLC has such a high recurrence rate, we chose to speak with survivors across all phases of disease experience: from the newly diagnosed patient making treatment decisions, to the patient undergoing chemotherapy, and to the long-term cancer survivor. Survivors with advanced-stage (Stage IIIB, Stage IV) NSCLC 2 were recruited with the assistance of a medical oncologist. All patients who were approached decided to participate in this study. Informed consent was collected at this time.

RESULTS

Themes

Three major themes affecting patterns of communication were described in the first part of this study. These were: loss of the illusion of life and health, including how the self was diminished by the cancer experience, fears about pain and a future colored by the threat of death, and finally an increase in feelings of alienation, due to an inability to adequately share these experiences with others. These themes highlight the difficulty of living with NSCLC. During interviews, patients spoke about how alone they felt, how the diagnosis had disrupted their lives, and their desire to speak with other NSCLC survivors who were also struggling with this disease. In the interviews, patients also spoke about how their experiences significantly (and often negatively) affected their ability to communicate with clinicians and significant others who had not shared similar experiences of disruption. The second part of this study focused on how survivors described the cultural and cognitive process of becoming an expert to gain greater insight into what NSCLC survivors did to repair some of the damage caused by this disease.
Table 1. Participant questions.

Questions for Part I.

1. Where are you from? How did you find out that you had lung cancer? When were you diagnosed? Did you have any symptoms?
2. Is this your first encounter with NSCLC? Did you ever have cancer before?
3. What did you know about lung cancer prior to your diagnosis? And now?
4. What did hearing that someone had cancer mean to you? Before cancer? Now?
5. At what age were you diagnosed with any cancer? What stage?
6. How do you remember your doctor/nurse telling you that you had cancer? How did you feel cancer? What do you remember about the experience? Did you let your family know? Who did you tell? Did you detect that people treated you differently as a consequence of knowing that you had cancer?
   What was your treatment regimen? Number of weeks/cycles?
   Surgery________________________ Radiation________________________
   Chemotherapy________________________ Other________________________
7. What discomforts if any did you experience during your treatments? Hair loss? Fatigue? Did you feel pain?
8. What would you say were the more painful aspects of your experience? How would you describe them?
9. Before the treatment? During? Now? Can you separate out the different aspects of the experience? Describe the pain? Was it just a physical sensation? Emotional? Spiritual?

Questions for Part II:

1. Do you talk with other people about lung cancer? Have you noticed any problems communicating that you have NSCLC to other people? If so with whom did you talk; if not why not?
2. Recently there has been a lot in the literature suggesting that more women are living longer and surviving lung cancer — how has this emphasis on lung cancer in the news affected your life? Your relationships?
3. Did you ever feel alone in this experience?
4. What did you do to get over this feeling?
5. Did you talk with a counselor, or therapist?
6. Did you talk with other survivors of NSCLC? At what point in your treatment did you talk with other survivors? How did this experience change your life?
7. What does life mean to you now? And if there has been a change, how has it changed?

Loss of an illusion of health and of life

A diagnosis of advanced-stage NSCLC, debilitating treatments, the continued threat of pain and death is always a devastating experience, causing personal, social and psychic disruption in advanced-stage NSCLC patients. Similar to previously described quantitative studies on this subject, [5, 8-9] upon being interviewed; NSCLC survivors described their losses, fears of pain, they articulated how NSCLC diminished their sense of self, and the threat of dying; amidst these increased feelings of alienation [49]. Still others expressed fears of suffering, that they would die alone, or in pain from this disease.
In an account of being suddenly faced with the loss of health, a grim prognosis, and a loss of life, Anna Ye, a 39-year-old, Asian-American computer engineer, who was diagnosed in June, 1999, with Stage IV NSCLC stated:

