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Running Head: Social Support

Social Support and Lung Cancer

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Honors Senior Project

College Of Nursing

University of Alabama Huntsville

Fall 2006

Social support is defined as a network of relatives and friends who provide positive feedback (Connett, 2005). In the case of lung cancer patients, their social support consists of people in their lives that are pulling for them to do well. For many, their social support system consists of family members, relatives, friends, church members and caregivers. Adequate social support is a vital part of coping with cancer because cancer is overwhelming and the diagnosis affects every aspect of a person's life. Lung cancer is the leading cause of death in both men and women with an overall 15% survival rate at five years (NCI, 2006). Lung cancer support groups provide lung cancer patients, caregivers and their families in the community with information, support and a sense of fellowship as they live with the disease. Some of the purposes of lung cancer support groups include providing information about the different aspects of the disease and treatments available, providing a place where various individuals with lung cancer can share their experiences and also providing an environment which gives emotional and spiritual nourishment, plus reinforcement to each other. The main aim of this research study is to examine the value of social support and support groups to lung cancer patients and their caregivers. Furthermore, this study will describe how family caregivers seek support in order to cope with the complex physical, psychological, and interpersonal issues in the palliative treatment phase of advanced lung cancer.

Social support is important because it increases one's sense of belonging, purpose and self-worth, and promotes positive mental health (Klemm & Wheeler, 2005). Four types of social support include emotional support, instrumental support, motivational support, and informational support. Emotional support consists of comforting gestures, which are intended to alleviate uncertainty, anxiety, stress, hopelessness, and depression.

Simply knowing that people are available if needed can be comforting even without physical presence. Emotional support also includes normalizing situations by diverting attentions away from the problems at hand (Connett, 2005). Instrumental support includes providing tangible goods such as health care supplies. It also involves providing services such as transportation for the person. Motivational support consists of complements, reminders, encouraging words and understanding of the person's pain. Informational support consists of knowing general information about the person's illness and ways to improve and assist the individual's quality of life (Stewart, 1989).

Lung cancer patients can obtain support from family, friends, significant others and even support groups. Support groups are groups of people who share a common bond and come together on a regular basis to discuss problems and experiences with each other. Social support is not the same as a support group. Social support is a network of family, friends, colleagues and other acquaintances one can turn to in times of crisis or simply for fun and entertainment. Some support groups are usually facilitated by health care professionals and leaders who have personal experience or are very aware about the disease. The primary goal of most groups is to ensure that no one living with the disease or condition that the group serves ever has to feel alone again. Majority of support groups are full of legitimate patients who truly wish to share in a unified bond with others who understand.

Support groups are thought to be useful in assisting caregivers to cope with the demands of care giving. Support groups prevent caregivers from getting burnt-out and also offer them a means to express their feelings and fears. There are many support groups available that include face-to-face meeting (having conversations with other

people in similar situations), online resources (such as chat rooms where people talk to each other about their similar situations), and phone conversations (telehealth / telemedicine). Previous research found that most caregivers preferred talking to others face-to-face instead of over the phone or online. Social support does play a very important role for both lung cancer patients and their caregivers because a positive reinforcement creates encouragement, motivation, and happiness. Social support provided by support groups augments the resources available from the health care provider. Therefore, health professionals may provide important information to patients and their caregivers about the importance and availability of support groups.

Further evidence of the importance of support groups was described in a research study led by researchers at Stanford University who examined the effects of psychosocial treatment on survival of patients with metastatic breast cancer (Spiegel, Bloom, Kraemer & Gottheil, 1989). These researchers evaluated 86 women with breast cancer that had already metastasized. Fifty of the women attended weekly support groups for one year or more in addition to receiving standard medical treatment, while 36 women received only standard medical intervention. The study found that women in the breast cancer support group reported feeling less anxious, less depressed, and less bothered by pain. Also, the researchers later discovered an even more remarkable finding; the women in the support groups survived an average of 18 months longer than the others. Four years after the study began, one-third of the participants in the support groups were still alive, while all 36 of the other women had died. The researchers believe that there is a relationship between biological and psychosocial variables.

