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THE LONGITUDINAL EFFECTS OF CANCER TREATMENT ON SEXUALITY IN INDIVIDUALS WITH LUNG CANCER

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THE LONGITUDINAL EFFECTS OF CANCER TREATMENT ON SEXUALITY IN INDIVIDUALS WITH LUNG CANCER

By

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ABSTRACT

THE LONGITUDINAL EFFECTS OF CANCER TREATMENT ON SEXUALITY IN INDIVIDUALS WITH LUNG CANCER

By

Judith Ann Shell

All cancers have the potential to diminish sexual functioning. The purpose of this study is to examine changes in sexual functioning, as perceived by people with lung cancer, during treatment (chemotherapy only or chemotherapy and radiation therapy) for their disease. The extent to which age, gender, social support, and mood status affects sexual dysfunction is also identified.

The sexual functioning of lung cancer patients in two different treatment groups was measured pre-treatment, at 2 months and 4 months into treatment. The study was conducted primarily in an out patient cancer clinic in the south, in cities in close proximity to the center, and over the internet. Fifty-nine of 84 eligible patients participated in this longitudinal survey study. Sexual functioning was measured by the Derogatis Interview for Sexual Function, Self-Report, social support was measured by the Social Provisions Scale, and mood status was measured by the Derogatis Affects Balance Scale (DABS). The Bonferroni technique, based on Student's t statistic was used to analyze change in sexual function *within* the two treatment groups between three points in time. Change over time was also analyzed for social support and mood status. Results indicate that sexual function decreases after treatment, particularly between time one and two of survey completion (mean decrease, 4.35 points); this was not significant at any of the three time points at level $\alpha = 0.05$ jointly. Between time one and two, there is a significant decrease ($P = .004$) in mood status according to the DABS Affects

Balance Index (ABI). Change in mood status between time one and three (decrease) and time two and three (slight increase) is not significant. Overall, there is no significant change in the subject's perception of social support over the four month period. Independent samples *t* test was used to analyze change in sexual function *between* the two treatment groups at three points in time and no significant change was realized. Pearson chi-square indicates correlation between the administration of the two different treatments and cancer type (small cell and non small cell lung cancer) ($P = 0.001$). Three multiple linear regression models performed regression analysis between the DISF-SR raw score and each predictor variable (i.e. treatment, age, gender, social support, & mood status). Age was a statistically significant factor affecting sexual function at all three test points ($P = .000$, $P = .000$, $P = .030$ respectively). Gender significantly affected sexual function at the level $\alpha = 0.05$ at time two only. Between test points one and two mood status did have a significant relationship to the subjects' sexual function at level $\alpha = 0.05$. This was not realized at test point three. Social support did not affect sexual function significantly at any of the three test points, however social support was found to significantly affect mood status at all three points at level $\alpha = 0.05$.

Most of the patients in this study entered with a sexual function that was below normal. These data suggest that although there was not a significant decrease in sexual function, patients sexual function did worsen and a decrease was related to age, gender (at time two), and mood status (at time three). Therapists, in all settings, alert to this fact can address sexuality concerns at the beginning of treatment and normalize feelings of inadequacy. Further research will enable therapists to provide specific age and gender-related interventions to improve quality of life, increase well-being and reaffirm hope.

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DEDICATION

This dissertation is dedicated to my loving parents, Robert and Elvera Short (aka Speed & Rose). It is also dedicated to my beautiful children, Kimberly and Larry, and my daughter-in-law, Jennifer. Finally, it is dedicated to the love of my life, Conrad.

ACKNOWLEDGEMENTS

This dissertation could not have been done without the participation and support of my fabulous patients. They gave of their time and efforts to make this information available to all people who are managing their lives with lung cancer and those dedicated to caring for them and their families. Without them, this publication could not be possible.

I also wish to acknowledge my family and friends who have a great support to me. With their love, good thoughts and prayers, I was able to be creative and productive. I depended daily on God's help and support, and He saw fit to sustain me.

My dissertation chair, Dr. Marsha Carolan, and my committee, Dr. Robert Boger, Dr. Barbara Given, and Dr. Lillian Phenice have supported and mentored me along the road to scholarship. All of the other professors in Human Ecology at Michigan State University are also to be commended for their interest in and caring for their students.

There were many others who assisted me in my dissertation endeavor; medical assistants, nurses and physicians took time out of their busy schedules to assist me in finding subjects. They are, Maria Ball, Maria Contreras, Monica Smiley, RN, MSN, Kimberly Kennedy, RN, MSN, Cynthia Crumpton, RN, MSN, Mickie DeMichael, LPN, Dr. Arnold Miller, Dr. Jorge Otoya, Dr.Maria Flores, and my statistician consultant, Dr. Ying Zhang. The Oncology Nursing Society, the American Cancer Society, Michigan State University (i.e. Beatrice Paolucci Memorial Scholarship, Jean Davis Schlater Dissertation Fellowship, and other unrestricted grants) all provided scholarships to ease financial anxiety and allowed me to follow and realize my dream.

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CHAPTER ONE

Introduction

The diagnosis of a chronic illness like cancer can be a significant crisis in the lives of individuals and families (Gilbar, 1994; Kaye & Gracely, 1993; Manne, 1998; McDaniel, Hepworth, & Doherty, 1992). Crises can undermine the client's self-esteem and self-efficacy, and it is not unusual for them to lose skills they have already developed for dealing with difficult situations. Generally, clients are unprepared for the physical changes, alternating periods of stability and change, and the uncertainty of future functioning. Due to multiple losses, chronic illness demands new ways of coping, changes in client/family self-definitions, and various periods of adaptation (Kaye & Gracely, 1993; McDaniel, et al., 1992; Rolland, 1994). As well, because families must interact with a multitude of systems (e.g. health care, work related, spiritual, etc.), they encounter many opportunities for conflicts about roles, belief systems, and expectations for optimal attention to health care.

Of the many people faced with cancer each year, those who have a diagnosis of lung cancer are among the most common. Over 169,500 new cases of lung cancer were diagnosed in 2001 (down from 178,000 in 1998), and approximately 157,400 individuals will die from the disease this year. Even though the one year survival rates have increased from 32% in 1973 to 41% in 1993, and the five year survival rates are up from 12% in 1974-76 to 14% in 1989-96 (American Cancer Society, 1998, 2001), lung cancer remains one of the most deadly forms of this disease. Although death often is the first fear, the potential exists for other stressors (Ryan, 1996; Schain, 1985). The treatment for lung cancer including possible surgery, chemotherapy and/or radiation therapy (wh

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(whether surgery is possible or not), the possible spread of malignancy, psychosocial issues, and emotional distress, and an uncertain prognosis are all factors that necessitate life-style adjustments.

Even though the mirror may not reflect immediate outward alterations in physical appearance with a diagnosis of lung cancer, the image presented can no longer be trusted; the body has betrayed its keeper. It is alien. This crisis of cancer is intensified by its invasive nature, society's reaction to it, and by the effects treatment can cause in relation to changes in body image even when no outward change in appearance may be obvious or visible. Treatment with chemotherapy and/or radiation therapy can be devastating particularly if the patient begins in a debilitated state. Changes in role function due to the inability to continue working, or a deflated body image from an altered appearance and/or fatigue can threaten the individual with a loss of feelings of femininity or masculinity, as well as a loss in physical sexual functioning. Four decades ago, Masters and Johnson (1966) stated that almost half of all couples who are physically and psychologically "healthy" have had sexual problems at some time during their relationship. And, they continue to educate the public about how health problems and chronic illness can impact sexual relationships (Masters, Johnson & Kolodny, 1994). It is reasonable to assume, then, that many individuals with cancer, and particularly those who must undergo treatment, will have some type of sexual concerns given the added pressures of their disease. These concerns, in turn, can affect the couple relationship.

Although surgery is presently being used more often for the treatment of lung cancer, chemotherapy and radiation therapy remain the mainstay for this disease. Much of the literature regarding sexual side effects from chemotherapy or radiation therapy i

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relates primarily to the genital-urinary, colorectal, breast and hematological cancers or to how the treatment affects the testicles and ovaries, as well as fertility issues (Monga, 1995; Shell, 2001; Shell, 2002). Chemotherapy can cause toxicities in both men and women. Specifically, patients often feel increased weakness, fatigue, and intermittent nausea and vomiting the first few days after a treatment (Auchincloss, 1991). Soon after treatment begins, skin changes (dryness or acne) and defacement from hair loss occurs which can destroy self-confidence and a sense of sexual inadequacy can ensue. As well, a drop in the hemoglobin count (red blood cells) can cause shortness of breath and further increase fatigue. Additional ramifications produce ovarian and testicular dysfunction that usually returns to normal after treatment ends. However, women may experience amenorrhea (cessation of periods) or irregular menses, hot flashes, decreased libido and vaginal atrophy, and men may undergo a decreased or absent sperm count and difficulty with erection and ejaculation (Auchincloss, 1991; Shell, Bell, Dougherty, 1996; Shell, 2001). Collectively, these symptoms are not only troublesome, but can create a lack of sexual desire and perhaps cause the patient to withdraw from any kind of intimacy, affection or physical gratification.

Although radiation therapy does not cause many of the same type of systemic side effects that chemotherapy does, it can cause a reaction in the skin, and the color darkens. This can be embarrassing and create a self-consciousness attitude. Radiation can also cause fatigue especially when used in conjunction with chemotherapy. While treatment is in progress and after its completion, the sense of being feminine or masculine may be hindered simply due to the fact that helpful drugs like narcotics and anti-nausea medication along with the general feelings of fatigue may influence the sexual

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response cycle. However, these patients need to be made aware that other means of sexual expression can provide satisfaction and pleasure through increased closeness, both physically and emotionally.

As clients experience the various dilemmas which arise once a cancer diagnosis has been made, social support is considered to be a crucial element in effective adaptation during cancer treatment and beyond (Baron, Cutrona, Russell, Hicklin & Lubaroff, 1990; Manne, 1998; Stam, Koopmans, & Mathieson, 1991)). Social support is also reported to be predictive of lower patient distress (Northouse, Dorris, & Charron-Moore, 1995). Cancer patients have identified the most helpful kind of support from family and friends to be emotional and instrumental (tangible) (Dunkel-Schetter, 1984; Manne, 1998; Neuling & Wienfield, 1988; Pistrang & Barker, 1995; Smith, Redman, Burns, & Sagert, 1985). Although family and friends do play a significant role, Primomo, Yates, & Woods (1990) report that the greatest amount of emotional and perceptible support is received from the spouse. Marital partners, as well as supportive friends and other persons may even influence survival from the disease in a positive manner (Neale, Tilley, & Vernon, 1986; Waxler-Morrison, Hislop, Mears & Kan, 1991). Quinn, Fontana, and Reznikoff (1986) reported on a sample of male lung cancer patients and their perception of spousal support. This 3-month longitudinal study indicated that men who received more spousal support at first assessment acknowledged less distress at second assessment.

Bolger, Foster, Vinokur & Ng (1996) report, however, that support has not always been found to provide beneficial effects. Their 6-month longitudinal study examined support from significant others, and reported on levels of distress. Differences in support did n

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did not relate to changes in emotional distress; this suggests that support did not have a beneficial effect.

As early as the 1970's, studies relating the importance of social support to various areas of physical and mental health are evident in the literature. Early researchers proposed that individuals would adapt to stressful life experiences if they had sufficient social support, and these researchers were able to show that supportive relationships did help to manage their stressors (Cassel, 1976; Cobb, 1976, 1979). The model they used is termed the *buffering* hypothesis; it proposes that during times of stress, social support provides a protective role by augmenting coping behaviors (Cobb, 1979). Cohen & Wills (1985) claim that there is mixed support for the buffering hypothesis and its attempt to link stress, social support, and health. However, Russell and Cutrona (1984) reported at an American Psychological Association convention "research has consistently indicated that individuals who have better interpersonal relationships are less prone to the development of physical and mental illnesses." (p. 2)

A second model used to measure the effects of social support is termed the *direct effects* model. According to this model, social support has a positive effect on health and well being whether or not stress is present (Russell & Cutrona, 1991).

Clearly, the person with lung cancer experiences considerable emotional distress, which can include depressed mood; depressed mood is reported as common in lung cancer patients (Hughes, 1985; Ryan, 1996; Sarna, 1993). This distress can amplify the perception of physical symptoms (dyspnea, fatigue, & pain), contribute to a decline in activities of daily living, and increase suffering (Klemm, 1994). Several studies have investigated the role, which psychological factors, both positive and negative, play during and

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and after treatment for cancer (Ayers, Hoon, Franzoni, Jatheny, Cotanch, & Takayanagi, 1994; Derogatis, Abeloff & Melisaratos, 1979; Dobkin & Bradley, 1991; Ryan, 1996). Dobkin and Bradley (1991) conclude that psychological factors play a role in sexual functioning in the cancer population, and that negative emotional states may disrupt sexual vigor and eagerness. Burbie and Polinsky (1992) report that, "failure to deal with these emotional problems successfully may lead to interpersonal difficulties such as impaired sexual functioning, social isolation and strained relationships" (p. 26). As well, anxiety or depression along with a sense of lost personal control over a very basic bodily function like breathing, may also be disturbing to the patient, and cause them to avoid intimate contact. Yet, John Bancroft (2001) explains that negative mood may actually "perpetuate" sexual interest and responsiveness. He claims that about 15-20% of the subjects in their survey reported an increase in sexual interest when they were in a negative mood; this phenomena is age- and gender-related, and Bancroft (2001) states that, "young men are most likely to report this effect" (p. 1).

Even though there continues to be a high incidence of lung cancer in men and women, few studies concerning the psychosocial impact of this disease on individuals, couples, or families have been forthcoming (Dobkin & Bradley, 1991). Specifically, there have been no studies with individuals or couples concerning the impact that treatment for this disease has on their sexual function, and whether social support and/or mood status may explain variation in the level of sexual functioning during the treatment process and/or beyond. For many individuals with lung cancer, treatment is palliative rather than curative; treatment provides a modest improvement in survival and may be restricted to symptom relief. Consequently, "... a rapidly fatal course forces the patient

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and family to confront many fundamental changes in everyday life that requires correspondingly rapid adjustment" (Bernard & Ganz, 1991, p. 216). Although treatment for lung cancer can deplete energy and cause side effects, a high level of social support and a positive mood state may impact on the individual's ability to adjust, and to realize a more healthy sense of femininity and masculinity. We must learn what their sexual function needs are along the treatment trajectory so prompt intervention is rendered, especially since their prognosis is not as good as with other cancer diagnoses. Once the individuals' capability to function sexually has been assessed and identified, continued research with couples and families will be essential to define the extent and nature of the supportive care services that therapists should provide to enhance care. Only then can appropriate intervention be made available to and with the entire system.

As part of an inter-disciplinary team, marriage and family therapists can provide a therapeutic environment for individuals/families by helping them realize and acknowledge their strengths and resources when responding to the cancer crisis, and to cultivate adequate levels of social support, especially if few family members are available. They also can impact how the patient copes with the occurrence of emotional turmoil and depressed mood, promote the individual's/family's ability to experience effective communication in relation to illness and its meaning, further the ability to accept unacceptable feelings, and maintain family integrity. This, in turn, will empower individuals and families to respond with more skill and confidence to the cancer crisis and experience a better quality of life.

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This study identifies factors that contribute to sexual dysfunction in the person with lung cancer who is receiving treatment with chemotherapy alone or chemotherapy and radiation therapy. Prevalence information related to sexual dysfunction is also identified. Differences are examined in sexual functioning as perceived by females and males before, during and/or after treatment for their disease. The extent to which social support and mood status affects sexual dysfunction is also identified. Lung cancer is one of the most frequently diagnosed cancers in men and women, and continues to have an unsatisfactory clinical outcome that can progress rapidly irrespective of treatment. Consequently, people with lung cancer are at high risk for psychological morbidity. The effect on the sense of being a sexual (feminine or masculine) person will, in turn, have an effect on the individual and their partner. Therefore, optimal psychosocial support, including support of sexual functioning, must evolve into a major management goal in this previously understudied population. Once knowledge is attained, the marriage and family therapist can positively influence quality of life at the appropriate point in time, and through further study, provide research-based intervention.

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Importance of the Study

There are many systems affected by a chronic illness such as cancer, and they may include (but are not limited to) the following:

1. Family relationships and friendships outside the home (human resources). Through behaviors learned inside the family from parents and grandparents, and outside the family from peers, all participating individuals acquire a repertoire of skills, attitudes, and values to preserve and perform in the family, with friends, at work, and in the community.

2. Family professions. The need to provide for family maintenance and to achieve personal and family goals motivates the adult individual to work (Andrews, Bubolz, & Paolucci, 1980).

3. Economic resources. Individual members and families are able to contribute socially and economically through participation in market (industry and agriculture) and nonmarket (human resource maintenance and household production) activities, which positively impacts the family, community and society (Andrews, et al., 1980).

4. Community resources. Interdependent systems that provide families with (social) support include formal organizations and informal networks. Social welfare, health care, and nonprofit organizations such as the American Cancer Society are formal groups that provide required services. Informal networks (neighbors, friends, nurses, support groups) are just as important because they provide valued assistance and human nurturance.