I am only 39 years old. I started to have some wheezing and some blood in my spit. I could not breathe, and on June 11th — I will never forget that day. I had an x-ray and the results were not good. I was sent to the lung specialist. He did a biopsy. I did not appreciate his bedside manner. This doctor delivered the news while I was flat on my back tubes everywhere and he just dumped it on me. He said, Ms. Ye, even though I am married, I whispered yes, he said it is lung cancer, and it has spread. Then he looked away. He never looked into my eyes. He was very precise, and his time with me was very brief and very short. I cried, and then he was gone. He never even looked at me. On June 16th I came here. On the 28th I started chemo on July 2 till now. We got books about this disease but for a while nothing sunk in. Reading about NSCLC especially before 1997, you read it and you know you are going to die. All the protocols are scary. I used to get panic attacks you know I was afraid to sleep. I sometimes think I will not wake up. Some days I am hopeful but on other days… I am only 39, what did I do to deserve this?

William Johnson, a white, 63 year old farmer and 8-month survivor of Stage IV, NSCLC described a similar reaction to his diagnosis. He began:

I was diagnosed on April 8, 1999. I went from health to this. Five-bypass surgeries and they find a spot on the X-ray. I had the surgery and then had these treatments. Four different times after the first treatment I wound up in the hospital. Heart problems, low blood sugar, a severe rash, and I vomited for two days. Two weeks later all my hair fell out, my nails hurt, my bones ached, I was so tired, I could not eat a thing, and I could barely breathe. I have worked all my life to retire to be with her (refers to wife). She used to work in a sweatshop sewing clothes. She just retired. We wanted to be together, and now I can’t breathe and I feel like there is no time left.

In a related story, Paul Roberts, a white 67-year old male, was initially diagnosed in 1994 with a stage II tumor. Accompanied by his wife in clinic in 1999, he described in what had become a very raspy voice, not only finding out that he had cancer, but that his cancer had returned. He began our interview by stating how he woke one day spitting up blood. Then he claimed:

I had felt fine for some time but in the bathroom I noticed I spit bloody saliva into the sink. I spit up blood for a couple of days. I went on a vacation, spitting up blood. I smoked for 41 years and yes I was aware of the risk factors. I was and am clinically depressed. I got back from vacation, still spitting blood and I saw the internist and thought it would be ok. They got a chest X-ray. Found out it was cancer. This made my depression real bad. So I asked how long have I got? Twenty-five percent chance of living? Two years right? Before this you know I was an international banker. I managed other people’s money. Numbers matter. I saw the surgeon, stage I, operated on in July 1994. My right lung is two-thirds of the way gone. I almost died in the intensive care for 10 days. I never saw a medical oncologist, no radiation oncologist, just Dr. Faher every six months. All was fine till it came back that first time in March 1997. Saw a shadow. Left lung filled with cancer. Left lung this time. I went to all these places. Everyone said ok let’s operate. They opened me up in June and seems like soon after I went to sleep and opened my eyes it was noon. They had only started at 7am. The doctor told me they couldn’t get at it since it was too extensive.

While most survivors spoke about this painful and often dramatic transition from health to illness, others reported feeling stigmatized, claiming that they didn’t understand why physicians and other medical professionals were so obsessed with their smoking behaviors. Sarna, in one of the few examinations of the psychosocial
issues faced by survivors of lung cancer, noted that despite some modest advances in treatments for primary disease that the attitudes of clinicians have not altered radically, which is another psychosocial factor in treating survivors with this disease [5]. NSCLC survivors also often reported that clinicians were also quite judgmental if they perceived that the survivor still smoked, reflecting perhaps the significant amount of burnout and frustration of clinicians treating survivors in this population [49]. They often also reported that there was limited sympathy for them, since they were seen to have caused their disease. This might be why William Johnson, the 63-year old, retired farmer, made it his personal agenda to tell the research nurse who asked him about his smoking history, how he felt. In a biting critique of being stigmatized, he exclaimed:

You know, not everything needs a reason. I mean you have tons of folks whom never smoked and got lung cancer. And tons who did and never got lung cancer. And then you got me I smoked and I got lung cancer. So what! I chewed cigars and smoked for 26 or 28 years. What caused this, my doc said bad luck, bad genes, or it could have been the farm chemicals, who knows, and who cares. I got it so why do you all ask that does it really matter? Is that all you care about? You know, not everything needs a reason. You just concentrate on curing me ok.