In the lung cancer context, the use of support groups and social support does play a very important role for the caregiver. Family caregivers provide the majority of care for the patients with limited life expectancy. Spouses providing end of life care for lung cancer patients describe an average of 120 hours per week of care giving and rates of depression three times higher than non caregivers (NCI, 2006). In this research study, the qualitative portion of a mixed method pilot study was examined to assess the importance of support groups and social support to the caregivers of lung cancer patients (Riley, 2005). Interviews were done with family care givers taking care of their loved ones with advanced phase of lung cancer (N= 15). The majority of interviewed caregivers reported that they had adequate social support system. They described receiving support from their church members, friends, families, siblings and going to a monthly group meeting with people in similar situation. Descriptions of social support include strength received from many sources. For example, "I think the one thing that has just overwhelmed the both of us was the participation of relatives and friends. You have what you call, so-called friends, and you never know to what extent that friendship goes until; we didn't know until this happened to him. It has been; our church members, our church family, they have just been wonderful and I just encourage everybody if you don't have a church connection, please hurry up and get you one." Another caregiver described varying levels of support. For example, "Yes, the church family has been very supportive; friends have been very supportive; family has been a challenge" and "Having someone there to talk to helped." The caregivers that attended support groups stated that they enjoyed being able to talk face-to-face with other people in their same situation. The ability to discuss their experience brought a sense of relief that they were not alone. As lung cancer progresses, many family caregivers' over time may experience exhaustion, depression, disrupted

routine, isolation, physical illness and most times financial worries (Klemm & Wheeler, 2005).

The challenges faced by a person living with lung cancer are unique. Attending a lung cancer support group for lung cancer patients may provide one with some of the necessary tools needed to meet these challenges. Lung cancer patients need special resources to access support. Most individuals find online support groups very helpful. It may be comforting to chat with other people facing similar situations. Chat rooms however, are not the best source for locating health information, especially if they are not monitored by trained health care professionals. In a review of current online websites, some of these groups now offer several options such as telephone support for those who do not have access to an internet and face to face. Churches in the community may provide transportation for lung cancer caregivers and patients if they are interested in attending a support group meeting. Supportive resources located in a review of online support resources include:

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- <http://cancer.stanfordhospital.com/forPatients/amenities/cancerPatientServices/cancerSupportGroups/csgGroup>
 - www.cancersupportivecare.com
 - www.cancer.orgwww.cancerlinks.com
 - www.nccc.org/cis.htm
 - www.nci.nih.gov
 - www.nlm.nih.gov/medlineplus/ency/article/002150.htm
 - <http://www.cancercare.org/>
 - www.cancersurvivorsnetwork.com
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Table 1. List of Current Online Resources.

The complex nature of social support may be illustrated graphically. For example, in Figure 1 below the arrows describing relationships are linked and connected. This means

that the lung cancer patient needs support from their health care provider, the health care provider gets support from the system, social support system receives support from the caregiver, caregivers get support from the social support system and the support groups provide support for the lung cancer patient. Therefore, every aspect of this chain is very crucial and important to each other. Support groups are very helpful to both the lung cancer patient and the caregiver because they get to chat and talk with people in similar situations. In Figure 2 each circle is connected with each other and signifies that each link is valuable. The caregiver, lung cancer patient and support system are all interconnected and related.