5. Environment. According to Bubolz and Sontag (1993), the

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environment includes natural, human-constructed, and human behavioral (social-cultural) components and this constitutes our life-support system. Environmental impact in this client population includes the air necessary to breathe (which may be polluted by cigarette smoke), space necessary to live in, and time spent while taking treatment for cancer, managing the side effects, and for post treatment recuperation. Roles, rules, decision-making, and other interactions such as attitude, love and trust will also be modified and changed.

6. Family relationships inside the home. These relationships will include the intimate relationship of the couple. Factors that impact this relationship in people with lung cancer may be how the treatment/s will affect their sexuality. Many researchers report that cancer and its treatment have an untoward effect on sexual function; this may range from 40% to 100% (Derogatis & Kourlesis, 1981; Ginsburg, Quirt, Ginsburg, & MacKillop, 1995; Quinlan, Epstein, Carter &, Walsh, 1991; Ryan, 1996; Schover, Evans &, von Eschenbach, 1987).

In addition to the impact cancer has on the systems that support client/family activities of daily living, the avalanche of physical and emotional upheaval creates a psychosocial crisis. One of the quality of life changes that can occur due to cancer and cancer treatment is sexual functioning. Most psychosocial studies that incorporate sexuality exclusively, or as a variable, usually involve patients with "genital" cancers (e.g. breast, gynecological, prostate, testicular) (Anderson, 1996; Anderson & Elliot, 1994; Fransson & Widmark, 1996; Meyerowitz, Desmond, Rowland, Wyatt, & Ganz, 1999; Smith & Reilly, 1994; Stanford, Feng, Hamilton, Gilliland, Stephenson, Eley, et al., 2000; Syrjala, Schroeder, Abrams, Atkins, Brown, Sanders, et al., 2000; Young-

McCaughan, 1996). As a result, there are very few sexuality studies that include patients with non-genital cancers (e.g. head and neck, esophagus, lung); this provides less than optimal assessment and/or intervention relative to this populations' psychosexual anxieties (Gritz, Carmack, de Moor, Coscarelli, Schacherer, Meyers, et al., 1999; Monga, Tan, Ostermann & Monga, 1997; Siston, List, Schleser & Vokes, 1997).

Although there are some psychosocial studies related to individuals with lung cancer, there are none that specifically pertain to sexual function during and/or after treatment for this disease (Bergman & Aaronson, 1995; Bergman, Aaronson, Ahmedzai, Kaaasa & Sullivan, 1994; Bernard & Ganz, 1991a, 1991b; Buccheri, Ferrigno, Topmburini & Brunelli, 1995; Cella, Bonami, Lloyd, Tulsky, Kaplan & Bonami, 1995; Ganz, Lee & Siau, 1990; Ginsburg, et al., 1995; Gralla & Moinpour, 1995; Hollen & Gralla, 1996; Hollen, Gralla, Kris & Cox, 1994b; Hopwood, Stephens & Machin, 1994; Klemm, 1994; Ryan, 1996; Sarna, 1993a, 1993b; Schag, Ganz, Wing, Sim, & Lee, 1994). This is of particular importance because lung cancer will likely continue to be one of the most common and life-threatening diseases in the coming century. Affirmation of the importance of sexual function in this client population is significant because it validates this individual's right to continue to feel valued as a woman or a man even though they have a formidable disease. Through a more empathetic understanding of the emotions and behavior of this individual from a sexuality standpoint, the therapist will be able to provide more sensitive support and enhance quality of life for both client and partner.

Ecologically speaking, specific knowledge about the impact of treatment on sexuality is essential for marriage and family therapists to be able to provide timely, appropriate and ample social support, optimal use of resources, and to implement in

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intervention programs. Once this knowledge is ascertained, therapists will be encouraged to become more aware of and more attentive to the sexual needs of individuals/couples diagnosed with and being treated for lung cancer. The prevalence of sexual dysfunction obtained from this study will also benefit future, more in-depth research.

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Research Questions

1. When adjusted for pre-treatment level of sexual functioning, are there significant differences (alpha = .05) in sexual function within and between the two treatment groups at 2 months and 4 months into treatment?

2. To what extent does age explain variation in level of sexual function in people with lung cancer?

3. To what extent does gender explain variation in level of sexual function in people with lung cancer?

4. To what extent does mood status explain variation in level of sexual function in people with lung cancer?

5. To what extent does social support explain variation in level of sexual function in people with lung cancer?

Hypothesis

Ho 1: Sexual function as measured by the Derogatis Interview for Sexual Functioning, Self-Report is the same for people with lung cancer after treatment of the disease as it was before treatment.

Ha 1: Sexual function as measured by the Derogatis Interview for Sexual Functioning, Self Report is lower for people with lung cancer after treatment of the disease than it was before treatment.

Ho 2: Variation of sexual function is not explained by age for people with lung cancer.

Ha 2: Variation of sexual function is explained by age for people with lung cancer.

Ho 3: Variation of sexual function is not explained by gender for people with lung

Ha 3: Variation of sexual function is explained by gender for people with lung cancer.

Ho4: Variation of sexual function is not explained by mood status for people with lung cancer.

Ha4: Variation of sexual function is explained by mood status for people with lung cancer.

Ho5: Variation of sexual function is not explained by social support for people with lung cancer.

Ha5: Variation of sexual function is explained by social support for people with lung cancer.

Theoretical /Conceptual Model

Lung cancer is the leading cause of cancer-related deaths in men 40 years of age and older and in women 60 years of age and older (Greenlee, Hill-Harmon, Murray & Thun, 2001). Research and education efforts have apparently begun to influence both males and females, because incidence rates decreased 3.2% in men between 1992 and 1997, and have started to decline in women aged 40 to 59 (Greenlee et al., 2001). However, lung cancer still accounts for approximately 31% of cancer deaths in men and 25% in women. Since 1987, lung cancer mortality rates continue to surpass breast cancer rates in women (Greenlee et al., 2001).

Many individuals are initially diagnosed with metastatic disease (disease which has traveled outside the lung to other areas of the body) that ultimately leads to death. However, if the patient presents with disease diagnosed at an early stage, multimodal therapies, such as surgery, chemotherapy, and radiation therapy are increasing overall and five-year disease free survival rates (Langer, 1998). Individuals with lung cancer must learn to adapt, not only to the physical, biological, and social conditions related to the effects of the cancer treatment, but more specifically to how the disease will affect their overall quality of life; this includes their interactions as females and males from a sexuality perspective. The ability to profile whom may be at risk for the development of sexual dysfunction during and/or after treatment will prevent undetected and untreated problems.

Generally, when one speaks of sexuality, it is often assumed that sexual intercourse is the issue. However, sexual functioning is much more than just the sex act itself. The World Health Organization (1975) defines sexual health as the integration of

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the somatic, emotional, intellectual, and social aspects of sexual being in ways that are positively enriching and that enhance personality, communication and love. Sexual functioning connotes the totality of the human being, unlike the word sex, which connotes a physiologic act. The broader term includes the socio-cultural, psychological and ethical, as well as the physical components of sexual behavior (Hogan, 1985). Because sexual functioning and human sexual response do not occur in the physical realm alone, emphasis also must be placed on how the diagnosis of lung cancer and its treatment may affect not only sexual function, but feelings experienced in the psychosocial realm as well. The vector/mathematical model is useful for visualizing the way in which various elements may combine to produce a state of sexual functioning (Figure 1). The vector model of sexual desire combines the positive and negative aspects of both physical and psychosocial factors to illustrate how a state of sexual desire is produced at a particular point in time (Masters, et al., 1994). Likewise, this same model can be used to illustrate possible positive and negative effects of treatment for lung cancer and how they may affect the person's total level of sexual functioning (e.g. sexual cognition/fantasy, sexual arousal, sexual behavior/experience, orgasm, & sexual drive/relationship). As well, during and after treatment, the aspects of social support and mood status may affect sexual function in a positive or negative manner. Human sexuality underlies the complete range of human experience and contributes to peoples' lives in many ways; therefore, it is the purpose of this study to explore the relationship between lung cancer and its treatment to possible dysfunction in human sexuality.

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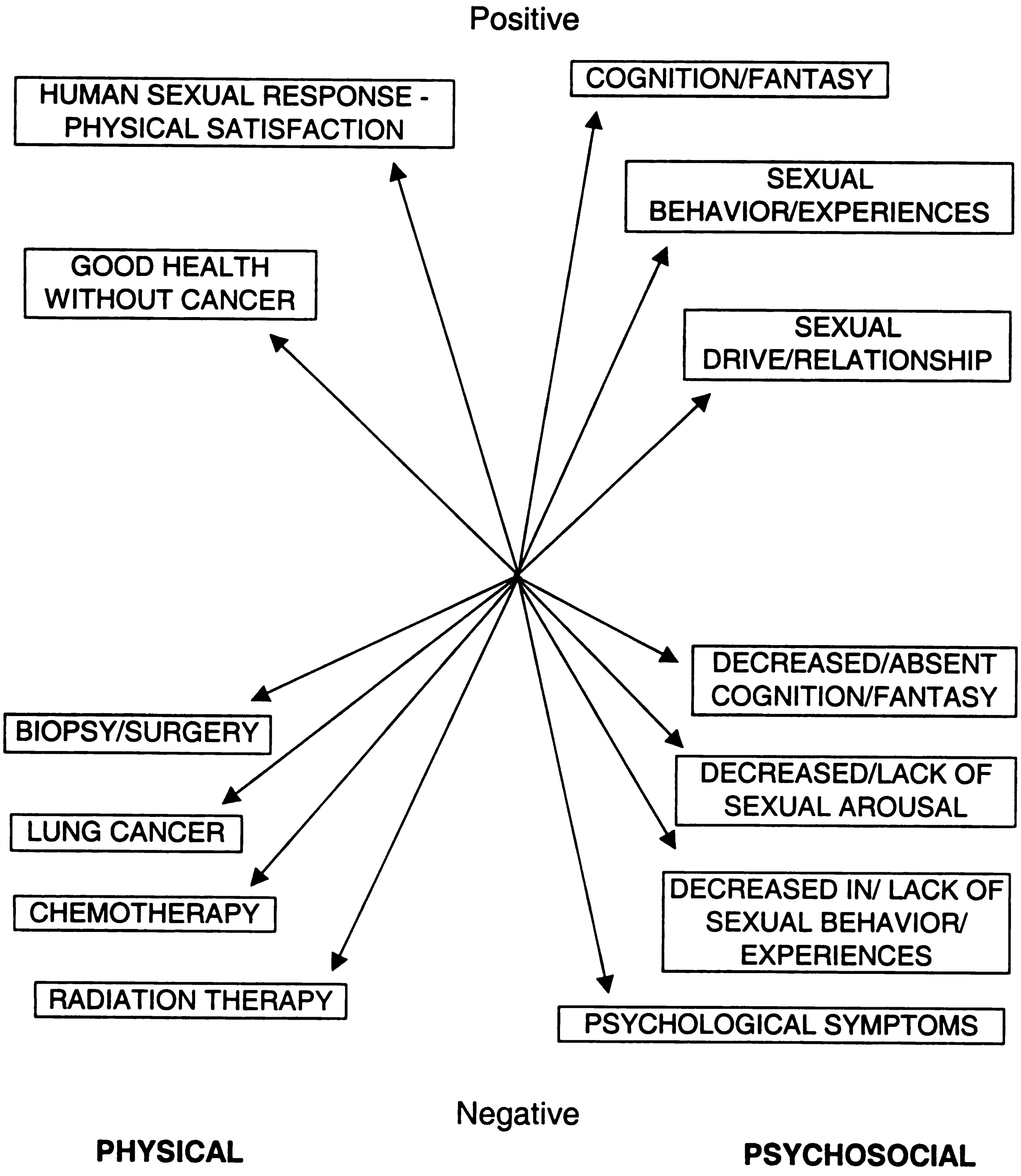
THEORETICAL MAP



Adapted from Vector Model in
Masters, Johnson & Kolodny (1994)

Figure 1

Conceptually, the process unfolds in this way: once the individual has been diagnosed with lung cancer via a procedure [e.g. bronchoscopy (visualizing with a scope), or a type of biopsy], decision-making regarding the treatment process begins. The patient may endure removal of a segment of lung, removal of a lobe of the lung, or removal of one entire lung (rarely), and/or they may then begin treatment with chemotherapy alone or chemotherapy and radiation therapy. If the patient is in poor medical condition (e.g. an 80 year old woman with heart problems), they may offer radiation alone. The diagnosis along with any of these treatments or combinations may have an effect on the patients' sexual functioning over a period of time. This process is depicted on the conceptual map (Figure 2). The various components of sexual function (e.g. sexual cognition/fantasy, sexual arousal, sexual behavior/experience, orgasm & sexual drive/relationship) are interactive and also may influence one another. Likewise, a high, intermediate or low level of social support and/or a positive or negative mood status may also influence sexual function

The total environment of the individual with lung cancer changes abruptly with diagnosis and commencement of treatment. Depending on how ill individuals perceive themselves and their role (female, male, and/or feminine, masculine), the inter-relationships with family and friends, neighborhood, community, and work will be affected. Economic independence may require sacrifices and consumption of energy and resources in an attempt to get through treatment and recover from illness. The individuals' ability to adjust and cope with the modification of their environment will depend on their interaction within the ecosystem: perception of social support from friends and family, current mood status that may include feelings of depression, and reciprocal influence of all aspects of the illness.

Ecologically speaking, no human being lives in a vacuum nor can an individual be completely independent. Rather, we continually interact with our environment that encompasses physical, biological, social, economic, political, aesthetics, and structural surrounds. There are three distinct but interrelated "environments" which comprise the human ecosystem: natural, human constructed, and human behavioral. All resources necessary for life are provided within these environments (Bubolz & Sontag, 1993).

Bronfenbrenner's (1979) ecosystemic model consists of four separate, but nested systems wherein the individual develops. They include the micro, meso, exo and macro systems. The microsystem consists of the immediate environments where the developing individual lives. This includes the activities, roles, and interpersonal relationships, and the face-to-face interactions with living people (including a sexual relationship) and with nonliving artifacts. The developing individual comes in contact with people (social support resources) who also have their own belief systems, temperament and personalities. This environment may include areas such as home, school, work or the medical community. Important aspects of the individual to which Bronfenbrenner (1986) pays attention include cognitive capabilities that account for competency of the individual, socio-emotional aspects that account for personality and temperament (mood status), and person as active agent (decision making). The mesosystem is the interface between the microsystems containing the individual and how they interact and impact one another. The exosystem comprises systems outside the personal Microsystems of the individual which have a indirect impact on the developing individual, while the macrosystem envelopes all of the other systems and influences or is associated with the creation of our values, norms cultures and subcultures. Subcultures of a macrosystem may include two parent families, single parent families, and families living in an urban setting versus a rural setting (Bronfenbrenner, 1986). All of these systems will interact and impact on the person/family who has recently been diagnosed with lung cancer. Once knowledge is attained and because the marriage and family therapist has a systemic background, she/he will be able to interact and intervene within these systems to empower this person/family.

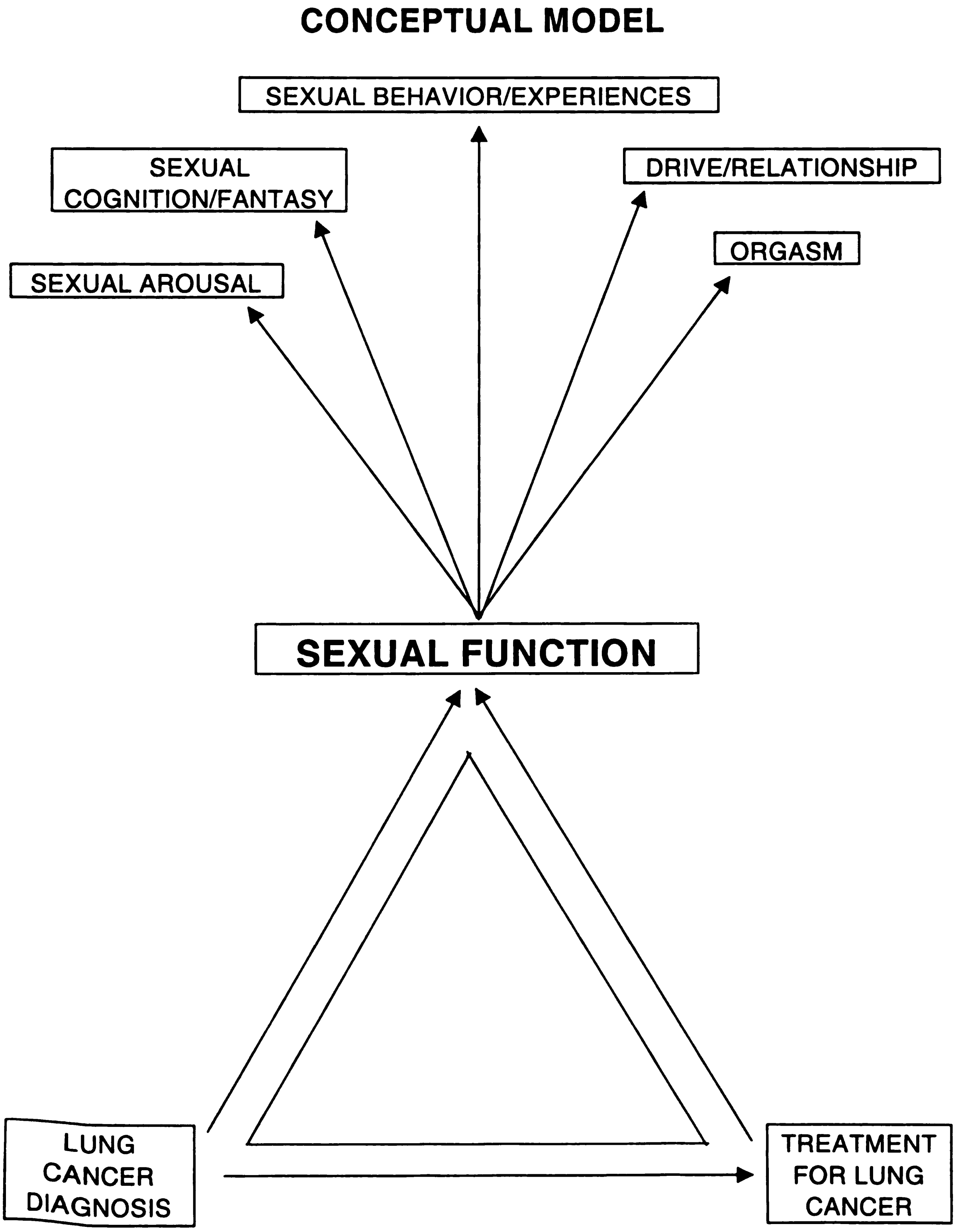

CONCEPTUAL MODEL
SEXUAL BEHAVIOR/EXPERIENCES
SEXUAL COGNITION/FANTASY
DRIVE/RELATIONSHIP
ORGASM
SEXUAL AROUSAL
SEXUAL FUNCTION
LUNG CANCER DIAGNOSIS
TREATMENT FOR LUNG CANCER

Figure 2

Conceptual and Operational Definitions

The dependent variable in this study is level of sexual function.