**Fears of cancer and related pain**

Clinical perspectives and survivors’ expectations and experiences often differ, particularly in terms of the mental and emotional effects of the experience of cancer and related pain [10], the language used to describe pain, and controlling, understanding and alleviating the suffering it causes. Pain is a synonym for a variety of symptoms. Unrelieved pain increases the suffering of the survivor [50] and an increase in pain (based on survivor self-report) in advanced-stage NSCLC in one major study was associated with a 27 percent increase in death [51]. As pain is a synonym for a variety of other symptoms, survivors universally described their pain in terms of feeling diminished by lung cancer, and in their decreased hopes for a decent quality of life. Others found it difficult to think about the possibility of a future in the advanced stages of their illness. Often, when survivors experienced any pain that seemed different than “normal,” they feared that their tumor might be growing at an exponential rate. The majority also felt alone with their pain. The experiences of Amos Night a 73-year-old African American man, who was diagnosed with Stage IV NSCLC in October of 1999, highlight these previous points. He noted:

I am afraid I will never get well. When I hurt I am afraid it’s growing. My brother is here and yet I am still alone. The coughing, the tiredness just never ends. See all that coughing (he coughs). Nothing comes up. This is never going to end till I die is it? You know mine began as cough pain and weight loss. I was initially diagnosed with bronchitis. I was diagnosed with cancer three months ago. I keep coughing and I am sick. I am half way through chemo and half way through radiation. I had pneumonia and I was in the hospital for 18 days. I am tired all the time. I cough constantly. The doc says its just pressure but I consider it pain. I hear echoes in my hearing because of the cisplatin. I can’t seem to do nothing right. My life hasn’t changed at all except I am scared and sick all the time. This fear, you know, it wraps around a body. I am scared of all this pain and scared I will die coughing. Do you know what that feels like, like you are breathing and it ends in a cough caught short in the breath. Life is not more precious now and it never was. But I am just scared I won’t live to find out.

To visit the possibility of the alleviation of his pain and suffering, Mr. Night asked questions that the clinician cannot generally answer. What we also learned was that the majority of survivors felt a
similar fear. This fear was that at the end of their lives, they would die in agony from cancer-related pain, and that their pain would not be effectively controlled, nor would their suffering be adequately relieved. As a consequence of these experiences, patients also feared that they would no longer be the persons they had been in any recognizable form. Research studies show that their fears are quite grounded, since the majority of cancer-related pain remains under diagnosed and too much cancer pain goes untreated [50, 52-53].

Cheryl Hopkins was a white, 56-year old woman who was initially diagnosed with Stage I adenocarcinoma of the lung. Speaking as a three-year survivor, recently diagnosed with metastatic disease that had spread to the bone; her particular experiences of living with NSCLC were also aggravated by persistent pain, which significantly contributing to her limited independence, decreased function, and an overall diminished quality of life. During one extremely long episode of pain, Cheryl articulated the dominance of pain on her life. She began:

You know I no longer remember what it is like to not be in pain. I can’t think of anything else but the pain and I can’t concentrate at all. It has been like this for two years. I have pain all over, under the cuff of my right arm, the doctor calls it sub-clavicle pain, and on my arm. I am on a break from Taxol. I have three weeks off. I have lost time because of pain. I have pain that increases when I have chemo and I have pain that increases when I don’t have chemo. I am damned. I have no taste anymore because of this. I am so tired, I hurt and my pain is barely controlled. I can’t explain it. I lose my train of thought all the time, I have no life but I try to stay upbeat. I ask why. I am religious but I still ask why all the pain and I ask Jesus what did I do wrong? You know I have asked him to take me, just now. Sure I smoked for a few years. It has to be environmental. I have grandchildren. I ask Jesus what did I do to deserve all the pain. I want him to take me. Do you understand me at all? I am so unclear these days. You know I am ready to leave this world. I can’t concentrate at all. I can’t take much more. My husband cries all the time. He doesn’t want me to leave him. But I know I will. I can’t do anything else. I think about this all the time. The dying. Most of the time I think about the pain.