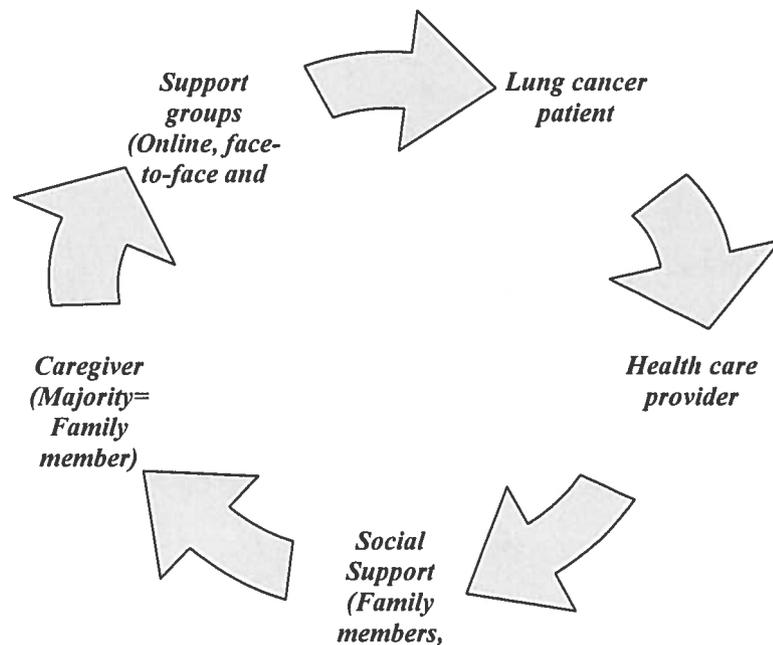


Figure 1. Inter-related Nature of Social Support.

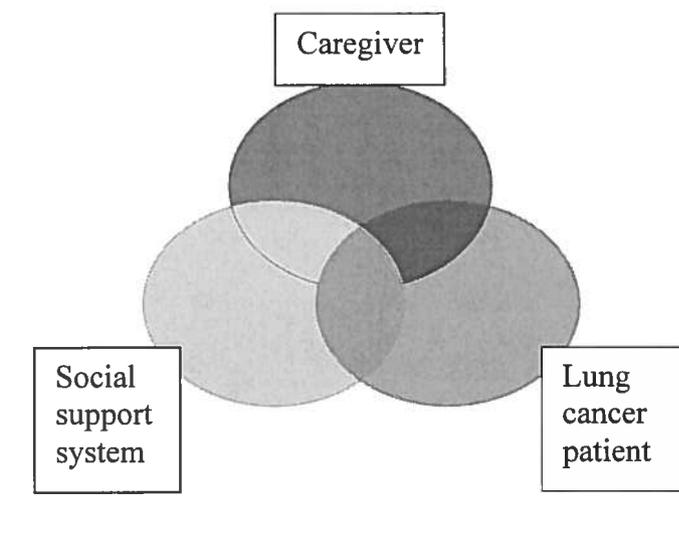


Figure 2. Relationship of Support.

The caregiver of the lung cancer patients may also need emotional and social support in order to keep taking care of the lung cancer patient. Most caregivers have close relationships with the care receiver, that is, a spouse/partner, parent, child, friend or other significant relationship. Care givers, many of whom are older adults, may experience caregiver role strain when they have physical, emotional, social, and financial burdens that can seriously jeopardize their own health and well being. The home health nurse needs to recognize signs of caregiver role strain and suggest ways to minimize or alleviate the problem (Kozier, Erb, Berman, & Snyder, 2004). Being a caregiver to a lung cancer patient could sometimes be emotionally draining so, having a support group is very beneficial.

One example of a new cutting edge study of support groups identified in the review of literature involves the use of a computer and webcam to provide support via the internet (NCI 2006). The patient should be able to access the internet in order to be a part of this support group. This support group is very similar to other online support groups;

however, it includes direct access to a health care professional. The patient can turn on his or her webcam and talk to the health care professional one on one if they want to without going to the hospital. This project could be very beneficial and cost/ time efficient to lung cancer patients all over the world as well as the physician. This idea is innovative but it limited by issues of cost especially for those individuals who cannot afford a computer or those who reside in rural areas and have poor internet access.

An important clinical application of this research is the description of the value of supportive resources for patients and family caregivers. Research emphasizes the important responsibility of the health care provider to inform patients and their caregivers about the importance of adequate support and the availability of support groups in the community. Health care professionals should know all the resources available in their community for patients and family caregivers. Support system plays a very crucial role for the caregiver, the lung cancer patient, their families and loved ones. Further study is needed to explore options that make support more accessible for all cancer patients and families including those in rural areas. Research is also needed that addresses issues of cultural diversity and ethnicity, factors that influence access and acceptance of social support.

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