Conceptually, sexual function refers to natural bodily functions that begin in utero and are in some measure subject to conscious control, as well as, feelings of masculinity and femininity, gender identity, and body image (Fogel, 1990).

Operationally, level of sexual functioning will be measured by using the Derogatis Interview for Sexual Functioning, Self-Report (DISF-SR) that includes, sexual cognition/fantasy, sexual arousal, sexual behavior/experience, orgasm, & sexual drive/relationship (Derogatis, 1987). Quantitatively, this self-report represents the status and quality of the individual's current sexual functioning.

The independent variable in this study is type of treatment for lung cancer.

Conceptually, type of lung cancer treatment refers to chemotherapy only or chemotherapy and radiation therapy.

Operationally, type of lung cancer treatment will be measured by indicating if the patient received chemotherapy only or radiation therapy and chemotherapy. This information will be obtained from the patient's chart, from self-report, or from treatment nurse report.

The control variables in this study are the patient's gender and age, their perception of social support, and mood status.

Conceptually, gender and age refers to all those men and women 18 years of age or older diagnosed with lung cancer.

Operationally, gender and age will be measured by the patient's socio-demographic information form.

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Conceptually, social support refers to situational and perceived support including, but not limited to, friendships, work relationships and kin relationships (e.g. marriage), which help the individual adapt to stressful life experiences.

Operationally, social support will be measured by the Social Provisions Scale, which includes attachment, social integration, reassurance of worth, reliable alliance, guidance, and opportunity for nurturance (Russell & Cutrona, 1984).

Conceptually, mood status refers to current emotional well being, with an inclination toward a positive or negative stance.

Operationally, mood status will be measured by the Derogatis Affects Balance Scale that includes 8 primary affect dimensions, 4 positive and 4 negative. The 4 positive dimensions are joy, contentment, vigor, and affection. The 4 negative dimensions are anxiety, depression, guilt and hostility. This multidimensional mood and affects inventory can measure the mood/affect status of community, medical, or psychiatric respondents.

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CHAPTER TWO

Review of Literature

There is a growing body of literature that supports the fact that cancer affects the family as well as the patient diagnosed with the disease (Burbie & Polinsky, 1992; Germino, Fife, & Funk, 1995; Manne, 1998; Meyerowitz, Leedham, & Hart, 1998; Sarna & McCorkle, 1996). Weisman and Worden (1976) reported that people newly diagnosed with cancer experience emotional distress, and during the first 100 days, concern is focused on existential issues of life and death. Then, as they begin to learn to live with cancer, they become refocused on health, work, finances, self and relationships, and they can resume many normal activities. However, as Germino et al. (1995) report, the emotions and behavior of one family member will affect the family as a whole, and this is an important aspect to remember as the sexual function of the individual with lung cancer is examined.

Individuals with lung cancer report various distressing symptoms that interfere with their activities of daily living and contribute to psychosocial concerns, especially during treatment. These reports often encompass fatigue, a decline in physical health, and an overall diminished quality of life (Hollon et al., 1994b; Sarna, 1993a; Sarna & McCorkle, 1996; Varricchio, Frankel, Rittenberg, Sarna, Smith & Wilkie, 1997). The physical effects of the illness and its treatment are well documented, and various interventions are in place to increase individual comfort. However, in order to enhance psychosocial quality of life likewise, concerns must be identified and interventions developed to maximize function and minimize distress.

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Until the past 15-20 years, sexuality was rarely, if ever, recognized as a factor that could cause psychosocial distress, even though Dr. Mary Caldrone founded the Sex Information and Education Council of the United States in 1964. A milestone for human sexuality was set in 1966 when Masters and Johnson (1966) published their classic book on the human sexual response, however, it was not until 1975 that the World Health Organization addressed sexuality as an aspect of health (World Health Organization, 1975). Since this introductory period, research relative to this particular realm has markedly increased, particularly in the field of cancer. However, most of the investigative studies have been done in relation to genital cancers (e.g. cervix, uterine, breast, testicular, prostate) or to cancer in general. Other cancer sites, like lung cancer and head and neck cancer, have been relatively ignored.

A review of past and current literature will establish a theoretical base whereby the present research can begin. Because of the paucity of specific sexuality studies related to individuals with lung cancer, more of the literature to be reviewed will discuss other cancer sites, especially genital and breast cancers.

Sexuality and Cancer

In 1985; Hogan provided a brief overview of sexuality issues associated with cancer individuals. She includes the influence of cancer on sexual practices, the physical and the psychosocial effects of cancer and its treatment on sexuality, and sexuality and the dying individual. Hogan (1985) does not, however, indicate how this information may assist the practitioner caring for individuals with a site-specific cancer.

Ingle (1990) reported many of the same general areas of concern for the cancer individual and his/her sexuality, and gets more specific in relation to male and female

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physical effects, as well as fertility issues. General psychological and sociocultural factors reviewed are helpful but not specific to the individual with lung cancer.

Schover & Jensen (1988), distinguished researchers in the field of cancer and sexual function, provide an excellent overview of sexuality problems that commonly occur in men and women with a chronic illness, and cite specific cancer related examples in this review. They examine effects on both the individuals' and the couple's sexuality; four main factors can be identified which include physical, body image, psychosocial and relational concerns. Physically, low sexual desire, erectile dysfunction, female arousal-phase dysfunction, and male and female orgasmic dysfunction may result from fatigue, stress, chronic pain, nerve and/or vascular damage, neurotoxic chemotherapy, and hormonal effects (Schover & Jensen, 1988). Body image disturbances and deficits in self-esteem may result from premature aging due to decreased hormones, surgical disfigurement, weight loss and other side effects of radiation and chemotherapy. In a later reference, Schover (1989) speaks to psychosocial issues which includes, fertility (both in young and middle-age couples), the possibility of an extramarital affair, a lack of social support in unmarried patients and their reduced motivation to find a partner or even to socialize. Couple relationships may also suffer during treatment for cancer if there is lack of ability to show caring, share feelings or negotiate disagreements, role inflexibility, or if the couple does not share similar needs for intimacy.

As the literature is examined according to the aforementioned four main factors related to sexuality concerns, age and gender is noted in several of the studies. Obviously gender is an important focus if the study is gender specific (e.g. prostate or breast). These studies often reveal that, age notwithstanding, treatment with chemotherapy an

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and/or radiation therapy can impact sexuality in a negative manner.

Physical Factors

Physically/physiologically, reports of sexual dysfunction following cancer treatment with surgery, radiotherapy, and chemotherapy range from 10 to 90% (Syrjala et al., 2000). Problems from surgical procedures usually stem from damage to the autonomic nervous system, vascular compromise of the genitals, or endocrine effects. However, Monga (1995) reports "disfigurement from any cause produces psychosocial problems, altered body image, anxiety, and depression. Premorbid psychological status, stability of the relationship, and coping skills will influence postoperative psychological function. Psychosocial dysfunction is one of the major factors influencing sexual problems in cancer patients" (p. 422). Schover, et al., (1987) note low sexual desire as a common occurrence with patients who cope poorly with cancer and are depressed, while Spiegel & Diamond (1998) explain that uncertainties with sexual function occur with as many as 80% of breast cancer patients due to distress at treatment initiation.

Although many discussions in the cancer literature that emphasize sexuality relate to the genital malignancies, there are some recent studies related to sexual function in the head and neck cancer population (Siston, et al., 1997). Extent of disfigurement from the cancer itself, its treatment with surgery, or treatment with radiation therapy can impact the patient's quality of life, including their sexual life (Gritz, et al., 1999; Monga, et al., 1997). In the Monga study, the mean age of the fifty-five patients who participated was 65.1 years (range 48 to 76). Nineteen patients were less than 65 years old and 36 were over sixty-five. Although there was no significant relationship between age and interest in sex between the two groups, the older patients were significantly more satisfied with

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their sexual partner ($p < .05$). Patients younger than 65 tended to perceive a lower quality of current sexual functioning ($p = .057$), but read erotic material more frequently. Patients over 65 reported higher rates of fantasizing and better functioning in the areas of arousal and intercourse; there was no significant difference between the two groups in satisfaction with orgasm (Monga et al., 1997). De Boer, McCormick, Pruyn, Ryckman, & van den Borne (1999) reported physical symptoms that include speech problems, dry mouth and throat, difficulty swallowing, and pain. These symptoms along with disturbances in psychosocial functioning are reported to have a negative effect on sexual functioning.

Treatment for prostate cancer is often associated with disruptive side effects that frequently include urinary incontinence and sexual dysfunction. Generally, men treated with nerve sparing radical prostate cancer surgery (removal of the prostate gland and surrounding tissue) meet the criteria for potency, although only about 32 % experienced normal rigidity of erections (Leandri, Rossignol, Gautier, & Ramon, 1992; Quinlan, et al., 1991). Age, clinical and pathologic stage of disease, and the extent of nerve preservation did correlate with potency after surgery. Even if men had operative sparing of the neurovascular bundles (nerves and blood vessels that affect erection), those over 70 years of age had postoperative potency only about 22% of the time (Quinlan et al., 1991). Bladder dysfunction and sexual impotency have also been reported after surgery for colorectal cancers [incidence runs between 15-100% depending on where resection (removal of tumor) takes place in the abdomen] (Koukouras, Spiliotis, & Scopa; 1991; Santagelo, Romano, & Sassaroli, 1987; Stanford, et al., 2000). Erectile dysfunction along with dry orgasm is experienced when patients undergo cystectomy (bladder remo

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removal) for bladder cancer as well; incidence runs between 70-100% (Monga, 1995; Schover, et al., 1986). However, Hurney and Holland (1985) state that sexual desire is usually not impaired. Testicular cancer surgery, which ranges from simple orchiectomy (removal of the testicle) to extensive retroperitoneal lymph node resection (lymph nodes removed from the groin up into the abdomen), can be the cause of dry orgasms, failure of ejaculation and perhaps fertility problems (Dobkin & Bradley, 1991; Monga, 1995; Schover & vonEschenbach, 1985).

In women, sexuality problems prevail most frequently in those who have been treated surgically for gynecological cancers and can range from 0% to nearly 100% (Anderson, 1987, 1996; Anderson & Elliot, 1994; Weijmar, Van de Wiel, Hahn & Van Driel, 1992). Often, the frequency of intercourse is the only indicator of the quality of sexual function, however, Schover, Fife, & Gershenson (1989) found that disturbances of libido and orgasmic function frequently follow cancer treatment and postmenopausal women are even more likely to experience dyspareunia (painful intercourse) along with decreased desire and arousal. Anderson (1989) studied 47 women with early stage gynecologic cancer prior to treatment and then at four, eight and twelve months post treatment. Outcomes are compared with two matched comparison groups (18 women treated for benign disease and 57 healthy women). Frequency of intercourse decreased for the women treated for disease both benign and malignant. A decrease in sexual excitement is pronounced for the women with disease and is more severe in women with cancer. Of the women treated for cancer, 30% were diagnosed with a sexual dysfunction (Anderson, 1987). More recently, Anderson (1996) reported on women treated for gynecologic cancer and found that consequent to cancer treatment, women report

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problems with their ability to resume sexual intercourse. However, she also found that preventive strategies at the time of cancer diagnosis are more effective than interventions during recovery.

Radiotherapy can be just as devastating to both men and women. A decline in sexual performance with the prevalence of erectile impotence, along with a decrease in libido, has been reported from 10-84% in men undergoing external beam radiation for prostate cancer (Banker, 1988; Monga, 1995; van Heeringen, Schryver, & Verbeek, 1988). Erectile impotence from radiation therapy may be caused by constriction of vessels following treatment (Fransson & Widmark, 1996; Monga, 1995). Fransson & Widmark (1996) studied 199 radiation patients with prostate cancer (mean age, 71 years), and compared them to an age-matched group of healthy men. Results revealed that there were higher levels of sexual dysfunction in the patient population; this was most obvious in men less than 70 years old. Disturbance in the maintenance of sexual function was prominent in men 70 to 74 years; men over 74 years did not perceive decreased sexual function as a major problem. General health and sexual function prior to treatment is thought to be related to prevalence (Monga, 1995). Radiation to the testicles can also lead to impotence along with infertility, and can lead to an indirect hormonal effect causing loss of libido, erectile difficulties and ejaculatory problems (Hussey, 1994). Pelvic irradiation in women is responsible for ovarian failure and causes physical effects such as amenorrhea, sterility, vaginal dryness, fibrosis, ulceration, and infertility (Lamb, 1995). This, in turn, causes loss of femininity, libido, orgasm, a lack of pleasure, dyspareunia and postcoital (after intercourse) bleeding (Bruner & Boyd, 1999; Cust, Whitehead, & Powels, 1989; Schover, et al., 1989).

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Many chemotherapy agents affect gonadal function and these effects are classified as immediate, early or late. Men experience injury to testicular function, and atrophy along with oligospermia (decreased sperm) or aspermia (no sperm) can occur (Monga, 1995; Rieker, 1996). This type of endocrine dysfunction can lead to a decrease in sexual desire and erectile dysfunction (Drasga, Einhorn, & Williams, 1983; Monga, 1995). Likewise, women encounter amenorrhea and menopausal symptoms, vaginal dryness and loss of elasticity, and experience dyspareunia due to the dryness and irritation from chemotherapy induced ovarian failure (Andrieu, Ochoa-Molina, 1983; Ganz, Greendale, Petersen, Zibecchi, Kahn & Belin, 2000; Gershenson, 1988; Gradishar, & Schilsky, 1988; Lamb, 1995;). Schover, Montague & Schain (1996) assert that women over the age of thirty who receive combination chemotherapy will stop menstruating and usually don't resume menses after treatment ceases. Kaplan (1992) reports on the "estrogen deficiency syndrome" and the "female androgen deficiency syndrome" due to chemotherapy treatment. Both syndromes can lead to problems with the female excitement phase, libido and orgasm, response to sexual stimulation, and loss of sexual energy and erotic pleasure. Current sexual functioning was described in sixty-seven women diagnosed with breast cancer (mean age 56.2 years) who were treated with chemotherapy or endocrine (hormone) therapy (Young-McCaughan, 1996). Controlling for endocrine therapy, the women treated with chemotherapy were more likely to report weight changes, hot flashes, and mood swings. They were also more likely to report vaginal dryness, a decreased libido, dyspareunia and more difficulty achieving orgasm.

Body Image

"Body image involves an individual's perception of his or her body and is derive

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derived from past experiences, social interactions, and current sensations in response to input received from vision, touch, hearing, and the perception and reactions of others" (Shell, 1998, p. 183). Furthermore, a positive body image is significantly linked to sexual satisfaction (Masters, et al., 1994). Katz, Rodin, and Devins (1995) affirm that impaired body self-esteem (their descriptor for body image) in individuals with disfiguring cancer treatments is one of the most consistent empirical findings in their literature review. Individuals with a diagnosis of lung cancer not only experience a most feared diagnosis often with a fatal result, but many also endure months of insult to their bodies and body image. Temporary or permanent disfigurement, wounds and scars cause a level of distress that many patients hesitate to admit. Less severe alterations (e.g. weight loss, skin changes, hair loss, shortness of breath) can be just as devastating (Shell, 1998). In one study, 40 cancer patients who had experienced hair loss due to chemotherapy treatment reported a lost sense of control and power over their very being, along with changes in self-perception, self-esteem, and sense of self (Pickard-Holley, 1995).