Cheryl’s personal and social experience with NSCLC was intensified by unrelieved pain. It became understandably difficult for Cheryl to think or talk about anything else. Cheryl had learned to expect pain, a pain that could not be controlled, due to the viciousness of a particular tumor (pancoast tumor), which is generally characterized by a widespread destruction to the rib, spine and severe neuropathic pain. This type of pain is difficult to treat through traditional drugs such as morphine. As a consequence of this persistent pain, Cheryl’s life, body and self became filled with pain. Moreover, over time, she came to lack faith in anyone’s or anything’s ability to adequately relieve her suffering.

Alienation — a barrier to effective communication

When we first met Mr. David Robertson, a 64-year-old African-American man, a retired construction worker, and a three-year survivor of NSCLC in January, 1999, he bluntly stated that there are certain pains that you just can’t understand unless you have had cancer. He went on to say that there are just certain aspects of the experience that you (a person who does not have NSCLC) just wouldn’t get. Three months later, at a follow-up visit to the clinic, he made a similar statement. We reminded him that he said the same thing during our initial meetings, and he merely smiled back and stated, “I meant what I said.” Mr. Robertson’s remarks are similar to what literary scholar Elaine Scarry claimed in her influential text, The Body in Pain [11]. Scarry
describes how pain defies language, occurring on a fundamental level of bodily experience, which language encounters attempts to express and fails to adequately encompass. Due to a particular complexity, those who exist outside the pain experience often fail to grasp the significance of these experiences on the sufferer [11]. So how can the clinician effectively enter into the NSCLC patient’s experiential worlds, so as to treat and effectively alleviate their pain suffering? This seemingly no-win situation remains one of the major barriers to the adequate management of cancer and related pain.

Yet, another significant barrier to the effective management of cancer pain is rampant fears of addictions from the opioids used to treat pain in advanced and terminal cancer in the United States. These fears exist across racial, class, and gender lines on part of survivors, family members and medical professionals. We met Eleva Michaels, a white, 44-year-old, indigent woman initially diagnosed with Stage I NSCLC. At the beginning of her treatments, clinicians were sympathetic, at least until they learned that Eleva also had hepatitis B and C and was a recovering drug addict, and that her liver was so damaged from alcohol abuse that she was not eligible for any chemotherapy protocols. Due to her inability to get chemotherapy and to keep her schedule for radiation, within six months Eleva was diagnosed with lung metastases to the bone (femur). Though she had received her prescriptions, Eleva had none of her pain medication. While she believed that her family had stolen her pain medications, her accusations were often met with disbelief. In our interview, she articulated how she had to work extra hard to get her pain medications. She eloquently stated how this particular barrier, the stigma of addiction by medical professionals, had also increased her suffering. She asserted: I came here today for a lung spasm. I had three seizures and I again was sent to a surgeon for a biopsy. My right lung feels bigger where my husband kicked me. I can’t breath and I hurt, all of me. Hurt both shoulders, hurt left arm, hurt hand, my neck hurts all the time. My head feels too heavy to hold up. If I am off my pain meds I can’t move and I can’t think. I am pain and it controls me, everything I do, my activities, I just hurt all the time. And I am unsatisfied with the pain management 98 percent of the time. I used coke and other drugs. I stopped, ok. I think they fear I am still using that is why I can’t get relief. I think the docs don’t believe I am in pain. The nurses’ whisper and look at me with pity but I know they don’t really care. Bitches, to them I am just an addict who may or may not have pain. They don’t believe me. Yeah I still smoke because it calms me. I feel in control of this (points to her cigarette) but not the pain. I am dying why should I give up my one pleasure. You know I have constant anxiety. I don’t want to die but I will from this cancer. Sure people are worried. My family says they care but I had to drive myself to this emergency room. I am on morphine and I almost fell asleep at the wheel. They give me no support. Who really cares about me?