Breast cancer and one of its treatments, mastectomy (removal of the breast), is known to affect the concept of body image in relation to a loss of femininity and disruption of body image (Lasry, Margolese, Poisson, Shibata, Fleischer, & Lafleur, et al., 1987; Margolis, Goodman, & Rubin, 1990; Meyerowitz et al., 1999; Schover, Yetman, Tuason, Meisler, Esselstyn, Herman, et al., 1995).

Men who must undergo radical prostatectomy for cancer also encounter disturbing problems with body image (Ofman, 1993). If "nerve-sparing" surgery is not possible or ineffective, the inability to achieve or maintain an erection will devastate a ma

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man's body image and self-esteem, regardless of age. Urinary incontinence may curtail social activities because this circumstance is difficult to conceal and is associated with uncleanness (Shell, 1998; Stanford, et al., 2000). Hormonal manipulation is usually the treatment of choice if prostate cancer recurs, and these medications can cause hot flashes, mood swings, and a thinning of the hair, in addition to impotency, all of which can have a negative influence on male body image (Messing, Manola, Sarosdy, Wilding, Crawford, & Trump, 1999).

Psychosocial

Many researchers have clearly shown that cancer treatment can be particularly destructive from an emotional and social point of view. Head and neck cancer is particularly devastating because it usually affects the facial area and surgeries are often quite mutilating. Gamba, Romano, Grosso, Tamburini, Cantu, & Molinari (1992) studied 66 head and neck cancer patients from 6 months to 8 years after surgery. These patients were divided into two groups relative to degree of disfigurement (minor = 36%; extensive = 64%). Interviews were conducted with close-ended questions that assessed self-image, relationship with partner, family, and friends, and overall impact of therapy. There was a significantly higher impact in extensive vs. minor groups regarding changed self-image (57% vs. 25%, p<. 05), a worsened relationship with partner (27% vs. 0%, p<. 05), a reduced sexuality (74% vs. 39%, p<. 01), and increased social isolation (36% vs. 12%, p<. 05) (Gamba, et al., 1992). Espie, Freelander, and Campsic (1989) assessed a "cohort" of patients who had major oral surgery for evidence of psychosocial disturbance. Forty-one percent had significant levels of psychological distress (symptoms) comparing mood disorder, social dysfunction or both. Predictors revealed that females and young people were at greater risk for distress. Monga et al. (1997) examined fifty-five of 101 head and neck cancer patients who were willing to answer several questionnaires (e.g. Derogatis Inventory of Sexual Functioning, Multidimensional Health Locus of Control). They found that the majority of these patients experienced problems with sexual functioning, and that younger patients had poorer sexual function than those over the age of sixty-five.

Disruption in activities of daily living associated with physical and emotional sequelae is often described in the literature due to a breast cancer diagnosis and treatment (Ganz, Rowland, Desmond, Meyerowits, & Wyatt, 1998; Meyerowitz, et al., 1999). Bloom, Cook, Fotopoulis, Palmer, Gates, Brigham, et al., (1987) reported on data from 412 women, studied over a 1-year period of time. Those studied included women treated for various maladies that included, mastectomy, cholecystectomy, biopsy for benign disease, and a group of healthy women. None of the women experienced pre-existing psychiatric illness. Greater psychological distress related to social and interpersonal relationships was seen in the mastectomy patients, however, their overall findings suggest that the risk is low for the development of severe reactive anxiety or depression in women treated with mastectomy for breast cancer. There are also accounts among women with breast cancer that describe the development of sexual avoidance at diagnosis because they anticipate rejection by their spouse, even though men often "tune out" the missing breast and focus on the pleasure of lovemaking (Kaplan, 1992). In their study of fifty breast cancer patients, half of who were premenopausal and half who were not, Ghizzani, Pirtoli, Bellezza, and Velicogna (1995) found that good functioning of the marital relationship aided in the adjustment to illness in the younger women. The menopausal women, however, depended more on an extended network of emotional support. Marital adjustment was also associated with adequate sexual functioning in the younger cohort (Ghizzani, et al., 1995). Gamba et al. (1992) reported a worsened relationship with the partner in their study with sixty-six individuals with head and neck cancer. Those with a greater degree of disfigurement experienced more relationship problems, along with a changed self-image and reduced sexuality. Although the literature does reveal disturbance in couple relationships among men with testicular cancer, it tends to be moderated by flexibility in relationships, good marital communication patterns, mutual supportiveness and previous marital satisfaction (Gritz, Wellisch, & Siau, 1990).

Through a thorough literature review, it becomes clear that psychosocial research and intervention is scant for the individual with lung cancer, and no studies were identified that dealt specifically with sexuality or sexual function before, during or after treatment for lung cancer. A study by Cella, Orofiamma, Holland, Silberfarb, Tross, Feldstein, et al., (1987) revealed the relationship of distress to the extent of disease and performance status in 455 patients with small cell lung cancer. Clearly, the study gives the reader only broad-based information and does not specifically touch on sexuality problems that can arise. The association between extent of disease (ED) and performance status rating (PSR) and the outcome of psychological distress in this population was investigated. Psychological distress was measured by the standardized Profile of Mood Status (POMS). "Gender, age, marital status, education, performance status, extent of disease and two relevant interaction terms (PSR X ED and Gender X ED) were analyzed using multiple linear and hierarchical regressions. The final index resulted in five levels of ph

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of physical impairment, which bear an approximately linear relationship to increasing levels of distress (p. < .001). These data suggest that PSR is an important factor in modeling POMS distress at both levels of ED, and that ED becomes an influential factor with poorer performance status only" (Cella, et al., 1987, p. 1661). Bernard and Ganz (1991a, 1991b) reviewed the literature since 1975 regarding psychosocial issues in lung cancer patients and concluded that a number of areas needed further investigation. This two-part review placed emphasis on the multidimensional construct of quality of life, and sexual function is included within this construct. They also identified areas for future investigation and state that, "our review and recommendations emphasize the need for integrating the evaluation of psychosocial issues into the routine medical care of the lung cancer patient." (Bernard & Ganz, 1991, p. 484). A Canadian study examined psychiatric illness and psychosocial concerns in 52 newly diagnosed lung cancer patients, 75% male and 25% female; ninety-four percent were 50 years of age or over. Of the 20 outcome measures, one was related to the patients' sexuality and that was "loss of libido" (Ginsburg, et al., 1995). They found that this patient population commonly experienced symptoms of potential psychiatric significance and psychosocial concerns. Specifically, in regard to sexuality concerns, 25 (48%) acknowledged loss of libido; this was severe in twenty-seven percent. (Ginsberg et al, 1995). Twenty-nine percent were concerned about their families and how they would cope, and eight percent worried about work and finances, however good family support systems were evident in most cases.

Sarna (1993b) reported on a group of 69 women (average age 61 years) with lung cancer and the impact this disease had on quality of life. There is greater disturbance in their quality of life than in women with other cancers, particularly in women with recurrent lung disease. They have more problems, greater psychological distress, and greater marital dysfunction. There is a 38% decrease in sexual activity; many are no longer interested in sex, nor do they feel sexually attractive (Sarna, 1993b). Ryan (1996) has offered information on the role of behavioral medicine as an approach to several of the psychosocial issues associated with lung cancer in women. She reports that behavioral interventions such as relaxation, meditation, and social support may be used to augment medical treatment for nausea and vomiting, decrease painful suffering, and decrease anxiety associated with shortness of breath. They may also be used to promote a sense of control, reduce emotional distress, and enhance overall quality of life and hopefulness (Ryan, 1996). In a sample of 56 lung cancer patients (mean age of 60 years, 62% male), Klemm (1994) explored the correlation between daily hassles, demands of illness and social support to psychosocial adjustment. She found that demands of illness were predictive of psychosocial adjustment (higher scores meant decreased adjustment). Subjects reported generally high social support, low daily hassles, and moderately low demands of illness (Klemm, 1994). Finally, quality of life was assessed in adult survivors of lung, colon and prostate cancer. The investigators reported significant physical, psychosocial, sexual, medical interaction, and marital problems in all three groups (Schag, Ganz, Wing, Sim, & Lee, 1994). However, lung cancer survivors experienced more problems than the others and it was determined that "patients who survive cancer do not return to a state of normal health" (Schag, et al., p. 127).

In a recent literature review, Manne (1998) examined the impact of cancer (breast, lung, prostate, colon, and testicular) on both the patient and the healthy spouse. She explained that a cancer diagnosis can have a significant impact on the family system, and

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and that “an illness in one spouse can alter the couple’s emotional balance, finances, division of responsibilities, and social activities” (Manne, 1998, p. 188). Findings suggest that distress levels are likely to increase over time in couples who experience disease with a poor prognosis which is likely to recur (Manne, 1998).

Clearly when the literature is reviewed, it becomes evident that psychosocial research and intervention related specifically to sexual function and sexuality is available for various cancer diagnoses, especially breast and prostate cancer. However, there is a paucity of information regarding the psychosocial and sexual health needs of the individual with lung cancer. It is essential that marriage and family therapists, particularly those working within the medical community, become more aware of, knowledgeable, and more attentive to the needs of individuals with lung cancer. Attention to symptoms and concerns can then be addressed in a systematic way. This study will investigate how treatment for lung cancer impacts sexual function, and what effect social support and mood status may contribute.

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CHAPTER THREE

Methodology

Assumptions

A set of assumptions lies behind this research study that are listed and then discussed. Assumptions are "something taken to be true even though the direct evidence of its truth is either absent or very limited" Dr. Norma Bobbitt (personal communication, September, 1997).

Metatheoretical Assumptions: Assumptions about this research in relation to previously created theoretical assumptions about sexuality.

Assumption 1: This is an important area to study.

This research makes an important contribution to knowledge related to human sexuality. Because no investigator has studied lung cancer patients and how their sexuality is affected by treatment for this disease, this research is deemed "good". This patient population is often considered irrelevant because of their poor prognosis, however, now that they are living longer, it is necessary to care for the whole human being, not merely their cancer and its physical symptoms. This provides for a better quality of life. Masters and Johnson (1966) tell us that one half of all couples have some type of sexual problems during their relationship, and these are healthy individuals. It is, therefore, assumed that the patient population with lung cancer may have some type of sexual dysfunction during and after their treatment.

Assumption 2: There is a need to develop theory about the possible sexual dysfunction in lung cancer patients.

The diagnosis of lung cancer continues to increase in females and to decrease onl

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only slightly in males. Because these patients are beginning to live somewhat longer, they deserve to have the same quality of life that other patients with cancer claim. There is, however, a paucity of theory development related to their sexual needs. Theory related to healthy individuals and the factors that affect their sexual desire is already evident (Masters, et al., 1994; Snarch, 1991, 1997).

Social Definitionist Assumptions: Assumptions regarding lung cancer and its treatment and how the person perceives the effects on their sexual function.

Assumption 1: Different treatments create different outcomes related to the sexuality of patients with lung cancer.

Research has examined how different treatments affect the sexuality of patients with other types of cancer such as breast, cervical-uterine, prostate, and testicular. According to Bernard and Gantz (1991a, 1991b), people with lung cancer have many psychosocial issues and concerns. They have not been studied sufficiently to reveal anything specifically related to their perception of how treatment affects their sexual function and/or whether dysfunction is present.

Assumption 2: A contributory intervention related to sexual function, created for patients with lung cancer who will be or are taking treatment, is interpreted as promoting a positive outcome during and after completion of treatment.

The outcomes that are to be expected would have to be specified. The basis for this assumption is the fact that positive outcomes have been realized for patients with other types of cancer; they have been effective and interpreted by the patient as positive (Anderson, 1987; Schover, 1989).

Research Design

This exploratory study measured level of sexual functioning, social support, and mood status of lung cancer patients, using the Derogatis Interview for Sexual Functioning, Self Report: Female or Male Version (DISF-SR) (Derogatis, 1987), the Social Provisions Scale (SPS) (Cutrona & Russell, 1987), and the Derogatis Affects Balance Scale (DABS) (Derogatis, 1975a) respectively in two different treatment groups at three points in time. The DISF-SR (female or male version), SPS, and DABS were given to patients 1) at first diagnosis (diagnosis done by biopsy or lung surgery), either pre-treatment or within 3 weeks of initiation of treatment, 2) at 2 months after first measure, and 3) at 4 months after first measure. Treatment groups are designated according to type of treatment: chemotherapy only and chemotherapy preceded, followed by, or concurrent with radiation therapy. A measurement of sexual functioning, social support and mood status taken after diagnosis, but before the patient is too far into treatment, reduces error variation in the dependent variable.

Data Collection Procedure

The nursing staff of out patient chemotherapy and radiation therapy units was enlisted to identify newly diagnosed lung cancer patients, and notified the investigator of their admission to the department/office. If the investigator was not on site, the nurse requested permission from the patient for the investigator to call and explain the study to them via the telephone. The investigator called remote sites on a weekly basis to ascertain whether there were newly identified patients to be called.

The investigator also identified patients. Once a subject was identified, the investigator determined eligibility for participation in the study. An explanation of the study

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study given by the investigator took place privately with the subject, either in an examination room, the investigators' office, or via telephone, and informed consent obtained (See Appendix A), along with patient sociodemographic data (See Appendix B). If the subject was contacted in person, the study was explained and they were given the DSFI-SR, the DABS, and the SPS to read before signing the informed consent. The subjects were informed that they would be surveyed initially, and at two month and four month intervals after the first survey had been completed. Whether the subject was approached in the clinic or via the telephone, they were always instructed to read over the surveys first before signing the consent, especially because of the sensitive nature of the DISF-SR. The subjects were encouraged to ask questions related to the surveys or the consent if they did not understand the time frame, how to complete them, or if they had other concerns. The subjects were reminded that they were not obligated to participate and that they could discontinue the study at any time.

If the subject agreed to participate after reading and understanding the surveys, informed consent was obtained. The subjects were offered a copy of the consent, and either completed the surveys at the clinic, took them home and returned them at a later date, or completed and returned them via the mail. Completion time for all three surveys took approximately 15 to 20 minutes. If the subjects completed the instruments at the clinic, the investigator remained nearby to answer questions of any kind. If the subjects took the surveys home or if they were contacted via telephone, a toll free number to the investigators' office was provided in case there were questions.

If the subject was contacted via telephone only, again, the study was explained in depth. If the subject agreed to have the survey forms sent to them, they were reminded that there was no obligation to participate. Whether or not they chose to participate, they were requested to send the surveys back. A self-addressed, stamped envelope was provided for the subject to minimize time and cost for them.

Those subjects who agreed to participate were studied over a four-month period from the time they completed the first survey providing they stayed alive, were without brain metastasis, and were able to complete the instruments. After the initial administration of the DISF-SR, the SPS, and the DABS, telephone contact was maintained with the subjects so follow-up surveys could be administered. If the subject was not present at the clinic at the specific two or four month interval, the subject was called on the telephone and the surveys were mailed to their home to be completed. Subjects from whom surveys were not returned within two weeks received a follow-up phone call from the investigator as a reminder to complete the surveys and send them back to the investigator.

Protection of Human Participants

An explanation of the study by the investigator took place in the treatment room, the investigators' office, or via the telephone and informed consent obtained. Because of the sensitivity of the subject matter of this study, a private room was used to ensure the privacy of the individual subject. The investigator, and only the investigator, obtained the sociodemographic data after informed consent was obtained. Completed surveys and sociodemographic forms were coded to correspond with the consenting subject's name. The coded sheet was kept separately from the completed surveys and sociodemographic forms. No one but the investigator had access to the coded sheet and it was used only to contact individuals for follow-up. All materials related to the subjects were kept under lock and key in the investigator's office. In the final report, all data was aggregated and no subject was singled out or identified.

Setting and Sample

This study was primarily conducted in a chemotherapy out patient clinic and a radiation therapy department in a cancer center in the south. Due to the fact that patient accrual was slow, the study branched out to cities in close proximity of the cancer center. Again, due to slow accrual, it was decided to extend the study to lung cancer patients on the Internet. The sample consisted of all patients, male and female, identified in these settings with a new diagnosis of small cell or non-small cell lung cancer. Information about the type of malignancy, the treatment received, and other clinical data was obtained from the patient, the patient's clinic chart, and/or from the nurse who identified the patient to the investigator. The investigator received pathology reports for fifty-five of the 59 participants. Patients were eligible for the study if they met the following criteria:

1. the patient must be 18 years of age and older
2. the patient must have a diagnosis (new or recurrent) of small cell or non-small cell lung cancer confirmed by pathology report or by patient report
3. the patient may have been diagnosed via bronchoscopy, biopsy (needle or open lung), wedge resection (portion of the lung removed), or removal of a lobe of the lung

4 The patient could have any stage disease (I through IV)

5. the patient must be able to read, understand, and speak English
6. treatment must consist of chemotherapy only or chemotherapy preceded or followed by, or concurrent with radiation therapy

6. all patients must give informed consent to participate
7. patients with other forms of cancer (excluding basal-cell skin cancer) who are disease free for 10 years or more will be eligible.