REPAIRING THE MIND-BODY LINK: THE NARRATIVE PROCESS OF BECOMING AN EXPERT

In describing the varying experiences of living with lung cancer, one can clearly see that there are few life experiences that actually prepare a person to become a personal expert of a disease like NSCLC. We can only presume how difficult it is for someone outside these survivors’ personal worlds of suffering, to enter the language of their experience, so that they can gain an in-depth understanding of these experiences. Nevertheless, it is important that NSCLC survivors attempt to share their experiences with others, with those who suffer from this disease, and with those who witness their experiences. This sharing is empowering, since patients ultimate-
ly become engaged in a unique process of learning to become experts of their illness experiences.

The process of becoming an expert of one’s own disease involves a slow biopsychophysiological process that is difficult, uncertain, and occurs over time. One reason this process seems to move rather slowly (at least initially) is because it involves the construction of a cognitive apparatus based on lived experience, dedicated to coping with a particular task, or experience. The establishment of this apparatus, or what we term “expertise,” concerned with a familiar activity, comes into existence in the brain through repeated practice and experience [59]. In addition, we suggest that it is the experience of social support that could potentially activate a biopsychosocial mechanism where psychological and physiological experiences become integrated, thereby facilitating the transition from novice to expert. Melzack has described a similar process of learning in terms of the pain experience. He states that pain is a multidimensional experience produced by a characteristic neurosignature patterns of nerve impulses generated by a widespread distribution of neural networks in the brain. All inputs from the body undergo cyclical processing and synthesis, so those characteristic patterns are impressed on them in the neuromatrix. The neurosignature as the outflow from the body/self neuromatrix is projected to areas of the brain and is transformed into an ever-continual stream of awareness. The experience of the body/self is thus involved in multiple dimensions, such as sensory, affective, physiological, etc., making a contribution to distinct portions of the neurosignature [60]. Put differently, a pattern-generating mechanism exists in the brain that is capable of sustaining an image of the body upon which sensory data are played [61].

Similarly, in the expert’s memory there is an amazingly comprehensive store of partial and total configurations, which allows the expert and not the novice to recognize a situation in an instant and know what needs to be done next. One important aspect of social support occurs when cancer survivors talk with other survivors. The sharing of their experiences of suffering with other survivors provides a crucial template that exponentially increases the momentum of this process of learning on the part of the survivor, making the process of becoming an expert happen. David Robertson described his process of becoming an expert and beginning to repair the disparity between his individual body/self and the world of other people through the experience of sharing and of being understood by a survivor at the same stage of disease. He began:

I was in pain all the time. Once I was in pain so bad I had to go to the emergency room. Then I had the nausea due to chemo and diarrhea. I had pain in my legs and since that surgery I always had pain in my sides. It is a throbbing pain. Last time I could not get out of bed for two days after the last chemo. I have come to expect the pain in my side from the surgery. I know it but I have to try and forget I have cancer to enjoy myself. Sometimes I can and sometimes I can’t but at least I know that pain. What helped me was one woman I met, had the same disease I have, same stage, now she understood me. We spoke of everything. What happened when she was diagnosed? What she did for a living? How she could no longer work? How she felt and who she was? If there was a future because at the time I met her she had been alive two years. Two years with chemo. Two years still coming in for treatments. Two years alive. Two years with this thing. Hard to imagine for you isn’t it? It’s true. Now she is dead. But I am alive. And she helped me cause she had felt and had the same thing. Now she is dead. You know there is no way to predict this cancer.