Patients were not eligible if:

1. the patient had prior treatment with chemotherapy or radiation therapy within 10 years.
2. the patient was found to have brain metastasis during the course of treatment.

Over an 18-month period of time, a sample size of 59 patients was accrued: 23 (39%) patients in the chemotherapy only group and 36 (61%) patients in the chemotherapy and radiation group. There were 46 (78%) non-small cell cancer patients and 13 (22%) small cell patients: 32 female and 27 male patients. When patients became ineligible or died during the study period, an attempt was made to replace them. Permission for this study was requested from Michigan State University, as well as from individual physician's offices.

Instrumentation

The dependent variable, difference in sexual functioning, was measured using the Derogatis Interview for Sexual Functioning, Self Report (DISF-SR) (Derogatis, 1987, 1997). This self-report is designed to measure the quality of current sexual functioning in quantitative terms. The DISF-SR is a multidomain instrument designed to assess sexual function. This self-report assessment modality was created along with an interview version. The author concluded that some measurement applications require the increased flexibility of the clinical interview, while others may be more suitable to respondent self-report (Derogatis, 1997). First, the interview version, DISF, was created and submitted for validation. Development of the DISF-SR followed and care was taken to design self-report items equivalent to the interview questions.

The DISF-SR is composed of twenty-five questions that measure sexual function, and includes five separate domains that essentially parallel the sexual response cycle: sexual cognition/fantasy, sexual arousal, sexual behavior and experience, sexual orgasm, and sexual drive and relationships (Masters & Johnson, 1966; Derogatis, 1987). Each domain has from four to six items (five items for sexual cognition/fantasy, arousal, and behavior/experience, six items for orgasm, and four items for drive/relationship) that are preceded by a question. Each item is rated using frequency or satisfaction scales. Due to the authors research experience in human sexuality, he chose to use "nine-point frequency scales (0 = not at all and 8 = 4 or more times per day) for the first three domains, five-point satisfaction scales (0 = not at all and 4 = extremely) for the fourth domain, and a combination of nine-point and five-point scales for the fifth domain" (Derogatis, 1997, p. 294-295).

The DISF-SR can be interpreted on three levels: the item score (e.g., "Feeling a sense of relaxation and well-being after orgasm"), the domain score (e.g., Sexual Cognition/Fantasy), and the total score (e.g., DISF-SR total score) (Derogatis, 1987). To calculate the item "raw" score, the patient is asked to rate each item (e.g. for arousal the rating is 0 to 8); a higher score represents better functioning. When each subscale within a domain is totaled, the domain "raw" score is realized (the range is 0 to 40 for fantasy, arousal, and behavior subscales; the range is zero to 24 for orgasm and for the drive subscales). Finally, the total "raw" score from all five domains is added to secure the total score. All raw scores are converted to standardized Area T-scores.

Representative norms have been developed for the DISF and the DISF-SR based on several hundred nonpatient community respondents (samples of 122 and 277, respectively) (Derogatis, 1997). The norms are gender specific. They are represented as standardized scores in terms of Area T-Scores, and Area T-scores provide accurate percentile equivalents (i.e., T-score of 30 = 2nd percentile; T-score of 40 = 16th percentile; T-score of 50 = 50th percentile; T-score of 60 = 84th percentile; T-score of 70 = 98th percentile, etc.) (Derogatis, 1987).

> "Area T-scores are generated through a normalizing transformation that is superior to simple linear transformations in that it ensures that the actuarial characteristics of the normative sample are retained. Such transformations preserve the centile equivalency both within and across respondents...This is so whether comparisons are being made across individuals or across domains within a single individual's DISF/DISF-SR profile. The latter feature enables meaningful comparisons of strengths and weaknesses within an individual's sexual functioning profile. The former characteristic enables an accurate estimate of the level of enhancement or decrement of an individual's (or group's) level of functioning relative to the normative sample"(Derogatis, 1997, p. 295).

In interpreting DSFI subscales, deviations below the 50th percentile are interpreted as relative deficiencies in important aspects of sexual functioning, while elevations above the 50th percentile are viewed as relative strengths.

Administration time for the DSIF-SR is approximately 15 minutes; this is about five minutes less than the DISF takes to complete. Repeated experience promotes reduced administration time with either instrument. Derogatis (1987) reports that the DISF-SR can also be used to evaluate patient sexual performance by the spouse, with certain modifications in format.

Internal consistency and test-retest reliability data for the DISF/DISF-SR are reported using samples of 168 and 122 patients respectively (Derogatis, 1987). Internal consistency coefficients tend to be high and well within an acceptable range; orgasm and cognition/fantasy reveals the highest consistency at .80 & .79 respectively, while behavior/experience at .77, arousal at .76 and drive/relationship at .74 are also acceptable values. Test-retest coefficients are based on a 7-day retest interval and range from .80 to .90; the stability coefficient for the DISF-SR is .86 (Derogatis, 1987).

Interrater reliability coefficients were established by 16 clinician/raters training for a multicenter drug trial. DISF domain coefficients demonstrated high values as follows: orgasm at .84, drive/relationship at .86, behavior/experience at .88, arousal and cognition/fantasy at .90 and .92 respectively. The Interrater coefficient total score was a convincing .91.

The DISF/DISF-SR clearly exhibits construct independence and validity with low correlations among the domain scores and moderate to high correlations between domains and the total score (Derogatis, 1987). Based on two normal (168 individuals) and one sexually dysfunctional group (26 women with female orgasmic disorder), Pearson product-moment correlations are provided. The mean domain intercorrelations range from .23 to .39, while the average correlations between domain and total score are .60 to .71 (Derogatis, 1987).

A principle components analysis predicated on the DISF-SR records of 252 subjects with erectile disorder (DSM-IV diagnosis) was undertaken to validate the instrument's internal structure (American Psychiatric Association, 1994). The men were participants in a multicenter drug study. A factor pattern matrix resulted in six factors, "accounting for 71% of the variance in the matrix [and] were retained on the basis of a mineigen criterion" (Derogatis, 1997, p. 297). The first two factors had high loadings ranging from .75 to .89, and they represented domain four and one respectively. Factor one had one external item that loaded on domain five. Factor three represented domain three, but two out of five items did not load on this domain. These items, instead, loaded on factor four. This was thought to occur because factor four represented an autoeroticism dimension and the said items (item 3.1 "Reading or viewing erotic books or stories" and item 3.2 "Masturbation") established high loadings on this factor (Derogatis, 1997). The item 2.4 "Experiencing a full erection during masturbation" from the arousal domain loaded onto factor four, as well. Factors five and six substantiated domains two and five, although they had a larger range, between .41 and .89. Derogatis (1997) reports that "overall, 21 out of 25 DISF/DISF-SR items (i.e. 84%) had factor loadings highly consistent with the hypothesized domain structure of the instrument" (p.299).

Predictive validity for the DISF-SR is demonstrated through two studies that involved 43 men diagnosed with prostate cancer who were to undergo radiation therapy (Zinreich, Derogatis, Herpst, Auvil, Piantodosi, & Order, 1990a, 1990b). At the time of diagnosis, the DISF-SR was used to screen for impotence, although detailed clinical evaluation dictated conclusive criterion for the patient's erectile status. The 43 men were categorized as follows: 16 (37%) were determined to be fully functional, 15 (35%) were marginally functional, and 12 (28%) were diagnosed with male erectile disorder according to the DSM-IV (Diagnostic and Statistical Manual) (American Psychiatric Association, 1994). Their DISF-SR scores all fell into the lower one-third of the normative distribution with DISF-SR mean total scores at 56.7, 29.2, and 17.6 respectively (Derogatis, 1997). Regarding these scores, the investigator reports that, "they are in the ordinal order one would anticipate if the test was a valid measure of sexual functioning, and differences between the groups were statistically significant, F = 5.63, $p < .01$" (Derogatis, 1997, p. 301). Further analysis using logistic regression placed 16 patients into a sexually functional group and 27 patients into a sexually dysfunctional group. For each one-point drop in the DISF score, the probability for sexual dysfunction increased .88 (significance, $p < .002$; 95% confidence interval at .82 to .96). DISF-SR discriminative efficiency is high with sensitivity at 89%, specificity at 75%, and predictive value of a positive is 86%, therefore verifying the sensitivity to quality of sexual functioning (Derogatis, 1997). The DISF-SR has also been employed in a large study examining sexuality in head and neck cancer patients (Monga et al., 1997). Fifty-five of 101 consenting patients participated and most reported arousal problems, over half had orgasmic problems, and 58% didn't participate in sexual intercourse. However, most of these patients were not depressed. Overall, although this population experienced various sexual problems, sexuality was a priority in most of the patients studied (Monga et al., 1997).

The control variable, social support is measured using the Social Provisions Scale (SPS). This is an instrument that assesses different facets of social support, and has been used in several studies to examine how six individual social provisions influence adaptation to stress in different populations (Baron, et al., 1990; Cutrona, 1989; Cutrona, Cole, Colangelo, Assouline, & Russell, 1994; Russell & Cutrona, 1991). The scale consists of 24 items, with four items assessing each social provision. Of the four items in each provision, two are worded in a positive manner and two in a negative manner. "A score for each social provision is derived such that a high score indicates the individual is receiving that provision" (Russell & Cutrona, 1984, p.1). The six social provisions to be measured were based on the theory of Robert Weiss concerning the provisions of social relationships (Weiss, 1974). They are as follows:

I. Attachment: a close, intimate relationship with another person...

II. Social Integration: being enmeshed in a social network...where the person shares common interests and engages in social activities.

III. Reassurance of Worth: relationships with colleagues at work, where the person derives a sense of competence and esteem through relationships with others.

IV. Reliable Alliance: usually provided by relationships with kin...

V. Guidance: having individuals whom the person feels have knowledge and expertise in certain areas that can be relied upon for advice.

VI. Opportunity for Nurturing: typified by the parent-child relationship...

(Russell & Cutrona, 1984)

These constructs are designed to permit valid assessment of perceived social support. Therefore, respondents are asked to rate the degree to which their social relationships are supplying each of the six provisions previously mentioned. A Likert scale is used with 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree.

Some of the items are reversed before scoring. Time needed to complete the scale is approximately five to seven minutes.

Reliability analysis for the revised (24 item) Social Provisions Scale was undertaken with a sample of 1792 subjects: 1183 introductory psychology students (Cutrona & Russell, 1987), 303 public school teachers (Russell et al., 1987), and 306 military nurses (Constable & Russell, 1986). Reported reliabilities for the six social provision subscales proved adequate with coefficient alphas ranging from .653 to .760; reliability for the total SPS score was .915 (Cutrona & Russell, 1987).

Confirmatory factor analysis was conducted to evaluate the factor structure of the scale. The same sample of 1792 students, teachers and nurses participated. Based on their responses, a covariance matrix was computed and initial analysis evaluated the fit to be quite good, X2 (237. N = 1792) = 1690.91, given the large number of subjects to respond. Although consistent differences in patterns of association with various outcome variables have been found for the six provisions, factor analysis does support the six-factor structure. "The correlations among the social provisions appear to represent the influence of a general or global social support factor. However, the individual provisions also appear to reflect distinct aspects of support. We therefore conclude that the Social Provisions Scale assesses both specific components of social support in addition to the overall level of support available to the person" (Cutrona & Russell, 1987, pp.49-50).

Cutrona and Russell (1987) felt it was important to demonstrate that measures of social support impact health independently of other influences like relevant personality or social skill factors. Therefore, 242 college students completed multiple sets of measures to evaluate the discriminant validity of the Social Provisions Scale (Cutrona & Russell, 1987). The social support measures completed include, the Social Support Questionnaire (Sarason et al., 1983), the Index of Socially Supportive Behaviors (Banera, Sandler, & Ramsay, 1981), a measure of attitudes toward use of social support (Eckenrode, 1983), the Marlowe-Crowne Social Desirability Inventory (Crowne & Marlowe, 1964), the Beck Depression Inventory (Beck et al., 1961), and the introversion-extraversion and neuroticism scales from the Eysenck Personality Inventory (Eysenck & Eysenck, 1975). The students also completed a stressful life events assessment specific to college students. Results indicated that correlations were much higher between the Social Provisions Scale and measures of social support (range = .352-.458) than between the SPS and measures of the other variables (range = -.278-.289). All correlations were statistically significant except student "number of stressful events". Although these zero-order correlations were significant, Cutrona and Russell (1987) remained concerned that the non-social support variables could in combination account for scores on the SPS. Therefore, they used a hierarchical multiple regression analysis to examine this issue. The variables, measures of social desirability, depression, introversion-extraversion, neuroticism, and stress were entered first and accounted for 14.3% of the variance in social provisions scores, F (5,236) = 7.57, p< .001 (Cutrona & Russell, 1987). Once the influence these factors exercised over total social provision scores had been statistically controlled, the social support measures were entered into the equation. The support measures accounted for an additional 18.1% of the variation in the social provision scores, F (4,222) = 14.88, *p*< .001. Therefore, measures of social support are more closely related to scores on the Social Provisions Scale than the other relevant variables (Cutrona & Russell, 1987). Cutrona and Russell (1987) summarize by stating,

> "the evidence from this study clearly supports the discriminant validity of the Social Provisions Scale. Although the measure does appear to be related to measures of social desirability, introversion-extraversion, and neuroticism, our results indicate that the measure assesses a construct that is distinct from these latter measures. Most importantly, however, the Social Provisions Scale appears to add to the explanation of psychological distress over and above the influence of these related variables" (p.52).

Several studies using the Social Provisions Scale have been done since the 1987 research report on the scales' validity and reliability. Research has been conducted with various groups related to the perceptions and ratings of social support using the Social Provisions Scale. Study results in one group of 115 pregnant adolescent girls, and the adults who know them well, showed a moderate level of agreement between adolescent and informant support ratings. However, significant predictors of post-partum depression scores came only from the adult informant ratings. Cutrona (1989) states that, "the ability of informants' ratings of social support to predict the adjustment of the adolescents to a major life stress was viewed as evidence that the commonly found link between social support and mental health reflects more than self-report biases" (p. 723). More recently, two other studies used the Social Provisions Scale. They included, 1) the test of a process model in relation to social support, stress and depressive symptoms among the elderly (301 adults 65 years or over) and, 2) perceived parental social support and academic achievement in 418 undergraduates (Russell & Cutrona, 1991, Cutrona, et al., 1994). Although in different settings, both studies revealed that social support lead to a positive outcome or prevented a negative component; deficient social support lead directly and indirectly to consequent depression in the elderly, and perceived parental social support (reassurance of worth) of students related significantly to objectively assess academic performance. Finally, social support and its relation to immune function in the spouses of cancer patients have also been assessed using the Social Provisions Scale. Of the 24 spouses who participated in the study, there was evidence of greater immunocompetence on two of three dynamic measures in those who reported high levels of social support (Baron, et al., 1990).

The Derogatis Affects Balance Scale is a measure of mood or affect, and provides a profile of four positive (joy, contentment, vigor, affection) and four negative (anxiety, depression, guilt, hostility) affects plus five global measures (See Table 1). There are twenty adjectives, which describe both the negative and the positive, affect dimensions: forty in total. A five-point Likert scale measures each item ranging from 0 = "Not-at-all" to 4 = "Extremely" (Derogatis, 1996, p.4). As well, the five global scores provide summary measures of affective status at a higher order, and comprise the following: the Positive Total Score (PTOT), the Negative Total Score (NTOT), the Affects Balance Index (ABI), the Affects Expressiveness Index (AEI), and the Positive Affects Ratio (PAR) (Derogatis, 1996). Table 2 provides a summary of the global scores.

This 40-item questionnaire is written at an eighth grade reading level and takes approximately five minutes to complete. Derogatis (1996) asserts that the DABS can be used repeatedly over time to monitor affective status, and that "practice effects which could conceivably bias repeated administrations appear to be absent" (p. 11). Scoring for the DABS begins with the 8 primary affects dimensions. Five specific item scores within each dimension are summed to arrive at the raw score; four dimensions are positive and four are negative. A DABS Score/Profile Form is available to simplify this process and can be used to plot the current affective status. For the global scores, first the PTOT and NTOT are calculated by adding the sums of the four positive affects and the four negative affects respectively. To provide the Affects Balance Index, the NTOT is subtracted from the PTOT and this number is divided by the constant 20 (i.e. PTOT – NTOT /20 = ABI). To provide the Affects Expressiveness Index, the PTOT and the NTOT are added together regardless of valence. To provide the Positive Affects Ratio, The PTOT is divided by the AEI (i.e. PTOT / AEI = PAR) (Derogatis, 1996).

Table I – DABS Primary Affects Dimensions

POSITIVE AFFECTS DIMENSIONS	DEFINITION
Joy	A core dimension of positive affectivity, a central facet of the emotional feeling state of happiness
Contentment	A core aspect of positive affectivity; expresses a cognitive component of self-satisfaction
Vigor	The action component of positive affectivity, reflecting an enabling energy source
Affection	Refers to the individual's capacity to engage in positive emotional correspondence with others
NEGATIVE AFFECTS DIMENSIONS	DEFINITION
Anxiety	A core component of negative affectivity with origins in the fundamental mechanisms of "fight-flight"
Depression	A core component of negative affectivity characterized by sadness, apathy, dejection and dysphoria
Guilt	A complex affective state based up the perception/ belief that he/she has failed to adequately assume significant responsibilities
Hostility	An affect state with its origins in the fight-flight system. Perceived events (threats, challenges) evoke this anger state

Norms have been developed for the DABS and include a community population norm based on 480 community residents, an inpatient depression norm based on 339 hospitalized depressed patients, and an asthmatic medical outpatient norm based on 100 asthmatic outpatients (Derogatis, 1996). Gender-keyed norms have not been established because even though slight gender differences have been realized, they are deemed "clinically insignificant from a magnitude of effect perspective" (Derogatis, 1996, p. 13).

Table 2 – DABS Global Indices

DABS Global	Definition	Interpretation
PTOT	$\sum$ All Positive Items (i.e., 20 + item scores	Primary DABS measure of positive affectivity
NTOT	$\sum$ All Negative Items (i.e., 20 – scores)	Primary DABS measure of negative affectivity
ABI	(PTOT – NTOT) /20	Principal DABS measure of affects balance
AEI	$\sum$ (PTOT + NTOT)	Measure of affective expressiveness or intensity
PAR	PTOT / AEI	Proportion of total affective expression due to positive emotions

As with the DISF/DISF-SR, this instruments' norms have been generated using standardized scores known as area T-scores; this type of scoring has previously been explained. The DABS area T-scores are identical to the DISF/DISF-SR T-scores (e.g. T-score of 35 = 7th percentile, 60 = 84th percentile, & 70 = 98th percentile).

To insure instrument precision, internal consistency and test-retest reliability is often used with self-report inventories such as the DABS (Derogatis, 1996). Based on a sample of 355 psychiatric patients, coefficients α ranged as follows, positive affects, .84-.92; negative affects, .79-.85, which indicates item homogeneity. Test-retest samples are smaller, but indicate temporal stability, as well. A sample of 16 breast cancer patients were assessed one week apart, and test-retest coefficients for positive and negative affects ranged from .80-.84, and .78-.82 respectively. Another sample comprised of two sets of older adults was calculated for global scores only. The first sample included 21 healthy adults over 60 years and they were tested 2 months apart; scores ranged from .70 for the AEI to .87 for the ABI. Thirteen patients suffering from Alzheimer's type dementia were tested one month apart with test-retest coefficients ranging from .40 for AEI to .71 for NTOT & PAR. These expressed coefficients indicate acceptable test-retest reliability.

Construct validation for the DABS was accomplished at two discrete levels of structure: the eight primary affects dimensions and the constructs of positive and negative affectivity. DABS scores from 355 psychiatric inpatients were examined using principal components analysis with an orthogonal varimax rotation (Derogatis, 1996). Of the eight DABS dimensions, three factors reflected positive affects and three reflected negative affects. These six accounted for nearly 70% of the variance in the matrix. A combined joy/contentment dimension, an affection dimension, and a vigor dimension reflected the positive affects, while a combined depression/guilt factor, an anxiety, and a hostility factor reflected the negative affects. A perfect eight-factor structure was not attained, however, the analysis did confirm a majority of the constructs (Derogatis, 1996). Verification of the positive and negative affectivity factors was also performed using principal components analysis with orthogonal varimax rotation; two principal components emerged which accounted for 72.2% of the variance (Derogatis, 1996).

Practical utility of an instrument is verified through its predictive validity. Although the DABS has many applications as a primary outcomes measure, the studies reflected in this paper will relate to cancer populations and sexuality research. An early study using the DABS investigated cancer morbidity and mortality and the role psychological factors played (Derogatis, et al., 1979). Statistically significant results indicated that the DABS "negative" affect measures were able to discriminate "long" from "short" survivors. In a related study with twenty-six testicular cancer patients, the DABS was used along with other predictors to evaluate 19 long-term survivors (over seven years) and seven short-term survivors (dead within the first year). This analysis using the DABS disclosed significantly higher levels of anxiety, hostility and depression in the long term compared to the short term survivors (Edwards, DiClemente, & Samuels, 1985). These investigators postulated that high negative, rather than positive, affectivity, indicated a successful manner of coping relative to the cancer and its treatment.

In a seven-year follow-up study with first recurrent breast cancer patients, the DABS joy scale, along with other measures, was able to significantly predict length of survival using a Cox proportional hazards model (Levy, Lee, Bagley & Lippman, 1988). Generally, using other prediction methods, the investigators also found that positive mood states were associated with longer survival, and determined that these states represented resilience or hardiness to some extent (Levy, et al., 1988). Other investigators who work with breast cancer patients have used the DABS' measures to predict compliance with chemotherapy regimens, and to compare agreement in affect status between spouses after mastectomy and at one month (Ayers, et al., 1994; Northouse & Swain, 1987). Ayers et al., (1994) found that high scores on dimensions vigor, anxiety and depression predicted good compliance, while high DABS scores on dimensions guilt and hostility predicted poor compliance. Northouse and Swain (1987) used the DABS with breast cancer patients and their spouses to reveal agreement in affects states; both spouse and patient showed a significant decrease in positive affects right after surgery, but a return to normal was noted one month later.

The DABS has been used extensively in sexuality studies due to the fact that it is a subtest of the Derogatis Sexual Functioning Inventory (DSFI) (Derogatis, 1975). Studies of the affective profiles of men and women with common sexual dysfunctions have found that, "individuals suffering from these disorders (i.e., premature ejaculation and male erectile disorder in men; hypoactive sexual desire and female orgasmic disorder in women) demonstrated affects balances a full standard deviation below the normative mean" (Derogatis, 1996, p. 27). Compared to healthy controls, people with common sexual dysfunctions exhibit negative affectivity that is elevated ($p <. 001$) and positive affectivity that is suppressed ($p < .001$) (Derogatis, 1996). A related study using the DABS examined women suffering from anorgasmia (female orgasmic disorder) (Derogatis, Schmidt, Fagan, & Wise, 1989). Low desire, histrionic, psychiatric disorder, and constitutional were identified as subtypes of this disorder through cluster analysis. Findings revealed "constitutional" and "low desire" produced "modest positive affects suppression, but were essentially clinically unremarkable" (Derogatis, 1996, p. 28). Histrionic and psychiatric disorders demonstrated substantially negative affects balances, and a significant loss of positive affectivity (Derogatis, et al., 1989).

In relation to healthy individuals, a study with approximately 250 men and women in a community setting was undertaken, where quality of sexual functioning and feelings of well being were assessed. The DISF was used to assess sexual functioning and the DABS measured affectivity and well being. Significant correlations were revealed between the DABS positive affects, including the PTOT and the ABI, and the

DISF domain and global scores. The only significant correlation revealed between the DABS negative affects and the DISF was on the orgasm scale. The investigators proposed that these findings support the fact that negative affectivity is less sensitive than positive affectivity as an indicator of well being and functional status in healthy individuals.

Data Analysis

Summary statistics will describe the sample.

Research question 1. Multiple paired samples *t* test adjusted by the Bonferroni technique tested change in sexual function within the two treatment groups between three points in time: pretreatment, at two months and at four months into treatment. Independent samples *t* test was used to test change in sexual function between the two treatment groups at the aforementioned three test points. Correlation between treatment and lung cancer cell type was analyzed using chi-square test for independence of two classifications.

Research question 2 & 3. Multiple linear stepwise regression determined the influence of age and gender on sexual functioning. This measurement used data obtained pretreatment, at two and four months into treatment.

Research question 4 & 5. Multiple linear stepwise regression determined the influence of mood status and social support on sexual functioning. This measurement used data obtained pretreatment, at two and four months into treatment.

CHAPTER FOUR

Results

Between June of 2000 and February of 2002, surveys from 59 of 84 eligible subjects were received. Those twenty-five subjects who chose not to participate did so for various reasons and wrote comments like, "I'm not interested", "I decided not to do it", "This isn't for me". Seven chose not to participate because they were not comfortable with the questions or because they didn't want to answer the sexuality questions. Seven non-responders sent back the forms with no note of explanation, eight said they just didn't want to participate, and three others became too weak to complete the surveys after they said they wanted to participate.

Subjects are primarily from the southern United States, (N = 53), and additional subjects are from across the country, (N = 6). As would be expected in a lung cancer cohort, approximately 78 percent have non-small cell lung cancer, while 22 percent have a diagnosis of small cell lung cancer. Ninety-three percent have pathology confirmed lung cancer, while the other seven percent were confirmed by a nurse or by the patient themselves; three of the patients accrued over the Internet were unable to obtain their pathology reports. In the non-small cell category, there are more subjects with stage III and IV disease (70 percent) than with stage I and II (30 percent) (see Table 3). Of those subjects with small cell lung cancer, 46 percent have limited disease, while 54 percent have extensive disease. The 59 patients are, however, quite evenly distributed with regard to which treatment they were given; 39 percent received chemotherapy only and 61 percent received chemotherapy and radiation therapy. All are fully ambulatory, whether or not they have symptoms; 44 percent are unable to work but care for most personal needs, and 56 percent are able to carry on normal activity (see Table 3).

Table 3 Clinical Characteristics of Sample

Characteristics	Number	Percentage
Cancer Diagnosis		
Non-Small Cell Lung Cancer (NSCLC)	46	78
Small Cell Lung Cancer (SCLC)	13	22
Stage of Disease		
NSCLC		
Stage I	2	4
Stage II	12	26
Stage III	9	20
Stage IV	23	50
SCLC		
Limited	6	46
Extensive	7	54
Treatment Status		
Chemotherapy Only	23	39
Chemotherapy/Radiation Therapy	36	61
Karnofsky Performance Status		
Normal Activity (90) Normal activity	2	3
(80) Normal activity with effort	24	41
(70) Unable to carry on normal activity	32	54
(60) Requires occasional assistance	1	2

Karnofsky (1949)

Of the 59 subjects, eight completed the surveys one time only, and subsequently died of their disease or had complications before the two-month test point. Fifty-one individuals completed the surveys at the first and second test points, however two of the subjects' surveys were lost in the mail (the investigator never received the surveys) at the two-month test point, and one subject lost his second social support survey. Consequently, only 48 surveys could be evaluated at the second test point. Forty-one subjects completed the surveys at the third test point. Of the remaining six of 12 subjects who did not complete all three surveys, two died from their disease, two contracted brain metastasis, and the other two chose not to continue due to their poor clinical status or other personal reasons. Overall, participation is favorable for a study of this kind, and excluding those who died, 69 percent were able and willing to continue in the study for the four-month period. Many subjects were extremely enthusiastic and verbalized pleasure at being able to help future individuals with lung cancer cope more effectively. Several actually contacted the investigator if they did not receive their surveys at the assigned date, and many wrote thank you notes for being asked to participate.

The range of time between the start of treatment (chemotherapy only or chemotherapy and radiation therapy) and completion of survey number one varies between 20 days before treatment start to 28 days after treatment start. The mean number of days between treatment start and survey start is13 days; the standard deviation (S.D.) is 7.55. Of those patients who started the survey before treatment began, the mean number of days is 10 days, and the standard deviation is 8.34. An attempt was made to begin subjects on the study as close to treatment start as possible so their pre-treatment sexual function could be measured accurately and treatment would not interfere with either their actual sexual function or their perceptions of how well they were functioning.

Data Analysis

The sample is predominately white, married, with a high school or less education, and from a lower-middle class group (53% earned less than $30,000). There are slightly more females than males, 54 percent and 46 percent respectively, and they range in age from 28 years to 83 years, with a mean of 60.6 years and a S.D. of 11.4 (see Table 4). Ethnic background reveals only 8.5% non-whites. Seventy-five percent of the subject population is married, which possibly provides an advantage for a more normal sexual

Table 4 Demographic Characteristics of Sample

Demographics	Number	Percentage
Race		
White	54	92
Hispanic	2	3
African American	2	3
American Indian	1	2
Marital Status		
Married	44	75
Divorced/Separated	6	10
Widowed	6	10
Single	3	5
Education		
Less than High School	6	10
High School Graduate	33	56
Some College	10	17
College Graduate	9	15
Postgraduate work	1	2
Employment Status		
Employed Full Time	9	15
Employed Part Time	3	5
Not Employed	14	24
Retired	33	56
Family Income		
Under $40,000	40	68
$40,000-$70,000	12	20
Over $70,000	5	9
Unknown	2	3
Age (years)		
28-39	2	3
40-49	7	12
50-59	20	34
60-69	15	26
70-79	13	22
80-89	2	3
Gender		
Female	32	54
Male	27	46

function than for those without partners. Fifty percent of the subjects are retired. Slightly more than 33% have at least 2 years of college or more.

The majority of patients experienced problems with sexual functioning at all three test points. According to the Derogatis Interview for Sexual Function, Self Report (DISF-SR), all but three of the subjects (95%) performed below the norm for sexual function (below the 50th percentile) at the first test point (see Table 5). At the second test point one subject who had functioned below the norm at time one, scored above the 50th percentile at time two, but then reverted to below the norm at the third test point. Two of the subjects (3%) functioned above the 50th percentile at all three test points.

At each of the three survey test points, the subjects tended to report below the norm on the Affects Balance Index (mood status): time one = 65% below the 50th percentile, time two = 75% below the 50th percentile, and time three = 62% below the 50th percentile (see Table 6). The ABI score range is from 25 to 80. However, they tended to perceive high social support with generally higher scores at each test point (see Table 7).

Research Question 1. When adjusted for pre-treatment level of sexual functioning, are there significant differences (alpha = .05) in sexual function within and between the two treatment groups at 2 months and 4 months into treatment?

The Bonferroni technique, based on Students' *t* statistic was used to analyze the change in sexual function *within* the two treatment groups between three points in time: before treatment (chemotherapy only or chemotherapy & radiation therapy) began and at month two and four after treatment had started. The Bonferroni technique is used when constructing the confidence intervals. In order to construct a 95% joint confidence interval of the paired difference among the three test points, a 99% individual confidence interval is created for each pair. Each pair consists of the following: pair 1 = raw data DISF-SR total score between time one and time two, pair 2 = raw data DISF-SR total score between time two and time three, pair 3 = raw data DISF total score between time one and time three (See Table 8).

Sexual function (DISF raw data score) decreases after treatment with chemotherapy or chemotherapy and radiation therapy, particularly between time one and time two of survey completion (mean 4.35 points), and between time one and time three of survey completion (mean 3.10 points). There is very little difference in the score between test point two and test point three (mean .05 points). None of the sexual function score decreases are statistically significant at the level $\alpha = 0.05$ jointly between any two time points.

Before analysis of change in sexual function *between* the two treatment groups was performed, the chi-square test for the independence of two classifications was done to ascertain the relationship between cancer treatment (chemotherapy only and chemotherapy and radiation therapy) and cancer type (small cell and non small cell lung cancer). For the patients with non-small cell lung cancer, 72% received chemotherapy and radiation therapy treatment, while only 23% of patients with small cell lung cancer received said treatment. This indicates a clear relationship between the administration of the two different treatments and the cancer types (P = 0.001 by Pearson Chi-square test) (See Table 9).

Table 5 Sexual Functioning as Measured on DISF Questionnaire: T Scores of 5 Domains of Sexual Functioning in Lung Cancer Patients

	Cognition/Fantasy	Arousal	Behavior	Orgasm	Drive/relationship	Total	Normal*
Mean							
Time 1 (N=59)	35.68	29.00	32.05	30.42	30.56	29.49	50
Time 2 (N=50)	35.04	29.14	32.92	30.24	30.12	28.59	
Time 3 (N=39)	33.43	30.78	32.24	32.95	32.00	27.82	
Standard Error							
Time 1	1.42	1.58	1.45	1.54	1.54	1.85	
Time 2	1.44	1.76	1.56	1.56	1.59	1.70	
Time 3	2.1	1.89	1.61	2.00	1.84	1.60	
Standard Deviation							
Time 1	10.88	12.14	11.17	11.81	11.80	11.57	10
Time 2	10.06	12.30	10.91	10.90	11.10	10.64	
Time 3	13.66	12.13	10.34	12.78	11.81	10.00	
Range							
Time 1	51	40	38	43	38	36	55
Time 2	46	52	40	45	41	34	
Time3	46	35	30	45	40	38	
Minimum							
Time 1	20	20	20	20	20	20	20
Time 2	25	20	20	20	20	20	
Time 3	25	20	20	20	20	20	
Maximum							
Time 1	71	60	58	63	58	56	75
Time 2	71	72	60	65	61	54	
Time 3	71	55	50	65	60	58	

*T-score of normative nonpatient population has a mean of 50 and a standard deviation of 10

Table 6- Statistical Measures for Affects Balance Index T-score

Group	Mean	Median	Mode	Range	Variance	Std Deviation
Time 1 (N=59)	46.42	45.00	45	60	207.32	14.40
Time 2 (N=49)	43.08	43.00	36*	58	190.45	13.80
Time 3 (N=41)	45.46	43.00	20*	58	262.20	16.19

* Multiple modes exist. The smallest value is shown.