Anna Ye, also described what can be considered as a similar process of learning to become an expert. She claimed:
My journey to cure still goes on. You know what has been my shining light. Getting that phone call from Matt Johnson. I called his number. One week later he called me back. He was diagnosed in 1995. Same stage. Same disease. Ten years older. He had 30 weeks of chemo and now he is fine. He calls in to check on the drugs I am getting. He calls to see how I am. He is an inspiration for me because he sends a map of what he did. A person with the same cancer. Non small cell lung cancer. Alive, four years later. With his map, I could live a long time. In my lung cancer group we have a person with a one-year remission. Knowing this gives me strength to carry on. Just being there does help. Knowing someone else who had this and lived helps. Even if they don’t live along time. It helps. It is not like chemo.

There is rarely a cognitive apparatus in place to make immediate sense of the experience of living with NSCLC. Nevertheless, through experiences of social support from other survivors, through narratives of experience, multiple forms of expertise through learning emerge over time. Moreover as David and Anna highlight in this process of learning, new symptoms and signs are compared to one’s own pre-existing cognition’s in particular one’s own prototypes for disease, pain, or fatigue [62]. Images, sensations and experiences of others are compared and referenced within the context of building an ongoing cognitive apparatus. Thus, survivors become experts through learning, integration, and by sharing their cultural, experiential, physiological, and cognitive predicaments, which are unfortunate consequences of living with advanced-stage NSCLC. This shared understanding of cognition and learning, broadens the scope of control, serving as a means by which “experts” can learn to cope with new situations, both the easily recognizable and the new and challenging, which often come with this illness, expanding the domain of what they had previously learned to cope with efficiently [59]. Therefore, it is often through the narration of their experiences that the individual reconnects to others, their experiences of living as survivors, merged with and mirrored by the experiences of other survivors, which builds a continually revised cognitive and experiential map of survival from NSCLC.

**Limitations**

There are several limitations in this pilot study. Perhaps the most significant one is that the number of study participants was small. Thus, until other studies are completed on this subject, it will be difficult to generalize these findings to all patients with advanced-stage NSCLC. In addition, this study only describes the experience of living with NSCLC as it affects communication on a variety of levels of patients with NSCLC. Thus, only one side of the story is revealed. While the goal of this pilot study was to evaluate the experiences of NSCLC from the patient’s perspective, future studies on this topic should also evaluate the experiences of the clinicians who treat NSCLC patients, and perhaps the experiences of patients with small cell lung cancers (SCLC) as another comparison. This inclusion of clinicians’ experiences as well as the experiences of patients with SCLC could also add to the fruitful debate of clinician-patient communication in oncology, and lung cancer in particular. Furthermore, future studies in this area might also expand upon the study design by including an assessment of biological variables (i.e., the measurement of diurnal cortisol) and the quantitative assessments of mood, depression and anxiety in NSCLC patients. These variables have been shown to be of relevance in analyses, which examine the plausible link between social support, psychoneuroimmunology and survival time in patients with advanced tumors [40, 41]. The addition of these variables could certainly build upon our study design, thereby serving as a means to further validate...
the plausibility of our findings. Nevertheless, despite these apparent limitations, valid aspects of these NSCLC survivors’ experiences emerged in significant ways that could enhance understandings of clinician-patient communication in oncology care, and of patients with NSCLC.

**DISCUSSION**

The experience and struggle to live with advanced-staged NSCLC is perhaps best summarized by Dot Maklin, a 55-year-old grandmother, maintenance worker, and a rare 11 year survivor NSCLC, who upon being interviewed, powerfully stated:

> We all do what we can to survive. I have lived 11-years with non-small cell lung cancer. I was diagnosed with brain and bone mets. I was sent home to get my affairs in order. Then I came here. But you see once you’ve had lung cancer. Lung cancer. Well, you think every ache, every pain is lung cancer. You just can’t help it.