Table 7-Statistical Measures for Social Support Total Raw Score

Group	Mean	Median	Mode	Range	Variance	Std Deviation
Time 1 (N=59)	79.88	81.00	70	32	88.59	9.41
Time 2 (N=48)	78.23	79.50	71*	62	157.46	12.55
Time 3 (N=39)	78.87	79.00	72*	46	123.85	11.13

* Multiple modes exist. The smallest value is shown.

Table 8 – Joint 95% Confidence Intervals of Paired Difference at Any Two Time Points for DISF Raw Data Scores

	N	Mean	Std. Deviation	Lower	Upper
Pair 1 RAW1 & RAW2	49	4.35	16.790	-2.09	10.78
Pair 2 RAW2 & RAW3	39	.05	13.268	-5.71	5.81
Pair 3 RAW1 & RAW3	41	3.10	16.441	-3.85	10.04

RAW = DISF total raw score

Table 9 – Treatment/Cancer type Crosstabulation

		Lung Cancer Type		
		Non-Small Cell	Small Cell	Total
Treatment	Chemo only	13	10	23
	Chemo/RT	33	3	36
Total		46	13	59

Independent samples *t* test was used to analyze the change in sexual function *between* the two treatment groups at three points in time. At test point one and two, the chemotherapy and radiation therapy group scored higher on the DISF than the chemotherapy only group (mean score, 9.99 and 4.13 more points respectively). At test point three, the chemotherapy only group scored higher (mean score, 1.52 points higher). Results indicate that there is no statistically significant difference in sexual functioning *between* the two treatment groups at the three test points (See Table 10).

Table 10 – Test for Difference of Sexual Function Between Two Treatment Groups at Three Time Points

	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95%Confidence Interval of the Difference Lower Upper
RAW1 Equal variances assumed	-1.450	57	.153	-9.99	6.888	-23.781 3.805
RAW2 Equal variances assumed	-.546	47	.588	-4.13	7.560	-19.336 11.083
RAW3 Equal variances assumed	.204	39	.840	1.52	7.446	-13.542 16.578

RAW = DISF total raw score

In summary, there is no evidence that sexual function as measured by the Derogatis Interview for Sexual Function, Self-Report is influenced by treatment over a four-month period of time. There is also no significant difference in the sexual function of the subjects according to type of treatment (chemotherapy only vs. chemotherapy and radiation therapy)

Change over time was also investigated for mood status and social support using the multiple paired *t* test. There were more missing values for social support than for other variables primarily due to lost data via the mail and by the subjects themselves.

The Bonferroni technique is again used when constructing the confidence intervals, and to analyze the change in mood status and social support within the two treatment groups between three points in time. A 95% joint confidence interval of the paired difference among the three test points is constructed, and a 99% individual confidence interval created for each pair. Again, the pairs consist of the following: pair 1 = score between time one and time two, pair 2 = score between time two and time three, pair 3 = score between time one and time three.

Regarding mood status, results show that right after treatment began, between time one and two, the Affects Balance Index (ABI) (T-score) score decreases significantly (P = .004). Between time one and three, the ABI also decreases, and interestingly, between test points two and three there is a slight increase in the ABI T-score. However, the decrease between time one and three and the increase between time two and three are not significant at level $\alpha = 0.05$ jointly (See Table 11). Overall, there is no statistically significant change at level $\alpha = 0.05$ jointly in the subjects' perception of social support between any of the three time frames (See Table 11).

Table 11 – Joint 95% Confidence Intervals of Paired Difference at Any Two Time Points for Mood Status and Social Support

	N	Mean	Std. Deviation	Lower	Upper
Pair 1 ABI1 & ABI2 (T-scores)	49	3.31	7.763	.33	6.28
Pair 2 ABI2 & ABI3 (T-scores)	39	-.26	9.768	-4.50	3.98
Pair 3 ABI1 & ABI3 (T-scores)	41	2.51	10.812	-2.05	7.08
Pair 1 SS1 & SS2 (raw scores)	48	2.60	11.932	-2.02	7.23
Pair 2 SS2 & SS3 (raw scores)	37	1.95	6.060	-.76	4.66
Pair 3 SS1 & SS3 (raw scores)	39	.74	7.465	-2.50	3.98

ABI = Affects Balance Index (Measure for Mood Status), T-score = Standardized Score
SS = Social Support

Research Questions 2 & 3. To what extent does age/gender explain variation in level of sexual function for people with lung cancer?

To explore the extent to which age and gender affect sexual functioning, three multiple linear regression models were constructed on sexual functioning adjusted for treatment across the three test points. Regression analysis between the DISF raw score of the dependent variable and each predictor variable [i.e. treatment, age, gender, mood (affects balance index) & social support] was performed. (Mood and social support will be reported later). At all three test points, age was a statistically significant factor (P = .000, P = .000, P = .030 respectively) affecting sexual function. At the first test point, for two patients with all characteristics the same but age, a patient 10 years younger will be expected to have about 11 more points on the total raw score of the DISF (See Table 12). Gender was not statistically significant at time one or time three, however, it was significant at time two at the level $\alpha = 0.05$. Results at time two imply that males tend to have more normal sexual functioning than their female counterparts. If other characteristics remain the same, male subjects will be expected to have about 15 more points on the total raw score of the DISF than females (See Table 12).

In summary, in relation to age, there is statistically significant evidence at level $\alpha = 0.05$ to support the fact that sexual function as explained by age varies for people with lung cancer at all three test points. Younger people with lung cancer are expected to score higher on sexual functioning than older people. In relation to gender, even though the male with lung cancer tends to function better than the female, this difference didn't appear to be statistically significant at level $\alpha = 0.05$ except at test point two.

Research Question 4. To what extent does mood status explain variation in level of sexual function in people with lung cancer?

To explore the extent to which mood status affects sexual functioning, the three multiple linear regression model is again used to regress mood status adjusted for treatment, age, gender, and social support across the three test points. Regression analysis between the DISF raw score of the dependent variable and each predictor variable [i.e. treatment, age, gender, mood (affects balance index) & social support] was performed. At test points one and two, mood status was found to have a significant relationship to the subjects' sexual function at level $\alpha = 0.05$ (See Table 12). At test point one, for two patients with all characteristics the same except mood status (ABI, T-score), a subject with 10 more points on the ABI will be expected to yield about seven more points on sexual functioning. At the third test point, there is no significant affect of mood status on sexual functioning (See Table 12).

Table 12 – Regression Analysis for Sexual Functioning

	Coefficients	Std. Error	t statistic	P Value
Time 1				
(Constant)	30.25	31.968	.939	.352
Treatment	8.954	6.150	1.456	.151
Patient Age	-1.078	.263	-4.096	.000
Gender	9.894	6.087	1.625	.110
ABI 1 T-score	.691	.227	3.047	.004
SS 1	8.05	.355	.029	.822
Time 2				
(Constant)	38.804	31.435	1.234	.224
Treatment	-8.52	6.547	-.001	.999
Patient Age	-1.068	.279	-3.830	.000
Gender	14.739	6.519	2.261	.029
ABI 2 T-score	.936	.279	3.356	.002
SS 2	-5.13	.297	-.173	.864
Time 3				
(Constant)	51.378	38.868	1.322	.195
Treatment	-2.699	7.357	-.058	.716
Patient Age	-.723	.329	-2.267	.030
Gender	9.776	7.888	1.239	.224
ABI 3 T-score	.377	.311	1.213	.234
SS 3	-6.04	.460	-.013	.990

ABI = Affects Balance Index (Measure for Mood Status), T-score = Standardized Score
SS = Social Support

In summary, in relation to mood status, there is statistically significant evidence at level $\alpha = 0.05$ to support the fact that sexual function as explained by mood varies for people with lung cancer at test points one and two. People with lung cancer who have a higher score on the ABI are expected to score significantly higher on sexual functioning at time one and time two. Although people also score higher on the ABI at the third test point, this is not significant at level $\alpha = 0.05$.

Research Question 5. To what extent does social support explain variation in level of sexual function for people with lung cancer?

To answer this question, the same model is used to regress social support adjusted for treatment, age, gender, and mood status. Level of social support is found to have no significant affect on the lung cancer patient's sexual function at all three test points (See Table 12).

Although social support did not have a statistically significant relationship to sexual function, it was logical that it may play some significant role relative to the patient's quality of life. One reasonable conjecture is that social support may influence the subjects' mood status, and indirectly affect sexual function. To examine this supposition, the investigator regressed mood status (ABI) on social support and adjusted for age, gender and treatment. The results clearly indicate that social support positively affects the mood status significantly at level $\alpha = 0.05$ at all three test points. Mainly, subjects who feel that they are receiving a higher level of social support, tend to have higher mood status, especially at the third test point (See Table 13).

In summary, in relation to social support, there is no statistically significant evidence at level $\alpha = 0.05$ to support the fact that sexual function as explained by social support varies for people with lung cancer at any test point. However people with lung cancer who have a higher level of social support do score significantly higher on the ABI at level $\alpha = 0.05$ at all three test points, particularly at the third test point.

Table 13 – Regression Analysis for Mood Status Using ABI T-score

	Coefficients	Std. Error	t statistic	P Value
Time 1				
(Constant)	-10.463	19.133	-.547	.587
Gender	.811	3.651	.222	.825
Patient Age	.219	.155	1.414	.163
Treatment	-4.403	3.642	-1.209	.232
SS 1	.620	.196	3.165	.003
Time 2				
(Constant)	-14.244	17.040	-.836	.408
Gender	-4.389	3.499	-1.254	.216
Patient Age	.313	.145	2.159	.036
Treatment	.524	3.577	.146	.884
SS 2	.557	.138	4.027	.000
Time 3				
(Constant)	-49.143	19.714	-2.493	.018
Gender	1.436	4.344	.331	.743
Patient Age	.233	.171	1.360	.183
Treatment	4.828	4.058	.012	.991
SS 3	1.000	.187	5.347	.000

ABI = Affects Balance Index (Measure for Mood Status), T-score = Standardized Score
SS = Social Support

CHAPTER FIVE

Discussion and Implications

This is the first study of its kind with a distinct focus on the sexual function of people with lung cancer. Overall, few investigators have studied the variables that influence psychosocial adjustment in people with lung cancer. In addition, sexuality has been relatively ignored in the lung cancer population. This is possibly due to the poor outcome when diagnosed with lung cancer, or to the fact that sexuality is often equated with cancers of the reproductive organs (Ginsburg, et al., 1995; Ryan, 1996). This longitudinal research has begun to identify factors that affect the sexual functioning in lung cancer patients over time, and this information will be able to be applied to future research with these deserving individuals.

It has been previously noted that sexual function frequently declines in people with cancer, especially as they experience treatment (Alfonso, Cohen, Levin, & Simon, 1997; Burbie, 1992; Schover, et al., 1996). Although the findings from this study did not present significant data to confirm that sexual functioning in lung cancer patients would be worse over time due to treatment, their sexual functioning did worsen somewhat as they went through either chemotherapy alone, or chemotherapy and radiation therapy. The majority of subjects entered the study with abnormal sexual functioning according to their DISF-SR scores, which upholds findings from Ginsburg et al. (1995) whereby they report that several of their subjects (48%), who were being treated, experienced loss of libido even before the diagnosis of lung cancer. Clinically, if the therapist is aware that sexual functioning may be decreased in this population even before treatment begins, they can address it with the person and normalize possible feelings of inadequacy. The patient can be informed that they may have already become weakened and debilitated by their lung cancer and this can inhibit sexual activity. After the cancer diagnosis, but before treatment begins, sexual desire may decrease because of anxiety about survival. These anxious feelings can overpower either the patient or partner and lead to an emotional crisis. Therapists can provide encouragement by explaining that tumor response to chemotherapy and radiation therapy will often take away symptoms and improve physical performance. Bernard and Gantz (1991) acknowledge that treatment can play a helpful role in the ability to adjust to a cancer diagnosis. Even the fact of discussing sexuality, an important aspect of quality of life, may give the person with lung cancer hope and increase their sense of well-being.

In this study, there is a significant correlation between treatment type and type of lung cancer at $P = 0.001$. More patients with non-small cell lung cancer (72%) are treated with chemotherapy and radiation therapy than with chemotherapy alone. Only 23% of patients with small cell lung cancer received both chemotherapy and radiation therapy which is usually because fewer of these patients present with limited disease where this is the treatment of choice. This is the usual treatment pattern for both types of lung cancers according to Wozniak and Kraut (2001). This data signifies that the study population results were probably not biased because of treatment out of the ordinary. Even though the treatment correlated with the cancer type, there was no statistical difference between treatment groups (chemotherapy only vs. chemotherapy and radiation therapy) relative to DISF-SR raw scores. This is similar to Sarna's (1993b) research where she revealed that symptom distress (sexual activity decreased for 38% of the women) was not significantly different in relation to treatment status or to type of lung cancer. This is indicative of the fact that both non-small cell and small cell lung cancer patients, regardless of treatment with chemotherapy alone or with radiation and chemotherapy, have similar responses in relation to sexual functioning over time.

Age clearly was a significant factor in relation to sexual function. It was found that at all three test points, if the subject was younger, their sexual function was better. Because the average age of the study population was about 60 years old, this data speaks to the fact that people with lung cancer who are undergoing treatment are more likely to have a decreased sexual function. Although reports in the literature remind us that a decrease in sexual function and ability is often found with increased age, it must be remembered that many older adults are still sexually active (Fransson & Widmark, 1996). Richard (2001) explains that sexual feelings aren't necessarily reserved for young people, and she reports, on a sexuality survey conducted by the American Association of Retired People (AARP), that 25% of seniors 75 years old and older enjoy sexual intercourse about once per week. Because the person with lung cancer may be in an older age group, does not preclude the need to address their sexual function with them and their partner. Conversely, because the younger patient is more likely to be sexually active, sexual function should be addressed with these people as well. At any age, people with lung cancer must be appraised of the changes in their bodies due to the illness, told that treatment can produce side effects that may interfere with sexual function, desire and pleasure, and that self image can also affect the physical response to sex (Shell, 2001). Since lung cancer and its treatment disrupt normal sexual activity, other expressive behaviors can be encouraged. Although some patients may be trying to rationalize a way to put aside their sexual function due to lack of interest or physical ability, mere suggestion of alternative methods of expressing love and care may be met with delight. A gentle caress or massage, loving words or gestures, soft touching or even simply holding hands can validate humanness. Not only older adults with lung cancer, but also most of the people diagnosed with lung cancer, have a lower level of sexual function. Therefore, further research is needed to ascertain this population's sexuality information needs, and the preferred method and setting for receiving this information.

According to the DISF-SR raw score, overall, males being treated for lung cancer tend to experience a more normal level of sexual functioning than females, and this is significant at the two month period. There was no significant relationship at pretreatment or at the four month period. One can speculate that significance may be related to the fact that, before treatment begins, females have not lost their hair, and neither have other body changes occurred (e.g. weight loss, skin changes). At the four-month period, women may have become used to the fact that these changes have occurred, and then begun to adapt to a different body image. However, at the two-month test point, their sexual functioning is significantly more affected than the males, and this may be due to the shock of hair loss, weight loss, and potential skin changes, along with hot flashes, decreased libido and vaginal atrophy. Conversely, because these women tend to be around 60 years old, they may not be experiencing the hot flashes and vaginal atrophy caused by chemotherapy's effect on the ovaries which younger women experience. These are aspects that investigators are not sure about because, as Susman (2001) explains, research relative to female sexual dysfunction while undergoing chemotherapy is generally 20 years behind that of men, thus speculation is more tentative. In addition, statistical significance of age and gender relative to sexual functioning is logical given the fact that society values women who are young and beautiful more highly than the older (and perhaps bald) woman (Shell, 1998). The older male (even when bald) is much more socially accepted from a sexual or viral standpoint as evidenced by the older movie star like Sean Connery being recently voted the most "handsome" or "sexy" man alive by the Gentleman's Quarterly magazine! Burbie and Polinsky (1992) comment that during active treatment for cancer, there is an effect on sexual desire and response that includes, "...feeling sexually unattractive because of hair loss, loss of a body part, nausea, and weight loss or gain" (p. 23). Manne (1998) adds to this opinion as she communicates that females with cancer are at higher risk to experience distress than males, as are the wives of cancer patients at higher risk. Because so little is known about women and their sexual function during cancer treatment, this study may provoke increased curiosity relative to the sexuality needs of women with lung cancer, as well as the needs of both sexes. This may spark the development of proper intervention at the appropriate point in time.

Social support had no direct significant impact on the sexual functioning of lung cancer patients at any test point, and this was somewhat surprising. As a result, further investigation was conducted and it was found that social support did significantly impact positively on mood status at all three test points, and particularly at the four month period (test point three). This upholds results from several studies that examined the effect that social support had on perception of psychological distress, psychosocial adjustment, anxiety and depression (Irvine et al., 1991, Neuling & Winefield, 1988, Northouse et al., 1995, Quinn et al., 1986, Roberts et al., 1994). Those subjects who reported a high level of social support had decreased distress and depressive symptoms, and better psychosocial adjustment. Because this data supports a significant relationship between mood status and sexual functioning, a higher level of social support appears to affect sexual function, then, in an indirect manner.

Social support is concerned with "the nature of the interactions occurring in social relationships", and it refers to both situational and perceived support (Klemm, 1994, p. 1059). Although a spouse or other social network often proffers social support, it can also be provided by a therapist, which may permit a new and important added social network. Whether in a group or on an individual basis, psychotherapeutic support gives the patient the experience of caring and relatedness. Because social support was significantly related to mood status throughout the study, therapists and other caregivers can be alerted to the need for continued support or to the initiation of support resources for newly diagnosed lung cancer patients. Speigel (1998) encourages the facilitation and development of open communication between family members to share in problem solving which reduces anxiety and depression among people with cancer. This study's results suggest that this support is needed before and during treatment.

From the Derogatis Affects Balance Scale, the Affects Balance Index (ABI) T-score was used to evaluate overall mood status in an attempt to capture the most significant changes relative to sexual dysfunction. This particular global index not only measures negative affects, but measures positive affects too. Derogatis (1975b) states that, "...it is not the absolute level of negative emotion that has predictive value in sexual dysfunctions, but rather the balance between positive and negative emotional experiences" (p. 5).

Over time, there is a significant decrease in mood status between time one and two, and although mood also decreased between time one and time three, there was no significance found. Interestingly, mood status actually increased slightly between time two and three, but again, not significantly. Conjecture may be that as people are diagnosed with lung cancer, they immediately contemplate their demise and have little hope and they plunge into despair. However, as treatment is introduced that has the potential to prolong life, hope is resurrected, and help is afforded to adjust to the cancer diagnosis (Bernhard & Ganz, 1991b).

One notable finding from this study was that mood status does affect sexual function. The better the mood, the higher the patient tended to score on the DISF-SR and this was significant at the first and second test points (pretreatment and at month two). Because many patients report depression and anxiety when diagnosed with cancer, and those with a more severe illness like lung cancer report even higher depression rates, the therapist may be more alert to assess carefully for this symptom. In turn, if depression is treated proactively with therapy and antidepressants, potential sexual dysfunction may be reduced and patients can have a more satisfactory quality of life as they journey through treatment. As an aside, due to the significance of this finding, there may be an indication that an intervention may most appropriately be delivered at either or both of these times. Albeit, Schover, et al. (1987) found that there was no difference in outcome of counseling with cancer couples in relation to timing—whether before, during or after cancer treatment. Although this study sample may not be fully generalizable to the total population of lung cancer patients, this reported response is not unlike other related studies in the literature. The literature clearly advises us that mood status impacts sexual desire, and negative emotional states such as depression and despair may disrupt sexual activity, not only intimate encounters, but other aspects of sexual function (e.g. closeness, touching, hand holding, caressing) as well (Burbie & Polinsky, 1992; Monga, 1995). A depressed mood may preclude tender physical nurturing between patient and spouse or partner at a time when it is perhaps most needed. Although sexuality is only one aspect of the patients' quality of life, when mood status is effectively addressed, many aspects of the patients' life may improve.

Strengths and Limitations

There are several strengths to this study. One prominent strength is that this is a study to explore the sexual function of people with lung cancer without looking at other aspects of quality of life. This study was not clouded with other psychosocial (e.g. smoking behaviors, role activities like work, parenting responsibilities, financial issues, etc.) and co-morbidity issues, consequently, more in depth information relative to sexual function and what may impact sexual function was learned. Due to previous reports in the literature, the variables of social support and mood status were relevant to the nature of the study and have been shown to affect sexual function both directly and indirectly.

This is a longitudinal study that took place over a four-month period of time with some of the patients still taking treatment. There are very few psychosocial longitudinal studies with lung cancer patients, and most of the studies have been done on a one-time basis or over one to three months (Cella et al., 1987; Ginsburg, et al., 1995; Houston & Kendall, 1992; Klemm, 1994; Quinn et al., 1986; Sarna, 1993; Schag, et al., 1994). A study of this kind can begin to inform therapists and help them understand the time course of changes in sexual function, mood status and social support, and the potential impact that treatment, age, gender, mood status, and social support have on sexual function over time.

In this study, sexual function, mood status and social support were measured by self-report questionnaires, and self-administered questionnaires are quite sensitive when used to measure various sexuality parameters (Fransson & Widmark, 1996). Although the DISF instrument used to assess sexual function is not cancer specific, there are few instruments that are specific to cancer patients and none specific to those with lung cancer. The Derogatis instrument has been used in other sexuality studies in the cancer population and it is very brief, which tends to promote higher completion compliance by the subject. Syrjala et al., (2000) report that most of the sexual function self-report measures reviewed were flawed thereby limiting use in clinical trials across populations. They also found that cancer patients tend not to answer sensitive questions or are too tired to complete lengthy instruments (Syrjala et al., 2000). Conversely, when given the opportunity and anonymity, people may be more truthful with sensitive issues like their sexual function and activity. In this study, there were no DISF instruments with missing data.

The DABS self-report survey was used because it had no somatic content questions like "fatigue" or "appetite loss" for subjects to evaluate. This is unlike some of the other instruments (e.g. the Beck Depression Inventory) where subjects are asked to report on symptoms that can also be caused by the cancer itself, thereby possibly masking a true depression (Manne, 1998).

Each of the self-report instruments that were used were very short and required minimal patient time to complete (approximately 15 to 20 minutes). Therefore, patients were willing to participate in the study, and all surveys that were returned were complete and without missing data.

All subjects except one were placed on the study within 24 days of beginning treatment, and several were placed on study before treatment began. This decreases the likelihood that perception of sexual function was biased by the treatment.

There are also various limitations to this study. This is not a randomized study and it does not have a control group. However, this is an exploratory study done to provide a familiarity with the topic of sexual function in lung cancer patients. Babbie (1992) explains the purposes for an exploratory study and they are: "(1) to satisfy the researcher's curiosity and desire for better understanding, (2) to test the feasibility of undertaking a more careful study, and (3) to develop the methods to be employed in a more careful study" (p. 90).

The study sample, while adequate with power to detect changes, is still small and may not be fully generalizable to the total population of lung cancer patients, however, there is no other sexuality study with which to compare these results. The study population was primarily from one southern state, but a few came from several other areas across the United States, which enhances generalizability.

Although there was almost an equal number of female to male subjects, the recruitment of minority subjects was less than optimal. There were no known gay or lesbian subjects. Participants included only two African Americans, two Hispanics, and one American Indian, and all others were white and heterosexual. This was disappointing since the main cancer center where subjects were accrued is in a large Hispanic area. Several Hispanics that would have been potential subjects could not participate because they could not read and speak English; they were not approached. Notably, then, the experiences of other cultures, races and sexual orientations are not realized.

The number of subjects who participated in the study declined at each test point, which is a limitation of all longitudinal studies of cancer patients. Problems were also realized with the postal service, and with the loss of surveys by the subjects.

The personal nature of this study (sexual function) could add potential limitation to these findings because responses may have been biased due to reluctance to report sexual activity, as noted by other investigators (Catania, Gibson & Chitwood, 1990; Schover et al., 1995). The standardized instrument that was used to measure sexual function (DISF-SR) may not have been sensitive enough to capture particular sexual issues of people with cancer, in particular, lung cancer. These nuances possibly could have been realized by including a qualitative approach such as interview, but that was beyond the scope of this study. As well, although the DISF instrument has been used extensively with cancer patients, it does not have any questions relating to "intimacy" within the relationship. It asks how satisfied the subject is with the present relationship, but does little to realize factors other than the physical aspects of sexual function.

The Social Provisions Scale has not been normed in a cancer population except for in relation to the immunocompetence in a small group of cancer patients. Other scales may provide data that are significant with regard to social support's influence on sexual function.

There were variations in the method of administration of the instruments. Some subjects were approached by the investigator in person, while others had only telephone and Internet communication. Those who were not approached in person may not have felt as inclined to ask questions and could have misinterpreted parts of the instruments. As well, they may have felt less invested in the study, although several of those subjects contacted via phone and on the Internet wrote thank you notes for being asked to participate.

There are several confounding variables that were not controlled for and they include factors such as tumor stage, partner, previous sexual activity, other co morbid diseases, smoking history, surgical resection of tumor, and certain medications that could affect sexual function (e.g. antihypertensives, hormones, antidepressants, narcotics, etc.). Patients who had had surgery for their lung cancer were fully recovered before beginning chemotherapy or radiation therapy and most were taking pain medication either intermittently or not at all. It would have been helpful to have at least a brief sexual history from the subjects to ascertain their perception of sexual function before treatment started.

Implications for Future Research

A psychotherapeutic approach for people who suffer with lung cancer can be a powerful and important component of treatment which can help to reduce distress, improve coping, and enhance interaction in relationships with family and with health care professionals. One purpose of this exploratory study is not only to document that a problem exists for the lung cancer population, but to use this data to design further studies that include a spouse or partner, along with intervention at the most suitable point in time. An example may be one of low sexual desire due to depression and side effects of chemotherapy. The patient may be treated for depression with therapy and/ or medication and be told not to expect sexual desire to return immediately after a treatment session. This may be the approach needed to reassure the patient and validate their humanness.

As researchers learn more about the changes that take place in sexual function in the lung cancer population over time, fears can be replaced by facts that explain potential problems. The efficacy of a structured counseling program intervention such as sexual rehabilitation counseling can be assessed through randomized, controlled studies. Medical family therapists or other healthcare providers can intervene at different points in time to provide patients and partners: information regarding the impact of treatment on the phases of sexual functioning, permission to explore alternative sexual expression, and teaching sensate focus exercises to structure noncoital foreplay. Patients can be taught that there are ways to return to being sexually active by building on strengths (both physical and emotional) that the person has retained and by constructing new ones. Further research may also create intervention according to gender and age in the lung cancer population. Although this study population was around 60 years of age, lung cancer continues to include younger individuals, more women than men are now inflicted with this disease on a yearly basis, and since 1987, lung cancer has surpassed breast cancer as the leading cause of death and accounted for 25% of all female cancer deaths in 2001 (Greenlee, et al., 2001). Clearly, more research to develop empirically supported intervention can enrich our knowledge of which modes of psychosocial interventions are most effective and in which group of patients.

Finally, the assessment of sexual functioning in people with lung cancer suffers from a lack of reliable and valid instruments appropriate for this population. This quantitative study used a short reliable and valid questionnaire to assess sexual functioning, but it was not specific to individuals with lung cancer. There is also a lack of qualitative information for people with lung cancer concerning their sexual functioning. Future studies could incorporate a qualitative section so patients and partners have a means to communicate their concerns and needs using their own words.

Conclusion

From an ecological perspective, the quality of life of the person with cancer and the quality of the environment are dependent on one another. There can be no differentiation between the well-being of the patient and family and the well-being of the entire ecosystem, because parts and wholes are interdependent (Bubolz & Sontag, 1993). Ecological values stem from virtues "that contribute to the ultimate good and to quality of life and include: health versus sickness; education and learning versus ignorance; loving and nurturing relationships versus those that are hateful and destructive; work that is productive and has meaning versus that which is stultifying and unproductive, and work environments that help create personal identity versus alienation…" (Bubolz & Sontag, 1993, p. 426.). Important components of health, love, nurturance, productivity, etc., are the person's sexuality and their perception of femininity and masculinity. When disease and treatment compromise this aspect of quality of life, it is imperative to provide increased social support and resources so the person who is ill can feel a sense of respect and live with dignity.

All marriage and family therapists who work in the medical community as medical family therapists, or those therapists who see cancer patients on a regular basis should be aware of the importance of addressing issues of sexual functioning in this patient population. Marriage and family therapists who work in or in conjunction with a medical environment are well located to assist a broad range of cancer patients and partners who realize a problem associated with cancer, its treatment and their sexual function. Even though sexual functioning is an important aspect of quality of life, therapists often find it difficult to approach the subject. This dissertation highlights sexual function for a particular group of people, those with lung cancer, because they have been relatively ignored, and they deserve to have their life validated as well as all other people with cancer. Reiker (1996) reminds us that every ill person acquires a 'spoiled identity' and a critical illness like cancer touches every aspect of a person's life. She recounts that one survivor wrote, "The loss that accompanies illness begins in the body, as pain does, then moves out until it affects the relationships connecting that body to others" (Reiker, 1996, p. 18).

APPENDIX A

Informed Consent

INFORMED CONSENT
The Longitudinal Effects of Cancer Treatment on Sexuality in Individuals with Lung Cancer

INVESTIGATOR: Judith A. Shell, RN, PhDc, Michigan State University, 407-482-4374.
CO-INVESTIGATOR: Marsha Carolan, PhD, Michigan State University, 517-432-3327.

You have been asked to participate in a research study. This study is being conducted by Judy Shell, RN, PhDc, a medical family therapist and doctoral student at Michigan State University. In order to decide whether or not you should agree to be part of this research study, you should understand enough about its risks and benefits to make a judgment. This process is called informed consent.

This consent form gives information about the research study that will be discussed with you. After an explanation of the study is given, you will be asked to sign this form if you wish to participate.

PURPOSE OF STUDY

The purpose of this study is to evaluate sexual functioning and social support in people undergoing treatment for lung cancer. Although many studies have been done with patients who have other kinds of cancer, no studies have been done and no information regarding sexuality in lung cancer patients exists. Approximately 90 patients will participate in this study.

BENEFITS AND RISKS

There are no direct benefits to you for participating in this study. You may have increased knowledge about your sexual functioning which may improve your quality of life, and recognize that any concerns you may have about your sexual functioning are not unusual. Other potential benefits of this study will affect future patients with lung cancer. Increased knowledge may increase/improve quality of life for patients and enable health care providers to address related issues with improved insight.

The possible risk to you may be psychological discomfort while answering the Derogatis Interview for Sexual Functioning: Self Report, Affects Balance Scale, or the Social Provisions Scale due to the private nature of questions regarding sexual behaviors, your mood and affect, and your support systems.

OTHER INFORMATION

These questionnaires will be given to you three times; once at the time of your diagnosis, once 2 months later, and one more time 4 months later. It will take you approximately 30 minutes to fill them out each time. Because of the sensitive nature of the Derogatis Interview for Sexual Functioning: self Report questionnaire, you will be able to read it over before you make your decision to participate in this study.

____________________Patient Initials

If you are uncomfortable about answering any of the questions on the questionnaire, you do not have to respond.

You understand that you will receive no payment for your participation in this study. The investigator and/or delegated representatives may inspect your medical records for informational purposes where appropriate and necessary. You have been assured that your confidentiality will be preserved and that your name will not be revealed in any reports or publications resulting from this study. Your confidentiality will be further preserved because a code number will be used to identify you rather than your name. Your name will not appear anywhere on the questionnaire.

Should you have any questions regarding your rights as a patient, you may call the University Committee on Research Involving Human Subjects (UCRIHS) representative, David E. Wright, PhD, at the following number, (517-355-2180). Should you have any other questions regarding this study, you may call the principal investigator, Judy Shell at 407-482-4374.

You have the right to refuse to participate in this research study (thereby refusing to sign this consent form) if you so desire without any fear of additional treatment being affected or withheld. In addition, you may refuse to continue to participate in this study at any time after the start of the study without fear of prejudice to additional treatment. Therefore, should you refuse to participate in this study, it will not affect any medical or other type of treatment that is to be provided for you. You will be given a copy of this consent form, and your signature indicates that you have volunteered to participate in the study having read the information provided.

PATIENT'S/PARTICIPANT'S SIGNATURE	WITNESS' SIGNATURE

DATE

INVESTIGATOR'S CERTIFICATE

I have fully explained to the patient the nature and purpose of the above described study and the risks involved in its performance. I have answered and will answer all questions to the best of my ability.

INVESTIGATOR'S SIGNATURE	INVESTIGATOR'S NAME PRINT

DATE

APPENDIX B

Patient Sociodemographic Form

PATIENT SOCIODEMOGRAPHIC INFORMATION

1. Patient Age (years) ____________________

2. Gender ____________________

3. Race/Ethnicity
   American Indian/Alaska Native ____________________
   Asian/Pacific Islander ____________________
   Black (Non-Hispanic) ____________________
   Hispanic ____________________
   White (Non-Hispanic) ____________________
   Other ____________________

4. Marital Status
   Single ____________________
   Married ____________________
   Divorced/Separated ____________________
   Widowed ____________________

5. Employment Status
   Full-time (40 hours/wk. or more) ____________________
   Part-time (less than 40 hours/wk.) ____________________
   Not employed ____________________
   Retired ____________________

6. Highest level of education completed
   Grade School ____________________
   High School/General Ed Degree ____________________
   Associate Degree ____________________
   Baccalaureate Degree ____________________
   Masters Degree ____________________
   Doctoral Degree ____________________

7. Family Income
Under $10,000 ____________
$10,001-$20,000 ____________
$20,001-$30,000 ____________
$30,001-$40,000 ____________
$40,001-$50,000 ____________
$50,001-$60,000 ____________
$60,001-$70,000 ____________
$70,001-$80,000 ____________
$80,001-$90,000 ____________
$90,001-$100,000 ____________
Above $100,000 ____________

8. Presence of Brain Metastasis ____________

9. Stage of Disease ____________

10. Performance Status (Karnofsky) ____________

11. Type of Lung Cancer ____________

12. Type of Treatment ____________

13. Treatment Start Date ____________

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