Advanced-stage NSCLC is clearly a devastating disease, exacerbating a disruption between the mind, body, and the social world of the individual cancer survivor. Because it is such a shattering experience, these patients often feel that they are not understood, living as they do with significant losses, impairments, fears of abandonment, agonizing pain, and an alienation caused by a self, diminished by arduous treatments and the reality of death. As a consequence, NSCLC survivors often find it difficult to describe their experiences with others who do not biologically, psychologically, and existentially share their same experiences of cancer, pain, and suffering. This alienation is caused by the struggle to live with NSCLC, by the attempts to create a sense of meaning out of the experience, and by limitations in sharing the trauma of these experiences with other people. It is this very struggle that contributes to the unmaking of language, the survivor’s social world, as they knew it, and the meanings of their social reality. All of these factors logically contribute to the very real difficulties of communicating with clinicians and significant others.

We began this paper by suggesting certain possibilities in terms of how medical researchers might begin to expand and build upon how we have traditionally looked at barriers to effective clinician-patient communication in oncology. While the majority of studies evaluating these barriers tend to focus on the medical encounter *per se*, we chose to begin with a broader definition of communication on a variety of levels, including its disruption, at the level of individual biological and neurological processes. From there, we then suggested that the individual experience or encounter with cancer, while clearly an individual experience, is also part of a social process. The disruption in social life or environment caused by this cancer occurs on two levels. The first is represented by a breach in the communication patterns within the individual patient. The second level reflects the limits of the patient’s ability to effectively access a cognitive template to create a language to share their experiences with others. Thus, the significant distress, depression, and alienation that have characterized NSCLC patients, not only highlight the gravity of this particular disease. It also draws attention to the limited tools that patients have access to as they try to cope with and communicate some of the more dire consequences of their experiences with others. Finally, and perhaps most significantly, it also directly points to a failure on the part of oncology professionals to provide adequate skills and social support, which could potentially serve as a counter and aid to this breach in communication between advanced-stage NSCLC patients and their caregivers.
The need to talk about experiences of "surviving and coping" with NSCLC was clearly prevalent in the patients who chose to participate in this particular study. Nonetheless, these patients need to develop the skills and tools to communicate and share their experiences with others. The potential to structure narratives around supportive encounters, such as support groups that focus on the unique experiences of being an advanced-stage cancer survivor can aid the individual in their attempts to repair some of the damage to communication caused by this disease [63]. Indeed, performance status, of which mood and affect are important and interrelated components, influence the course, including the quality of survival in those patients with advanced staged tumors [40-41]. Narrative is, therefore, one important tool working in concert with a variety of other tools, which could potentially facilitate an important biopsychosocial mechanism that could decrease the survivor's sense of being diminished by this disease. One important facet of this narrative process involves seeking social support from other survivors, which enables the patient to create a cognitive map of emotional and physiological experience. This cognitive map, while shifting and changing over time and experience with this disease, alleviates some of patient's suffering by assisting the survivor in learning to become experts of their own illness experience. This transition between the private, personal, indescribable experiences of the pain and suffering of the novice to other more social experiences via social support creates expertise through language [10-11, 59, 63]. In turn, the ability to create a common language based on this experience with others who similarly suffer legitimizes the survivor's experiences. The end result is that these NSCLC survivors are better able to share their experiences with others, including their clinicians. Additional work in this field lies in educating survivors about their options and by listening to the wisdom of what NSCLC survivors say, as they are ultimate experts of their experiences. And finally future work in this area must continue to examine these narrative processes, including their roles in facilitating the multiple forms of communication that are both expressed and disrupted by the experience of living with NSCLC.

ACKNOWLEDGEMENTS: This research was supported, by a Cancer Prevention Fellowship, National Cancer Institute Grant #3R25 CA5770-8S2.

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